Telling and Re-telling Stories: Staff Witnessing Narratives from People Diagnosed with Dementia

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ABSTRACT

People navigate an array of emotive and competing narratives which construct the landscape of dementia in the UK. Dominant narratives include biomedical explanations of behaviour and the economic burden of old age. Narratives of person-centred care are equally inflated with emphasis on staff ability and ambivalent definitions of good care. These dynamics risk undermining the heterogeneity of alternative stories from people associated with the label as well as for the people around them. In the current study, the narrative approach of outsider witnessing practice (OWP) was utilised to explore the social location it offered in hearing subjugate narratives of identity from people with a diagnosis of dementia (PDwD) and the narratives of the impact of hearing these from staff. Two PDwD and two staff members were recruited from a dementia day centre, seven stories were produced and analysed. The methodology of narrative analysis was employed to specifically focus on the presence of the wider dominant narratives, experiential stories and interactions in the storytelling constructions of identity. Analysis revealed the significance of social interaction in the constructions of identities for PDwD within OWP, verbal biographical stories weighed significantly in producing shared values and cultural norms, however the interactional elements co-constructed and validated identities of humour, privacy, empathy, determination and many more. Individual staff interviews revealed the pressures faced in providing good support, however OWP offered validation in staff's more relationship focused approaches in working with PDwD. Implications of the current study include the role of OWP in clinical practice as a space to elicit counter narratives in dementia and health settings as well as raising awareness of professional's contributions to identity constructions of the people who use services. Moving pressures off of individual staff to provide person centred care and hear staff's personal and relational narratives of care which can help expand understanding of how best to support each person most meaningfully. Finally, targeting the wider political and societal assumptions by bringing spaces for alternative narratives to be heard more readily in the public realm can diversify the narratives of dementia.

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1. INTRODUCTION

There are an estimated 850,000 people diagnosed with dementia (PDwD) in the United Kingdom (UK) (Knapp et al, 2014). Each individual has a varied life story before receiving their diagnosis and continue their stories with it. Bryden (2005: 11) described the following:

> "each person with dementia is travelling a journey deep into the core of their spirit, away from the complex cognitive outer layer that once defined them, through the jumble and angle of emotions created through their life experiences, into the centre of their being, into what truly gives them meaning in life."

Bryden's statement highlights the layered experiences each person diagnosed with dementia (PDwD) can have. This raises questions around how does one connect those experiences meaningfully to the world around us? However, the label of dementia also carries significant meanings independent of personal experience. Kitwood (1997) argued of the dominance of the medical model in defining dementia and PDwD within political and healthcare realms. It was argued the deficit-focused standard paradigm[1] ignored personal meaning and hindered personhood[2]. For Batra, Sullivan, Williams and Geldmacher (2015: 2), the medical model of dementia implies a PDwD is less than a "whole person", "lacking selves" and "missing something". A tension between dominant narratives of dementia and personal meaning begs the question of what does this mean for identity[3] in the context of dementia?

The current chapter will begin by outlining my personal connection to the area of dementia and the current socio-political context surrounding PDwD. Following this, I explore the literature on narratives, identity and employment within dementia and dementia care, before identifying current gaps in research and how this study aims to address them.

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[1] A term used by Kitwood (1997) to describe the traditional and accepted medical framework of dementia

[2] A term devised by Kitwood (1997) to describe the relational and personal aspects of an individual including PDwD

[3] Further exploration and definition of identity will be in section 1.6

1.1 Personal Context: Locating Myself

A researcher's background and positioning can influence every aspect of the research, from what one chooses to investigate to how we frame and communicate findings (Malterud, 2001). Therefore, my personal context and connection to the area of dementia is important to explore.

Growing up in a Sikh-Punjabi community within Britain placed me between two cultural contexts in regard to views of elders and, in particular, PDwD. Dominant discourses from western media and schooling described elders as frail and requiring relocation into care homes. These notions jarred with Punjabi narratives, where abandoning your parents was a sign of dishonour and the preferred future was for elders to move into their child's home. I was often told to stay true to my Punjabi ways; to show elders respect readily, as disrespect would reflect badly on my parents, similar to Jutlla's (2011) findings with Punjabi carers. The term dementia was seldom heard, instead, elders were mostly seen as sharp and wise or conversely forgetful in their old age. These dual positions highlighted how dementia and old age were open to interpretation and different meaning.

As a dementia befriender in my teenage years, I would visit a White-British woman at home once a week. I learnt a lot about the history of my local area, the war and her life story. Dementia was not dominant in those conversations and I would often leave feeling rewarded and full. However, as an assistant psychologist within a care home liaison team many years later, I saw PDwD being attached to medical explanations first and foremost, such as behavioural, psychological symptoms of dementia (BPSD). The majority of the team's interventions were aiming to bring the personal meaning back into PDwD's care through life-story work, personalised care plans and modelling conversations, similar to those I had experienced as a befriender. During this time, I witnessed grave injustices and prejudices towards PDwD that I had never been exposed to before, which left me feeling upset and angry. However, I also witnessed good practice in care homes which honoured person centred care (Kitwood, 1997) and aimed to maintain the personal meaning each PDwD held.

1.2 Wider Context

Dominant medical and economic narratives surrounding dementia link to current drivers in the wider context and networks for PDwD. Dementia services and businesses are anchored to particular meanings when constructing support. Wider government and research commentary on dementia services reinforce these connotations of what is deemed appropriate and good support.

1.2.1 Political-Economic

Dementia has received increased attention from governments and politicians (Innes, 2009). In the UK, a landmark event for PDwD was the Prime Minister's Challenge on Dementia (Department of Health [DoH], 2015). Launched during a coalition government, it set out to address key areas in improving the lives of PDwD and their families. This followed on from Living Well with Dementia - National Dementia Strategy (DoH, 2009), which set out to raise awareness, encourage earlier diagnosis and improve care. Increased diagnosis has since become a political priority, as has prevention, and influences both research and healthcare contexts. Evans (2014) argued against this push, highlighting increased diagnosis cannot promise improvement in the lives of PDwD. In addition, Brunet (2014) warned of this drive to diagnose leading to overdiagnosis and, therefore, attaching the label to those who may not need it. This suggested an overarching need from the macro level to label individuals, over personal experiences. Early diagnosis can serve wider agendas of producing numbers for prevalence reporting to policy makers (Innes, 2009) and providing earlier intervention to prevent later more costly interventions (Geldmarcher, 2002).

Banerjee (2012) described the economic costs of dementia in the context of the global financial recession of 2008-2012, during which the above policies were released; likening the cost of dementia to be similar to the 18th largest company in the world with an estimated global cost of $604 billion. The release of the National Dementia Strategy (DoH, 2009) appeared to respond to the Dementia UK Report (Knapp et al, 2007) and National Audit Office (2007) reports, which highlighted the high cost and cost inefficient working with increased prevalence of PDwD and called for a government response. In addition, Knapp et al (2007) warned of an estimated further prevalence increase of 154 percent in the UK by 2051. Prevalence reporting as seen above, is often accompanied by emotive language such as the "the dementia epidemic" (Wilson & Fearnley 2007: 1), painting a narrative of panic. Innes (2009) questioned the strategic use of language during prevalence reporting to gain attention and further investment from policy makers in research and services.

1.2.1 Healthcare and Legislation

Healthcare has also seen an increased pressure to diagnose, with government ambitioning to diagnose two thirds of people with dementia by 2020 (DoH, 2015); this requires healthcare professionals to recognise signs associated with dementia and for the public to accept the dementia explanation of such signs (Innes, 2009). Public Health England (2018) and the National Institute for Health and Care Excellence (NICE, 2015) recommended health professionals also became well versed in activities which aided prevention, protection and promotion for PDwD. Prevention focused on encouraging healthier lifestyles to reduce risk factors and improving organisational working to support this preventative approach. These policies and guidance have narrated dementia as a medical phenomenon which needed protecting against through individualised lifestyle changes and education. Robertson (1990) highlighted how aiming at the individual level and pathology, over more structural-level concerns, was more appealing to policy-makers; it produced tangible solutions with minimal threat.

On the other hand, NICE and other professional guidance also promoted person-centred care, defined as a guiding set of principles of good dementia care. These include professionals acknowledging the human value, individuality and life experiences of people regardless of cognitive ability or age, as well as recognising the important role of relationships and interactions in wellbeing (NICE, 2018). A clear acknowledgement by a governing body of creating personalised environments for service users, promoted personal narratives to be heard within a wider political storyline. However, Dewing (2008a) argued the varying definitions of person-centred care opened space for ambivalence in these named principles and practices. In particular, interchangeable use of the terms ‘patient-centred’ and ‘person-centred care’ in practice which warranted differing meanings of professional and service user relationships (Dewing, 2008a). McCormack and Reed (2006: 129) claimed person-centred practice required healthcare professionals to prioritise personal meaning and relationship above the often competing evidence base for technical or clinical interventions. Therefore, combing the personal and professional narratives to aid “effective engagement between persons”. The extent of person-centred care is further dependent on the organisational context in which it is provided and requested. Davis (2004) criticised the use of the term to comment on individualised staff ability rather than naming wider organisational processes which may make it more difficult to achieve. It is important to be aware of these power dynamics and how it contributes to narratives about best practice and professionalism (Innes, 2009).

Similar splits in dementia policy drivers have been witnessed across different nations. Longley and Warner (2002) attributed similarities in policies across Europe to two dominant positions; political-economic and humanitarian. The two positions observed within healthcare and government policy appear to be in competition, although one may overpower the other in different contexts (Afuape, 2011). Cantley (2001) described policies as often representative of other long-standing ethical issues and power struggles. This may elucidate the contentiousness within current dementia policy and practice, including debates around cost, responsibility and safety (Cantley, 2001).

Legislation and law regarding the choices and protection of PDwD has developed with the introduction of laws such as the Mental Capacity Act (MCA, 2005) and Care Act (2014). NICE (2018) advised utilising legislation to promote the inclusion of PDwD and their loved ones in care-related decision-making. This was also supported by governing policies such as the National Dementia Strategy (DoH, 2009) and PM’s Challenge (DoH, 2015). Introduction of the MCA (2005) served to protect PDwD against “prejudicial assumptions” of their ability and addressed previously denied basic rights in choice and autonomy, including in regard to their place of residents (Boyle, 2008: 532). However, Boyle (2009) criticised the extent of this protection, claiming social care services narrowly focused on the more basic needs while claiming to promote independent living of PDwD. Although the humanitarian and ethical meaning is explicitly named in policy and legislation (Longley & Warner, 2002), additional competing agendas challenge what is claimed. Assumptions of biomedical and cognitive impairment have placed limitations to the extent that this autonomy can be judged as acceptable. O'Connor and Purves (2009) questioned the transfer of power in decision-making to professionals who can deem a PDwD as lacking capacity. Despite the MCA advocating the right and support to autonomy of people lacking decision-making capacity (Boyle, 2008), the code of practice of the Act cautions decisions made may not comply with the view of service users being assessed (Department of Constitutional Affairs, 2007: section 5.38). Additional MCA systems of best interest and independent advocates serve to make decisions in the best interest of PDwD rather than honouring choice completely. In addition, literature has found healthcare professionals central to this process are equally confused regarding moral and legal implications (Robinson, Dickinson, Bamford, Clark, Hughes & Exley, 2012; Evans, 2014). This is suggestive of the contradictions surrounding those with a label of dementia and believing their personal accounts and desires; thus, Boyle (2010) pointed how legislation contributed to the social exclusion it claimed to address.

1.2.3 Research

The politicisation of dementia is not limited to government and public service. It has extended into academia and influences the body of knowledge which, in turn, informs policy and healthcare. Research priority and funding are key influences in constructing and maintaining particular meanings of dementia. As part of the PM's Challenge funding into dementia research doubled to over £60 million (DoH, 2015). Pickett et al. (2018) highlighted the global research ambition to develop a cure and/or disease modifying therapy by 2025, with a global increase in research funding since 2013. Of the £60 million of increased funding in the UK, £13 million was for social research. There was a greater push for advances in brain scanning and investment into biomedical centres (DoH, 2015). Biomedical explanations and cures of dementias connect to wider narratives of tackling the growing prevalence and cost of PDwD through treatment and early diagnosis. However, the call to "hear the voices" of PDwD (O'Connor & Purves 2009: 16) in dementia research was also prioritised in the

PM’s Challenge (DoH, 2015), setting an objective to enable engagement of PDwD and their carers in research.

Historically, the inclusion of individuals with a label of dementia in research has not always been the same. Methods of including individuals with a label of dementia developed from using proxy informants, observation and finally hearing the voices of PDwD directly (Innes, 2009). Within evidence-based healthcare, similar progression to include service users in research and service development has been witnessed. Patient and Public Involvement (PPI), has been advocated at government, healthcare, academic and activist group levels. Groups including Dementia Action Alliance (DAA), DEEP (Dementia Engagement and Empowerment Project), and TIDE (Together in Dementia Everyday) advocated for more PPI, adopting the motto “nothing about us without us” (Parveen et al. 2018: 992). However, Charlesworth (2018) reflected on the power imbalances within the PPI movement, between researchers’ and lay persons’ knowledge validity. She raised experiences of researchers questioning the representativeness of including lived experience of dementia, especially within contexts privileging scientific fact over personal accounts. In addition, the inclusion of PDwD to gain support of researcher views can risk tokenism, with less conforming views seen as undesirable. Despite a call for better access, the inclusion of the voices of PDwD still faces barriers, as well as continual lack of opportunity (Swarbrick et al, 2016). It appears research represents a similar split between political-economic and humanitarian drivers as seen in other contexts surrounding PDwD (Longley & Warner, 2002).

1.3 Defining Central Terminology

The above sections paint a story of multiple interpretations and representations surrounding PDwD and dementia care services. Therefore, it is important to be transparent of the meanings I infer when using the term dementia; a shared language between myself and the reader will aid the creation of shared meaning.

The meanings constructed from the term dementia are multiple and contested, but the definitions are important to consider in appreciating the widespread effects of the label. Post (1995) raised the question of what constituted as dementia versus normal ageing in a hypercognitive culture. The dominant biomedical standard paradigm of dementia (Kitwood, 1997) is typically defined as:

> Dementia is an umbrella term for a range of conditions that cause damage to the brain. This damage can impact on a person's memory, thinking, language and their ability to carry out everyday tasks. There are many conditions that cause dementia. Alzheimer's disease is the most common, but there are many others, including vascular dementia, Lewy body dementia and fronto-temporal dementia. (Mental Health Foundation, 2015)

However, terminology has changed over time to include other perspectives into the definition of dementia. DEEP stressed the misrepresentation of the word dementia by the media. In addition, it advised avoiding terminology with "curl up and die" connotations such as "suffering from" dementia, "sufferers" and "demented", amongst many others and instead proposing "person living with dementia" and/or "person living well with dementia" (DEEP, 2015). The current study does not aim to contest the existence of a biomedical dementia and instead will focus on the influence and weight of the explanation on meaning for individuals and relationships. Therefore, terms such as people/person with a label/diagnosis of dementia or PDwD will be used to describe participants and expand the focus to include the personal experience over diagnosis.

Furthermore, personal, political and research context highlighted the pervasive effects dominant stories of dementia had upon identity narratives. Therefore, similar to the wording of Hughes and Castro Romero (2015), 'diagnosed with' dementia in PDwD was also used to describe participants over the grammatically correct 'with a diagnosis of'. This was to create further space between realist narratives of dementia as a present entity within a person and acknowledged the influence in the act of diagnosis upon those diagnosed. Despite technicality, 'diagnosed with' is increasingly used in conversational communication and thus further increases accessibility of the current study to the lay person.

1.4 Literature Search Strategy

The literature reviews were inspired by the current contested terrains PDwD and staff navigate in the UK. More specifically, the roles that personal narratives have played when expressed and heard in the context of political, economic and biological-dominant narratives.

Literature reviews were conducted electronically using EBSCOHost (PsychINFO and PsychARTICLES, and Academic Search Complete) between September 2018 and April 2019. Three separate literature searches were carried out to establish the literature around narratives, identity and staff experience in relation to dementia. The full terms, parameters and inclusion/exclusion criteria for each search are listed in Appendix A. Reference lists of relevant papers were also drawn upon to identify articles which may not have populated from the searches, as well as Google Scholar searches to identify any grey area literature. Furthermore, hand searches of key texts and journals in the area of dementia care, evidence presented within legislation and conversations with colleagues were also drawn upon to gather literature.
The following summary of results and critical review of the literature will be presented in this chapter in a narrative form.

1.5 Literature Review I - Narratives and Dementia

Literature was searched using terms including “dementia” (all variants included), “narrative”, “story telling” and “experience” and there was no restriction on publication date. A total of 94 papers were yielded, of which 28 remained following removal of duplicates and inclusion based on criteria (see Appendix A). Overall, a majority of excluded papers focused on neurological and cognitive ability in PDwD to produce narratives. Further excluded papers included those that did not include PDwD experience, were not in English and were narrative reviews of unrelated topics; in the remaining 28 the following themes emerged.

1.5.1 Power and discrimination

Literature highlighted the effects of dominant storylines on the identities and power of PDwD as well as the resistance to this domination. The following section summaries key narratives and actions from the literature.

1.5.1.1 Control and Fear

As seen in Section 1.2, dominant storylines included that of the medical model. Literature criticised the reductionist effects of the biomedical explanation of dementia, in which the embodied experience and wider social relationships are ignored (Mitchell, Dupius & Kontos 2013; Kitwood 1997; McParland, Kelly & Innes 2016; Lyman, 1989). Mitchell et al. (2013: 3) described the “inter-relational violence” and othering effects of the “medical colonisation” upon PDwD and families. Literature painted a strong medical ownership of the truth, cascaded down upon multiple levels with an apparent acceptance of the social death of PDwD (Lyman, 1989). However, Zeilig (2013) highlighted the uncertainty within the organic facts of some dementias, with the pathology of dementia being difficult to distinguish from other age-related brain changes. In addition, literature mapping the history of dementia demonstrated how biomedical knowledge of dementia has also been self-contradictory and reactive to wider factors overtime (e.g. Holstein 1997; Fox 2000), as well as conceptualisations shifting from mental health to a disease category (Ticehurst, 2001). This suggests the legitimacy of dementia as a medical truth is questionable, yet it is widely accepted as absolute. Literature was mainly polarised and damning of the medical narrative with limited acknowledgement of alterative narratives from PDwD directly. These included the appreciative stories of receiving a diagnosis to explain the changes in cognition they experienced, seeking positive ways to go forward and gaining access to the right support (Wilkinson & Milne, 2003).

Literature also attributed the rise of the medical paradigm to close links with social control. Dementia related behaviours challenges the social order of normal and acceptable behaviour in society and thus opening it to medical explanation (Innes, 2009). For example, James and Moniz-Cook (2017) argued the challenging behaviour or BPSD narratives in dementia services can also be seen as an expression of distress and need of the PDwD or of those around them, questioning for whom is it a challenge? The “medicalisation of deviance” (Lyman 1989: 598) can keep the focus on individual pathology, protecting the wider societal level, while blame and solutions are more contained and easily managed. Literature suggests the narrow focus onto neurobiology and neuropsychology may be symptomatic of desperately seeking a cure for either dementia (Contrell and Schultz, 1993) or ageing and death (Harding & Palfrey, 1997).

Literature also uncovered the dominant narratives of fear and loss of self with dementia within different contexts. This is particularly problematic, since the loss of self can underrate the humanity of PDwD in society (Batra et al, 2015). Zeilig (2013: 216) highlighted the “zombie” and “living death” depictions of PDwD in population literature, based on society’s disgust and horror at the ageing process. The perceived loss of self-narratives have again been attributed to biomedical paradigms within which there is little room for the personal (Mitchell et al, 2013). Perry and O’Connor (2002) welcomed a social constructionist shift in literature to understand the loss of self as a product of societal processes and possible action to change this. However, McParland et al (2016) cautioned the recent counteracting of the tragedy stories with living well stories as a way to ensure the person remains firmly in the societal narratives. They argued the dichotomising of dementia into negative versus positive stories may not allow space for stories of loss and sadness being expressed safely, re-enacting dominance in narratives around PDwD.

1.5.1.2 Stigma and Discrimination

When considering the power structures and social conversations surrounding PDwD in society, looking at how older adults are perceived is also important (Innes, 2009). Literature provided a socially constructed view of ageing, with dominant narratives being bestowed upon a homogenous group of individuals over the age of 65 (Castro Romero 2016). These included the economic burden of old age (Walker 2012; Castro Romero 2016; Robertson 1990) and of bodily decline (Gullette 2004; Mitchell et al 2013; Vincent 2003; Innes 2009). Post (1995:3) stated “clarity of mind and economic productivity determine the value of a human life”. This statement is profound in understanding the processes which can lead to the discrimination of elders and PDwD. The burden and decline stories have also been evidenced to be internalised by individuals. Ballard, Elston and Gabe (2005) interviews of 32 women aged 51 to 57 years old highlighted a difference between private and public ageing. Women internalised changes in bodies and memory as signs of ageing, which restricted their self-belief in continuing to engage in age restricted activities. However, these women's stories gendered context of ageing may have also contributed to these experiences, therefore more nuanced than Ballard and colleagues claimed.

Further to old age related stigma, literature suggested the label of dementia is equally value laden, resulting in feelings of disempowerment and self-stigma. McGowan's (1993) interviews with PDwD highlighted feelings of shame and guilt are storied. However, literature equally deemed dementia-ism as a social process (McParland et al 2016; Brooker 2004), pointing to society's need to distance PDwD as symptomatic of the fear narratives named above (Harding & Palfrey 1997; McParland 2016; Killick & Allan 2001). The intersectionality of old age, dementia and other differences can result in the different levels of discrimination for PDwD.

1.5.1.3 Not Hearing the Communications

Further discrimination was found in the values applied to what PDwD communicate. Literature highlights the various assumptions regarding what PDwD are and are not able to do, for example, Goldsmith (1996) named common assumptions of PDwD being too unreliable and confused to be valid respondents. Mitchell et al (2013) summarised the undermining effects of medical language upon the communications of PDwD, including labelling expressions as denial, confabulating, aggressive and other problematising terms. These findings echo social constructionist conceptualisations of a constitution of knowledge dependent on socio-historical context (Gergen, 1994). However, communication can be viewed as a basic human need, within which personhood can be constructed and expressed (Kitwood, 1997). Indeed, Saunders, de Medeiros, Doyle, and Mosby's (2011) discourse analysis of observed conversations within a residential setting highlighted the role communication played in forming social identities and friendships. Linguistic and non-verbal devices were similar to those without a label of dementia, supportive of PDwD ability to communicate. However, the study focused primarily on PDwD's ability while minimising the effects of staff's communication in the formation or preservation of identities, skewing understanding of the discourses.

Guendouzi, Davis and Maclagan (2015) also showed how PDwD were persistent and adaptable in expressing themselves, using social context to express their role and beliefs within conversations. It was suggested, instead, that barriers in communication were in listeners' expectations rather than an inability to express. This inward reflection on the listener forces us to consider the personal as well as societal barriers in hearing PDwD. Killick and Allan (2001) noted the diminished social interactions between PDwD and staff through staff's escape into tasks, suggesting it as a form of avoidance in confronting the fear narratives. Literature suggests a social context not conductive to communication silences PDwD more so than pathology (Goldsmith 1996; Kitwood 1997; Killick & Allan 2001; Sabat & Harre 1992).

A further source of invalidation was found within literature regarding capacity. As seen in Section 1.2.2, capacity is a contentious concept with longstanding effects. Sabat (2006) criticised the role neuropsychology testing played in solidifying the lack of capacity and competence for PDwD; supporting a biomedical absolute truth over the personal meaning of truth. Instead, Sabat (2006) advocated for building a relationship with PDwD to determine the meaning-making behind the behaviours deemed due to lack of capacity. However, we cannot ignore the inherent power imbalance between professional's and PDwD's relationship, despite efforts to understand the other's meaning making (O'Connor & Purves, 2009).

As Post (2000:5) stated:

> "Rather than allowing declining mental capacities to divide humanity into those who are worthy or unworthy of full moral attention, it is better to develop an ethics based on the essential unity of human beings and on an assertion of equality despite unlikeness of mind."

This highlighted a need to counteract stories of worth based on perceived rationality, instead drawing on the personal connections between all to make meaning. Literature criticised both capacity and agency as discriminatory to those who did not fit rationality privileging constructs (Dewing 2008a; Dewing 2002; Boyle 2004; Boyle 2014). However, Boyle (2014) conducted unstructured interviews and observations with five PDwD who had greater speech and cognitive difficulties, to explore how agency was expressed. It was shown agency still prevailed in less cognitive means. For example, one female participant was often assumed as dependent and passive in the care home but would express short emphatic statements as well as gestures to communicate her desires. Other participants spoke in short utterances of their hopes and values as well as using imagination in conversations within conversations. This revealed that despite communications being undermined through the construct of capacity, there are a variety of means to regain agency through social interactions. Boyle (2014: 1141) went on to label this “assisted autonomy”, in support of less individualised constructs of capacity and agency.

1.5.2 Narratives and resistance

Although a scene is set for the oppressive dynamics surrounding PDwD, there is a body of literature exploring resistance through the use of narratives. As Fels & Astell, 2011 stated, storytelling is an important medium of communication and opportunities for connection with other people.

1.5.2.1 Life Story

A large body of literature represented the role of life story (LS) and biographical narratives in contributing to PDwD wellbeing and selfhood (Kaiser and Eley, 2016). Identities and personhood through LS were a key theme in literature. Westius, Kallenberg and Norberg (2010) LS interviews of 21 PDwD showed content of life events, values and emotional attitudes were central throughout the stories. Participants reflected on how expressing their LS provided a sense of meaningfulness and continuity and no participant focused on their diagnosis, with the authors attributed to the sense of continuity of identity. However, LS interviews focused on the verbal biographical constructions of LS in promoting identities and did not consider the social interactions of the storytelling in participant’s positive experiences. Similarly, Moos and Bjorn (2006) systematic review of LS interventions revealed three aims: to raise self-esteem, improve quality of life and change behaviour. Although the potential of LS stories is evidenced, Moos and Bjorn (2006) cautioned on the focus on individual change, efficiency and quantitative measurement distanced from personal meaning and relationships.

Service change centred around LS work has been welcomed (Goldsmith; 1996, Heggestad & Slettebø 2015), however, implementation has been varied. Kaiser (2018) cautioned of the prescriptive use of LS in services based of rigid beliefs on what constituted LS and who qualified. McKeown, Ryan, Igleton and Clarke's (2015) case studies of LS revealed cases of the individual's meaning not being honoured, for example, with the use of a proxy person re-storying the PDwD's life from their own set of meanings, as well as the PDwD's additions being missed out of the final product. Kaiser (2018) attributed the less meaningful LS interventions to the aim being the product rather than seeking personhood. Hydén (2013) criticised the individualisation of personal narratives for PDwD while ignoring the more embodied and performative aspects of storytelling. A case study revealed the interactions between storyteller and listener served as a resource in expressing selfhood (Hydén, 2013).

As seen in Section 1.2, personal and experience narratives in other context, such as PPI, have been used as both alternatives to dominant narratives as well as maintaining their acceptance. Hillman, Jones, Quinn, Nelis and Clare (2018: 1) interviews with PDwD and informal carers involved in service user movements revealed a "narrative economy", whereby personal biographies and stories were exchanged for more funding for services. This contributed to the body of literature criticising the use of narratives in research contexts as tokenistic by researchers in positions of privilege (Williams & Keady 2006; Parland et al 2016; Charlesworth 2018).

1.6 Literature Review II – Person within the Dementia Discourse

The second literature search was exploring literature, including terms such as "dementia", "self", "identity" and "person" (see Appendix A). This search yielded

101 results with no restrictions applied. Papers which focused on neurological or biological markers of, family/caregiver experience exclusively or those not in English were excluded; 35 papers remained.

1.6.1 Self and Identity Constructs

1.6.1.1 Cognitive

A large amount of literature referred to the biomedical definitions of self and identities being excluding of PDwD. this was evident in the amount of excluded literature from the search due to this focus. Kontos (2004) challenged the cognitive explanations of self as the modern self construct's popularity grew in the 17th Century leading to brain and self becoming a single entity. Therefore, deeming any change to the brain as a change to the self. However, as Batra et al (2015) found, participants with a label of dementia and markedly different cognitive functioning had preserved elements of self and identity compared to those with no dementia label. This called outward to the social context within which identity and self are constructed. However, changes in cognitive functioning did amount to some changes in identity narratives. In particular, reflections on the embodied identities changed through references to e.g. poor memory. (Westius et al. 2010). Despite literatures strong condemnation of cognitive narratives of self and identity, they persevered in some individual's personal narratives, nonetheless.

1.6.1.2 Relational

More relational and socially constructed conceptualisations of identity and self were present in the literature. Kitwood (1997) defined the intricate social processes around PDwD, which resulted in this dehumanisation, as 'malignant social psychology' (MSP). Dementia as a label was also seen as a form of MSP to be counteracted by shifting focus from the label onto the person through social interaction. This was supported as Macrae (2010; 2011) interviewed nine individuals with a label of dementia who reported no loss of self was felt in the context of meaningful and unchanged relationships since diagnosis. A similar framework to personhood was that of Sabat and Harré (1992) and Sabat (2002). Selfhood for PDwD was proposed in three forms: self one (personally referred identity), self two (beliefs about physical attributes of identity) and self three (public identity needing cooperation from others). Sabat (2002) presented case studies whereby PDwD demonstrated self one and two in interviews as well as interactions with others. Sabat, Napolitano and Fath (2004) demonstrated the fluidity of self three depended on the relational other. If focus remained on self two, identity was restricted to the patient role and Sabat (2003: 85) similarly coined such reductionist interactions as “malignant positioning”. Equally, relationships had the ability to cooperate with the individual to reduce embarrassment and create a more socially valued identity (Sabat, 2003). Additional literature has demonstrated the constructions and maintenance of identity through co-constructions rather than being individually created and expressed (Crichton & Koch 2007; Caddell & Clare 2011). When it came to researching such concepts, Tolhurst, Weicht and Kingston (2017a) criticised the narrow definitions of relational in research literature, calling for researchers to also consider the interactions between researcher and participants to further understand the relational aspects of identity formation. As well as consider each participant’s social context in analysis.

1.6.1.3 Storying identity

Literature has demonstrated the social processes within which identity is storied by PDwD. Clare, Quinn, Jones and Wood (2016) interviewed 64 PDwD and carers regarding their identity representations. Three profiles emerged: illness identity, ageing identity and no problem identity. Reports of low mood appeared to be highest for those identifying with the illness narratives. This led to authors questioning the benefits of enforcing the illness framework of dementia on wellbeing. Instead, it was suggested for society to match as closely to the narratives held by the individual. Others have demonstrated storied identity based on social roles and relationships (e.g., Batra et al 2015; Macrae 2010; Harris & Keady 2009). The construction of narratives of identity were not always time and place consistent, however, a case study by Hydén and Örulv (2009) highlighted how this did not seem to affect the storied self; participants demonstrated developing new ways or other skills (e.g., non-verbal) to negotiate their identities in social settings. The embodied and interactional aspects of narrating identity have also emerged in the literature (Hydén 2011; Hydén & Örulv 2009), however it appeared to undermine the significance of personal history in the storying process. De Fina (2015) highlighted the biographical versus interactional debates surrounding narrative identities in research. She argued both aspects can contribute to identity constructions and identities can be plural, contradictory and context-dependent for every individual.

1.7 Literature Review III - Professionals within Care Context

The final area of literature searched related to staff and professionals in dementia care. Search terms included “dementia, “care”, “professionals”, “staff” and “attitudes”. A total of 78 papers were produced and following inclusion, based on criteria such as direct staff accounts (see Appendix A), 21 papers remained.

1.7.1 Staff Experience

Qualified and unqualified care staff provide a majority of socialising for PDwD in a residential setting and can contribute to supportive social environments (Kitwood, 1997). Jakobsen and Sørlie’s (2010) interviews of care staff revealed a conflict of professional issues and providing person-centred care. This led to feelings of powerlessness, burn out and low job satisfaction. Clissett, Porock, Harwood and Gladman (2013) found staff felt a disparity of values between higher organisation level and care level. For example, although communication with the person receiving the care is known to be beneficial, it may not always be seen as “legitimate work” (Killick & Allan, 2001:288). Literature showed this disparity as a frequent factor in job satisfaction and staff wellbeing (Ward, Vass, Aggarwal, Garfield & Cybyk 2005; Killick & Allan 2001). These findings support recommendations by Kitwood (1997) of organisations creating cultures which allow their employees to flourish and be person-centred for both staff and PDwD. Supporting staff to engage in person-centred care was witnessed to improve job satisfaction (Zimmerman et al 2005; Moyle et al 2016), staff’s sense of competence (Mullan & Sullivan 2016) and lessen feelings of being burdened (Hayajneh & Shehadeh 2014).

1.7.2 Use of Stories

Literature has shown the benefits of increasing PDwD’s personhood and staff job satisfaction. Kellett, Moyle, McAllister, King and Gallagher (2010) found staff reported feeling more empowered and confident to be relationship-centred once they knew more about the person. They described this stepping out of the disease-saturated context allowed staff and family members to see the person as a whole. LS work has been shown as an avenue to provide increased person-centred care (Ertiz et al 2016; Thompson 2011) as well as challenge medicalised views of PDwD (Broadhead, 2012). However, LS literature did not consider the personal backgrounds and social positions of staff and perpetuated the personal and professional split in dementia care. It also highlighted the power imbalance of sharing personal information for PDwD compared to those without a diagnosis.

1.8 Narrative Framework and Witnessing

The significance of narratives in influencing PDwD experiences, relationships and sense of identities in the literature reviews complimented key principles of more narrative focused frameworks and theories of therapy (White & Epston 1990; Morgan 2000; White 2007). Morgan (2000: 2) described narrative practice as a “respectful, non-blaming approach to counselling and community work, which centres people as experts in their own lives”. Principles of narrative practice closely associated with LS work and other narrative thickening practices[4] include the belief that stories of people’s lives are socially constructed, stories of dementia have real effects in shaping identities and futures, people’s lives are multi-storied and rich and stories of abilities are enabling (Kaiser, 2018). Young (2010), when using narrative practice with people with memory problems, highlighted the necessity to adapt and find new means to connect rather than assume no meaning existed. She went on to support narrative approaches in shifting elders with memory problems from having problem saturated storylines to more varied, socially constructed, personal stories. This highlighted the potential of narrative principles addressing the problematising dominant narratives named in the literature reviews of this chapter.

Listening to PDwD can provide great insight and validation, regardless of severity (Kitwood 1997; Goldsmith 1996). The narrative practice of outsider

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[4] A key principle of the narrative framework to thicken often neglected and thin subjugate narratives in client’s lives through various re-authoring narrative practices (White, 2007)

witnessing connects an individual’s stories to a wider listening audience, where acknowledging an individual’s preferred story can be powerful for both the teller and the listener (White, 2007). White (2007) used “definitional ceremonies” to share individual’s stories with others, the term was first seen in the work of anthropologist Barbara Myerhoff (1982) with an elderly Jewish community in California, USA. Individuals were witnessed to use storytelling to connect and build collective identities, which in turn validated self identities. Myerhoff (1982) argued as a minority group, the significance of such social actions for Jewish elders to feel connected. White (1995) adapted the definitional ceremonies into the therapeutic context to acknowledge people’s preferred identities. After listening in on a conversation between a therapist and client regarding their preferred narrative, witnesses to the conversation were posed four main areas of enquiry. These were outlined by White (2007) to explore: expressions heard, images conjured in the listener, personal experiences evoked from listening and finally, reflections on how the listener was transported or moved by listening. Next, the initial teller hearing these discussions, commented on how it had resonated with them to hear their witnesses’ accounts. This process drew upon hearing personal narratives and interactional elements of narrating which were also themes identified in literature reviews of the current study for dementia-related literature. Blake and Kaiser (2019) used various narrative practices to inform staff formulation at an older adult’s day hospital. Outsider witnessing practice (OWP) was seen to elicit strength-based stories of clients as well as enhance values of the team and encourage system-wide thinking. This supported the use of OWP in connecting and re-connecting staff to shared themes and values in a dementia context, something claimed by narrative therapists in therapeutic work (Carey and Russell, 2003).

1.9 Clinical and Research Relevance

From reviewing the current political and research narratives surrounding dementia and those associated with it, it is apparent there is a symphony of stories and conflicting truths co-existing. Admittedly, some are more dominant than others, but all find space to exist, bringing rich and complex meanings. This raises the questions of what effect this has on those associated closely to the label of dementia and how do the less dominant stories find space?

Literature has argued the malignant effects of more dominant biomedical and fearful narratives have on PDwD's personhood and wellbeing as well as causing disconnect between those with and those without a diagnosis. However, literature has also indicated the effects can be mediated through more relational and interactional aspects of communicating such as storytelling. As clinical psychologists directly and indirectly supporting PDwD and staff, seeking to promote space for less dominant narratives is imperative. Questioning taken for granted truths and stories can honour the rich and complex experience for every individual as well as illuminate any shared or connecting stories between individuals. The use of the narrative practice of outsider witnessing in dementia-related settings have not been extensively explored in academic literature specifically. Exploring the impact of the social location of OWP in hearing the personal narratives of PDwD and staff can bring further understanding of its uses in clinical practice.

1.10 Aims of the Research

Research aimed to consider the use of OWP in creating a storytelling experience for PDwD and staff. Constructions of identities by PDwD and the impact of hearing the other's chosen narratives on staff's narratives could be captured through qualitative research methods.

From my earlier experiences of the diverse narratives of older age and/or dementia, my influence on the current study's aims included a stronger assumption of alternative narratives being present for PDwD and people around them. Thus, needing exploration through research and storytelling. In earlier experiences, stories were a key space to hear alternative narratives and interacted strongly to the cultural and professional narrative contexts I found myself in. Similar to staff hearing PDwD's stories in OWP, the current research aimed to explore the impact for those holding such interacting narratives as professionals.

1.11 Research Questions

The research questions elicited from literature review and aims were:

- What identities do people with a diagnosis of dementia story?
- How does hearing these preferred identities impact staff?

2. METHOD

I will begin this chapter by outlining the epistemological position I held as a researcher and the underlying principles of selected methodology. I will then provide a detailed account of the data collection, transcription and analysis process.

2.1 Epistemological Position

Explicitly stating assumptions held allows the reader to link philosophical reasoning to the methods selected in exploring the research questions. Epistemology is concerned with the “nature of knowledge” and how we come to know the truths in this world (Burr, 2003: 92). When considering the current study, it was important to question assumptions of truth and knowledge around concepts such as dementia, identity and narratives. In addition, the study sits within the profession of clinical psychology, which carries its own dominant beliefs of what constitutes knowledge in both practice and research. These include the position of scientist-practitioner, which privileges empirical evidence as truth, which can adopt a more realist position in clinical psychology (Davidson, Harper, Patel & Byrne, 2007).

2.1.1 Social Construction

Upon reviewing the current context of dementia in the UK, the contested definitions of knowledge and truth led me further away from a realist epistemology. Instead, knowledge was assumed as being fluid to surrounding social contexts and interactions. Therefore, this study assumed a social constructionist epistemological position; considering the use of narratives and language as social actions which construct truths and meanings (Barker, Pistrang & Elliot, 2002). Furthermore, this position considered my own personal context and interactional influence on the current study’s assumptions and eventual outcomes (Braun and Clark, 2006). I will further reflect on this influence in the critical review (see Section 4.2).

The research questions assumed a subjective concept of identity, something that is relative to social interactions, broader context and other’s interpretations

(Perry & O' Connor, 2002). As Baldwin (2006: 101) stated "Our experience, lives and selves are storied", highlighting the interactional constructing of identity and self rather than an internal existing entity. However, Riessman (2008) warned of the modern preoccupation of narratives as means of accessing personal identities, arguing instead that narratives are beyond the individual and storytelling had a strategic social function. The study's broader position on narrative allowed further consideration of this process in which narratives were created, known as narrativity (Baldwin, 2006). The current study assumed narrativity is a reactive process, depending on an audience's recognition of narrative and conformity to social narrative rules. This is contrary to more traditional realist beliefs of narratives being individually produced (Riessman, 2008). When exploring the social construction of identities, narratives and interaction between the two, the current study needed to employ a methodology which could attend to the interactional and contextual factors equally.

2.2 Narrative Analysis

Congruent with epistemological positioning, the methodology of narrative analysis (NA) was employed to explore how PDwD storied their identity and the impact of this on witnessing service staff. In addition, when working with PDwD, narratives elicited may not have been in linear form or categories and NA could appreciate these assemblies (Willig, 2008). The following section contextualises NA and specifies the NA employed in the current research.

2.2.1 The Narrative Turn

As many authors have stated, there is no singular definition of narrative or NA (e.g. Reismann 2001; Earthy & Cronin 2008; Andrews, Squire & Tamboukou 2008). However, Riessman (2008:1) describes NA as a "a family of approaches which share in common a storied form". Esin, Fathi and Squire (2013) expanded, that NA gave researchers the tools to attend to the different levels of a story, including the personal and social contexts in which it is performed and interpreted.

In relation to other methods in social sciences, Rosenwald and Ochberg (1992) argued NA disrupted traditional forms of analysis which privileged more realist explanations of data. NA moves away from empiricism, instead privileging "positionality and subjectivity" (Riessman 2001: 696). Most qualitative methods can be described as social inquiry, interested in gathering stories of life and experience. However, NA shifted from exploring the 'what was told' to 'how it was told'. (Earthy & Cronin, 2008), and asking why was the story told that way? (Riessman, 1993).

2.2.2 Challenges of Narrative Analysis

NA had been selected on the basis of its broad scope to explore the different constructions of identities through varied social constructions of narratives (Earthy & Cronin, 2008). However, limitations of the approach also arise from its expansive and subjective nature. As Riessman (2008) highlighted, the same text can be interpreted many ways, Bamberg & Georgakopoulou (2008) argued the local context specificity of interpretations made generalisability in the traditional sense far more difficult to achieve for research. However, Riessman (2008) went on to argue generalisability was achieved in a different form to realist population approaches. These included generalising cases to related theoretical inferences common in anthropological and sociological research. Section 2.9 further expands on assessing the creditability of NA. Further criticism of NA arose from the immersed position of the researcher in the construction of findings (Bell, 2002), taking away from the analytic process and making the focus more therapeutic (Ellis and Bochner, 2000). Although a criticism in the objective and empirical sense, the current study assumed stories to have effect on all involved, including the researcher. The clear reflections and interpretation allowed my subjectivity to be made explicit and furthered the experiential understanding rather than accumulate knowledge (Emerson & Frosch, 2004).

2.2.3 Current Study's Narrative Parameters

The following section specifies how wider assumptions of NA guided the current research's methodology. NA is "not a homogenous identity" (Earthy & Cronin, 2008:6) and authors have attempted to propose different typologies (Riessman 2008; Mishler 1995; Phoenix, Smith & Sparkes 2010; Roberts & Shenhav

2014). Defining the parameters of NA for the current study was initially guided by the two questions posed in Robert and Shenhav (2014: 4). Firstly, the "status of narrative" was defined as a representation of social interaction and construction rather than a single, independently existing, entity. Secondly, the current study perceived narratives as the objects of exploration, with oral stories as the basis of analysis. Analysed as a whole rather than reconstructed into categories and smaller narratives to fit the approach. These assumptions ruled out more structural approaches to NA (Robert & Shenhav, 2014).

The NA approach utilised was further refined by first readings of the data. Although initial assumptions were explicitly held and guided data collection, it was the first readings which informed me of the narrative as a whole. Determining the analysis framework prior to data could break the individual's whole narrative into pre-defined categories of data and take away from their subjective experience (Riessman, 1993). From the initial interviews and first reading, key narratives of wider political context, personal experience and interactional dynamics were elicited. In addition, narrative roles varied across the OWP for the PDwD, staff and researcher. Therefore, the framework for NA was adapted from Plummer (1995). Plummer's sociology of story-telling emphasised the social production and consumption of stories, defining three groups in story-telling (See Figure 1).

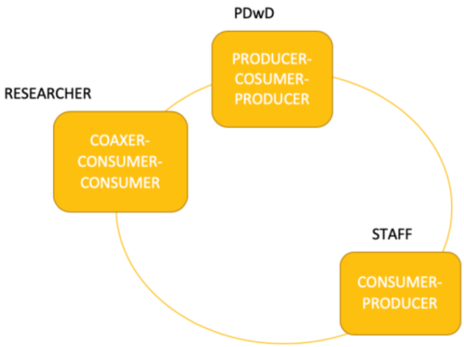


Figure 1: Social interaction in storytelling adapted from Plummer (1995) with role changes in OWP

The "producer" of the story in the current study included the PDwD who initially shared their story, the audience members who later shared their reflective stories and later the staff members in individual interviews. The "coaxer" was myself in the platform I provided and questions I asked. Finally, the "consumers" included the staff audience who contributed to the social location of the story-telling, the PDwD as staff performed their narratives of reactions and myself as I also non-verbally and verbally responded to witnessing these productions. Plummer's framework considered the joint action of story-telling, with analysis capturing the complex changes in roles and thus social location in OWP. The units of analysis included those defined in performance analysis to capture interactional qualities of the narrativity. These included changes in intonation, acting out characters, changes in tense etc. (Riessman, 2008). Finally, an additional adaptation to the proposed model of analysis was from experience-centred narrative approaches (Ricoeur, 1991; Squire, 2008), to respond to narratives of personal experience. The analysis appreciated the meaningfulness of the experiences participants drew upon in their narrative responses, but also that these reconstructions depended on the social context of the interview and wider societal context (Squire, 2008). Units of analysis were the verbal content regarding personal life story, regardless of sequenced order. These included meaningful stories of actual events, values, transformation and/or change. Both frameworks emphasised the political and power processes that story-telling represented, accordingly, the analysis explored how the narratives related to wider political context surrounding the current interaction (see Figure 2).

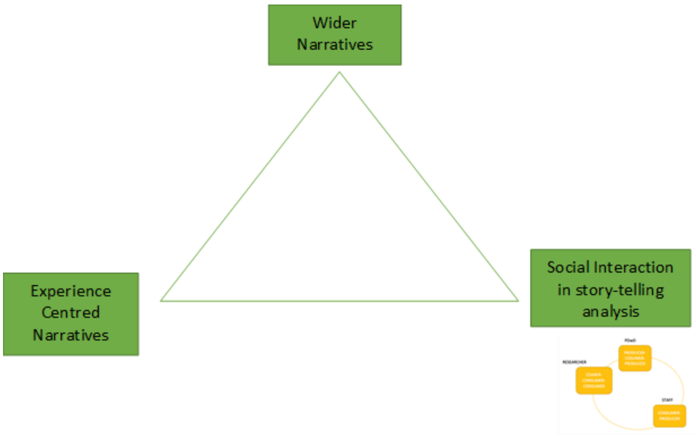


Figure 2: Narrative framework of analysis adapted from Plummer (1995) and Ricoeur (1991)

Overall, the current research approached the data favouring subjectivity (Riessman, 2008), non-traditional forms of narrative (Baldwin, 2006), contextual meaning and the social interaction of stories gathered (Andrews, Squire & Tamboukou, 2008). These influences were deemed fundamental to explore the research questions in context and checking analysis with participants and reflexivity were central to the approach (Squire, 2008).

2.3 Data Collection

2.3.1 Narrative interviewing

A combination of semi-structured and unstructured individual interviews were utilised as a means to access narratives from staff and service user participants (See Appendix B). With the assumption that storytelling is a social process it was important to consider all attendees' influence, including my presence and questions. In the initial portion of the OWP in which the PDwD was asked to tell their story, and during individual staff interviews, I attempted minimal questions. The aim was to reduce the verbal influence I had on the narratives produced and preserve trustworthiness of the data (Riessman, 2008). However, to support the needs of the interviewees with memory problems, recommendations were taken from the literature. This included selecting an environment which was "conductive to communication" (Goldsmith 1996: 58), without noise, nor busy with activity and people. In addition, questions beginning with 'why' were avoided, as well as questions which put pressure on participants to recall their recent actions (Haak, 2002). Instead, initial questions included "tell me about your life"? and "What is important for others to know about you"? These aimed to give space to narratives of personal opinion (Nygard, 2006), as well as to bring a perspective on relationships and others. Follow up questions functioned to clarify, as well as repeat interviewees' words if it was felt utterances were incomplete (Killick & Allan, 2001). In addition to verbal questioning, I attempted to be more aware of my non-verbal contributions. These included matching pacing of the interviewees rather than rushing (Killick & Allan, 2001), holding calm and open facial expressions and body posture throughout the interview, as well as being fully engaged through active listening, giving non-committal and open responses (Goldsmith, 1996), and in a conversational style (Batra et al, 2015). This self-awareness served in the individual staff interviews also.

2.3.2 Outsider Witnessing - Group Interview

As Plummer (1995: 87) stated “for narratives to flourish there must be a community to hear”. As outlined in Section 1.8, outsider witnessing offered a connection between producer and active consumer not possible in individual interviews alone. Expressing stories and witnessing in one sitting allowed the storyteller to immediately see their effect on their audience, as well as provide relatable consent to continue (see Section 2.7.2), once in the room with an audience who were familiar to them. Staff audience were informed that the interview may not have carried on if the individual did not consent at any point. The process of outsider witnessing, as outlined by White (2007), was followed in the current study. Four semi-structured questions were posed to each staff audience member to explore their reactions to hearing the PDwD’s story. Prior to the OWP, staff were informed of OWP principles as recommended by White (2007).

2.4 Participants

2.4.1 Recruitment

A Jewish day centre in London agreed to take part following a consultation with the managers in person and in phone calls as well as providing an invitation letter (see Appendix C). Attendance to the monthly Memory Café allowed me to approach relatives, PDwD and staff about the research and build a relationship. This was guided by recommendations from literature regarding building a relationship with participants as crucial in qualitative research (Nygard 2006; Bogdan & Biklen 1998). Research aims were introduced to all participants with opportunities for further questions given through contact details provided and an offer of visiting again. Care staff/relatives of potential participants diagnosed with dementia were provided with the information sheet (see Appendix D & E), asked of usual ways the individual communicates consent/non-consent, personal background relevant to taking part and establishing time for introductions.

A contract was co-created with management and preliminary dates for weekly visits to speak to individuals, to gather information and gain consent, were agreed (See Appendix F). Possible participants with memory problems or a diagnosis of dementia were identified by staff and approached during visits to inform them of the project. Staff participants approached me, showing interest to listen to the service user's story and being interviewed.

As seen in the narratives of dementia in Section 1.2, a close association between memory difficulties and dementia can pathologize normal ageing (Post, 1995) and increasing narratives of fear (Zellig, 2013). Dominant medical research narratives further highlight memory problems as not the cognitive hallmark of every dementia and therefore inaccurate to treat memory difficulties as synonymous for dementia (Innes, 2009). However, the term memory problems also serve as a normalising and more accessible term of reference as seen in the naming of dementia diagnostic services as 'memory clinics' (NICE, 2015). Furthermore, my position as healthcare professional may have further led participants to the more biomedical dementia narratives of identity. Therefore, the use of both memory problems and/or dementia was utilised in the recruitment of the current study, with verbal explanation to participants not experiencing memory problem specific narratives of dementia. It was hoped choice in a term most closely identified in the narratives of participants would have generated more diverse narratives of identities and expanded recruitment. My role as researcher was to discuss and align to the most appropriate descriptive stories held by each participant.

2.4.2 Inclusion Criteria

The criteria included service users who had memory problems, regardless of level, and staff employed at the same service. The study aimed to include people with cognitive difficulties who had capacity to consent to take part and the process of achieving this is outlined in Section 2.7.2. If any participant did not consent to take part in research, the interview would be terminated. Two PDwD and two staff members was an appropriate number of participants for the depth NA offered. Participants also had to be English speakers and over the age of 18 (See Table 1).

2.4.3 Participant demographics

Pseudonym	Gender	Age	Ethnicity	Diagnosis	Role at Location
1. Gerry	Male	81	White-British	Dementia	Service User
2. Kevin	Male	55	White-British	None	Dementia Support Worker
3. Sandra	Female	60	White-British	None	Senior Dementia Support Worker
4. Jim	Male	78	White-British	Dementia	Service User

Table 1: Table depicting participant information. Pseudonyms are used to protect anonymity.

2.5 Procedure

Following the period of relationship building and information gathering, the following procedure was followed to collect data in an informed and organised process across participants and settings:

- Participants with memory problems or diagnosis of dementia who had been identified by staff and/or relatives were introduced to myself and direct permission was sought from participants to discuss research.
- Consent was gained through one to two unhurried meetings, in which information was provided in the most accessible form and continually re-checked each meeting (see Appendix G). This included the visual information sheet addressed to PDwD (see Appendix H) with verbal explanation and conversational discussion of the research aims (Nygard, 2006).
- Staff participants who showed interest in taking part provided consent by signing the participant consent form (see Appendix I).
- A time was agreed with all relevant stakeholders including management, staff participants, service user participants and relatives for the interviews. It was made clear that interviews could be subject to change dependent on participant needs.

- Staff were informed of the OWP process and main principles beforehand
- On re-attending the site to conduct the interview, the participants were informed of the interview process and consent re-checked. The confidential room was set up as suitable for the participants' ease (e.g. round table to encourage conversational context).
- I interviewed the PDwD, exploring identity as they storied, with two staff participants present and listening with no verbal input.
- Staff reflected on what they heard with White's (2007) four categories of enquiry (see Appendix B) with the interviewee present.
- The interviewees were further asked to comment on what had been said if they wished.
- Following the group interview, staff were interviewed at a later date on the experience of taking part in the OWP (see Appendix B).

2.6 Transcription

The process of transcription contributes to the analysis; Riessman (2008:28) emphasises "in constructing a transcript, we do not stand outside in a neutral objective position, merely presenting what was said", highlighting the power researchers have over constructions of narratives when converting oral interviews to text. Therefore, it is important to transparently outline the process of transcribing within this study. Analysis began promptly after the interviews, with hand written notes containing my initial thoughts, reactions and observations. These were guided by Earthy and Cronin's (2008) recommendations to capture non-verbal tones, body language and facial expressions, something not apparent in text conversion. Both interviewer and interviewee were included in transcription, with the assumptions of interactional elements being paramount in the storying process (Riessman, 2008). In addition, pauses, intonation changes and actions were transcribed to further capture the interactions between myself and participants.

Audio recordings of interviews were typed out word-for-word into a word processor and transcribing conventions were adapted from Frosch and Emerson (2005), as seen in Appendix J.

2.7 Ethical Considerations

2.7.1 Ethical Approval

Ethical approval was sought from the university research ethics committee (REC) and was granted in January 2019 (see Appendix K). No other ethical approval was needed to conduct the research within non-NHS settings, including the day centre. Local approval from management was granted following a meeting between service managers and wider management, for which I was requested to provide evidence of enrolment at the university and disclosure and barring service (DBS) clearance.

2.7.2 Process Consent

Definitions by the MCA (2005), may exclude PDwD in some decision making due to memory difficulties and other non-typical cognitive functioning affecting legal capacity (Dewing, 2008b), although the MCA guidance states assessments of capacity must be time and decision-specific, rather than broadly assumed. However, McKeown, Clarke, Ingleton and Repper (2010) argued that obtaining consent from PDwD by traditional means excluded the voices of those with cognitive difficulties. Traditional exclusionary ethics research methods include cognition-privileging assessments of capacity which disadvantage PDwD's wishes (Post 1995) or by obtaining consent by proxy (Nygard, 2006). These assumptions of providing informed consent ignore "non-cognitive ways" of expressing one's wishes to participate in research (Dewing 2008b: 162). More inclusive methods for PDwD in the consent giving process have emerged over the years in healthcare research (Dewing 2002, 2008b; Hughes & Castro Romero 2015; Mckeown et al. 2010). A commitment to "being with another rather than doing to or doing for" (Dewing 2002: 160) has shifted emphasis onto the relationship between researcher and PDwD in the consent gaining process.

The current study employed the Process Consent methodology adapted from Dewing (2008b) and Hughes and Castro Romero (2015) to gain consent from PDwD in the most meaningful and ethical form (See Table 2). Dewing (2008b) described the method as designed to recognise the situational and residual signs of capacity, traditional competency-based consent and capacity assessments missed. The fundamental elements include evidence gathering

(Cowdell, 2008) and ongoing consent monitoring (McKeown et al, 2010). Process Consent method field diaries were adapted from Hughes and Castro Romero (2015) (see Appendix G). As outlined in Section 2.5, a period prior to approaching service users was dedicated to building relationships and familiarity. Haak (2002) named three conditions critical to creating relationships with PDwD: spending time, getting to know and making another feel at ease. This was extended to other members of the system I had entered, including relatives, staff and volunteers. In addition, information gathering of biography, interests and usual methods of providing consent/withdrawal established an inclusive and individual specific continuum of providing and removing consent. This also informed how best to provide information to the individual meaningfully and ascertain consent to take part. Examples of consent needing to be rechecked included verbally expressing a want to leave and non-verbal signs of tiredness or unsettledness. To ensure consent was maintained, I continuously requested and recorded consent from recruitment stage through to analysis feedback. A pattern of common concerns became apparent the more I asked, including concerns of being too tired or unable to participate which were reassured with rights to withdraw participation. Consistency in wishes to take part at different time points, decisions and settings was also witnessed and documented, suggesting a closer relation to wishes than traditional one signature recordings or consent via proxy (Hughes & Castro Romero, 2015). However, as Killick and Allan (2001) recommended, relatives' knowledge and experience is worthwhile exploring in some form, if not in decision to participate, therefore verbal discussions and a declaration forms (see Appendix L) were included in the information gathering stage.

The Process Consent method
(1) Background and preparation
(2) Establishing a basis for capacity and other abilities
(3) Initial consent
(4) Ongoing consent monitoring and recorded
(5) Feedback and support

Table 2: Stages of Process Consent method adapted from Dewing (2008b)

2.7.3 Confidentiality and Safety

Anonymity was protected by replacing names of participants with either self-selected or assigned pseudonyms; when other individuals were named during interviews their names were removed from transcription. Anonymity could not be fully protected within the day centre, due to participants knowing each other and numbers being small. Participants were explicitly made aware of this in information sheets (See Appendix D,E & H) and verbally. Data was stored in compliance with general data protection regulation guidelines (GDPR), this included data being saved onto a password protected computer. Encrypted recording devices were formatted, as well as signed paper forms being shredded once all data was uploaded.

Formal risk assessments highlighted the main risks to researcher and participants with agreed plans of action with the director of studies. These included potential for participants to become distressed or tired before or after the OWP and researchers lone working. Steps to protect safety and wellbeing are outlined in the procedures above (See Section 2.5) and risk assessment (See Appendix M).

2.8 Reflexivity

As mentioned in earlier sections, NA frameworks highlight the influence I, as the researcher, had on the meanings constructed throughout this study. The focus of analysis on the relational realm of which I was part of meant particular attention was given to the ways I responded and constructed narratives. In addition, the power held by me while carrying out this study needed commenting on as it invariably contributed to the producer’s accounts with me in the audience. To adopt a more reflexive and critical self-aware stance (Riessman, 2008), I kept a reflective diary of methodological decisions made, inferred meanings and assumptions I carried throughout the project (see Appendix N). In addition, a space was facilitated by the director of studies, with other narrative researchers, to reflect on the assumptions and experiences we brought to our projects.

2.9 Validity & Reliability

Riessman (1993; 2008) highlighted the importance of rigour and evaluation of all NA to be true to epistemological assumptions as well as participant meaning. The concept of “trustworthiness” of analysis was introduced as a more appropriate form of evaluating the method and outcomes of the current study, without succumbing to realist definitions of validity and reliability. The four areas of evaluation outlined by Riessman (1993) were employed to assess the trustworthiness of the current study: persuasiveness, correspondence, coherence and pragmatic use (See Section 4.2.1). These focused less on the accuracy of the narrative to real life events, due to the dependency of storytelling on social location and position of the narrator, therefore variation is expected. Instead, Riessman’s criteria moved away from objective definitions to prioritise social worth of the stories produced (Riessman, 1993).

3. ANALYSIS

The following chapter offers a summary of analysis of the OWP transcript of Gerry with Sandra and Kevin, individual interviews of Sandra and Kevin, OWP of Jim with Sandra, and final individual interview with Sandra. NA was conducted in a staged approach to ensure each area was given close attention. A sample of the analysis process at each stage can be found in Appendices O. To honour the interactional relationship between participant's experience-centred narratives, dominant wider narratives and social interaction in storytelling, each section will integrate all three of these aspects. Although attempts to tease out the three aspects have been made, at some points during analysis this was not possible without losing the co-dependency in the narrative meanings. Therefore, readers are invited to embrace the complexity of narrative construction re-presented in this chapter.

3.1 GERRY: "Whatever you want to call me, except something nasty"

I was introduced to Gerry by Sandra who, along with another manager of the centre, felt he would be suitable for the study. I met him a few times before the interview day and we would sit and talk over a cup of tea and play bingo together. Informants expressed to me that mornings were usually the best time to speak to Gerry and for staff to be available. Unfortunately, I was unable to recheck analysis with Gerry as he fell seriously ill shortly after the OWP.

3.1.1 "I grew into a much a much better person"

When speaking about his early childhood in London, Gerry recalled names and locations but would often also mention trouble in his adolescent years, including fighting and "gangster like things" [21]. However, the story progressed into the person he became after beginning work:

> [23-52] Yeah that was me starting up from say from about 10/12 and erm no I've had a lot of (p) fun not fun, but I've had I've been called in by the police once or twice for doing things I shouldn't do for the police. Which wasn't anything particularly you know (p) nothing not really naughty or anything

N: Okay (p) do you remember what that was like being called in by the police?
G: No not really because I've never really gotten into trouble with the police. Just a couple of words and that's it (laugh)
N: (Laugh) and how old were you then like a teenager?
G: I was no, less than a teenager
N: Less than a teenager?
G: Mmm
N: All round London?
G: Yeah and I used to go swimming there because that was one of my sports in [London]. And basically, that's me
N: Yeah, that's so your childhood?
G: Yeah well, I've always got something going on. But nothing important
N: Okay, so nothing important going on in life?
G: No nothing going on in life. Nothing like I would do to get arrested. Y'know? Nothing like that

[62-94] I've, I grew into a much a much better person. Yeah, and also, I've become a cab driver <N: ah><G: a> London cab driver after so many years. Which I, I didn't carry on with it. I didn't want to stay as a cab driver. I'm sorry I didn't now though
N: Now? You're feeling…
G: I'm sorry I didn't stay as a cab driver now. I should of carried on like that. I should of carried on like that
N: And so how long were you a cabby for? Quite a while?
G: Ooo (intake of breath) quite a few years. Must have been about I reckon about mmm 12 years
N: Wow, wow. A long time, I've taken that you've enjoyed it?
G: Oh I enjoyed it alright, but I didn't keep doing it. No, but that's about it really
N: Yeah, sounds like you kinda regret not doing it anymore?
G: Yeah, I'm, I'm really ashamed I didn't carry on doing it as a cab driver. I wish did stay as it y'know? But I didn't and that's it and now I'm sitting here talking to you. And I'm not a cab driver anymore so
N: Why, why do you wish you carried it on?

> G: Well it’s not a bad living. And it’s quite an interesting thing it’s a very interesting thing to be able to do driving a cab round London and all different parts of London yeah (p)

Considering the social interactions during the story telling, Gerry’s minimising and repetition of the non-severity of his interaction with the police performed a distance from this behaviour. As coaxer, I attempted to expand on his earlier experiences, however, Gerry maintained the self-image he wished to portray as a better person working. As an audience member, I felt a sadness and regret as he shared his stopping of driving and used my position of coaxer to expand on this. Gerry expanded his performance to include shame as well as an acceptance of the current situation.

Experience-centred analysis further teased out the experiential elements intertwined in the above extracts. Gerry’s transformative narrative was closely associated with his cab driving, while regret and shame were associated with Gerry’s current unemployment and retirement. Gerry’s statement of it being his choice, despite surrounding narratives, suggested the individual responsibility Gerry felt for his current situation. This echoed wider narratives of unemployment being an individual’s short coming as well as older adults burdening society. Gerry’s reference to the current room in which he was talking and not working, further exacerbated this. Further experiential meanings Gerry associated with his cab driving included the stimulation it offered as well as independence.

As Gerry spoke about his parents, he introduced the other jobs he had held before cab driving. Whilst his parents were in the fur trade, he went into carpentry; he explained what this involved as well as what it meant to him now:

> [222-258] But I wasn’t in the trade, I was sort of carpentry, all carpentry. Yeah (p) anything else dear?
> N: Yeah so you were in carpentry? It that the first job you did?
> G: No
> N: What was the first job you did?
> G: Robbery (laughs)

> N: (Laughs) Is this a confession because if it is…
>
> G: No (laugh) I'm only joking
>
> N: (Laughs)
>
> G: No, no (laughs)<N: (laughs)> I did do carpentry and I've done all different kinds of little jobs like that y'know <N: Mmm> carpentry, electricity<N:okay> I've done that fixing things up that broken like if that like if that (points to stool in room) little stool fell apart. I could fix it, put it together again y'know things like that all this do-it-yourself kinda stuff. I could still do it, but I don't really do anything now. Well, if I've if I'm at home, when I first moved into the flat where I lived. We had things that needed doing like, you know, things that needed doing you bring in some furniture and it needs sort of changing around, well I'll fix it and that's it. Then I'll leave it as it is, so I fix things takes things apart, y'know?
>
> N: And did people appreciate that? Other people?
>
> G: I did, because a lot of people appreciated it on me, I like seeing me working on stuff which I very very rarely do things still. But very rare I don't do much anymore. Now I come here in this club more than anything else now (cough) now that's what I do now. (points at Kevin) he bullies me (points at Sandra) she bullies me, and I bully them (laughs) <S: (laughs)><N: (laughs)> (laughs) joking of course.

Experience-centred analysis considered how fixing roles appeared to offer Gerry a sense of purpose and appreciation from others as well as himself. The subtle switch from others to self-pronouns signified how validating work had on his view of himself, which complimented wider economic narratives of worth. Gerry's use of present tense depicted a confidence and endurance in his skills, despite the opportunity to utilise them being limited. Wider gender and historical narratives surrounding carpentry and skilled labour placed them as typically male dominant occupations; Gerry's masculine identity was produced as he shared his story of occupying these roles. Considering the current contexts Gerry was in at the centre, wider narratives of reduction in activity in old age, as well appropriate activities for PDwD, prevented Gerry's values and masculinity associated with fixing activities.

At a social interactional level, Gerry's joke of bullying engaged the audience in humour but made an important comment on his position in the room as having less power. His use of humour was both engaging and appealing. His interaction with myself was one of affection, but I also had influence on the narrative Gerry would produce; we co-produced his less explicit narrative of humorous identity as I responded with laughter and banter. Gerry's narrative gained strength through his use of the stool in the room to demonstrate to the audience his ability, as well as the shift to present tense stressing his existing skill. This was particularly poignant given the two professionals in the audience may have been in a position to offer Gerry opportunities to be useful.

3.1.2 "I'm quite happy to be with people, you know?"

An additional narrative storied during Gerry's interview brought in the more social aspects Gerry valued throughout his life. He began with positive feedback to the staff and went into his experiences at the centre:

> [260-277] Everyone is wonderful here; it really is honestly. I mean that little fella before what was his name [Louis][5] he's a bit of a silly so and so. If we're gonna watch a film like we do sometimes in another room, he'll go and sit there and then he'll get up and go do and do something else and then he'll come back later, it's all different things <N: mmm> he's just a funny sort of guy but he's not a harmful person y'know? I like all people, y'know very very few people that I don't like, yeah and I mean I sincerely mean that. That's just my personality, but there's things I can do there's things I can't do. There're things I don't like to be told what to do.

> [333-351] G: Well, I don't think a lot of people talk bad about me, I don't know. I really know, but I don't care if somebody does want to talk bad about me. Because, I mean, what am I, what do I do? I don't care they don't like me, they can leave me
> N: Well, exactly yeah so people talking isn't something you value?

---

[5] Pseudonyms are given to protect anonymity

> G: I don't value that, I don't value people talking about me, I don't, I really don't care, yeah and that's it. If you don't like me, well then, I don't like you. But if you like me, well then, I'll give you a hug (laughs)
> N: and then my last question was what things do you think is important other people should know about you?
> G: Well really and truthfully. I hope people think that I'm honest and you know, I'm not a thief and anything like that I hope that people trust me
> N: That's really important?
> G: To me it is, to be trusted

The above extracts were mainly focused on relationships to others. Gerry presented his value of people as an integral part of his personality and the narrative of people at the centre was one of appreciation and sincerity. This was further marked by his change in tone from jovial to serious. However, Gerry's narrative also included certain boundaries he felt around people, including others hindering his choices and those who had negativity towards him. An additional importance of trust formed in our conversations around relationships, specifically. Gerry's delivery emphasised the importance of honesty and trustworthiness to the audience, present through his use of repetition and clarity in the statement. There was also no hesitation or delay before answering the question, which further conveyed a cruciality of this value.

Wider political-cultural levels of analysis emphasised the narratives of trust and control associated with Gerry's context. Gerry's audience of professionals were familiar with narratives of risk, best interest and capacity, associated with less trust and independence for PDwD. It further contextualised the function of Gerry sharing his value-based narrative with this particular audience, whose possible risk aversion had the power to undermine the values Gerry named and cherished. In addition, Gerry's historical and cultural context as a working-class adolescent may have further questioned his trust and honesty. Explicit denial of thievery, as well as the earlier joke of robbery being his first job, may have continued resistance to criminal narratives.

I posed the question for Gerry to name something he valued in life and Gerry brought in his home and significant relationships, in addition to the centre:

> [306-331] Now that’s a thing to think about, things I bralue, bralue (Laughs) <N:laughs> in life
> N: Value in life
> G: Value in life, well I value actually, quite value here at times you know, I’ve been doing this and other things but when I can go home, when I can go home that’s what I value, being at home. Yeah, I like my home. I like to go home, undress, put some different clothes on, have a shower and sit down and watch television, whatever (coughs)
> N: Sounds really relaxed
> G: Mmm?
> N: Sounds really relaxed at home?
> G: I’m always relaxed when I’m at home. My wife she’s really relaxed at home as well
> N: You value that, at home?
> G: Oh yeah, my home, my family
> N: Your family?
> G: Yeah, I’ve got two daughters and, no, two daughters have I got? Yeah, two daughters and my wife and two grandsons, they’ve gone to my daughters, you know, that sort of thing? But apart from that everything is, you know, nice. Yeah, I’m always happy and never miserable. Well, very, very rarely miserable

The home was presented as Gerry’s area of comfort and familiarity which was his domain. In a wider context of dementia, staying at home is often under threat, as services and legislation may be needed for additional support. Gerry’s clear separation of the club and home protected his home from external interference with a sanctuary-type image. Despite memory gaps, family was clearly highlighted as a value closely linked to his home. The mention of his wife introduced Gerry’s husband role; he went on to mention his father and grandfather roles, which enriched his character further. I was an engaged audience member, repeating his words, which encouraged the narrative to continue.

Our interaction following Gerry misspeaking displayed a normalisation over a simple mistake. I laughed with Gerry as he realised and repeated the phrase, as I was reminded of the social location in which this error had occurred, with an audience of dementia support staff and a trainee psychologist. Gerry's description of his home painted a vivid picture for his audience. I commented on the relaxed image I experienced from listening, which led Gerry to expand to other people in his home and family.

3.2 Witnessing Gerry's Story

Present as Gerry's outsider witnesses were Sandra and Kevin. Twenty minutes into the interview they were directly questioned by me with Gerry inputting also. The four open questions adapted from White (2007) were posed to them.

3.2.1 Expressions: "Made me feel emotional, I'm sorry to say"

The first question asked was one of "expressions" Gerry used which "caught your attention" or "struck a chord" [377-378]. Gerry's empathy was something that struck Sandra, who mentioned it frequently throughout the OWP:

> [379-396] (p) To me, I suppose it was the empathy that Gerry shows towards other people and understanding when he spoke about [Louis] so much empathy towards other people and he's supported other people <N: Mmm> when he's here. And he's calmed them down (p). You know, when they've been a bit, and, and the caring, he cares a lot for other people. I don't even think Gerry even realises how much you do it. I don't think he realises how much he supports other people Kevin?
> K: Yeah
> S: And it really made me feel a bit emotional I'm sorry to say
> N: Yeah that's really good, so it struck something_
> S: _Yeah it does.
> N: So, talking about [Louis] was something that <S: yeah>really_
> S:_Because he had a lot of insight and, and he reflected on that that, I remember that incident, do you remember that incident Kevin?
> K: Yeah
> S: And he reflected on it and the understanding he showed

> N: So<S: caring> when [Louis] was walking around, that’s when it was?
> S: Yeah and he sort of realises and really supportive (tearful), make me upset (laughs)

Experience-centred considerations highlighted the reminiscence Sandra experienced in Gerry’s recollection of Louis’ behaviour. It connected her to relational characteristics of Gerry which she valued and felt Gerry did not fully realise. I was moved by the display of emotions in the above extract; Sandra’s safeness to express the emotional impact of hearing Gerry’s story in front of Gerry, her colleague and myself. I was also somewhat surprised, as this countered wider narrative of professional and service user relationships where the personal was separated from professionalism. However, Sandra’s sorrow in feeling emotional echoed this wider narrative, signifying its presence in her experience. Gerry also grew tearful by the end of the extract and this resulted in an additional interaction of me touching his hand, acknowledging his reaction.

A further social-interactional focus on the use of emphasis and repetition by Sandra conveyed the impact of Gerry’s empathy on others which was further accentuated by Sandra’s switch to directly address Gerry. Kevin’s quick monosyllabic agreement reminded me of their team relationship as well as Sandra being Kevin’s senior in the room. My position as coaxer was evident in my follow up question, although on the surface it appeared to clarify Sandra’s answer, the term I used very much reinforced the nature of her narrative to be striking. Wider narratives permeated the social location within which Sandra and Kevin narrated and the shared professional meanings between the three of us. For example, Sandra’s half-completed sentence around people being ‘a bit’ [382] implied narratives of PDwD being unsettled and/or displaying behaviour that challenged.

3.2.2 Images: “Find your own way”

The second question I posed to Sandra and Kevin was an exploration of the “images” elicited by hearing Gerry’s story. Sandra starts responding:

> [453 – 475] And (p) to me Gerry had a strong personality, he was able to say: ‘no I’m not going to do this’ and you know you made the right

> decisions and you know you took the good path. And, erm, to me you're always seem to look for the, you know, the good things, you know, maybe among things that were bad you look for the good path. And I admire you for that and to me that takes a strong person to do that, you know?
>
> G: Thank you
>
> N: A strong person, this idea of a path, you followed a path?
>
> S: Yeah yeah you did, because people can go down the wrong route, you know. Think being able to say no even though you might of mixed with some people that did do things like, you know, was up to no good. You still was your own person. You was able to say, you know, what I'm not gonna be able to do that, and I admire you for that (p)
>
> G: Thank you
>
> N: Kevin, have you got any images?
>
> K: Yeah I, yeah I will try to add to that. It was really good what Sandra said, I think as well you try to find your own way in life. I don't know what your father was like but I think there's a lot of you in me. Because my dad never showed me to do anything but from what you've told us you always want to fix things, you wanna make sure everything's right. And I'm very much like that. So I think you're very independent, you've been made, you made yourself to be very independent, and I admire you for that as well. Because I know what it's like. Yeah you're a family man.

Sandra narrated Gerry's strength and morality as something integral to his being. His positive outlook created a sense of admiration in Sandra, which Kevin also echoed. Gerry's gratitude to Sandra suggested he also shared this narrative. Kevin developed this identity to include independence and being helpful and how it related to his own childhood experiences. A story of connecting values came across vividly through Kevin's story about his father. Wider narratives within the above extracts included morality as being an innate trait and strength to overcome bad behaviour.

A social interaction consideration of my coaxing to include Kevin's voice, created a pressure to perform, as seen by Kevin's initial hesitation and follow on from Sandra's storying. Kevin did not offer an image directly but accompanied it with his own life story. This may have been influenced by the social context of needing to perform something substantial for the researcher as well as building on his narrative of emotional connection to Gerry's story. The repetitive telling of Gerry's strength and morality gave strength to this narrative, although further strength was gained from the direct address to Gerry as an audience member as well as Sandra and Kevin's joint narrative creating a further validity in its performance.

3.2.3 Own Life: "So, we're basically the same"

After initial hesitation regarding the question of bringing personal and professional life experiences that connected to hearing Gerry's story, both Sandra and Kevin focused on professional settings. Gerry mostly stayed quiet during this question until the end, where he responded to Kevin's comparison narrative:

> [511-526] K: [Hearing other's stories] is sometimes it makes your own problems in life not so bad. And maybe that's Kevin talking, I can't talk (leans towards Sandra) for Sandra maybe she feels the same way. But I think that's why we all do this work as well, and we do it for a long time because you begin to understand and you respect people, as Sandra said <S: yes> but you respect, but when you know about people's lives like Gerry's life and all the other people that we know about here. I dunno? For me, it may it makes life, it takes the edge off as well. Yeah, I'm not so hard done by, because that person, that person had it bad
> S: I think it makes you appreciate I think it <K: yeah> it makes you appreciate your day like you could moan over something really trivial and think 'you know what? How dare I complain about that?' You know, something silly_
> K: _And I dunno about Sandra or if Sandra agrees, but it's [life story] very personal thing as well, isn't it? I think? It's quite personal?
>
> [615-620] G: But, I mean, I mean I'll everybody here I think I don't think there's one bad person in this place. You might get the odd sod sort of thing, you know, that might not be 100% but down below we're all equal
> S: We are, that's important too

> G: We’re all equal
> S: We’re all equal

Interactional and wider contextual elements of the narratives pointed to the power differences between myself and staff. Despite Kevin offering his life experiences earlier with his choice, I exerted power on both Sandra and Kevin to share non-professional self-narratives. As mentioned earlier, personal and professional narratives are often seen as separate, possibly explaining initial hesitation and Kevin talking in third person, distantly connecting to his reflective narrative. However, Gerry had spoken about his personal life without hesitation to professionals. This interaction mimicked wider power dynamics for PDwD, whose personal information is readily expected and shared amongst professionals around the individual. Gerry’s input and repetition of equality asserted the counter narrative to their professional-centred narratives in which Gerry was a vulnerable adult, although Gerry’s reference to not being 100 percent echoed this narrative profoundly. Thus, re-presenting the internalised defective identity narrative.

From an experienced-centred viewpoint, the hearing of other people’s life stories in his profession led Kevin to build understanding and respect for others, which in turn improved job satisfaction. Delivery of this statement was tentative in front of his manager, Gerry and I. Sandra aligned to Kevin’s values of respect and understanding, displaying the collective professional values. Comparing his life to PDwD led to gratitude of one’s own life and this demonstrated the value in comparing through stories of those less fortunate and gaining perspective.

3.2.4 Transportation: “It has to work both ways”

The final question of the OWP is about what difference hearing Gerry’s story had on Sandra and Kevin. Both referred to the bond and closeness they felt towards Gerry:

> [569-589] K: _And I liked the closeness today, if that’s what? (looks at Navi) <N: yeah yeah>for feedback <S: yeah><I like the closeness, because not saying I do or we feel more closer to you, but it’s knowing a little bit more about Gerry <S: yeah><and I find that very personal

<S: yeah it is><and it's very personal to you it its knowing more about you_
S: _And understanding what's <K: yeah> really important to Gerry and I think that's really important, because for us to know what's important we well, you know? We want to do that and make, make sure everything that is important we try and, you know? Put in place here at the club for ya_
K: We, we have we, we haven't heard Gerry
S: Mmm
K: Talk like this really to any degree <S: No><because we're, as you know, we're very centre-based and there's lots of people here, you know, we're all individual. But it's really interesting and nice <S:yeah> to, the closeness_
S: And we like to hear that, don't we, Kevin?
K: Yeah
S: We like to hear people's stories
G: Well, it's all the truth what I talk
<N: Yeah><S: sure>
G: I only tell the truth
S: We know that

The above extract highlighted the valued narratives both Gerry and his witnesses co-created. My presence and power in the room was noted as Kevin checked meaning with my aims before continuing. Kevin repeated the closeness and personal experience he had while engaging with Gerry's OWP. The experience-centred narrative was co-constructed, as Sandra interjected agreement as Kevin spoke and her narrative of increased understanding built on from Kevin's narrative of closeness. Sandra applied this to the service; using the collective "we" placed professionals as responsible to improve services through person-centred changes. Kevin's reference to the centre-based nature of the centre links to wider media and policy narratives regarding individual work in health and social support settings as difficult to achieve in busy and underfunded services. This was created in the social location with manager and outsider which made his reference to employment more direct. Sandra's redirect to values of listening may have equally been influenced by social location with an outsider or invisible audience possibly judging the centre's quality negatively. Gerry's final input brought him back into the interactions and bolstered the stories Sandra referenced as valid and truth, therefore worth hearing and strengthening his honest character narrative.

3.3 SANDRA: "They are important and they are valued"

Sandra is the senior support worker and manages the service. She has known Gerry since his first day there. We spoke in her office about the outsider witnessing ceremony she had been part of earlier that day.

3.3.1 Connection in work: "I just felt it made me understand Gerry more"

Sandra spoke about the emotional impact of taking part in the OWP with Gerry, with particular reference to witnessing him express himself:

> [124- 149] (Sigh) I found it really, I found it really, really emotional, I find it really emotional (p) just listening to Gerry when there were certain things that he said about other people and other members and how he felt. I found that really, really like, you know? I wanted to hug him. Or go over and really hug him, give him a cuddle, you know? Like, and just, you know (p) because he's sort of like exp-. He's letting out how, how he feels and he's expressing it. Because sometimes, Gerry don't, he turns everything into a joke but when he's sitting there like that, yeah I just really think we've like bonded, makes you feel like you can bond closer with him? By like, you know? Having that time sitting there listening to Gerry's life, you know.
> N: So, listening to him helped you bond?
> S: Yes. Yeah
> N: How was that kind of…
> S: Well, well we do do that, with other members but not be always in the same process. It might be like, we might like, you know? Like today I had one of our members come in, she got a bit tearful outside. [Story of lady becoming tearful and Sandra listening to find out there was a problem] it's listening it's really important, like Kevin is a good listener, I feel like I'm, I hope I'm a good listener but it's observation.

> [202-208] S: But I must say, I think anyone could come here anytime and see that it is because they're the basics the basic. Because (laughs) we've had you know? We've had like a little while ago um through the company, words that shouldn't say or you should say to members and I was like who's in here? But we know that member so by us knowing that member or we as we got to know 'em. We would know what we could talk about what we couldn't talk about.

Sandra's experience of listening to Gerry was narrated as an intense emotional reaction. Although she expected it to be emotional, the novelty in witnessing Gerry expressing himself in a different way was a positive experience. Gerry's calmness and comfort were constructed as different to his jovial and energetic presentation for Sandra, while connecting to her value of listening. She also felt increased bonding to Gerry, both relationally and embodied in physical contact. She connected this to the centre's and her own value, where she gave time to listen and valued getting to know members.

At a social-interactional level, the shift from the first person to "we" exhibited the collectiveness of the centre. My outsider position felt apparent as Sandra demonstrated good practice to me following my acknowledgement of her listening. Upon reflection, it may have been constructed as something they did not do normally; something Sandra did not feel was the case and needed defending. The storied example immersed me as the audience in getting a sense of the day to day skills required by staff. A wider narrative of service monitoring resonated in the above extracts and re-presented a disconnect between organisational definitions of good care and Sandra's priority of relationships.

3.3.2 "He's deteriorating but it's just nice where he was relaxed"

An additional narrative with a deficit and illness focus also emerged:

> [438-451] You know, he started off and when you listen to him when he was a young man and, and what he was, and obviously I knew there were certain things that he'd done in his life like, you know, when he was a handy-man and his, and like losing all of those, you know, he can't, he

> hasn't got the ability to do that and (p) you know, like when you sit with Gerry, there are certain things, even his speech, some of the words come out wrong, all these like little words, did you notice? I'm sure you did notice. [Another example of deterioration] He is, there's certain things that are you know that he's deteriorating but (p) it's just nice that like where he was relaxed, <N: Mmm> <S: He'd come out quite, he'd come out quite well when he spoke today, he was quite free-flowing and (p) he, he sort of like done it in the right context because there's another day he'll get that, totally like (p) confusion really […]
>
> I just felt like erm (p) I think Gerry needs it like, I think like because you, you know like (p) we're the ones who are caring for him, we're the ones who are responsible for him and (p) you know, you want to be with someone you know that is really like, you know, (p) looking after you and caring for you.

This narrative represented the wider interpretation of Gerry's behaviour in an accepted illness framework of dementia. Interactionally, Sandra listed errors she had witnessed Gerry make, which built a strong evidence-laden narrative of cognitive deterioration. This was further demonstrated in her recruiting me into this narrative. I noted her increased use of the term "you know?" which is both a common Londoner mannerism and invitation for the audience to feedback. The increased use while speaking about dementia in the medical and loss story, indicated a shared assumption of the wider loss narrative which was more difficult to articulate.

However, Sandra's narrative of supporting PDwD elicited an experience of empathising and protecting people from dementia. Witnessing Gerry in a relaxed and happy state, as well as having clear communication, appeared to be unexpected. Her comparison to days where he was more confused brought in the varied experiences she had in a supportive role with Gerry. She valued her role as being caring and responsible for PDwD but also echoed wider expecting stories of good care as minimising behaviours, which created discomfort such as cognitively atypical presentations or agitation.

3.4 KEVIN: “Kevin is a one-on-one person”

Kevin is a support worker at the centre and has also known Gerry from his first day at the centre. Our interview was four days after the OWP.

3.4.1 “So he hasn’t forgotten because it’s an actual feeling”

Kevin spoke about the novelty of the experience, and changes elicited for him both during and after the OWP:

> [36-50] It was quite moving as well (clears throat) because (p) actually giving someone like Gerry the opportunity (p) if you wanna go a bit deep? And give them the opportunity to express. And there’s a lot of, I think more deep stuff there that we might not, never be told of about. But what we, what we touched on I thought it was really good, really positive, I was a little bit wary that maybe he may have felt a little bit intimidated by, or something really personal people don’t want to share parts of their life. But I think with your professionalism. And the way that we, if you like, bonded together. I think we succeeded in learning quite a bit more about Gerry that we didn’t know <N: mmm> um and since last week as well, although he’s not been well, I feel he’s been a bit more closer towards me
> N: And vice versa, how did you feel towards him?
> K: Well, I always tried to get closer to people because then you start to build up a bonding relationship. But I think I found more it was coming more from him than me. And I think that maybe, because of last week’s meeting, he feels maybe a bit more trusted? I don’t know, but I could feel something there

Kevin narrated a bodily emotional reaction, when witnessing Gerry express himself, as well as a bonding. Changes were both individual and relational and although the direction of change mostly radiated from Gerry in Kevin’s narrative, Kevin’s concern in placing Gerry in the centre perhaps also narrated his own discomfort in sharing something personal. His narrative acknowledged the power differences during the OWP and wider narratives of good dementia support as containing and safe for PDwD. Kevin felt my professional position mediated the discomfort, further supporting the narrative of professional containment.

In social interaction, positioning himself, Sandra and myself as learning new information from Gerry's storytelling highlighted what the OWP represented for Kevin and his view of it being successful. Our conversation itself represented a task in which my agenda as a researcher was apparent in Kevin's use of a question to consider my needs. Considering the social location of our conversation, Kevin's comment on my professionalism and aligning himself with me with a collective "we" echoed a separation of professionals and service users with a label dementia.

3.4.2 "It's a busy place. One-to-ones don't often happen".

Kevin spoke about his preference for one-to-one working but the opportunity for this at the centre was much rarer than he would have liked:

> [61-66] It was nice that you offered me or gave me the opportunity to express. I liked that, yeah erm, yeah. It was really interesting for me, I think it's good that you allowed or gave me and Sandra the opportunities to, as well. It's not as if you've just come in and you're taking Gerry's history away and not invited us <N: yeah> yeah, I thought it was, thankfully gave me the opportunity (p)
>
> [163-186] But he's because of his illness he has been probably the most rudest person and insulting person towards me, probably in all the history of, of all my years [at the centre] (p). But now he seems to be very much different and he's not insulting and maybe a slight bit of respect towards me, which I like <N: mmm hmmm> um, and it helps, I think it helps it's a two-way thing. It's all intermingled. You know? I think it is.
> N: So, what about your end?
> K: (p) Yeah, so to answer your question, I now accept since our meeting, your meeting, I accept that he was rude to me and I take it that he couldn't help it. Whereas before our meeting. I suppose I didn't hold a grudge, but he was very insulting and I'm quite a

> sensitive guy. So, you think 'hold on a minute’, once a person, I always believe that if somebody opens their mouth and says something, they’ve said it, they’ve said it for a <u>reason</u>. And I think people can be very <u>spiteful</u> with their <u>mouth</u>. Yeah, I’m if you’re a bit sensitive it does hurt me a bit
> N: Yeah, I can imagine
> K: Since then, since our meeting I’ve overridden I’ve accepted insults, whereas before there was still very much prevalence, you know?

The above extracts painted vivid pictures of the experience of Kevin as a member of staff in dementia support. A tone of powerlessness, as well as gratitude, emerged as social interactional analysis highlighted how OWP allowed Sandra and Kevin to connect to Gerry. This aligned with Kevin’s one-to-one values. However, considering the social interactions in the second extract, my probe to bring in Kevin’s experience was an enforcing interaction for Kevin to expand his narrative and fit my agenda. In the context of emasculation by Gerry, this re-enacted and invalidated the meaning Kevin placed on Gerry’s transformation. This was emphasised by subtle changes in our interaction; Kevin shifted from a collective “our meeting” to “your meeting”, minimising his values of being treated well to support the narrative of change in him, answering my probe. My power in this exchange was marked and reminded me again of my agenda being in the forefront of Kevin’s narrative. Wider narratives include underrepresented narratives of difficult experiences and working conditions for care staff in dementia support services.

At an experience-centred level, a transformation narrative emerged. Kevin’s first narrative of humiliation and disrespect experienced with Gerry was intense; the tone brought in the pain their relationship signified. Initially, the story co-existed with the narrative of illness accounting for the experience. However, a contradiction signified the deeper violation to Kevin’s value-based narrative of being treated well by others. Kevin valued the increased respect from Gerry, a transformation from the OWP. Insults can be hurtful, as well as emasculating experiences between men, while a mutual respect can bring admiration and recognition.

3.5 JIM: "I'm okay once you get to know me, not many people do"

Jim had been attending the centre for six months and I met him a few times prior to the interview. He taught me how to play Kalooki, a card game he played regularly. The OWP was carried out with manager Sandra as witness.

3.5.1 "I'm a very hard person to get into"

Initially, Jim's responses were mostly single-worded, but he directed me to keep asking him questions. He also brought in Sandra, who sat next to him to support his responses:

> [167-181] N: Is there anything else about your life that you think is important for…
> J: No.
> N: …Everyone to know?
> J: Nope. <N: [inaudible]>ask Sandra, she'll tell you. She's interviewed me.
> N: Has she?
> J: Wh, when my wife and I came. You couldn't get much out of us, could you?
> S: Well, we just spoke <J: (whispers to N) [inaudible]> spoke about like the background, you know? […]What they like? And what they don't like? And it's interesting to, and what's important to ya?
> N: Yeah, you are really interesting. If, if that's the right word? I bet you've got a lot to tell? (Laughs) but you're a quiet person, you did say that.
> J: I'm very quiet.
>
> [575-599] You see, before she answers that, she doesn't really know me
> N: That's true
> J: She doesn't, she thinks she does but she doesn't really know_
> S: _I don't, I don't really think I know you
> J: She doesn't really know me, there's not many people here that do
> S: Because I think there's_
> J: I don't even know myself. That's the way I am, that's me. She can say whatever she likes, she wouldn't hurt me. She wouldn't hurt me, [Sally]

> her other colleague who runs the place, she can say whatever she likes. They won't hurt me. That's the way it is, they say what they think. You ask me a question, and they say what they think. And that's the way it is.

The above extracts demonstrated the value Jim placed on his privacy; this narrative threaded throughout the OWP. Considering the social-performative elements, it was apparent in Jim's short responses and directing the interview, he protected how his life story would be shared. Engaging the audience by asking Sandra to describe her experiences of interviewing validated his private man character, as well as exerted some control and power in the interaction. Jim linked his current experience of the OWP with being interviewed by Sandra when first joining the centre. This referenced a re-enactment of the invasion of privacy, which Jim resisted on both occasions. Sandra's explanation of gaining a story to understand was parallel to my research aims and assumptions. This emphasised the disparity between organisational priorities for person-centred care and people's wishes for privacy following a diagnosis of dementia.

Furthermore, being spoken about by others who think they know you was another wider phenomenon surrounding those with a label of dementia, in particular reference to the use of family and professionals as proxy. Jim's repetition of his point as someone difficult to know conveyed this personal narrative to his audience of two women whose agendas included getting close. Experience-centred analysis illuminated how this distance from others aided Jim in having a "nice and quiet" [316] life in which being disturbed by others was minimised. Safety came in this distance with others unable to hurt him, reminding me of the wider gender roles of being emotionally strong and less expressive as a male.

Another value Jim narrated during the OWP was one of speaking out against things he did not agree with. Despite being quiet and valuing privacy, verbalising his opinion was something integral to Jim's identity:

> [188-192] I say what I think. And you people know where they stand with me. Sandra will bare me out of that. I say what I think and that's it. Other

> people are different. And p-, everybody's different (p) I'm a very hard person to get into. Very hard indeed (p)
>
> [235-250] Yes (p) I say what I think. Either I'm liked for it or not liked for it. That's the way I am. That's me.
> N: Have you learnt that value from other people? <J: nope> or have you always been like that?
> J: I've always been like that.
> N: And what about your mum, dad and your sister? Are they like that as well?
> J: My parents are completely different, same as I am.
> N: Really?
> J: Yeah
> N: What are they like?
> J: Okay. Fine. They were okay
> N: Mmm, and similar like the idea they say the truth and…
> J: My father was more like me. I was more like my father. I was soft on the outside but hard on the inside.
>
> [330-343] Nobody tells me what to do. That's why I don't like Brexit. I don't like people telling me what to do, I do what I wanna do, and when I wanna do it. And that's it. Everybody's different. Everybody's different.

Jim's experience-centred narrative of expressing opinion emphasised the meaning he placed on it as a valued and implicit part of his identity narrative. Repeated use of "everybody's different" [343] throughout the OWP performed this meaning of identity as independent to social consensus and valued this uniqueness. Considering the interactional elements of this narrative, my coaxing with relational questions to expand the historical and social narrative of the value of being true to oneself was initially dominated by the narrative of autonomy. However, Jim identified a likeness between his father and himself with a tougher exterior, which echoed hegemonic masculinity narratives present throughout the OWP. Inviting Sandra to validate his expressive narrative also added to the performance; it positioned her as closer to Jim than myself and, therefore, able to support in this narrative.

Social control was voiced by Jim as a violation of his value on agency and was, therefore, expressed against. The use of an analogy with Brexit was something that struck me as an audience member to the wider narrative of independence. Upon reflection, I questioned why I felt so surprised by this comment and noted the wider memory difficulty narratives surrounding our interaction. Jim's bringing in of current politics asserted his position in the current political climate regardless of medical definitions of 'orientation' and 'capacity'.

3.5.2 "You'll find that most decent sportsmen are very quiet"

Jim bought in his sporting history readily into the OWP. Staff had made me aware of his skills but was unaware of the origin and meaning to Jim:

> [62-72] And I used to play (p) well I used to play a lot of sports. But table tennis was the main one, and there were two people playing on the table, I'll always remember this. And then the chap that won it, I said to him can I give you a game? And he said to me, I only play good players. So, I went 'well you wouldn't mind playing me then, do ya?' Anyway, I played him and kept him under the ten both games. I did, it's the truth. He said to me 'why didn't you tell me?' I said 'cause you talk too much'
> N: (Laughs) Yeah
> J: It's the truth. Anyway, everybody wanted to play me after that.
>
> [653-666] S: I don't think he gives himself like that credit he just sort of like_
> J: _Excuse me for interrupting, if you come to my place, I've got a trophy full of (p) I got a whole load of trophies. Load of trophies, I got bags of trophies. Which she (points at Sandra) doesn't know <N: yeah> about
> S: I've never seen 'em, no
> J: She's never seen 'em, she's got no reason to.
> S: Well I might I might come round
> J: I've, I've got loads, I've got<S: for lunch someday> loads of them. I have got loads of them

> N: All table tennis or…
>
> J: All table, <u>mainly</u> table tennis. I used to do a lot of running, used to play tennis. Used to do ev- lots of things in the army.

The narrative of sport signified the success and recognition it brought Jim in the past through many trophies and others' social actions towards him. The richness and meaning sport had for Jim's life story was demonstrated throughout the OWP. Above, Jim's tale was of an underdog to top dog transformation through a game of table tennis against a skilled opponent who underestimated him. The interactional impact of this story engaged the audience. A switch to present tense and impersonation of the characters gave me a vivid and emotive experience of listening to the story and I laughed as his character mocked the out-witted rival. The narrative was also positioned separately to Jim's present context of the centre, through frequent reference to the past and separating Sandra from this narrative. Performatively, Jim cut off Sandra from this narrative as she tried to speak about it. This marked a clear boundary between their personal and professional relationship.

Wider narratives of the centre and older age allowed less room and opportunity for rewarding activities for Jim. In contrast with the army, retirement provided less social recognition for Jim, as is the position for most older adults in society. His reference to the truth and legitimacy of his sporting history to the current audience reminded me of a fight for recognition. However, Jim's telling of the story as something permanent and relivable recreated it in a space which validated and heard it, possibly a change from some other spaces Jim occupies as an older man, where he may not be listened to with deference.

Conversely, Jim entered an additional layer to his sportsmanship and identity narrative with an example of his anger, as an exception to Jim's quiet sportsman narrative:

> [742-756] I was terrible, I had a vicious temper. Got a vicious temper. I was playing a guy; I always remember this. [London], it was in the, oh, when the top county championships. And I played this guy from [East England]. It came to 19-all in the final game. And he got the edge and he

> didn’t say sorry to me. And what did I do? I got my bat and I threw it at him
> N: (Laughs)
> J: I had a terrible temper; I did I threw it at him and_
> N: Did it hit him?
> J: No. <S: hope it did><N: (laughs)> and I lost the game
> N: Oh (sad tone)
> J: But it was me. That was me. I had a terrible temper. I still have. But I got to be pushed. There’s nobody here that pushes me. I’m pleased to say

The above extract represented anger, following losing the game of table tennis to an opponent who did not apologise. This warranted aggression but also brought a telling of regret and ownership as Jim told us the story. Jim unapologetically portrayed temper as a trait within him. In line with his narrative as an individual who spoke out against injustice, his temper was always present to protect his values. This included the present context in which he found himself at the day centre, which Sandra in the audience heard clearly, counteracting wider narratives of old age resulting in increased passiveness.

As a producer, Jim created a vivid reliving of this memory which engaged both me and Sandra differently. He set the scene of the game location and build up. By asking a question to the audience I felt intrigued to find out what followed. The throwing of the racket was unexpected for me resulting in a laugh and later curious question. Sandra on the other hand, sided with Jim’s character in the story sharing in his experience of outrage.

3.6 Witnessing Jim’s Story

Sandra witnessed Jim’s story alone and it soon became conversational between the three of us. The four questions were posed to Sandra and Jim either confirmed her answer or expanded further.

3.6.1 Expression and Images: “I just feel like he’s gone through life”

I posed the question exploring the expressions Jim used during his storytelling that Sandra connected with. She opened with phrases that painted Jim's straight-talking manner, and what experience it left her with:

> [419-453] I suppose I like the, you, I like the fact that with Jim you know where you stand. So, there's no in-between there's either black or white. This is how it is, if you don't like it. And I think that for me as a person, I like that in a person. That's me, and I, I really find that, that his personality by [inaudible] or Jim being like, it really, his personality I find it really attractive and I feel like want to be in his company. And I don't realise I don't think he even realises, you know? When you are here he makes me. Oh, I enjoy his company I enjoy talking, so that really is an important aspect about him_
> J: _Good answer, that's a good answer
> S: I like that
> J: That's a really good answer to your question
> N: it is, isn't it?
> J: Yeah I think it is.
> S: Yeah, and I like that
> N: How does it feel hearing?
> J: Alright, fine. Nice to hear it
> S: (p) I think like when he says okay, he's okay. It's like he doesn't, I don't think he really, you know? He just, just does things and he gives a lot, like to his family and he just don't make an issue about it, you know? It's like it's okay, I'm an okay husband, okay. I think he's more than okay, I'm sure he's support some a lot. And I'm sure he been saying about the man side of things he's been the one who's, you know? You've got the home, you're the man of the house and you provide for your family all through your married life, with your family. And I think you've done it without, without making a big, you know? A big issue, 'oh, look what I've done'. He just does it. He feels that's his role in life to do that, be the provider, the support. And provide and support your family to the best of your ability. The best you can. And he always says, 'you got to do the best you can' and he, I like that, it's a positive, and I like positive, like the positive things that he says.

Sandra’s narrative highlighted clarity and containment in Jim’s more direct expressions and exchanges. The connection she felt with Jim, during and outside his telling, was represented as something at a personal level which brought feelings of affection and positivity. An appreciation of his best standards while being modest was present in Sandra’s re-telling.

Social interaction between Jim and Sandra occurred as he punctuated with his agreement. Although his responses were short, this constructed an air of validation and the narrative being co-constructed. Upon reflection, the social-interactional positions had flipped between Sandra and Jim, with Jim now as an audience member and Sandra performing. This was evident in her switch to directly addressing Jim to engage with his family provider identity, before switching back to addressing me and my question. However, on the wider level, Jim was very much still in performer position. As two professionals in a dementia setting spoke about him in the third person, his interjections also served to maintain his story-telling rights and editorial control.

Wider narratives included that of maleness, which Sandra explicitly referenced and vividly re-constructed in her storied image of Jim. Jim’s maleness was associated with his past activities of being family-orientated, head of the household and a working provider for his family. Although directly addressed to Jim, the current context where these roles were minimised was highlighted by her use of past tense. This narrative construction echoed old age and emasculation through the loss of work and, thus, status which some older age men face.

Following a question regarding the images of Jim evoked for Sandra while witnessing his telling, Sandra introduced an additional image of Jim’s strength:

> [460-477] And it’s just an acceptance, like ‘this is the way it is, you get on with it’, this is the way it is, this is the way it is, rather than, you know? Some people go ‘oh, this is what happened’ and they can’t, you know? You don’t always look ahead. So, I always feel you’ve dealt with what’s been thrown at you. And you’ve had a positive outlook, so you just carry

> on. So, I just feel like you've always strived, you know? Through life, you've always strived. It is what it is, what can you do about it? So, move on. And so, I think you've had that sort of positive way about things you [inaudible]_
> J:_You can't see anything wrong with that at all
> S: You can, you c_
> J: _Can't fault that at all
> S: You can't change, you know? What's happened in the past, you can only go forward. You know?
> J: What's done is done.
> S: Yeah, like a realist, it is, what's done is done, let's move on
> N: Okay
> S: And I think that's a good quality and I like them qualities

Her sense of his resilience and drive made him unique to others. And his realist and positive perspective added to this experience-centred narrative for Sandra; something she appreciated. At a social-interactional level, Jim's rapid confirmation of this image suggested shared meaning. However, I was reminded of the context in which Jim's strength and resilience was narrated. As Jim entered another stage in his life, there were new challenges, such as his new label of dementia and entering a service related to it. The qualities represented by both Jim and Sandra as innate to Jim maintained continuity with his life-long identity and may have offered Sandra additional meaning from her profession.

3.6.2 Own Life: "My grandmother was a real character"

Following the OWP question of own life connections to witnessing Jim's story, Sandra spoke about her grandmother and the similarities she had with Jim:

> [529-555] I think, I like it and I, I like the story and I suppose (p) from my own life experiences (p) can I talk about my grandparents?
> N: Yeah, yeah
> S: My grandmother was really a character, who said it how it was, there was no in between. You liked her or you didn't like her, and that's it. And I admired her, I have a great admiration for her because that's a person,

> that's a sort of person I like. So, when I hear that from Jim and, I think there's an honesty there, you know? Like there's that honesty and I feel comfortable in, in, with people like_
> J: _With me, excuse me interrupting Sandra, with me, I say it as it is, if you got anything to say to me, you say it to me, and I tell you exactly as it is. And that's the way I am. That's the way it is. I'll have that (drags his glasses case across the table from near Sandra).
> <N: (Laugh)><S: [inaudible]>
> J: You know? I speak as I find, if I don't like you, I tell you and that's the way I am. Whatever it is, whatever it is. Everybody's different. Everybody's different
> S: That is it, everybody's is different. You know, everybody's is different_
> N: And allowed to be different
> S: Yeah, we are, and the effect we have on people or around us because we may say something, like we might offend them by saying something, you know? I don't agree or I don't like, you know? Everyone's entitled to their opinion. And, obviously, it's nice if you can do it in a way that you don't really go out your way to offend other people. But sometimes you want to get your opinion across

Interactionally, I was struck by the personal information Sandra had chosen to speak about with Jim, unlike in Gerry's OWP. This may be due to the familiarity with the question or change in context with Jim. However, I was reminded of the centrality of my power as she asked me for permission to share her personal narrative. Jim's interruption of Sandra's narrative of her grandmother built on the narrated honest-speaking self. His additional and repeated points were spoken with conviction. As an audience member, I was drawn into this shared value performed between Sandra and Jim. As Jim stated the acceptance of difference, Sandra repeated this and I shared my personal value. This was one of the rare moments during the OWP we all joined as performers, co-constructing the narrative of difference.

Experientially, Sandra's narratives of her grandmother re-presented her admiration for other's ability to speak with clarity and strength. Listening to Jim gave Sandra's narrative a sense of nostalgia and comfort; wider representations of elders in society as sources of comfort and wisdoms were echoed here as she bought in her grandmother. On the other hand, it highlighted the age differences between Sandra and Jim more, as well as jarring with his masculinity narrative. This may have further pushed Jim's interruption, to attempt to regain control of his narrative.

3.6.3 Transportation: "Can't always please everyone, as Jim always says"

Finally, the closing questions of transport and catharsis, Sandra spoke of the confirmation, as well as changes, of her approach to providing support:

> [792-821] I just feel like by just sitting here and listening to Jim it's understanding why, you know? Why, what makes Jim 'Jim'. You know? And obviously it's respecting how, how, you know? Respecting how we, obviously we'd never be telling you what to do. We wouldn't do that here anyway. We might advise you, like you say, if there was a reason, god. If there was danger or, you know? A best interest, but hopefully like, you know? We'd only do things that would be here for your benefit. So, I just think sitting here listening, understanding and hopeful, and the fact that you (p) you know how you feel about me and [Sally]. I think that's really nice. It's, you know? That it makes us feel that we're doing the right thing together and in supporting you. And that's just nice to hear?
> J: It's the truth. <S: yeah, I know> It's only telling you what I feel about you and [Sally] but I think you, I think you do a very good job. And a lot of people don't appreciate it, and they should appreciate it and they don't <S: um> 'cause there's people here worse off than me who don't appreciate the things that go on. You know that (looks at Sandra)
> <S: And> I don't know that
> S: And it's really nice like to hear that and I'm, you know? And I'm sure it's nice the fact that Jim could, if we wasn't doing anything that you didn't like, you could come and talk to us and we're approachable and we would try and amend it and make it so I was okay to, oh, best abilities. So, I think that's, by like being totally honest with each other and being able to work together like, you know? You know? A team really. And I think that's important like so when you come here it's your club. And we

> try and do the best for everyone. Can’t always please everyone as Jim always says
> N: (Laughs)
> S: But we do our best and hopefully we can_
> J: _That’s all you can do, is your best.
> S: And I, hopefully we can, you know, it’s good feedback
> J: You do your best, (looks at Navi) what else you wanna ask?

As an experience-centred narrative, Sandra’s transformation was re-presented in her understanding of Jim and the different aspects of his identity. Prior to the OWP, I was aware that Jim’s silent demeanour made him an enigma within staff narratives. The OWP offered counter narratives to those which surrounded Jim at the centre. Sandra’s recognition of Jim’s wishes of autonomy was reflected back to him, which may not have happened so explicitly before. However, wider “best interest” [799] professional narratives overshadowed this. Wider loss of autonomy for individual’s with labels such as dementia was present in Sandra’s professional context and role and mental capacity legislation. Additionally, Sandra drew out from the OWP the positive feedback on her management of the centre, which justified the approach she took in supporting PDwD. Wider narratives of less expectations of appreciation in the area of dementia care, present in both Sandra and Kevin’s other narratives, resonated in this narrative also.

Interactionally, Sandra addressed most of her value for open communication directly to Jim, demonstrating the collaborative core of this narrative. Jim’s response was powerful, with the use of repetition and clear outline of the correct behaviour in appreciating good work. The use of other members of the club who did not do this illustrated the violations of this in Jim’s context narrative. Jim’s final punctuating statement encapsulated Sandra’s best ability and directed me to ask the next question, moving on the conversation. This interaction reminded us of the current context in which I was an observer and outsider, as well as rounded the narrative to one of trying your best despite complexities and challenges.

3.7 SANDRA AGAIN: “I don’t judge Jim”

I revisited Sandra a week after the OWP. This was the second time Sandra had been an outsider witness and there was some overlap in her values to listen and support the choices of PDwD. However, key differences arose in her relationship with Jim compared to Gerry outside the OWP:

3.7.1 “He needs to talk. I think it’s good for Jim to talk”

Narrating her experience of Jim’s OWP, Sandra brought forward her values of good support:

> [49-66] I think listening is so important, it’s like, you know? To sit and listen, even if it doesn’t come out in the right context of what he’s actually trying to say? So, by sitting listening to him, it gives me more of an understanding, how to sort of sit with Jim, support Jim. Because I think he’s on a journey, he’s, he doesn’t know where this journey’s gonna take him. And I think he’s a bit scared? And like, you know? Even now he puts on this bold front, but you know? By just like knowing that there’s someone who can listen to him, I think that’s so important. And I feel quite humble like, like it makes me feel quite emoti (tut) not like emotional, like because it’s. These people have run lives and businesses and, you know? All, all of a sudden like little by little it’s getting taken away from him?
> N: <Mmm>
> S: And I just think, if we can make that journey (p) as nice and, you know? And you know? Make him feel valued, which I think is really important. I think then, then it’s all worthwhile coming here doing the job that we do.

> [350-366] Yeah I felt quite emotional towards Gerry I did. And I wanted to give him a big hug afterwards and then. I suppose with Jim (p) because he’s totally different you’ve got to approach him differently. So that’s, that’s the way so (p) I still feel a lot towards Jim because he doesn’t show it ‘cos but. Same time (p) I felt like I had to be strong for Jim to be. I felt like I had to be strong for Jim because I think Jim likes, like that

> mirror reflection of his self so if you're strong than, then he knows he can carry on? So that's how he makes feel? So sometimes, you know? You've got to be like, where I could, with Gerry I could be more be more emotional, go to his level. With Jim I feel like I got to his level. Doing the same thing (cough) but in a different way. And I feel there's different approaches with different people knowing that person. Because one way doesn't work for another person, you know?

Experience-focused analysis centred listening as a means for Sandra to access Jim from behind the tougher front she felt he had in place. In contrast to Gerry's OWP, the relationship narrative with Jim elicited a strength in Sandra to support Jim a different way. Adaptive and tailored support echoed wider person-centred care narratives, however, also connected with Sandra's value of congruence and respect between herself and members of the centre. Additional wider narratives surrounding the above extracts included that of the fear and loss associated with Jim's dementia label. Sandra's extensive experience of supporting PDwD may have exposed her to this narrative more so than others, further eliciting performing protectiveness. Good dementia care as something that made this uncertain and fearful journey more pleasant was a narrative that Sandra valued.

Social interactions during the above extracts supplemented Sandra's narratives of protector and adaptor. This included her emphasis on the point of fear she felt Jim was experiencing. Emotionality was hesitated upon and removed prior to Sandra's acknowledgement of the changes PDwD experienced. This was suggestive of emotion not being an appropriate response and instead Sandra's resistance to the injustice narrative was conveyed through the portrayal of things being taken by dementia.

3.7.2 "Dementia is a big, big thing"

As the interview closed, I opened the space for Sandra to ask me any questions she may have had; bringing in wider discourses surrounding PDwD, a narrative of injustice and complexity was constructed:

> [372-394] (p) Dementia a (laughs) always. Dementia's a big, big thing. And obviously it's, you know? It affects so many people and, you know? In life, and, you know, I just think it's gonna effect so many. And I just think like if there's anything that's gonna benefit, like helps people's with dementia their understanding of that (p) I'm for it. You know? If it doesn't, if it's done in a way like you've done it? Like you haven't imposed on anyone. If they, I'd want to walk out so, you know, I just feel like if I could contribute to helping? I want to. You know? I really want to just because I always think there needs to be an understanding (p) you know? They've got they, in situations they've got no control on no control of this. You know? Like loads of illness. But because, because it's, it's not cancer or other stuff. People don't always see it? So I just feel like the understanding obviously, and giving these people as much opportunity and rights as anyone else. And obviously, it's so important to me. You know? It really is a big thing. 'Cos people don't understand it. They don't, and in medical doctors and things like that, they go, they got no understanding of it, you know? You know I'm not medical at all but like it's so complex. It's so, so complex. And the brain's so complex as well.

Sandra's reference to dementia as a singular entity complimented the wider dominant realist medical narrative of dementia as a neurodegenerative condition, solely responsible of the social and emotional changes experienced by PDwD. However, Sandra's counter-narrative of medical professionals' lack of understanding also questioned medical authority. Her later acknowledgement of her not occupying this position echoed the status and dominance medical professionals had over care professionals' knowledge in regard to dementia. Throughout the extract, experiential analysis emphasised the importance she placed on the preservation of the choices and rights of PDwD in a climate of oppression. She also conveyed her experience of balancing the support she offered members while not imposing their choice.

Social-interactional analysis highlighted the performer and coaxing roles I assumed during the exchange; reflective notes revealed the discomfort I felt during the interview, with the power I held in the role of coaxer. Therefore, my broad invitation to elicit Sandra's narratives also functioned as a performance tool with which the power imbalance could be addressed, if only on a superficial level. Sandra’s response however, did not quite place her in a position of power. Her readily reference to the wider oppressions surrounding PDwD and her role in supporting them re-presented a narrative of limitation. This included the repetitive and vivid imagery constructed of dementia, one of a large personified force which took away PDwD’s control. The comparison to cancer served to construct the socially lowered position of PDwD due to the label being less hopeful and limited understanding. Sandra’s use of first person performed her strong desire to help and promote social inclusion. Her reference to my ability, reminded me of the context within which this project had entered the centre. I may have represented a teacher or source of additional skill to improve Sandra’s and her staff’s fight against the personified dementia.

4. DISCUSSION

The following chapter will discuss the results within the context of existing research, followed by a critical and reflective focus. Finally, I will explore the learning points and recommendations from the current research for professional, service and policy development.

4.1 Research Findings and Existing Literature

Answering the study's research questions, this section will consider the findings in relation to existing literature.

4.1.1 What identities do PDwD story?

Analysis of the OWP was the key focus in addressing this question, however, staff individual interviews served for comparison as well as consistency when interpreting the data across contexts.

4.1.1.1 Storytelling

Before continuing to name the content of the stories told, it was important to understand what definition of storied identities was most supported by the data. Despite some separation in narrative literature of biographical and interactional perspectives of identities (De Fina, 2015). In addressing the research question, data supported literature of PDwD and storytelling being a social action, thus, producing multiple socially dependent identities per individual (e.g. Hydén 2013; Hydén & Örluv 2009; Plummer 1995). However, historical and individual experience narratives shaped interactions with audience members and vice versa.

The category of life stories was partly created by my choice of questions, however, both stories varied greatly. Experience-centred analysis of Gerry's and Jim's stories further explored their life events and how these aided in the construction of their identities. Gerry's narrative from adolescent to working man opened further narratives of transformation, morality and strength. This was facilitated through the OWP space, where audiences were able to both validate and contribute these aspects of identity to the narrative. Both Gerry and Jim's stories contained life event and value based aspects which supported literature definitions of life story (Westius et al., 2010). The benefits of sharing one's story on internalised experiences such as self-esteem, quality of life and/or behaviour changes captured in literature (e.g. Moos & Bjorn, 2006), was not explicitly named in the current study. However, there was evidence of narratives of a positive shared experience being constructed within the OWP. Both PDwD and staff shared humour and appreciated values as well as non-verbal smiles and other interactions, supporting the beneficial perspective of the OWP (White, 2007). This contributed to the understanding of OWP within dementia care contexts as a space to co-create narratives, in particular, ones of less problem saturated identity (White & Epston, 1990). This was further supported in individual staff interviews which appreciatively commented on the novelty from the illness story.

In addition, data from staff interviews supported the more implicit and embodied elements of identity stories being experienced through audience member's re-presenting narratives. Similar to Hydén, and Örulv (2009), Gerry and Jim's stories of identity were also performed non-verbally; Gerry's humour and Jim's short responses created narratives of identities which carried into my reflective journal, witness re-tellings and staff interviews, although subtle changes in meaning existed across contexts. These findings further criticised the dominant findings in literature of individualised definitions of personal narratives.

4.1.1.2 Stories of Masculinity

For Gerry and Jim, wider narratives of masculinity influenced their identity stories. Existing literature focusing on masculinity narratives amongst individuals with a label of dementia is limited but has found certain narrative devices used by men to maintain personhood. Tolhurst and Welcht (2017b) found four themes in narrative interviews with men with a diagnosis of dementia. This included remaining unmoved, fighting back, emphasising social contributions and relating to services and professionals. Gerry's shame and regret from losing his employment was deeply moving and echoed narratives of economic burden of old age literature (Robertson 1990; Castro Romero 2016). However, similar to masculinity literature, Gerry's emphasis of existing skills in skilled labour and enjoying being useful for others, storied a masculine identity which persevered despite changes in social role. Jim on the other hand, constructed a masculine identity from past examples where he remained reserved and quiet at times to protect his best interest. These re-presented cultural narratives of a ‘stiff upper lip’ (Chapstick & Clegg, 2013), as well as remaining unmoved during testing times, displaying strength.

However, such hegemonic masculinity narratives were not internal to PDwD, but were equally brought to their identity narratives by their audiences. Sandra’s admiration of Jim’s strength and impressions of his ‘provider’ social role re-enacted dominant expectations of men of Jim’s generation. Despite wider context and narratives hindering masculine identity, such as less opportunity to work or play sports, this identity prevailed. Both narratives were introduced in the present tense with audience perpetuation. These findings supported the gendered experience of identity for Jim and Gerry and highlight the importance that wider social narratives have on the storied identity of PDwD. This emphasises the need to move beyond the narratives of old age, dementia and economic contribution more commonly associated to PDwD and appreciate the idiosyncrasy of identity narratives for each individual.

4.1.1.3 Stories of Control

Wider literature suggests the oppressive effects of dominant narratives of dementia upon PDwD and their surrounding systems. The pervasiveness of cognitive functioning equating identity explanations were present in both Jim’s and Gerry’s stories as well as staff interviews. This included Gerry’s reference to not being 100 percent and Jim’s comparison to other PDwD worse off than him. However, similar to Clare et al. (2016), resistance was present in the preference of identity narratives constructed by Jim and Gerry in their initial tellings as well as ongoing interactions. Explicit resistance to ‘social death’ (Lyman, 1989) and passiveness were storied as innate valued traits. Both Gerry and Jim exclaimed the importance of choice and physical resistance to being told what to do. Gerry’s value of equality and Jim’s value of difference advocated for nuanced idiosyncratic representations which contrasted more homogeneous narratives found in literature to dominate PDwD and older adult identities (e.g. Castro Romero, 2016). These narratives were bolstered by elongated conversations and acknowledgements in the OWP and carried into

Sandra and Kevin's recollections of these conversations in individual interview. Findings support the claims of OWP offering reclamation and redefinition of preferred identities in the reauthoring and acknowledging practices (Morgan, 2000; White, 2007; White & Epston 1990).

Their references to other members of the centre served to further distance themselves from dementia narratives and also validated their less problem focused identities. Although this may have simultaneously also contributed to othering and "inter-relational violence" against PDwD (Mitchell et al., 2013: 3), thus maintaining the dominance of the reductionist narratives. However, both stories also conveyed empathy for the experiences of the other PDwD at the centre, regardless of whether they identified with their label or not. This demonstrated their constructions of medical stories also had space for difference, creating choice and control in holding both meanings. This undermined literature claiming the all-encompassing and damning effect of medical narratives on PDwD (e.g. Mitchell et al, 2013; Zellig, 2013; Behuniak 2011). Gerry and Jim's narratives demonstrated the understanding such narratives brought in explaining other's atypical behaviour rather than malice.

Capacity related narratives were also seen to have oppressive contributions to PDwD's stories in literature (Goldsmith, 1996; Mitchel et al., 2013; Sabat, 2006). Gerry's values of trust from others and honesty highlighted the invalidating experiences PDwD face if deemed to lack capacity. By explicitly naming trust as part of his narrative, Gerry's meaning gained recognition in the OWP. This complimented Sabat's (2006) call for capacity assessment to focus less on competency and more on meaning-making at the individual level. Less explicitly, Jim's separation of professional and personal narratives further protected his identity story from the influence of professionals, who are often decision-makers in capacity assessments (O'Connor & Purves, 2009). This indicated a more indirect construct of narratives to resist wider influence. The value and demonstration of privacy in Jim's OWP expanded on literature to include more non-verbal constructions of meaning and choice. This is particularly poignant for people who are less verbal due to cognitive differences.

4.1.2 How does hearing these preferred identities impact staff?

Two sources of data contributed to exploring this question, individual staff interviews and the OWP; both had very different context and consequently varied narratives of impact were produced.

4.1.2.1 Person-centred care

As literature suggested, political drivers encourage person-centred care, despite conflicting definitions and over focus on staff ability (Dewing, 2008a; Davis, 2004). The findings in the current study were similar, with Sandra and Kevin representing the care culture of the entire centre to me and the invisible audience this study would have. Sandra's values of supporting PDwD included listening, respecting and promoting choice. Hearing preferred identities offered connection to shared values with Jim and Gerry which supported OWP literature (White 2007; Blake & Kaiser 2019). Storytelling was collaborative and, in the moment, offering validation of these narratives of good care. The current study also illustrated the more embodied and relational narratives of impact OWP had on Sandra and Kevin. Bonding, closeness and emotive reactions in the data mapped onto literature of life story working increasing staff connection to the individuals they supported (Kellet et al., 2010) but expanded narrative literature on the use of OWP in dementia settings specifically.

Kevin's gratitude for the opportunity to listen to Gerry, and desire for more opportunities like those in OWP, was illustrative of some discrepancy between the job roles he had and his most valued aspects of supporting PDwD. Literature suggested the deleterious effects this can have on staff wellbeing (Clisset et al., 2013; Jakobsen & Sorlie, 2010; Kitwood, 1997). Incongruence was also witnessed between narratives of professionalism and the relational focused narratives constructed in OWP. Hesitation in offering information of personal lives illustrated professionalism as separate to one's own experiences, placing staff in a novel situation. This questions the literature of person centred care as something empowering for PDwD and staff (Kitwood 1997; Clisset et al., 2013). The findings demonstrated the power imbalance present for PDwD in having to share personal information more readily than those without a label of dementia. As seen in interviews with Jim, this is not always compatible with PDwD's identities and values. This supports arguments for a collapse of personal and professional constructed boundaries to incorporate shared personal meanings (McCormack & Reed, 2006). However, wider narratives of risk management and capacity entered Sandra’s narrative both inside and outside the OWP. This represented conflicts in her dual positions in which duty of care was prioritised in keeping PDwD safe first and foremost, despite occasions where this clashed with her choice promoting values, often associated with person-centred care (Innes, 2009).

4.1.2.2 Medical Dominance

Staff are also surrounded by dominant medical narratives of dementia (Innes, 2009) and this was most apparent in the interview data. Sandra’s outline of Gerry’s deterioration in her individual interview maintained the dominant narratives of PDwD losing function, despite hearing Gerry’s preferred identity, which did not mention the label of dementia or deterioration. The change in context was significant in understanding the co-constructed narratives. An interview with a psychologist and professional warranted a construct which may not have been appropriate with a PDwD. Capacity was another key concept in invalidating the preferred identities in the OWP, despite not being mentioned overtly, it was present in the wider illness narrative. The dementia narrative also conjured up fear and loss, confirming previous findings (Zellig, 2013).These findings offer some insight into the limitations of OWP in having a sustaining impact on witnesses and more dominant narratives. On the other hand, OWP did offer an expanded conversation of less dominant narratives, illustrated with both Kevin and Sandra’s comments on the pleasant novelty in hearing Gerry speak; echoing literature demonstrating story-telling challenges medical and disease-saturated views (Broadhead, 2012; Kellet et al., 2010) as well as OWP aims of thickening subjugate narratives (White, 2007).

Current findings offered a more nuanced account than literature supportive of professional being compliant with the medical narrative (e.g. Innes 2009). Resistance to the illness narrative was present in both the individual interviews and OWP. Sandra’s questioning of the accuracy of medical knowledge named the discrepancy in preferred narratives of identities and medical professional explanations. The overshadowing of personal narrative was constructed as the cause of social exclusion of PDwD by society. Acknowledgement of personal narratives in OWP promoted space for such counter narratives and shone an important light on the dominance of the illness model not only on PDwD but also on the staff working in a dementia context.

4.2 Critical Review

This section will consider factors which may have limited the interpretations and narratives produced for the current study.

4.2.1 Trustworthiness of Analysis

As outlined in Section 2.9, Riessman's (1993) framework for narrative research was employed to evaluate the data of the current study. Here, a critical review will be presented with three of the four areas that Riessman proposed: the persuasiveness, correspondence and coherence of the data. The final area of pragmatic use will be presented when considering the implications of the findings for future research (see Section 4.3).

- Persuasiveness of the analysis considered the plausibility of interpretations presented in the current study. This is largely dependent on reader reaction (Riessman, 1993), although efforts were made to strengthen persuasiveness. These included the use of direct quotes to evidence theoretical claims. Interpretations demonstrated a transparent link to wider political and research context surrounding participant narratives. Reflexivity, as well as inclusion of my coaxing and other contributions to narrative construction, increased transparency and openness to the interpretation beyond my perspective.
- Correspondence considered how related the narrative I presented in analysis aligned with participant's narratives. Checking analysis with participants ensured their narratives were recognisable in my re-presentation and expanded more nuanced elements to interpret the narrative performance from the performer's perspective. This in turn also improved ethical practice when producing the story of the participants as well as rechecking consent. Correspondence to well-founded knowledge (Riessman, 2008), included linking to current literature and offering more

context than themes, allowing room for diverse and complex interpretations using key concepts.

- Coherence across different levels of meanings was considered at global, local and themal levels (Riessman, 1993) through the use of staged narrative analysis considering experiential, interactional and wider narrative levels. Transparency of steps led the reader to see the narrative progress from rationale onto analysis selection and then to interpretation.

4.2.1 Methodological Limitations

The questions I asked led participants to produce narratives of life story and were relationally favoured over other possible narrative forms. The context created by the group set up and White's (2007) questions aided narrative constructions, however, inference of the positive narratives of impact cannot be claimed fully. As White (2007) outlined, success of OWP is in the therapist maintaining focus on witnesses' feedback to verify the preferred story. As a researcher, I was unable to control for this without influencing the data more than needed. In addition, traditional OWP would occur with witnesses picked by the individual and preferred stories could be scripted or produced prior to the OWP. These factors would have produced a more centred and truer form of OWP than the present study created. However, as outlined in the aims of the research, the purpose was not to assess the effectiveness of the practice but analyse the social processes it contributed in the narratives produced.

Narrative research with minimum questions is idealised to minimise researcher influence (Riessman, 2008). However, to ensure participant comfort, as well as supporting those with memory difficulties, more follow-up and repeated last phrases were used throughout the interviews. As Riessman (2008) outlined, the goal of narrative interviews is to elicit long narratives rather than brief statements. Therefore, interviewing Jim required a lot more questions than for Gerry, Kevin or Sandra.

Riessman (2008) acknowledged the difficulties in capturing data for interactional analysis. Although I claim transparency in my interactions and contributions to narrative construction, I was only able to capture verbal and other transcribed data. Non-verbal interactions I was unable to record or recognise were lost, and limited the extent to which data was reflective of the interactions. Video recordings would have offered the most detailed account of interactions for analysis, including body language, smiles and nodding. I attempted to capture these aspects in my journaling as recommended by NA literature (Earthy & Cronin 2008; Riessman 2008), however this scope for capturing remained limited.

4.2.3 Ethics

Participant selection was another area of critique for the current study. Management of the centre put forward suitable participants for the current study which meant suitability was determined by professional's assumptions and denied opportunity to some service users over others. I attempted to open up selection by speaking about my study at the Memory Café, where many members and relatives attended. However, prior rapport building, which aided the process consent methodology and key to trust and familiarity, was only possible with Gerry and Jim. This is particularly poignant due to the evidence of gate keeping by professionals for PDwD (e.g. Nygard, 2006; Boyle 2009; McKeown et al., 2015).

Process Consent seeking offered an audit trail of checking and rechecking consent, which is more meaningful than single signature forms for people with memory difficulties (Dewing, 2008b). However, incomplete elements included checking analysis, as one participant fell seriously ill. Offers to visit and/or speak to his wife as proxy were given, however, not taken up. This questions the ethical claims of Process Consent, which can become open to interpretation in the research context if rigour is not upheld. To make consent seeking as meaningful as possible, summaries of analysis will be produced with the option to read the summary, full thesis or have a one on one presentations. These will serve to uphold informed consent as data is used for further publications.

Despite best efforts to minimise power difference, I inadvertently re-enacted power imbalances in several ways. The OWP interview created space to hear PDwD's voices which can be silenced for many reasons (Goldsmith, 1996).

However, by placing Jim and Gerry in a setting with three professionals, every error was magnified and open to interpretation within the label of dementia narratives. This was evident in the individual interview with Sandra following Gerry's OWP. Furthermore, talking about Jim and Gerry in the third person placed them in a position of exclusion; this was counteracted when witnesses switched to direct addressing at times. In addition, anonymity could not be protected within the service of both PDwD and staff. This was made explicit in participant information sheet and verbal discussion before proceeding with the study. This opened participants to influence upon employment or support at the centre if negative narratives were expressed. To mitigate this risk, the OWP was set up as a space for validation and acknowledgement rather than criticism prior to the interview. In addition, in checking analysis, participants were offered to voice any objection or concern with the data being used which they may not have wanted shared.

Similarly, to the narrative economy named by Hillman et al. (2018), I gained significantly using participant's narrative for my doctoral thesis. In comparison, participants did not gain such long-term benefits from taking part. To address this, a relationship post-research has been set up, supporting the service as a volunteer was agreed with management at the centre; offering a novel space for staff to reflect on their relationships with members and identify opportunities to develop their understandings of each other through narrative means. Additionally, speaking at the Memory Café ran by the centre also serves to introduce the uses of narratives work to wider systems, such as relatives, who can construct different identity stories.

Finally, while designing the current study an attempt was made to carry it out in an NHS inpatient unit. However, barriers were faced at the research ethics committee decision as well as the application phase regarding assumptions of competence-based capacity and inability (Sabat 2006; Cotrell & Schulz, 1993). This is not uncommon for research with PDwD or other labels of impairment (e.g. dementia researcher podcast 2019; Hays, Murphy & Sinclair 2003). Waite, Poland and Charlesworth (2019) called for researcher education and increased resources to challenge barriers in assumptions of professionals of PDwD's ability and contributions to research. The current study was later carried out in a third sector organisation using university ethical approval. This questioned assumptions made in the NHS context of PDwD's ability to safely contribute to research with consent and level of risk OWP entailed.

4.2.4 Reflections

Reflexivity was upheld throughout various stages of the study with use of supervision and journaling to ensure my assumptions were questioned as I recreated a narrative of findings. For example, supervision supported me in my strong attachment to Gerry's stories as he had fallen ill, and I had difficulty cutting his section to adhere to word count. This had unintentionally made the analysis disjointed and overbearing; losing his stories. Supervision questioned what benefit I was gaining from what I was presenting and how I could honour his stories without assuming too much without his checking.

Reflections on power and position as a researcher in the current project raised many questions in relation to Gerry, Jim, Sandra and Kevin. I was aware of my power as coaxer over staff members, but in the context of job roles and positions carried further meaning. I was an external person bringing in wider judgements of good dementia care, which can be intimidating. As a young Indian female, I brought my own inequalities, however, carried a lot of privilege and status (e.g. university education, close association to medical professions and employment), which opened my interactions with participants to further power dynamics. Additionally, I was not Jewish, which may have contributed to less familiarity and difference which would have taken more time to adjust to, if at all.

In addition, an attempt was made to connect the centre to local NHS dementia and older adult mental health teams. Management named this as a gap which my position as a professional could have helped bridge through introduction. However, this was difficult to achieve, and I reflected on service provisions in the area constructing this separation. The wider political push for dementia friendly communities (DoH, 2015) may not have addressed the separate organisational processes within NHS and third sector areas. Outreach work is not always possible in NHS settings and service remit as well as individual staff availability. I was also reminded of recent pushes for intergenerational working between older and younger generations from an All Parliamentary Political Group interim report (APPG, 2019) to aid this separation through community level interventions to share stories.

Revisiting my personal context from section 1.1, my dual position between Sikh-Punjabi and British narratives opened the possibility of varying and competing views of elders, PDwD and identities. I too, have had to occupy a multitude of narrative positions as a health professional and individual from an ethnic minority. This personal narrative of social shape shifting opened an appreciation for the complexity of narratives created with all participants, influencing methodology selection and the analysis process. The vastness of NA became overwhelming with this appreciation at times, but supervisory space allowed safe exploration. While carrying out the current study, my cultural narratives of respect for elders was prominent in the relationships I built with participants. This was particularly influential on the social location constructed in data collection which made this OWP space unique to this point in time. My personal narratives were present at every stage of the current study and reflexivity created room to explore their presence in the re-presentations I generated (Riessman, 2008).

4.3 Implications and Recommendations

This section will consider the implications of the findings of the current study at clinical, service and policy levels as well as provide recommendations for future research. This is particularly important as Riessman (1993) argued the usefulness of findings to the audience determined, the trustworthiness of the data. Operationalising the findings at different levels will be considered with the role of clinical psychology as expected from professional guidance on role and leadership (British Psychological Society [BPS], 2007).

4.3.1 Clinical Practice

The complex and multifaceted constructions of identity narratives must be recognised in practice beyond the more dominant medical and loss narratives engrained in professional settings. Clinical Psychologists (CPs) sit in the unique position of facilitating such alternative narratives through therapeutic means.

The current findings highlight the opportunities OWP give to conversations and acknowledgement of such preferred identities, specifically within a dementia context. Due to the social construction of identities apparent in the current study, OWP must be considered at both direct and indirect working to ensure these conversations occur with different parts of the social systems surrounding PDwD. Working psychologically with teams is associated with CPs (BPS, 2007) and narrative approaches can inform this role further. OWP can be relatively straightforward to set up and compliment existing meeting spaces for professionals and PDwD, such as multidisciplinary team (MDT) meetings and service user groups.

The therapeutic relationship is imperative for CPs and other professionals to consider when working with PDwD. Although the concept can be constructed using multiple different theoretical narratives, the current study highlighted the powerful role professionals held in constructing our client's stories of identities through a more interactional and embodied degree. The implications of this finding argue the responsibility CPs hold to both reflect on and address such power, through supervision and adapting a more conscientious approach. I acknowledge the strong role CPs hold in dementia diagnosis through neuropsychological testing and the current study does not negate the benefits a label of dementia can offer some individuals experiencing cognitive difference. However, it is important CPs continually nuance the dementia narrative with relational, historical and further idiosyncratic narratives with the knowledge these will be dominated by the dementia label from the moment the term is mentioned. In addition to the therapeutic relationship and narrative practice, these alternative narratives must be present in disseminations and team discussions to ensure they reach a wider audience.

4.4.2 Service Level

The current study demonstrated the strength, yet inconsistency, person-centred care held in staff stories. Service's dual positions in both adding and subtracting personal narrative must be acknowledged and balanced to get to a shared meaning of person-centredness. Findings highlighted the importance of narratives of person-centredness to be more fluid and dynamic, beyond static staff ability or professionalism. CPs can empower staff to use their relational and embodied knowledge more safely in reflective practice and designing organisations which validate and merit the personal in the professional. In addition, as leaders, CPs can ensure the voices of care and support staff are consulted to expand the illness narratives more closely associated with health professionals.

However, although it is important to bring in staff relational narratives, it can only improve person-centred understanding if the person's narrative is also present. A key finding in the current study was the disparity between being person centred and PDwD's values. The value of privacy and control for Gerry and Jim was incongruent with definitions of person-centred care. From this, it is more important to understand the social processes in providing and receiving support and acknowledge the PDwD's experiences of change in social position. Clinical Psychology can facilitate such spaces for service user feedback with an awareness of power differences and a need to be flexible. In this position, CPs can safeguard against service-wide pushes to be person-centred or help to prevent service user feedback from becoming tokenistic and forceful. The current study highlights this will not be a linear process and will take time, but as CPs we must ensure this complexity of human stories is honoured and revisited.

4.4.3 Policy and Political Level

As outlined at the beginning of this this paper, the public terrain in which PDwD navigate contain certain influential political stories. To ensure these homogenous narratives of PDwD and older adults are challenged, more space and support for narratives from different contexts must be given on more public platforms. The use of media, political challenger groups and meaningful service user feedback are just a few sources of scrutiny of dominant, taken for granted, truths. It is important the responsibility to challenge powerful narratives extends beyond health and social contexts, where CPs mainly reside. The current study highlighted the impact of economic worth, masculinity and invalidation on Jim and Gerry's stories of identity which were solidified within narratives of illness and retirement. Alternative narratives of dementia and old age can be introduced in non-conventional settings, such as schools and public spaces e.g. libraries. Building on the benefits of dementia friendly communities (DoH, 2015) and intergenerational working (APPG, 2019), CPs can advocate for such ventures through publicly supporting and consulting on policy developments. Creating contexts which encourage acceptance and listening to alternative narratives, which can also question society's implications in the constructions of identities and stigmatisation of PDwD.

4.4.4 Future research

The implications for future dementia related research methods from the current findings include the advances in Process Consent to gain consent meaningfully and ethically from individuals for which traditional singular signatures are not relevant. Embracing this practice as psychologists and researchers demonstrates a continuous relational commentary and an ethical and inclusive social research standard for others in the research community to follow. In addition, current findings have clearly indicated the subjective and interactional influence researchers have on participant stories and calls for an abandonment of an objective truth-seeking psychological research. This is a transparent acknowledgement of the humble knowledge academia can produce when collecting narratives and the use of reflection and rechecking with participants is a must.

Future research directions recommended by the current study include; offering space for individuals with additional context and social difference narratives, such as women with diagnoses of dementia's gendered experiences in constructing their identity narratives. Additionally, the push for greater diagnosis of individuals from ethnic minority backgrounds in healthcare (BPS, 2018) opens it to risk of overshadowing cultural and racial narratives of identities with dominant medical and western stories. It is important for research to consider the counter-narratives constructed from differences when accessing the experiences of PDwD and challenging the existence of homogenous stories.

4.5 Conclusion

In conclusion, the current study explored the storied identities of PDwD and the impact of hearing these stories on their staff. It highlighted the dependency of such stories on social process, past experiences and wider narratives surrounding the storyteller. OWP as a social location for such storytelling offered a protective space to explore more idiosyncratic productions without completely succumbing to dominant illness and loss narratives. Staff were appreciative of the novel space to explore the relational aspects of their work with PDwD. OWP was utilised as a space to witness PDwD in a different capacity to what has traditionally been seen, validate the support that PDwD valued as well as acknowledge violations of their values and roles in the story of person-centred care. Future practice and research must appreciate the personal stories PDwD have and reflect on the influence we, as a society, have on these individuals. CPs close proximity to the medical narrative places us in the unique position to bring in the nuanced and varied stories surrounding the people we support, both directly and indirectly. It is time to move away from the humanitarian versus medical divide and instead create narratives which acknowledge that both are present together and are not mutually exclusive. Dementia need not be the only meaning (of multiple meanings) when trying to understand another person or ourselves.

REFERENCES

Afuape, T. (2011). *Power, resistance and liberation in therapy with survivors of trauma : to have our hearts broken*. Hove: Routledge.

All Party Parliamentary Group. (2019). *Healing the generational divide interim report on intergenerational connection*. London.

Andrews, M., Squire, C., & Tamboukou, M. (2008). *Doing narrative research*. Cornwall: SAGE.

Baldwin, C. (2006). The Narrative Dispossession of People Living with Dementia: Thinking About the Theory and Method of Narrative. In *Narrative, Memory & Knowledge: Representations, Aesthetics, Contexts.* (pp. 101–109). Huddersfield: University of Huddersfield.

Ballard, K., Elston, M. A., & Gabe, J. (2005). Beyond the mask: Women's experiences of public and private ageing during midlife and their use of age-resisting activities. *Health*, *9*(2), 169–187.

Bamberg, M., & Georgakopoulou, A. (2008). Small stories as a new perspective in narrative and identity analysis. *Text & Talk*, *28*(3).

Banerjee, S. (2012). The Macroeconomics of Dementia—Will the World Economy Get Alzheimer's Disease? *Archives of Medical Research*, *43*(8), 705–709.

Barker, C., Pistrang, N., Elliott, R., & Barker, C. (2002). *Research methods in clinical psychology : an introduction for students and practitioners*. London: J. Wiley.

Batra, S., Sullivan, J., Williams, B. R., & Geldmacher, D. S. (2016). Qualitative assessment of self-identity in people with advanced dementia. *Dementia*, *15*(5), 1260–1278.

Bell, J. S. (2002). Narrative Inquiry: More Than Just Telling. *TESOL Quarterly*, *36*(2), 207–213.

Blake, D., & Kaiser, P. (2019). 'It reminds you really of what the job is about': Introducing narrative practices to an older adult day hospital. *Psychology for Older People: The FPOP Bulletin*, *145*, 47–52.

Bogdan, R., & Biklen, S. (1998). *Qualitative research for education: An introduction to theory and methods*. Boston: Allyn and Bacon.

Boyle, G. (2004). Facilitating choice and control for older people in long-term care. *Health and Social Care in the Community*, *12*(3), 212–220.

Boyle, G. (2009). The mental capacity act 2005 deprivation of liberty safeguards and people with dementia: The implications for social care regulation. *Health and Social Care in the Community*, *17*(4), 415–422.

Boyle, G. (2014). Recognising the agency of people with dementia. *Disability and Society*, *29*(7), 1130–1144.

Boyle, G. (2010). Social policy for people with dementia in England: Promoting human rights? *Health and Social Care in the Community*, *18*(5), 511–519.

Boyle, G. (2008). The Mental Capacity Act 2005: Promoting the citizenship of people with dementia? *Health and Social Care in the Community*, *16*(5), 529–537.

Braun, Virginia & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.

British Psychological Society. (2007). New ways of working for applied psychologists in health and social care: Working psychologically in teams. *Leicester, England: British Psychological Society*.

Broadhead, R. (2012). Starting out: Student Experiences in The Real World of Nursing. I am Proud of My Contribution to a Patient and His Family's Care. *Nursing Standard*, *26*(31), 27.

Brooker, D. (2007). *Person-centred dementia care : making services better*. London: Jessica Kingsley Publishers.

Brunet, M. (2014). Targets for dementia diagnoses will lead to overdiagnosis. *BMJ (Online)*, *348*(April), 1–2.

Bryden, C. (2005). *Dancing with dementia.* London: JESSICA KINGSLEY PUBLISHERS.

Burr, V. (2003). Social Constructionism. In *Social Constructionism*. Oxon: Routledge.

Caddell, L. S., & Clare, L. (2011). I'm still the same person: The impact of early-stage dementia on identity. *Dementia*, *10*(3), 379–398.

Cantley, C. (2001). Understanding the policy context. In C. Cantley (Ed.), *A handbook of dementia care*. Buckingham: Open University.

Care Act 2014 (C. 23). London: HMSO.

Carey, M., & Russell, S. (2003). Re-Authoring: Some answers to commonly asked questions compiled by Maggie Carey & Shona Russell. *International Journal of Narrative Therapy and Community Work*, (3), 63–90.

Castro Romero, M. (2016). Liberatory Praxis Alongside Elders. In T. Afuape & G. Hughes (Eds.), *Liberation practices : towards emotional wellbeing through dialogue*. Oxon: Routledge.

Charlesworth, G. (2018). Public and patient involvement in dementia research: Time to reflect? *Dementia*, *17*(8), 1064–1067.

Clare, L., Quinn, C., Jones, I. R., & Woods, R. T. (2016). “I Don’t Think Of It As An Illness”: Illness Representations in Mild to Moderate Dementia. *Journal of Alzheimer’s Disease*, *51*(1), 139–150.

Clissett, P., Porock, D., Harwood, R. H., & Gladman, J.R. (2013). The challenges of achieving person-centred care in acute hospitals: A qualitative study of people with dementia and their families. *International Journal of Nursing Studies*, *50*, 1495–1503.

Cotrell, V., & Schulz, R. (1993). The Perspective of the Patient with Alzheimer’s Disease: A Neglected Dimension of Dementia Research. *The Gerontologist*, *33*(2), 205–211.

Cowdell, F. (2008). Engaging older people with dementia in research: myth or possibility? *International Journal of Older People Nursing*, *3*, 29–34.

Crichton, J., & Koch, T. (2007). Living with dementia: Curating self-identity. *Dementia*, *6*(3), 365–381.

Davidson, S., Harper, D., Patel, N., & Byrne, A. (2007). Drawing Back the curtain: maintaining a critical approach. *The Journal of Critical Psychology, Counselling and Psychotherapy*, 7 (4), 201–210.

Davis, D. (2004). Dementia: sociological and philosophical constructions. *Social Science and Medicine*, *58*(2), 369–378.

De Fina, A. (2015). Narrative and Identities. In A De Fina & A. Georgakopoulou (Eds.), *The Handbook of Narrative Analysis*. Chichester: John Wiley & Sons, Inc.

Dementia Researcher. (2019). Podcast – Navigating Research Ethics [Audio Podcast]. Retrieved 7 January 2019, from https://www.dementiaresearcher.nihr.ac.uk/podcast-navigating-research-ethics/

Department of Constitutional Affairs. (2007). Section 5.38. In *Mental Capacity Act 2005. Code of Practice.* London.

Department of Health. (2015). *Prime Minister’s challenge on dementia. Delivering major improvements in dementia care and research by 2020*. London.

Department of Health. (2009). *Living Well with Dementia - National Dementia Strategy*. London.

Dewing, J. (2002). From ritual to relationship A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*, *1*(2), 157–171.

Dewing, J. (2008b). Process consent and research with older persons living with dementia. *Research Ethics Review*, *4*(2), 56–64. https://doi.org/10.1177/174701610800400205

Dewing, J. (2008a). Personhood and dementia: revisiting Tom Kitwood's ideas. *International Journal of Older People Nursing*, *3*(1), 3–13. https://doi.org/10.1111/j.1748-3743.2007.00103.x

Earthy, S., & Cronin, A. (2008). Narrative analysis in Chapter in N. Gilbert (ed) (2008) Researching Social Life , 3rd Edition, London: Sage.

Ellis, C., & Bochner, A. (2000). Autoethnography, personal narrative, reflexivity. In D. N.K & L. Y.S (Eds.), *Handbook of Qualitative Research* (pp. 733–68). London: Sage Publications.

Emerson, P., & Frosh, S. (2004). *Critical Narrative Analysis in Psychology*. *Critical Narrative Analysis in Psychology*. New York: Palgrave Macmillan.

Eritz, H., Hadjistavropoulos, T., Williams, J., Kroeker, K., Martin, R. R., Lix, L. M., & Hunter, P. V. (2016). A life history intervention for individuals with dementia: A randomised controlled trial examining nursing staff empathy, perceived patient personhood and aggressive behaviours. *Ageing and Society*, *36*(10), 2061–2089.

Esin, C., Fathi, M., Squire, C., & Flick, U. (2013). Narrative Analysis : The Constructionist Approach. *The SAGE Handbook of Qualitative Data Analysis*, 203–216.

Evans, S. (2014). What the National Dementia Strategy forgot: providing dementia care from a psychodynamic perspective. *Psychoanalytic Psychotherapy*, *28*(3), 321–329.

Fels, D. I., & Astell, A. J. (2011). Storytelling as a Model of Conversation for People With Dementia and Caregivers. *American Journal of Alzheimer's Disease & Other Dementias*, *26*(7), 535–541.

Fox, P. (2000). The role of the concept of Alzheimer disease in the development of the Alzheimer's Association in the United States. In P. J. Whitehouse, K. Maurer, & J. F. Ballenger (Eds.), *Concepts of Alzheimer disease : biological, clinical, and cultural perspectives*. Johns Hopkins University Press.

Friel McGowin, D. (1994). *Living in the labyrinth : a personal journey through the maze of Alzheimer's*. New York: Delta.

Geldmacher, D. S. (2002). Cost-Effective Recognition and Diagnosis of Dementia. *Seminars in Neurology*, *22*(1), 63–70.

Gergen, K. J. (1994). *Toward transformation in social knowledge*. London: Sage Publications.

Goldsmith, M. (1996). *Hearing the voice of people with dementia : opportunities and obstacles*. London: Jessica Kingley Publishers.

Guendouzi, J., Davis, B. H., & Maclagan, M. (2015). Expanding Expectations for Narrative Styles in the Context of Dementia. *Topics in Language Disorders*, *35*(3), 237–257.

Gullette, M. M. (2004). *Aged by culture*. University of Chicago Press.

Haak, N. J. (2002). Maintaining Connections: Understanding Communication from the Perspective of Persons with Dementia. *Alzheimer's Care Quarterly*, *3*(2), 116–131.

Harding, N., & Palfrey, C. (1997). *The social construction of dementia : confused professionals?* London: J. Kingsley Publishers.

Harris, P. B., & Keady, J. (2009). Selfhood in younger onset dementia: Transitions and testimonies. *Aging & Mental Health*, *13*(3), 437–444.

Hayajneh, F. A., & Shehadeh, A. (2014). The impact of adopting person-centred care approach for people with Alzheimer's on professional caregivers' burden: an interventional study. *International Journal of Nursing Practice*, *20*(4), 438–445.

Hays, S.-J., Murphy, G., & Sinclair, N. (2003). Gaining ethical approval for research into sensitive topics: 'two strikes and you're out?'1. *British Journal of Learning Disabilities*, *31*(4), 181–189.

Heggestad, A. K. T., & Slettebø, Å. (2015). How individuals with dementia in nursing homes maintain their dignity through life storytelling - a case study. *Journal of Clinical Nursing*, *24*(15–16), 2323–2330.

Hillman, A., Jones, I. R., Quinn, C., M. Nelis, S., & Clare, L. (2018). Dualities of dementia illness narratives and their role in a narrative economy. *Sociology of Health & Illness*, *40*(5), 874–891.

Holstein, M. (1997). Alzheimer's disease and senile dementia, 1885–1920: An interpretive history of disease negotiation. *Journal of Aging Studies*, *11*(1), 1–13.

Hughes, T., & Castro Romero, M. (2015). A processural consent methodology with people diagnosed with dementia. *Quality in Ageing and Older Adults*, *16*(4), 222–234.

Hydén, L.-C., & Örulv, L. (2009). Narrative and identity in Alzheimer's disease: A case study. *Journal of Aging Studies*, *23*(4), 205–214.

Hyden, L. (2013). Storytelling in dementia : Embodiment as a resource. *Dementia*, *12*(3), 359–367.

Innes, A. (2009). *Dementia studies a social science perspective*. London: Sage Publications.

Jakobsen, R., & Sørlie, V. (2010). Dignity of older people in a nursing home: Narratives of care providers. *Nursing Ethics*, *17*(3), 289–300.

James, I. A., & Moniz-Cook, E. (2017). Behaviour that challenges' in dementia care: An update of psychological approaches for home and care home settings. *Psychology for Older People: The FPOP Bulletin*, *140*, 66–68.

Jutlla, K. (2011). *Caring for a person with dementia: a qualitative study of the experiences of the Sikh community in Wolverhampton*. Keele University. Thesis.

Kaiser, P. (2018). Ordinary lives, extraordinary people: Life story work with people with dementia. *Psychology of Older People: FPOP Bulletin*, *141*, 27–32.

Kaiser, P. (2016). *Life Story Work with People with Dementia.* London: Jessica Kingsley Publishers.

Kellett, U., Moyle, W., McAllister, M., King, C., & Gallagher, F. (2010). Life stories and biography: A means of connecting family and staff to people with dementia. *Journal of Clinical Nursing*, *19*(11–12), 1707–1715.

Killick, J., & Allan, K. (2001). *Communication and the care of people with dementia*. Open University.

Kitwood, T. M. (1997). *Dementia reconsidered : the person comes first*. Open University Press.

Knapp, M. G., M. McCrone, P. Prina, M. Comas-Herrera, A. Wittenberg, R., & Adelaja, B. Hu, B. King, D. Rehill, D. S. (2014). *Dementia UK: Update*. *Igarss 2014*.

Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J., … & Stewart, R. (2007). Dementia report UK. Alzheimer's Society: London

Kontos, P. C. (2004). Ethnographic reflections on selfhood, embodiment and Alzheimer's disease. *Ageing and Society*, *24*(6), 829–849.

Longley, M. & Warner, M. (2002). The national policy context across Europe. In M. L. & B. L. M. Warner., S. Furnish (Ed.), *Alzheimer's disease : policy and practice across Europe*. Oxon: Radcliffe Medical Press.

Lyman, K. A. (1989). Bringing the Social Back in: A Critique of the Biomedicalization of Dementia 1. *The Gerontologist*, *29*(5), 597–605.

MacRae, H. (2011). Self and other: The importance of social interaction and social relationships in shaping the experience of early-stage Alzheimer's disease. *Journal of Aging Studies*, *25*(4), 445–456.

MacRae, H. (2010). Managing Identity While Living With Alzheimer's Disease. *Qualitative Health Research*, *20*(3), 293–305.

Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *Lancet*, *358*(2), 483.

McCormack, B., & Reed, J. (2006). Editorial: ‘Evidence-based healthcare – a lot of bull?’ *International Journal of Older People Nursing*, *1*(3), 129–130.

McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, *19*(13–14), 1935–1943.

McKeown, J., Ryan, T., Ingleton, C., & Clarke, A. (2015). ‘You have to be mindful of whose story it is’: The challenges of undertaking life story work with people with dementia and their family carers. *Dementia: The International Journal of Social Research and Practice*, *14*(2), 238–256.

McParland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: is there another way? *Sociology of Health and Illness*, *39*(2), 258–269.

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

Mental Health Foundation. (2015). *Dementia, rights, and the social model of disability*. London.

Mishler, E. G. (1995). Models of Narrative Analysis: A Typology. *Journal of Narrative and Life History*, *5*(2), 87–123.

Mitchell, G., Dupuis, S., & Kontos, P. (2013). Dementia Discourse: From Imposed Suffering to Knowing Other-Wise. *Journal of Applied Hermeneutics*, (2).

Morgan, A. (2000). *What is narrative therapy? : an easy-to-read introduction*. Dulwich Centre Publications.

Moss, I., & Björn, A. (2006). Use of the life story in the institutional care of people with dementia: A review of intervention studies. *Ageing and Society*, *26*(3), 431–454.

Moyle, W., Venturato, L., Cooke, M., Murfield, J., Griffiths, S., Hughes, J., & Wolf, N. (2016). Evaluating the capabilities model of dementia care: a non-randomized controlled trial exploring resident quality of life and care staff attitudes and experiences. *International Psychogeriatrics*, *28*(7), 1091–1100.

Mullan, M. A., & Sullivan, K. A. (2016). Positive attitudes and person-centred care predict of sense of competence in dementia care staff. *Aging and Mental Health*, *20*(4), 407–414.

Myerhoff, B. (1982). Life History among the Elderly: Performance, Visibility and Re-Membering. In J. Ruby (Ed.), *A Crack in the Mirror: Reflexive Perspectives in Anthropology*. Philadelphia, PA: University of Pennsylvania Press.

National Audit Office. (2007). *Improving services and support for people with dementia*. London.

National Institute for Health and Care Excellence. (2015). *Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset [NG16]*. London.

National Institute for Health and Care Excellence. (2018). *Assessment, management and support for people living with dementia and their carers [NG97]*. London.

Nygård, L. (2006). How can we get access to the experiences of people with dementia? *Scandinavian Journal of Occupational Therapy*, *13*(2), 101–112.

O'Connor, Deborah. & Purves, B. (2009). Decision-making, personhood and dementia: Mapping the terrain. In D. O. & B. Purves (Ed.), *Decision-making, personhood and dementia: Exploring the Interface*. London: Jessica Kingley Publishers.

Parveen, S., Barker, S., Kaur, R., Kerry, F., Mitchell, W., Happs, A., … Oyebode, J. R. (2018). Involving minority ethnic communities and diverse experts by experience in dementia research: The Caregiving HOPE Study. *Dementia*, *17*(8), 990–1000.

Perry, J., & O'Connor, D. (2002). Preserving Personhood: (Re)Membering the Spouse with Dementia. *Family Relations*, *51*(1), 55–62.

Phoenix, C., Smith, B., & Sparkes, A. C. (2010). Narrative analysis in aging studies: A typology for consideration. *Journal of Aging Studies*, *24*(1), 1–11.

Pickett, J., Bird, C., Ballard, C., Banerjee, S., Brayne, C., Cowan, K., … Walton, C. (2018). A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International Journal of Geriatric Psychiatry*, *33*(7), 900–906.

Plummer, K. (1995). *Telling sexual stories : power, change, and social worlds*. Chatham: Routledge.

Post, S. G. (2000). Key Issues in the Ethics of Dementia Care. *Neurologic Clinics*, *18*(4), 1011–1022.

Post, S. G. (1995). *The moral challenge of Alzheimer disease : ethical issues from diagnosis to dying*. Maryland: Johns Hopkins University Press.

Public Health England. (2018). Dementia: applying All Our Health - GOV.UK. Retrieved 6 August 2019, from https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health#guidance

Ward, R., Vass, A., Aggarwal, N., Garfield, C., & Cybyk, B. (2005). What is dementia care? 1. Dementia is communication. *Journal of Dementia Care*, *13*(6), 16–19.

Ricoeur, P. (1991). Life in quest of narrative. In D. Wood (Ed.), *On Paul Ricoeur: Narrative and Interpretation*. London: Routledge.

Riessman, C. K. (2001). Analysis of personal narratives. In J. F. Gubrium & J. A. Holstein (Eds.), *In Handbook of Interview Research*. London: SAGE.

Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks: Sage Publications.

Riessman, C. K. (1993). *Narrative analysis*. London: Sage Publications.

Robert, D., & Shenhav.S. (2014). Fundamental Assumptions in Narrative Analysis : Mapping the Field. *The Qualitative Report*, *19*(22), 1–17.

Robertson, A. (1990). The Politics of Alzheimer’s Disease: A Case Study in Apocalyptic Demography. *International Journal of Health Services*, *20*(3), 429–442.

Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J., & Exley, C. (2013). A qualitative study: Professionals’ experiences of advance care planning in dementia and palliative care, ‘a good idea in theory but…’. *Palliative Medicine*, *27*(5), 401–408.

Rosenwald, G. C., & Ochberg, R. L. (1992). *Storied lives : the cultural politics of self-understanding*. Michigan: Yale University Press.

Sabat, S. R., & Harré, R. (1992). The Construction and Deconstruction of Self in Alzheimer’s Disease. *Ageing and Society*, *12*(4), 443–461.

Sabat, S. R., Napolitano, L., & Fath, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer’s disease. *American Journal of Alzheimer’s Disease and Other Dementias*, *19*(3), 177–185.

Sabat, S. R. (2006). Capacity for decision-making in Alzheimer’s disease: Selfhood, positioning and semiotic people. *Australian and New Zealand Journal of Psychiatry*, *39*(11–12), 1030–1035.

Sabat, S. R. (2002). Surviving Manifestations of Selfhood in Alzheimer’s Disease. *Dementia*, *1*(1), 25–36.

Saunders, P. A., de Medeiros, K., Doyle, P., & Mosby, A. (2011). The discourse of friendship: Mediators of communication among dementia residents in long-term care. *Dementia*, *11*(3), 347–361.

Squire, C. (2008). Experienced-centred and culturally-orientated approaches to narrative. In M. Andrews, C. Squire, & M. Tamboukou (Eds.), *Doing Narrative Research*. Cornwall: Sage Publications.

Swarbrick, C. M., Doors, O., SDWG, Educate, Davis, K., & Keady, J. (2016). Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice). *Dementia*, 147130121667455.

The Dementia Engagement and Empowerment Project. (2015). Dementia words matter: Guidelines on language about dementia. Retrieved 28 January 2019, from http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf

Thompson, R. (2011). Using life story work to enhance care. *Nursing Older People*, *23*(8), 16–21.

Ticehurst, S. (2001). Is Dementia a Mental Illness? *Australian & New Zealand Journal of Psychiatry*, *35*(6), 716–723.

Tolhurst, E., & Weicht, B. (2017b). Preserving personhood: The strategies of men negotiating the experience of dementia. *Journal of Aging Studies*, *40*, 29–35.

Tolhurst, E., Weicht, B., & Kingston, P. (2017a). Narrative collisions, sociocultural pressures and dementia: the relational basis of personhood reconsidered. *Sociology of Health & Illness*, *39*(2), 212–226.

Vincent, J. A. (2003). *Old age*. London: Routledge.

Waite, J., Poland, F., Econ, M. A., Wiley, J., & Ltd, S. (2019). Facilitators and barriers to co-research by people with dementia and academic researchers: Findings from a qualitative study. *Health Expectations*, 1–11.

Waite, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health and Illness*, *39*(2).

Walker, A. (2012). The New Ageism. *Political Quaterly*, *83*(4), 812–819.

Westius, A., Kallenberg, K., & Norberg, A. (2010). Views of life and sense of identity in people with Alzheimer's disease. *Ageing and Society*, *30*(7), 1257–1278.

White, M.K. (1995). *Re-authoring lives : interviews & essays*. Dulwich Centre Publications.

White, M.K. (2007). *Maps of narrative practice*. W.W. Norton & Co.

White, M.K. & Epston, D. (1990). *Narrative means to therapeutic ends*. Norton.

Wilkinson, H., & Milne, A. J. (2003). Sharing a diagnosis of dementia - Learning from the patient perspective. *Aging and Mental Health*, *7*(4), 300–307.

Williams, S., & Keady, J. (2006). Editorial:The narrative voice of people with dementia. *Dementia*, *5*(2), 163–166.

Williamson, T. (2015). Dementia, rights and the social model of disability. *Journal of Dementia Care*, *23*(5), 12–14.

Willig, C. (2008). *Introducing qualitative research in psychology*. *Introducing Qualitative Research in Psychology*. New York: Open University Press.

Wilson, G. & Fearnley, K. (2007). *The Dementia Epidemic*. Edinburgh.

Young, E. (2010). Narrative Therapy and Elders with Memory Loss. *Clinical Social Work Journal*, *38*(2), 193–202.

Zeilig, H. (2013). Dementia as a cultural metaphor. *The Gerontologist*, *54*(2), 258–267.

Zimmerman, S., Williams, C. S., Reed, P. S., Boustani, M., Preisser, J. S., Heck, E., & Sloane, P. D. (2005). Attitudes, Stress, and Satisfaction of Staff Who Care for Residents With Dementia. *The Gerontologist*, *45*(suppl_1), 96–105.

APPENDICES

APPENDIX A – Literature Search Strategies

Literature Review One (Narrative and Dementia) Search Strategy

Databases:
PsychoINFO, PsychARTICLES & Academic Search Complete

Search Terms:
Dementia or alzheimer's or vascular dementia or lewy body or frontotemporal (235, 559) AND Narrative (1,449) AND Storytelling (234) AND Experience (94)

Limiters:
None

Inclusion Criteria

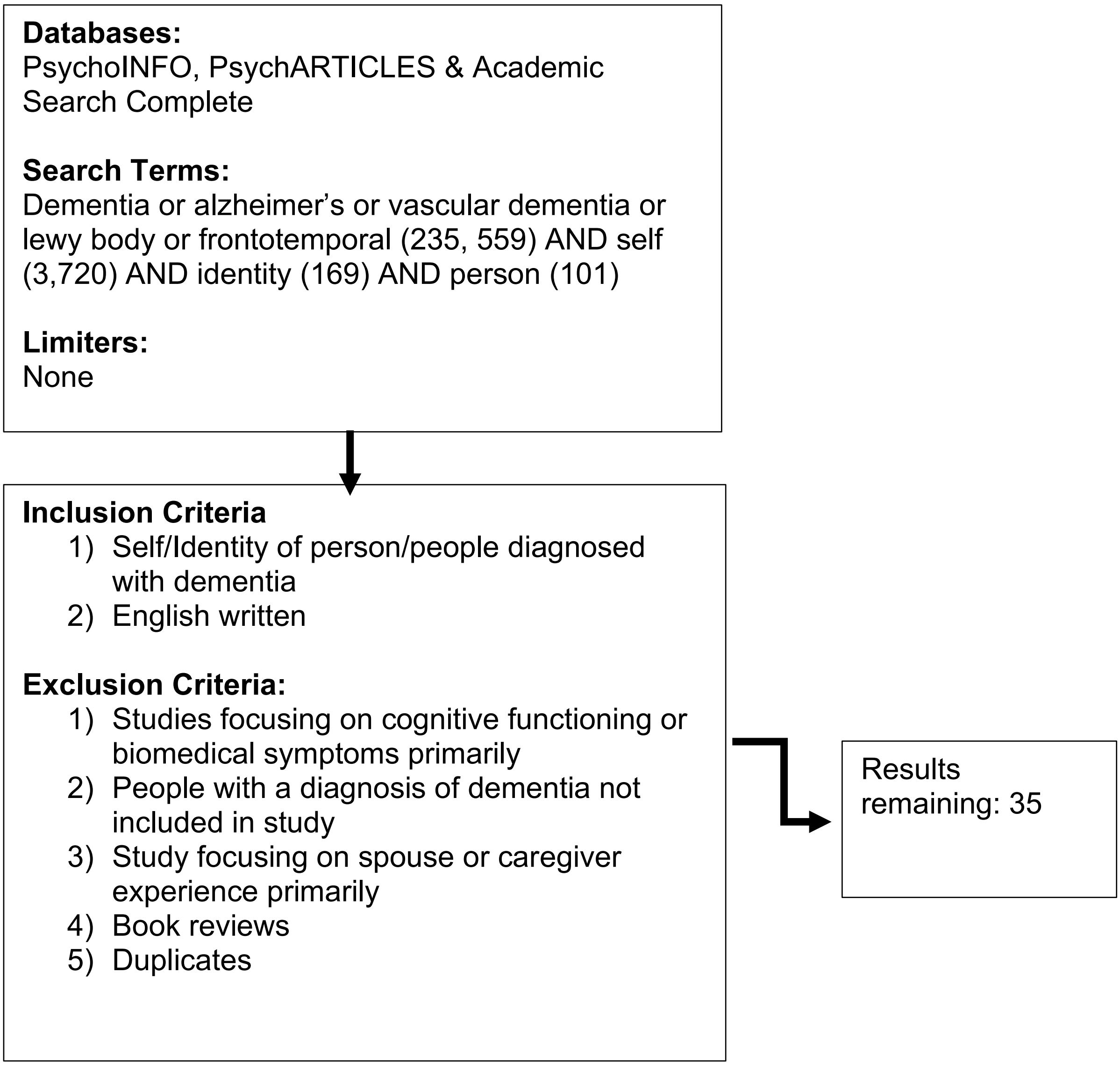
1) Use of narrative with people with a diagnosis of dementia
2) Exploration of Experience
3) English written

Exclusion Criteria:

1) Studies focusing on cognitive functioning primarily
2) People with a diagnosis of dementia not included in study
3) Study focusing on spouse or caregiver experience primarily
4) Studies focusing on diagnosis
5) Book reviews
6) Duplicates

Results remaining: 28

Literature Review Two (Person and Dementia) Search Strategy



Databases:
PsychoINFO, PsychARTICLES & Academic Search Complete

Search Terms:
Dementia or alzheimer’s or vascular dementia or lewy body or frontotemporal (235, 559) AND self (3,720) AND identity (169) AND person (101)

Limiters:
None

Inclusion Criteria

1) Self/Identity of person/people diagnosed with dementia
2) English written

Exclusion Criteria:

1) Studies focusing on cognitive functioning or biomedical symptoms primarily
2) People with a diagnosis of dementia not included in study
3) Study focusing on spouse or caregiver experience primarily
4) Book reviews
5) Duplicates

Results remaining: 35

Literature Review Three (Staff and Dementia) Search Strategy

Databases:
PsychoINFO & PsychARTICLES

Search Terms:
Dementia or alzheimer's or vascular dementia or lewy body or frontotemporal (106,908) AND care (22,017) AND professionals OR staff [title] (520) AND attitudes OR beliefs OR perceptions or satisfaction [title] (78)

Limiters:
Year of publication 1990-2019

Inclusion Criteria
Self/Identity of person/people diagnosed with dementia

1) English written
2) Direct staff experience
3) Dementia context specifically

Exclusion Criteria:

1) Duplicates
2) Dissertation/abstract only
3) Sexuality
4) Book reviews

Results remaining: 21

APPENDIX B - Interview Schedule & Debrief

Introduction:

Thank you for agreeing to take part in today's research. So I get everything accurately, I'm going to record today's conversations on this recorder and listen back to it later. Before we start I just wanted to go through the process. For the first 20 minutes or so I will talk to **[interviewee name]** about your life and what is important to you. And you will have an audience. I will ask a couple questions but it's mostly a space for you to use freely. I don't want to influence the way you tell your story too much. Next, I will invite [**staff 1 name]** and [**staff 2 name]** to talk about what they have heard you say. The questions posed to you two will focus on what images and ideas have been elicited in you personally. [**Interviewee name]** will have a chance to hear the effect their story has had on you, [**staff 1 name]** and [**staff 2 name],** and can add anything else at the end. You can share as much or as little as you would like, we can have a break at any point, and you have the right to withdraw at any time without having to give any explanation. Today our aim is to be open without making judgements. Are there any questions?

Purposed Interviewee Questions:

Based on 'informal conversation style' questions (Batra, Sullivan, Williams & Geldmacher, 2015)

1. Tell me about your life
2. What things do you really value in life?
3. What is important for others to know about you?

Purposed Audience Questions:

From Michael White, 2007 – Definitional Ceremonies

1. Identifying the expression

As you listen to the stories of the life of **[interviewee name]**, who is at the centre of this witnessing practice, which expressions caught your attention or captured your imagination? Which ones struck a chord for you?

2. Describing the image

What images of people's lives, of their identities, and of the world more generally, did these expressions evoke? What did these expressions suggest to you about these people's purposes, values, beliefs, hopes, dreams and commitments?

3. Embodying responses

What is it about your own life/work that accounts for why these expressions caught your attention or struck a chord for you? Do you have a sense of which aspects of your own experiences of life resonated with these expressions, and with the images evoked by these expressions?

4. Acknowledging transport

How have you been moved on account of being present to witness these expressions of life? Where has this experience taken you to, that you would not otherwise have arrived at, if you hadn't been present as an audience to this conversation? In what way have you become other than who you were on account of witnessing these expressions, and on account of responding to these stories in the way that you have?

Purposed Individual Staff Interview Questions:

1. When we met last, what were your initial thoughts before we started?
2. How was the experience for you?
3. What impact did it have on you afterwards?

Debrief

Thank you for taking part in the research, I hope you found it a useful experience and it may have raised some positive questions and feelings. I wanted to take this opportunity to tell you a bit more about the approach that I used and what will happen next. The approach of outsider witnessing has been used as a way to create space for the telling of stories that may not be often told. Terms like memory problems and dementia can often overshadow the person and the current research wanted to see if story telling could offer something else. By witnessing the preferred story of the person with a dementia diagnosis, both the audience and story teller are connecting on a different level, and perhaps questioning what might have been assumed beforehand.

I will be back to the service on **[date],** once I have analysed the data, to check with you its accuracy. Please contact me for further information or if you feel you would like further support after this experience. I will try to answer your questions and/or signpost you to the most meaningful and appropriate place if needed.

APPENDIX C – Invitation letter

PARTICIPATION INVITATION LETTER

Research title - "Telling and re-telling stories in dementia": a study exploring the impact of stories told on people with memory problems and staff.

Dear Sir/Madam,

You are being invited to be part of an exciting new research project at the University of East London (UEL). The current project will look into **the impact of storytelling in dementia care.**

The study will be commencing February 2019.

Who am I?

I am a trainee clinical psychologist in the School of Psychology at the University of East London and am studying for a doctorate in clinical psychology. As part of my studies I am conducting the research you are being invited to participate in.

All my experience before and during training has been in the NHS and am DBS checked.

What is the research?

I am conducting research into people with memory problems telling their own stories and the effects of hearing these stories on staff that work with them.

Research has shown how connecting an individual's story to a wider audience can be both powerful for the story teller and listener (White, 2007). Researchers and professionals know how important it is to include people with memory problems in research and hear their individual voices.

My research will be approved by a Research Ethics Committee (REC). This means that my research follows a standard of research ethics set by the university school of psychology.

It will involve:

- Around 1 hour group interview with 1 service user and 2 staff. In this I will ask a few questions but will mostly be listening. I will ask the service user to:
    - Tell me about their life
    - What they value in life
    - What is important for others to know about them

- 2 staff will listen to the story and I will ask them what they think and feel after hearing it
    - The questions are pre-set and ensure the answers safely focus on what staff members connected to, what they felt and whether it had any impact on their views. I will ask your relative/friend if they have anything to add further
- I will then interview the staff separately to explore the impact of hearing the story had on them at a different date (45mins-1 hour)
- I will return to feedback the initial findings to the participants and give opportunity to discuss/check

I also offer:

- To attend in person before the study to build rapport with the person with memory problems and tell them about the study
- Meet with relatives of possible participants to give more information
- Attend any staff meetings or handovers to further talk about the study

Why have you been asked to participate?

Your establishment fits the kind of setting I am looking for to help me explore my research topic. I am looking to involve people who are directly involved in the support of the person with memory problems.

I emphasise that I am not looking for 'experts' on the topic I am studying. You will not be judged or personally analysed in any way and you will be treated with respect.

You are quite free to decide whether or not to participate and should not feel coerced.

Your taking part will be safe and confidential

Your privacy and safety will be respected at all times. Your service and participants will not be identified by the researcher on any written material resulting from data collection. The group and individual interviews must take part in a room without interruption to ensure a safe space to discuss. Participants do not have to answer all questions asked of them and can stop their participation at any time.

All participants must have the capacity to consent to take part in the research, if a participant loses capacity during the study, participation will be ended.

What will happen to the information that you provide?

The group and individual interviews will be audio recorded and uploaded onto a password protected computer. In any written material, responses will be anonymised with the use false names. The service will not be named in the write up of the analysis. The anonymised data will be seen by supervisors, course examiners and may be published in an academic journal.

I will return to the service on to show you my initial analysis and check what I recorded was accurate to those involved.

Once the study is complete and successfully examined, recordings of the data will be destroyed. I will hold anonymised transcripts for three years to allow publication, after this time all data will be destroyed.

What if participants want to withdraw?

Participants are free to withdraw from the research study at any time without explanation, disadvantage or consequence. However, if they withdraw I would reserve the right to use material that you provide up until the point of my analysis of the data.

If you agree to take part?

You agree to:
- Allow me to advertise/speak about the research up to 4 weeks before an agreed interview date
- Provide a safe space to conduct the research

Contact Details

If you interested in hosting this novel research or would like to know more, please do not hesitate to contact me.

Navi Nagra at XXXXX@uel.ac.uk

Thank you for taking the time to read this information, I look forward to hearing from you.

Yours sincerely,
Navi Nagra, Trainee Clinical Psychologist

APPENDIX D – Audience Information Sheet

RESEARCH – WITH PEOPLE WITH MEMORY PROBLEMS AND THEIR STAFF
PLEASE READ

WHO AM I?

Hello, my name is **Navi** and I am a trainee clinical psychologist conducting some research for my doctorate in clinical psychology. I go to the University of East London (UEL).

💻

Email:XXXXX@uel.ac.uk

I have undergone relevant DBS checks

WHAT IS THE RESEARCH?

I am interested in **listening to people with memory problems telling their own stories** and the **effects of hearing these stories** on **staff** that work with them.

Research has shown how connecting an individual's story to a wider audience can be both powerful for the story teller and listener (White, 2007). Researchers and professionals know how important it is to include people with memory problems in research and hear their individual voices.

My research has been **approved by the UEL Research Ethics Committee (REC).** This means that my research follows a good standard of research ethics.

WHY AM I CONTACTING YOU?

As a **staff member** supporting people with memory problems, it is worth considering what you know about them? **Is there a way to know them differently?**

You will have the chance to be an **audience to their story**. I will be using a style of storytelling called '**outsider witnessing**' which gives space for you to hear your service user's story and see how that makes you feel.

WHAT WILL THE RESEARCH INVOLVE?

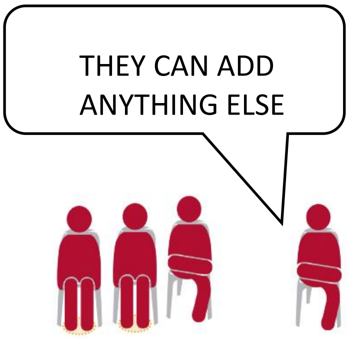
If you would like to take part you will be invited to watch an interview between myself and the service user. I will mostly be listening but will ask them to:

- Tell me about their life
- What they value in life
- What is important for others to know about them

I will also **record** the interview to listen back to later.

I will ask **2 staff members (including yourself)** what you **think and feel** after hearing it. The questions will be pre-set, and I will meet you beforehand to discuss them. The aim is to create a **non-judgemental** space with questions **safely focusing** on what you connected to. You do not have to answer every question if you do not want to.

The service user will hear what impact their story had on you. I will ask if they have **anything to add further**. This will take around **1 hour**



Later, and separately, I will ask you how you experienced this.

SAFETY AND CONFIDENTIALITY?

Your safety and comfort will be the upmost importance to me. I will be around before and after the interview dates if you have any questions.

After the interview I will listen to the recording and write out your words. So it is anonymous, I will **replace your name with a made up name (you can chose this other name)**. I will write up your responses in my **doctoral thesis** but anonymously. It may later get **published**. All recorded data from this research will be **destroyed in 3 years**.

As there will only be three of you, the other people will know you. This is because the research is interested to **see how you feel** after hearing the story of **someone you know. Confidentiality must be maintained** within the team supporting the service user. Unless there is anything they do not wish us to share with the staff team.

When I go to analyse the recordings, I will come back to **check with you** if everything is accurate.

WHAT IF THEY/I WANT TO WITHDRAW?

I will ask you to sign a consent to take part form at the start. **You will have the freedom to withdraw/decline consent to participate at any time without explanation, disadvantage or consequence. You will have the right to have the data you have given destroyed on request.**

IF YOU WOULD LIKE TO KNOW MORE?

You can get in touch with me **Navi Nagra** on:

💻

Email: XXXXX@uel.ac.uk

If you have any other questions or concerns about the study you can get in touch with my supervisor **Dr. Maria Castro Romero**

✉

School of Psychology, University of East London, Water Lane, London E15 4LZ

💻

Email: XXXXX@uel.ac.uk

OR

Catherine Fieulleteau, Research Integrity and Ethics Manager

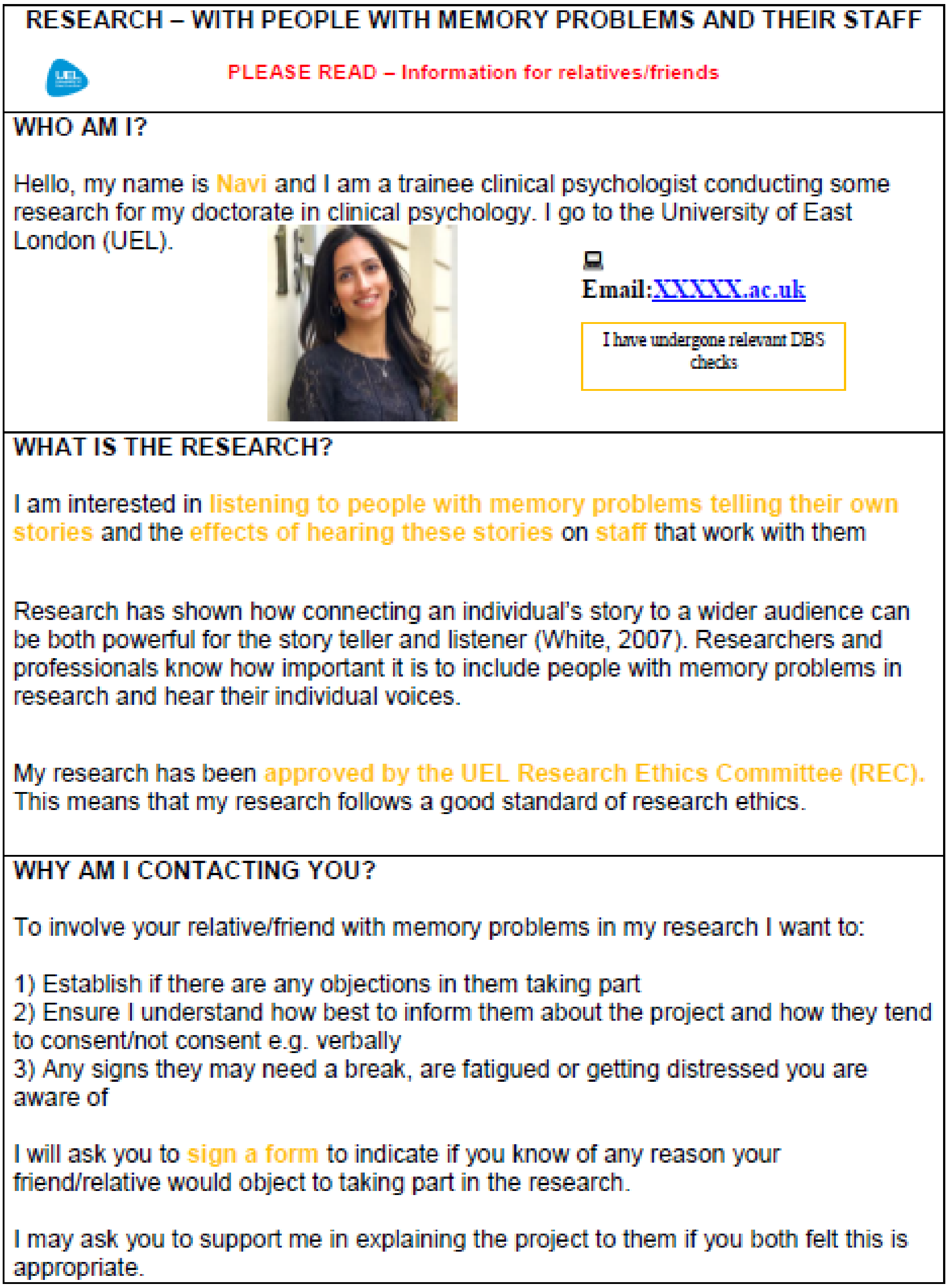
✉

Docklands Campus, University of East London, London, E16 2RD

💻

Email: researchethics@uel.ac.uk

APPENDIX E – Relative/Friend Information Sheet



RESEARCH – WITH PEOPLE WITH MEMORY PROBLEMS AND THEIR STAFF

PLEASE READ – Information for relatives/friends

WHO AM I?

Hello, my name is Navi and I am a trainee clinical psychologist conducting some research for my doctorate in clinical psychology. I go to the University of East London (UEL).

💻 Email:XXXXX.ac.uk

I have undergone relevant DBS checks

WHAT IS THE RESEARCH?

I am interested in listening to people with memory problems telling their own stories and the effects of hearing these stories on staff that work with them

Research has shown how connecting an individual's story to a wider audience can be both powerful for the story teller and listener (White, 2007). Researchers and professionals know how important it is to include people with memory problems in research and hear their individual voices.

My research has been approved by the UEL Research Ethics Committee (REC). This means that my research follows a good standard of research ethics.

WHY AM I CONTACTING YOU?

To involve your relative/friend with memory problems in my research I want to:

1) Establish if there are any objections in them taking part
2) Ensure I understand how best to inform them about the project and how they tend to consent/not consent e.g. verbally
3) Any signs they may need a break, are fatigued or getting distressed you are aware of

I will ask you to sign a form to indicate if you know of any reason your friend/relative would object to taking part in the research.

I may ask you to support me in explaining the project to them if you both felt this is appropriate.

HOW WILL THE RESEARCH INVOLVE MY FRIEND/RELATIVE?

I will approach your relative/friend to explain the research using a leaflet similar to this one. During this unhurried meeting, I will observe their responses on the information you provided and what they say. I will check they have fully understood and would like to take part.

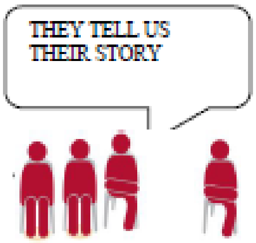
If your relative/friend has given consent to take part I will have an interview with them that will last around 1 hour. In this I will ask a few questions but will mostly be listening. I will ask them to:

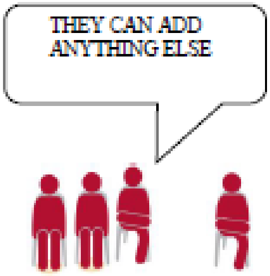
- Tell me about their life
- What they value in life
- What is important for others to know about them

I will also record the interview to listen back to later.

2 staff will listen to their story too and I will ask them what they think and feel after hearing it. This will be in front of your relative/friend.

The questions are pre-set and ensure the answers safely focus on what staff members connected to, what they felt and whether it had any impact on their views. I will ask your relative/friend if they have anything to add further.





Later, and separately, I will ask them how they experienced this.

SAFETY AND CONFIDENTIALITY?

Their safety and comfort will be the upmost importance to the researcher. Sometimes people with memory problems can feel frustrated or fatigued. If there is evidence of this happening the interview will be ended immediately, and your relative/friend supported.

After the interview I will listen to the recording and write out their words. So it is anonymous, I will replace their name with a made up name (they can chose this other name). I will write up the responses in my doctoral thesis but anonymously.

It may later get published. All recorded data from this research will be destroyed in 3 years.

The 2 staff members who hear the interview will know your relative/friend, but they will keep confidentiality within the team supporting them, unless there is anything you or your relative/friend do not wish them to share with the staff team.

WHAT IF THEY/I WANT TO WITHDRAW?

Consent to participate in the research will continuously take place every meeting and stage of the study. **Your relative/friend will have the freedom to withdraw/decline consent to participate at any time without explanation, disadvantage or consequence. They will have the right to have the data they gave destroyed on request.**

IF YOU WOULD LIKE TO KNOW MORE?

You can get in touch with me **Navi Nagra** on:
💻
Email: XXXXX@uel.ac.uk

If you have any other questions or concerns about the study you can get in touch with my supervisor **Dr. Maria Castro Romero**
✉
School of Psychology, University of East London, Water Lane, London E15 4LZ,
💻
Email: XXXXX@uel.ac.uk

OR

Catherine Fieulleteau, Research Integrity and Ethics Manager
✉
Docklands Campus, University of East London, London, E16 2RD
💻
Email: researchethics@uel.ac.uk

APPENDIX F – Contract

PARTICIPATION CONTRACT

Research title – "Telling and re-telling stories in dementia": a study exploring the impact of stories told on people with memory problems and staff.

Dear [Management Names],

Thank you for hosting this exciting new research project from the University of East London (UEL). The current project will look into **the impact of storytelling in dementia care.**

The study will be commencing March 2019.

Researcher: Navi Nagra, Trainee Clinical Psychologist
Organisation: [Centre Name]
Main Contact(s): [Management Name]

The following is a co-created contract between us in ensuring the above study is carried out safely and confidently in the coming weeks.

What should be expected from the researcher:

- To provide an ethically sound research experience, considering giving all involved informed consent through transparency and openness to questions
- Respecting participants and all others at the organisation's privacy and confidentiality
- To attend in person before the study to build rapport with the person with memory problems and tell them about the study – once or twice a week
- Meet with relatives of possible participants to give more information
- Attend any staff meetings or handovers to further talk about the study
- Adapting the approach to meet the needs of the people taking part
- Informing all relevant people of the study and what will happen to the data
- Returning after data has been collected to feedback findings

What should be expected from host:

- To support introduction to relatives, staff and residents who may be interested in hearing about the project
- Allow researcher to advertise/speak about the research up to 4 weeks before an agreed interview date
- Allow researcher to build rapport with the resident and staff taking before the interview
- Provide a safe and confidential space to conduct the research

<u>Proposed timeline:</u>	
Before the interview: • Meet with management and sign joint agreement for the study to take place • Approach staff to talk about the research and what their participation will involve • Staff/management to identify service user who may be interested in taking part • Researcher to information gather from staff and relatives • Relative to sign declaration • Navi will approach identified service user in unhurried meetings to speak about research and gain consent to take part (every meeting) • Arrange suitable date for service user and 2 staff members who are interested to take part	**February-March 2019**
Interview Day: • Around 1-hour group interview with 1 service user and 2 staff. In this Navi will ask a few questions but will mostly be listening. The service user will be asked to: - Tell me about their life - What they value in life - What is important for others to know about them • 2 staff will listen to the story and Navi will ask them what they think and feel after hearing it - The questions are pre-set and ensure the answers safely focus on what staff members connected to, what they felt and whether it had any impact on their views. Navi will ask the service user if they have anything to add further • I will then interview the staff separately to explore the impact of hearing the story had on them at a different time/date (45mins-1 hour)	**March-April 2019**
Post Interview: • Navi will return to feedback the initial findings to the participants and give opportunity to discuss/check • Findings will be amended to match staff and service user's meaning (this can happen on more than one occasion) • Navi will write up the research for a doctoral thesis as well as publication • Navi will return with the final write up and discuss with relevant parties how best to share the information and incorporate into practice	**May 2019 onwards**

We at **[Centre Name]** have read and agreed to the above expectations and timeline and agree to host the research

…………………………………………………
[PRINT NAME]
[ROLE]

I the researcher have read and agreed to the above expectations and timeline to carry out the research at **[Centre Name]**

…………………………………………………
[PRINT NAME]
[ROLE]

APPENDIX G – Example Process Consent Field Notes

Participant Name: XXXXXX XXXXXX

Researcher Name: Navi Nagra

Field notes form (adapted from Hughes & Castro Romero, 2015)

PROCESS STAGE	NOTES (Dated evidence, decisions made and action)
1. Establishing basis of consent - Provide staff/relative with research information sheet V - Staff/relative identify potential participant V - Establish usual ways person communicate consent/non-consent V - Gather information for any reasons for objection V - Staff/relative to introduce and seek permission for researcher to speak to potential participant V	[Date] • spoken to manager [manager name] face-to-face: XXXXXX attends the centre one and a half days a week, he is a quiet man and speaks his mind. He has recently started attending the centre (6 months) and they felt he has grown more comfortable engaging in a routine of playing cards, lunch time, tea breaks etc. • Usual ways of consenting/not consenting? – If XXXXXX no longer wants to e.g. play cards he will either voice this or get up and move onto something else. Direct questions posed to XXXXXX is the preferred method of gaining consent. Manager felt if XXXXXX got bored he was more likely to get up and move on. If XXXXXX does not like something he voices this e.g. ‘I don’t want it’ when referring to a meal choice • Staff to speak to wife re: any objections and consent for me to contact [Date] • Any reasons for objections? No reasons for objection to taking part identified by wife. • XXXXXX likes to be helpful and sees the centre more like work/a club. Also enjoys the routine and banter with staff. Described him as a serious man but with a jokey side • Manager ([manager]) recommended being direct in my explanation of the study as XXXXXX responds better to this. • [manager] to introduce me to XXXXXX to ‘talk about my research’
2. Initial consent conversation - Unhurried consent meeting V - Provide accessible information (verbal, visual etc.) V - Elicit consent and re-check for understanding V	[Date] • Memory Café. Sat at table with XXXXXX and other members. Introduced myself as a researcher with the centre for a few weeks to talk to people about their life stories for my thesis. The table spoke about the importance of education. [Date] • Sat with XXXXXX and other members at the beginning of the day and played a game of Kalooki. I was not very good and sat out the second game and moved onto another table. • Retuned just before lunch and was introduced by [manager] to talk about the study to which XXXXXX consented to hear ‘yeah gone on tell me’.

	• XXXXXX was provided with my PIS and he pointed out my picture and made a joke, he listened and we went through each box of the PIS, including right to with draw, extend of anonymity and recordings. • Agreed to take part –‘OK I’ll do it’ but ‘I’m a difficult man to get to know that’s just the way I am. But one thing I’ll tell you is I always tell the truth’ • When discussing aims and his interest in the study he said ‘I’d like see what you write about me. Will be really interesting’. • When asked if he had any concerns and he shook his head and said ‘No. No concerns’. I asked how he would tell me he didn’t want to do it anymore and he said ‘I’ll tell ya’. • Agreed to return in a week to do the interview in the activity room with 1-2 staff
3. Ongoing consent monitoring (interview stage) - Throughout interview re-check if behaviour changes e.g. cue indicating distress, fatigue, anxiety etc.V - If need to end interview re request consent at a different meeting (step 2) N/A	[Date] • XXXXXX recognised me as I entered stating ‘it’s you!’ • I sat with him with a cup of tea and went through the PIS again. He recalled seeing it before (referring to picture) and stated he was still happy to take part • Informed him time, room and who would be present • XXXXXX entered the room 15minutes earlier than the time and said ‘are we doing this now?’. I informed him we were just waiting for [manager]. • Consent rechecked and on audio recording as I ran through the process of the OWP, right to withdraw and anonymity • Short responses e.g. ‘pass’ – rechecked if he wanted to continue, he said he did, stating ‘carry on. Ask me another question’ and proceeded to smile and wink at me. This was indicative of humour. After this point responses became longer but with direction from XXXXXX to ask another question • Interview completed and informed of next step – speak to [manager], write up, come back to recheck
4. Ongoing consent monitoring (individual interview stage) - End of interview stage gain permission to discuss separately and why V	[Date] • Re-attended centred to speak to [manager] • Informed XXXXXX I would be speaking to [manager] separately about the interview to gain her experience of listening to his story even further. He agreed this would be okay.
5. Consent for any feedback of analysis	[Date] • Attended with preliminary analysis chapter plan and went through sections from his interview.

e.g. to themselves and/or staff - Gain permission to check over analysis V - Gain permission to publish analysis V	XXXXXX listened and would respond to every point e.g. ‘can’t disagree with that’, ‘that’s right’, ‘not sure about that’ • Requested I expanded on some points he did not think were clear e.g. ‘what do you mean?’ • Added his own expansions on points e.g. ‘I only like people who speak their mind too’ • Asked when I’ll have the thesis written up and stated ‘I look forward to reading it’. [Date] • Returned with analysis chapter – asked if wanted to read it, a summary verbally/written • He opted to read it – and proceeded to read his section of the chapter. He asked questions throughout e.g. ‘who’s [manager]?’ when referring to the pseudonym of his witness. • Noted to smile when reading his quotes • After reading handed back stating ‘very good. You write really well’ and ‘I speak as I find – that’s one thing about me’ • Discussed if happy for it to published – ‘yes’. After thesis submission was happy to receive either the chapter as it was there or a summary he did not mind. We agreed I would bring both and he can decide which one to keep. • Discussed dissemination at centre -he agreed but felt other members were ‘nutters’ and preferred for it to be presented more generally rather than name him e.g. ‘I think it’s best that way’ • Date told of when I will return

APPENDIX H – Interviewee Information Sheet

RESEARCH – WITH PEOPLE WITH MEMORY PROBLEMS AND THEIR STAFF

PLEASE READ

WHO AM I?

Hello, my name is **Navi** and I am a trainee clinical psychologist conducting some research for my doctorate in clinical psychology. I go to the University of East London.

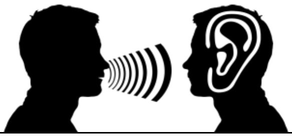
💻

Email: XXXXX@uel.ac.uk

I have undergone relevant DBS checks

WHAT IS THE RESEARCH?

I am interested in **listening to people with memory problems telling their own stories** and the **effects of hearing these stories** on **staff** that work with you.



WHY AM I ASKING YOU?

I would like to know if you are **interested in telling us about yourself and what is important to you**. Hearing what you have to say will both help **your staff and wider research understand you**. This is important when thinking about what people with memory problems need as individuals.

WHAT WILL HAPPEN?

I will have an **interview with you** that will last around **1 hour**. I will mostly be listening, I will just ask you to

- Tell me about your life
- What you value in life
- What is important for others to know about you

I will **record** the interview to listen back to later.

2 staff will listen to your story too and I will ask them what they **think and feel** after hearing it. This will be in front of you.

Later, and separately, I will ask you how you experienced this.

WHAT HAPPENS TO YOUR ANSWERS?

After the interview I will listen to the recording and write out your words. So it is anonymous, I will **replace your name with a made up name (you can chose this other name)**. I will write up your responses in my **doctoral thesis** but anonymously. It may later get **published**. All recorded data from this research will be **destroyed in 3 years**.

The **2 staff members** who hear your interview will know you, but they will keep **confidentiality** within the team caring for you, unless there is anything you do not wish them to share with the staff team.

IF YOU DON'T WANT TO TAKE PART ANYMORE?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. You have the right to have the data you have given destroyed on request.

If you **need a break** or want to continue at a different date, we will end/pause the interview and meet again later.

IF YOU WOULD LIKE TO KNOW MORE

You can get in touch with me **Navi Nagra** on:
💻
Email: XXXXX@uel.ac.uk

If you have any other questions or concerns about the study you can get in touch with my supervisor **Dr. Maria Castro Romero**
🖃
School of Psychology, University of East London, Water Lane, London E15 4LZ,
💻
Email: XXXXX@uel.ac.uk

OR

Catherine Fieulleteau, Research Integrity and Ethics Manager
🖃
Docklands Campus, University of East London, London, E16 2RD
💻
Email: researchethics@uel.ac.uk

APPENDIX I – Audience Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study (Audience)

"Telling and re-telling stories: Staff witnessing narratives from people diagnosed with dementia" – Researcher: Navi Nagra

I have read the information sheet relating to the above research study and have been given a copy to keep.

The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study will remain confidential to the researcher, their supervisor and the resident involved in the study. Unless I am there is reason to believe there is risk to me or others. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………….

Participant's Signature
……………………………………………………………………………………….

Researcher's Name (BLOCK CAPITALS)
……………………………………………………………………………………….

Researcher's Signature
……………………………………………………………………………………….

Date: …………………………….

APPENDIX J – Transcription Conventions

ADAPTED FROM EMERSON & FROSCH (2004)

KEY

- 1 line numbers
- (p) pause
- (6) pause longer than 5 secs
- … trail off
- Underline: any emphasised words either loud of elongated
- <N: speech><S: speech>: Overlap
- [inaudible]
- [NON PARTICIPANT NAME] someone’s name other than Jim, Gerry Kevin or Sandra

APPENDIX K – Ethical Approval Application and Approval Letter

UNIVERSITY OF EAST LONDON
School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

FOR BSc RESEARCH

FOR MSc/MA RESEARCH

FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

If you need to apply for ethical clearance from HRA (through IRIS) for research involving the NHS you DO NOT need to apply to the School of Psychology for ethical clearance also. Please see details on https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/NHS-Research-Ethics-Committees.aspx

Among other things this site will tell you about UEL sponsorship

PLEASE NOTE that HRA approval for research involving NHS employees is not required when data collection will take place off NHS premises and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

If you are employed by the NHS and plan to recruit participants from the NHS Trust you work for, it please seek permission from an appropriate person at your place of work (and better to collect data off NHS premises).

PLEASE NOTE that the School Research Ethics Committee does not recommend BSc and MSc/MA students designing research that requires HRA approval for research involving the NHS as this can be a demanding and lengthy process.

Before completing this application please familiarise yourself with:

The *Code of Ethics and Conduct (2018)* published by the British Psychological Society (BPS). This can be found in the Ethics folder in the Psychology Noticeboard (Moodle) and also on the BPS website
https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/BPS%20Code%20of%20Ethics%20and%20Conduct%20%28Updated%20July%202018%29.pdf

And please also see the UEL Code of Practice for Research Ethics (2015-16)
https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Documents/Ethics%20forms/UEL-Code-of-Practice-for-Research-Ethics-2015-16.pdf

HOW TO COMPLETE & SUBMIT THIS 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**
4. Email your supervisor the completed application and all attachments as **ONE DOCUMENT**. Your supervisor will then look over your application.
5. When your application demonstrates sound ethical protocol your supervisor will type in his/her name in the 'supervisor's signature' (section 5) and submit your application for review (psychology.ethics@uel.ac.uk). You should be copied into this email so that you know your application has been submitted. It is the responsibility of students to check this.
6. Your supervisor should let you know the outcome of your application. Recruitment and data collection are **NOT** to commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (See section 4)

ATTACHMENTS YOU MUST ATTACH TO THIS APPLICATION

1. A copy of the participant invitation letter that you intend giving to potential participants.

1. A copy of the consent form that you intend giving to participants.
2. A copy of the debrief letter you intend to give participants.

OTHER ATTACHMENTS (AS APPROPRIATE)

- A copy of original and/or pre-existing questionnaire(s) and test(s) you intend to use.
- Example of the kinds of interview questions you intend to ask participants.
- Copies of the visual material(s) you intend showing participants.
- A copy of ethical clearance or permission from an external institution or organisation if you need it (e.g. a charity, school, local authority, workplace etc.). Permissions must be attached to this application. If you require ethical clearance from an external organisation your ethics application can be submitted to the School of Psychology before ethical approval is obtained from another organisation (see Section 5).

Disclosure and Barring Service (DBS) certificates:

- **FOR BSc/MSc/MA STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS:** A scanned copy of a current Disclosure and Barring Service (DBS) certificate. A current certificate is one that is not older than six months. If you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice.
- DBS clearance is necessary if your research involves young people (anyone 16 years of age or under) or vulnerable adults (see Section 4 for a broad definition of this). A DBS certificate that you have obtained through an organisation you work for is acceptable as long as it is current. If you do not have a current DBS certificate, but need one for your research, you can apply for one through the HUB and the School will pay the cost.

  If you need to attach a copy of a DBS certificate to your ethics application but would like to keep it confidential please email a scanned copy of the certificate directly to Dr Tim Lomas (Chair of the School Research Ethics Committee) at t.lomas@uel.ac.uk

FOR PROFESSIONAL DOCTORATE STUDENTS WHOSE RESEARCH INVOLVES VULNERABLE PARTICIPANTS: DBS clearance is necessary if your research involves young people (anyone under 16 years of age) or vulnerable adults (see Section 4 for a broad definition of this). The DBS check that was done, or

- verified, when you registered for your programme is sufficient and you will not have to apply for another for the duration of your studies in order to conduct research with vulnerable populations.

Please read all guidance notes in blue carefully to avoid incorrect or insufficient applications

If yours is an online study using Qualtrics please see the example ethics application in the Ethics folder in the Psychology Noticeboard

SECTION 1. Your details

1. Your name:
Navneet Nagra

2. Your supervisor's name:
Dr. Maria Castro Romero

3. Title of your programme: (e.g. BSc Psychology)
Doctorate in Clinical Psychology (DClinPsy)

4. Submission date for your BSc/MSc/MA research:

5. Please tick if your application includes a copy of a DBS certificate (see page 3) ☐

6. Please tick if your research requires DBS clearance but you are a Prof Doc student and have applied for DBS clearance – or had existing clearance verified – when you registered on your programme (see page 3) ☒

7. Please tick if you need to submit a DBS certificate with this application but have emailed a copy to Dr Tim Lomas for confidentiality reasons (Chair of the School Research Ethics Committee) t.lomas@uel.ac.uk ☐

1. **Please tick to confirm that you have read and understood the British Psychological Society's Code of Ethics and Conduct (2018) and the UEL Code of Practice for Research Ethics** (See links on page 1)

X

SECTION 2. About your research

2. What your proposed research is about:

Please be clear and detailed in outlining what your proposed research is about. Include the research question (i.e. what will your proposed investigate?)

The proposed research aims to use qualitative research methods to explore the identity conclusions held in the stories of people with a diagnosis of dementia and staff involved in their care. The research aims to explore the impact of outsider witnessing on those bearing witness.
The research questions elicited from literature review at present include:

- What identities do people with a diagnosis of dementia story?
- How does hearing these preferred identities impact staff?

The research can highlight the use of narrative practice in the dementia and care context and how identity/identities is/are constructed within it. The study may show how the needs people diagnosed with dementia and staff can be heard through less conventional methods in clinical practice; once heard these can be advocated for at both organisational and individual level. In addition, involvement of people with a diagnosis of dementia in research is limited and this is a priority to address in health and academic settings (McKeown, Clarke, Ingleton & Repper, 2010).

3. Design of the research:

Type of experimental design, variables, questionnaire, survey etc., as relevant to your research. If the research is qualitative what approach will be used and what will the data be?

The proposed research will explore the identities (understood as socially and relationally co-constructed) in the narratives produced in the context of dementia and dementia care.

One individual affected by the diagnosis of dementia will be interviewed to explore their personal narratives. This interview will be witnessed by up to two staff members in the narrative therapeutic process of 'outsider witnessing', where 'a third party who is invited to listen to and acknowledge the preferred stories and identity claims of the person' (Carey & Russell, 2003: p.65). The questions posed to the audience of care staff will be from White (2007) ‘definitional ceremonies’ and will focus on imagery and emotions elicited in hearing the interviewee’s story to reinforce the person’s preferred stories.

10. Recruitment and participants (Your sample):

Proposed number of participants, method/s of recruitment, specific characteristics of the sample such as age range, gender and ethnicity - whatever is relevant to your research.

Interviewee – n =1
An individual who has memory problems and/or a formal diagnosis of dementia. Participants must be service users of the host organisation and will be either self-selecting or recommended by their relative/friend/staff. Researcher will seek permission from the individual to outline the study and seek consent following Hughes and Castro Romero’s (2015) guidelines for carrying out processual consent for people with a label of dementia.

Audience – n= 2
Staff participants must be involved in the same service as the interviewee, will be self-selecting and will be approached by the researcher prior to the interview to outline the study and seek consent.

As the focus of analysis is on individual narratives, a smaller sample is more appropriate. Due to the small scale of the research project and capacity of the researcher, English speaking will be a requirement for all participants.

Participants will be recruited from a local older adult organization (e.g., local care homes, charity branches and day centres in East London). Care homes and Alzheimer’s society branch managers have been contacted and made aware of the research with an offer to speak to staff, service users and relatives directly during visits and team meetings (see attached invitation letter to organisations Appendix A). This is to increase awareness as well as invite consultation on the recruitment process

11. Measures, materials or equipment:

Give details about what will be used during the course of the research. For example: equipment, a questionnaire, a particular psychological test or tests, an interview schedule or other stimuli such as visual material. See note on page 2 about attaching copies of questionnaires and tests to this application. If you are using an interview schedule for qualitative research attach example questions that you plan to ask your participants to this application.

A field diary* adapted from Hughes and Castro Romero (2015) will be used to document consent on a continual basis. On initial meeting, information will be provided with the view the individual is able to understand, retain, weigh up and communicate (MCA, 2005) their decision to take part. Subsequent meetings prior to the interview will be used with the individual to ensure consent is rechecked and rapport and communication style is established between interviewee and researcher (Nygard, 2006). A field diary will be filled out throughout the study to record verbal and non-verbal consent to participate (see field diary attached, appendix B).

An interview schedule will be used for the proposed study. Minimal open-ended questions in a ‘casual conversational method’ (Barat, Sullivan, Williams & Geldmacher, 2015) will be posed to the interview to elicit their personal narratives. The questions posed to the audience of care staff will be from White (2007) ‘definitional ceremonies’ and will focus on imagery and emotions elicited in hearing the interviewee’s story to reinforce the person’s preferred stories. Staff audience members will be interviewed separately at a later date to explore their experience of the outsider witnessing process, this will be up to 1 hour (please see interview schedule, appendix C).

12. 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?

~~YES / NO~~ / NA

13. Outline the data collection procedure involved in your research:

Describe in detail what will be involved in data collection. For example, what will participants be asked to do, where, and for how long? If using online surveys will you be using Qualtrics? Detail what you will include in the Qualtrics page that you intend to make available to potential participants (see the example ethics application for a student study using Qualtrics in the Ethics folder of the Psychology Noticeboard).

Audio recordings of the group outsider witnessing process and of later individual interviews with staff will be made and analysed.

Special considerations have been made with regards to the group interview aspect of the study. As Killick and Allan (2001) outlined include facial expressions, tone of voice and language used, all contribute to the experience of an interaction. Their recommendations included in the current study include: 1) Spend time building rapport with the individual with a diagnosis of dementia to grow familiar with each other and establish the best pace. 2) consider ‘unwelcome intrusion’ and power imbalance by establishing prior to the interview comfortability with the interview set up (e.g. provide questions to be asked beforehand, identify possible witnesses), 3) preferably witnesses will be familiar to the interviewee, although two staff is the maximum this can be reduced for comfort of the individual 4) setting up the space as ‘non-judgmental’ and clarifying order for all 5) avoid excessive follow up questions during the interview as may lead to anxiety through interrupting trail of thought.

The outsider witnessing group interview will be conducted by the researcher and will include an interview followed by guided outsider witnessing. The group interview will take up to 1 hour. Following this, the staff audience members will be interviewed separately to explore their experience of the outsider witnessing process, this will be up to 1 hour.

Analysis is estimated to take three months to complete with invitation to participant to check accuracy at a later date.

SECTION 3. Ethical considerations

14. Fully informing participants about the research (and parents/guardians if necessary):

How will you fully inform your participants when inviting them to participate? Will the participant invitation letter be written in a style appropriate for children and young people, if necessary?

As stated above, the upmost time and consideration will be given to ensure appropriate processural consent with individuals with memory problems. In addition to the visualised information sheet (see interviewee PIS attached Appendix D), the researcher will ensure a protected time to build rapport and establishing and re-stablishing consent is factored in. Information will be verbally explained, if needed with informant support. For meaningful consent, this will be continually re-checked at every stage of the research and responses recorded.

Staff participants will also be provided a PIS (see staff PIS attached Appendix E) with the opportunity to ask questions during periods I am present at the site e.g. during visits to build rapport with interviewee and/or during drop ins to staff meetings/handovers to present research.

15. Obtaining fully informed consent from participants (and from parents/guardians if necessary):

Is the consent form written in a style appropriate for children and young people, if necessary? Do you need a consent form for both young people and their parents/guardians? How will you gain consent if your research is collecting data online (e.g. using Qualtrics)?

To ensure participants with cognitive/memory difficulties are providing informed consent to take part, the researcher will employ processural consent methodology (Hughes & Castro Romero, 2015). Consent will be continually checked and rechecked at every stage of the study. On initial meeting, information will be provided with the view the individual is able to understand, retain, weigh up and communicate (MCA, 2005) their decision to take part. Subsequent meetings prior to the interview will be used with the individual to ensure consent is rechecked and rapport and communication style is established between interviewee and researcher (Nygard, 2006). A field diary will be filled out throughout the study to record verbal and non-verbal consent to participate (see field diary attached. Appendix B). If at any time the interviewee

wants to withdraw from the study their involvement will end. As part of the consent seeking methodology an informant will be sought to provide relevant information of how to best obtain consent from the individual (e.g., usual ways provide consent for other decisions), and any relevant background information (e.g., signs they are getting tired/distressed). They can also provide an introduction to the interviewee for the researcher.
Informants will be asked to sign a form to establish no known reasons why the individual should not participate (see consultee declaration attached. Appendix F).

This process is an alternative to a one-time signed consent form which may not be relevant for an individual with memory problems. Continual checking and re-checking consent fits the view consent is not static but a fluid process and to protect participants and promote inclusion it must be revisited (Iphofen, 2011). In addition, information will be provided in a visualised information sheet in lay terms (see interview and relative PISs attached. Appendix D & G), along with verbal explanation from the researcher with the opportunity to ask questions.

Staff participants will be requested to sign a consent form (see staff consent form attached, appendix I) in the presence of the researcher. Opportunities to ask question before, during and after signing the form will be provided and encouraged.

16. Engaging in deception, if relevant:

What will participants be told about the nature of the research? The amount of any information withheld and the delay in disclosing the withheld information should be kept to an absolute minimum.

N/A – participants will be fully informed as to the nature of the research

17. Right of withdrawal:

In this section, and in your participant invitation letter, make it clear to participants that ‘withdrawal’ will involve (1) participants being able to decide to not continue with participation in your research, and (2) the right to have the data they have supplied destroyed on request. You are asked to give participants a three-week window from the time they participate in your study to when they can withdraw their data. Make this clear in your participant invitation letter.

Note: If your study involves data collection through Qualtrics, it is essential that you ask participants to provide their own participant code on Qualtrics (e.g. two letters and two numbers) so that you will be able to identify them if they later want to withdraw their data.

Participants will be informed via the information sheet and verbally, of their right to withdraw from the research at any time, up until the point of writing the research up, without needing to give any reason and without any disadvantage. If a participant withdraws from the research, the researcher will remove and destroy any data source that has already been produced by the participant and these will not be referred to in any write up, presentation or discussion of the research.

Analysis will in part involve participants to check and re-check researcher's interpretations for accuracy of meaning, therefore there is no three-week window necessary to request their data to be destroyed.

18. Will the data be gathered anonymously?

This is where you will not know the names and contact details of your participants? In qualitative research that involves interviews, data is not collected anonymously because you will know the names and contact details of your participants.

~~YES /~~ NO

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

How will the names and contact details of participants be stored and who will have access? Will real names and identifying references be omitted from the reporting of data and transcripts etc? What will happen to the data after the study is over? Usually data will be destroyed after a study is over but if there is a possibility of you developing your research (for publication, for example) you may not want to destroy all data at the end of the study. If not destroying your data at the end of the study, what will be kept, how, and for how long? (suggested time is two years). It is advised that you destroy all names and contact details of participants at the end of your study regardless of how long will keep your data for. Make this clear in your participant invitation letter.

Personal data will be handled safely. Interviews will audio recorded on a device provided by UEL School of Psychology, will be transferred onto a password protected university computer before being deleted from the device immediately. Signed consent forms and other hard copies will be stored in a locked draw until being scanned and uploaded onto the password protected computer and hard copies destroyed. Electronic data will be stored up to 3-5 years. During interview confidentiality will be a requirement of all involved and mentioned by the researcher. Direct identifiers will be removed and replaced with a pseudonym.

20. Will participants be paid or reimbursed?

This is not necessary but payment/reimbursement must be in the form of redeemable vouchers and not cash. Please note that the School cannot fund participant payment.

~~YES~~ / NO

If YES, why is payment/reimbursement necessary and how much will the vouchers be worth?

SECTION 4. Other permissions and ethical clearances

21. Research involving the NHS in England

Is HRA approval for research involving the NHS required? ~~YES~~ / NO

Please see Page 1 of this application for important information and link

Will the research involve NHS employees who will not be directly recruited through the NHS and where data from NHS employees will not be collected on NHS premises?

~~YES~~ / NO

If you work for an NHS Trust and plan to recruit colleagues from the Trust will permission from an appropriate member of staff at the Trust be sought and is a copy of this permission (can be an email from the Trust) attached to this application?

~~YES~~ / NO

22. Permission(s) from an external institution/organisation (e.g. a school, charity, workplace, local authority, care home etc.)?

You need to attach written permission from external institutions/organisations/workplaces if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation.

Is permission from an external institution/organisation/workplace required? YES / NO

Not known at this stage as not secured. Please see organisation invitation letter attached (Appendix A) with view of email or written confirmation to be sought.

If YES please give the name and address of the institution/organisation/workplace:

COPIES OF PERMISSIONS (LETTER OR EMAIL) MUST BE ATTACHED TO THIS APPLICATION

In some cases you may be required to have formal ethical clearance from the external institution or organisation or workplace too.

23. Is ethical clearance required from any other ethics committee?

~~YES /~~ NO

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

Has such ethical clearance been obtained yet? YES / NO

If NO why not?

If YES, please attach a scanned copy of the ethical approval letter. A copy of an email from the organisation confirming its ethical clearance is acceptable.

Ethical approval from the School of Psychology 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 the School and other ethics committee/s as may be necessary.

SECTION 5. Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible.

If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.

24. Protection of participants:

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 (can be physical, emotional or psychological)? How will the safety and well-being of participants be ensured? Will contact details of an appropriate support organisation or agency will be made available to participants in your debrief sheet, particularly if the research is of a sensitive nature or potentially distressing?

The support organisation or agency that you refer participants to in your debrief letter should be appropriate. That is, is there a more appropriate support organisation than the Samaritans, for example (i.e. anxiety, mental health, young people telephone support help-lines?

Safeguarding
In the case of researcher becoming aware of any safeguarding issues within the host setting or disclosed by participants, appropriate flags will be raised. Participants will be made aware of this being the only reason to breach confidentiality. Any issues will be discussed with the director of studies immediately and local social care safeguarding leads will be contacted as and when necessary.

Distress from experience
Interviewee participant may feel burdened to speak to researcher for long periods of time. Prior to approaching the participant researcher will consult with relative and key worker to establish signs of discomfort and usual patterns. This will be considered throughout any interaction and interaction ended if any signs appear. The researcher will employ their clinical skills and experience with this population to recurrently ascertain comfort and consent to continue. It is assumed the practice of outsider witnessing may be new for all participants involved. The researcher will take responsibility to familiarise all involved of the process prior to the interview. During the interview, the questions will guide the responses to reflection on individual experience, rather than judgement of others: the researcher will ask pre-set outsider witnessing questions which will focus on creating a non-judgmental space to explore imagery and emotions raised in participants, following White (2007) (see attached, appendix C). In addition, the researcher will follow up staff participants in one on one interviews on the experience, which will also serve as an extended debrief. All participants will be revisited up to end of analysis stage to recheck consent and check on analysis outcomes. Researcher and Director of Studies contact details will also be provided for participants to contact if needed.

25. Protection of the researcher:

Will you be knowingly exposed to any health and safety risks? If equipment is being used is there any risk of accident or injury to you and how will you mitigate this? If interviewing participants in their homes will a third party be told of place and time and when you have left a participant's house?

No specific risks to researcher are identified. Researcher will inform DoS of date and time of planned interview/group interview and will contact once leaving. Interviews will be during opening hours of building.

26. Debriefing participants:

How will participants be de-briefed? Will participants be informed about the true nature of the research if they are not told beforehand? Will contact details of a support organisation be made available to participants via the debrief letter? All student research must involve a debrief letter for participants (unless the research involves anonymous surveys) so please attach a copy of your debrief letter to this application (see page 12).

As outlined above in section 24, the methodology will offer increased contact with the researcher prior to and following the interview to discuss any concerns. Additionally, a standardised debrief will be offered at the end of interviews to all participants. No external counselling organisations will be signposted, as there will be support within the participating organisation. Debrief will be verbal but written format will also be provided (see attached debrief and interview schedule, Appendix H & C)

27. Other: Is there anything else the reviewer of this application needs to know to make a properly informed assessment?

No.

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

YES ~~/ NO~~

If YES have you obtained and attached a DBS certificate? YES / ~~NO~~

If your research involves young people under 16 years of age and young people of limited competence will parental/guardian consent be obtained.

~~YES~~ / NO

If NO please give reasons. (Note that parental consent is always required for participants who are 16 years of age and younger)

* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, 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. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children see:

https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/Research-involving-children.aspx

29 Will you be collecting data overseas? ~~YES~~ / NO

This includes collecting data while you are away from the UK on holiday or visiting your country of origin, and distance learning students who will be collecting data in their overseas country of residence.

If YES in what country or countries (and province if appropriate) will you be collecting data?

Please click on this link https://www.gov.uk/foreign-travel-advice and note in the space below what the UK Government is recommending about travel to that country/province (Please note that you MUST NOT travel to a country/province/area that is deemed to be high risk or where essential travel only is recommended by the UK Government. If you are unsure it is essential that you speak to your supervisor or the UEL Travel Office – travelúel.ac.uk / (0)20 8223 6801).

SECTION 6. Declarations

Declaration by student:

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

Student's name: *Navneet Nagra*

Student's number: u1622890 Date: 8/1/19

Supervisor's declaration of support is given upon their electronic submission of the application

YOU MUST ATTACH THESE ATTACHMENTS:

1. PARTICIPANT INVITATION LETTER(S) – Appendix D,E & G

See pro forma in the ethics folder in the Psychology Noticeboard on Moodle. This can be adapted for your own use and must be adapted for use with parents/guardians and children if they are to be involved in your study.

Care should be taken when drafting a participant invitation letter. It is important that your participant invitation letter fully informs potential participants about what you are asking them to do and what participation in your study will involve – what data will be collected, how, where? What will happen to the data after the study is over? Will anonymised data be used in the write-up of the study, or at conferences or in possible publications etc.? Tell participants about how you will protect their anonymity and confidentiality and about their withdrawal rights.

Make sure that what you tell potential participants in this invitation letter matches up with what you have said in the application.

2. CONSENT FORM(S) Appendix B & I

Use the pro forma in the ethics folder in the Psychology Noticeboard on Moodle. This should be adapted for use with parents/guardians and children.

3. PARTICIPANT DEBRIEF SHEET Appendix H

This can be one or two paragraphs thanking participants, reminding them what will happen to their data and, if relevant, should include the contact details of a relevant agency or organisation that participants can contact for support if necessary. Should include the true nature of the study if your research involved deception.

OTHER ATTACHMENTS YOU MAY NEED TO INCLUDE:

See notes on Page 2 about what other attachments you may need to include – Example interview questions? Copies of questionnaires? Visual stimuli? Ethical clearance or permission from another institution or organisation? Current DBS clearance certificate?)

SCANNED COPY OF CURRENT DBS CERTIFICATE
(If one is required. See notes on Page 3)

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Max Eames

SUPERVISOR: **Maria Castro**

STUDENT: Navneet Nagra

Course: Professional Doctorate in Clinical Psychology

Title of proposed study: Telling and re-telling stories: Staff witnessing narratives from people diagnosed with Dementia

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved

Minor amendments required *(for reviewer)*:

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

MEDIUM (Please approve but with appropriate recommendations)

LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Dr Melanie Spragg)*:

Date: 15th January 2019

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

APPENDIX L – Relative/Friend Declaration Form

“Telling and re-telling stories in dementia”: a study exploring the impact of stories told on people with memory problems and staff.

Name of Researcher: Navneet Nagra, Trainee Clinical Psychologist

Please initial box

I ……………………[PRINT NAME] have been consulted about

…………….……..[PRINT PARTICIPANT’S NAME]

participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.

I understand if I have any questions or concerns I can get in touch with the researcher

I confirm I know of no reason why my relative/friend would object to being approached about or take part in the study

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

I understand that data collected during the study may be looked at by responsible individuals from University of East London

I agree to other care professionals being informed of their participation in the study.

Name of Consultee	Date	Signature

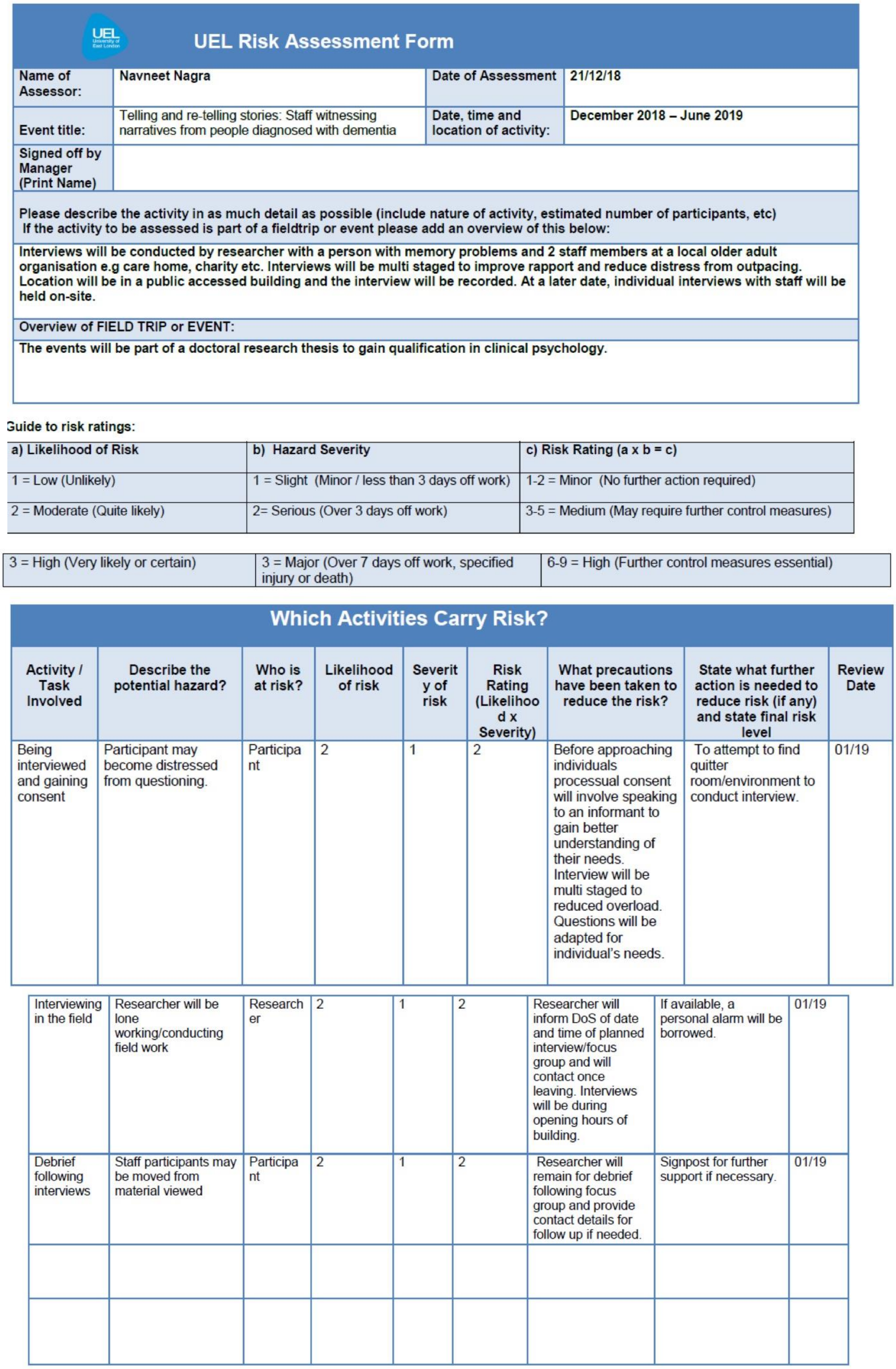
Relationship to participant:

Person undertaking consultation:

Name	Date	Signature

When completed: 1 for consultee and 1 for researcher site file

APPENDIX M – Risk Assessment



UEL Risk Assessment Form

Name of Assessor:	**Navneet Nagra**	**Date of Assessment**	**21/12/18**
Event title:	Telling and re-telling stories: Staff witnessing narratives from people diagnosed with dementia	**Date, time and location of activity:**	**December 2018 – June 2019**
Signed off by Manager (Print Name)			

Please describe the activity in as much detail as possible (include nature of activity, estimated number of participants, etc) If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:

Interviews will be conducted by researcher with a person with memory problems and 2 staff members at a local older adult organisation e.g care home, charity etc. Interviews will be multi staged to improve rapport and reduce distress from outpacing. Location will be in a public accessed building and the interview will be recorded. At a later date, individual interviews with staff will be held on-site.

Overview of FIELD TRIP or EVENT:

The events will be part of a doctoral research thesis to gain qualification in clinical psychology.

Guide to risk ratings:

a) Likelihood of Risk	**b) Hazard Severity**	**c) Risk Rating (a x b = c)**
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-5 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6-9 = High (Further control measures essential)

Which Activities Carry Risk?

Activity / Task Involved	**Describe the potential hazard?**	**Who is at risk?**	**Likelihood of risk**	**Severity of risk**	**Risk Rating (Likelihood x Severity)**	**What precautions have been taken to reduce the risk?**	**State what further action is needed to reduce risk (if any) and state final risk level**	**Review Date**
Being interviewed and gaining consent	Participant may become distressed from questioning.	Participant	2	1	2	Before approaching individuals processual consent will involve speaking to an informant to gain better understanding of their needs. Interview will be multi staged to reduced overload. Questions will be adapted for individual's needs.	To attempt to find quitter room/environment to conduct interview.	01/19
Interviewing in the field	Researcher will be lone working/conducting field work	Researcher	2	1	2	Researcher will inform DoS of date and time of planned interview/focus group and will contact once leaving. Interviews will be during opening hours of building.	If available, a personal alarm will be borrowed.	01/19
Debrief following interviews	Staff participants may be moved from material viewed	Participant	2	1	2	Researcher will remain for debrief following focus group and provide contact details for follow up if needed.	Signpost for further support if necessary.	01/19

A comprehensive guide to risk assessments and health and safety in general can be found in UEL's Health & Safety handbook at http://www.uel.ac.uk/hrservices/hs/handbook/ and a comprehensive guide to risk assessment is available on the Health & Safety Executive's web site at http://www.hse.gov.uk/risk/casestudies/index.htm. An example risk assessment is also included below.

APPENDIX N – Reflective Diary Extracts

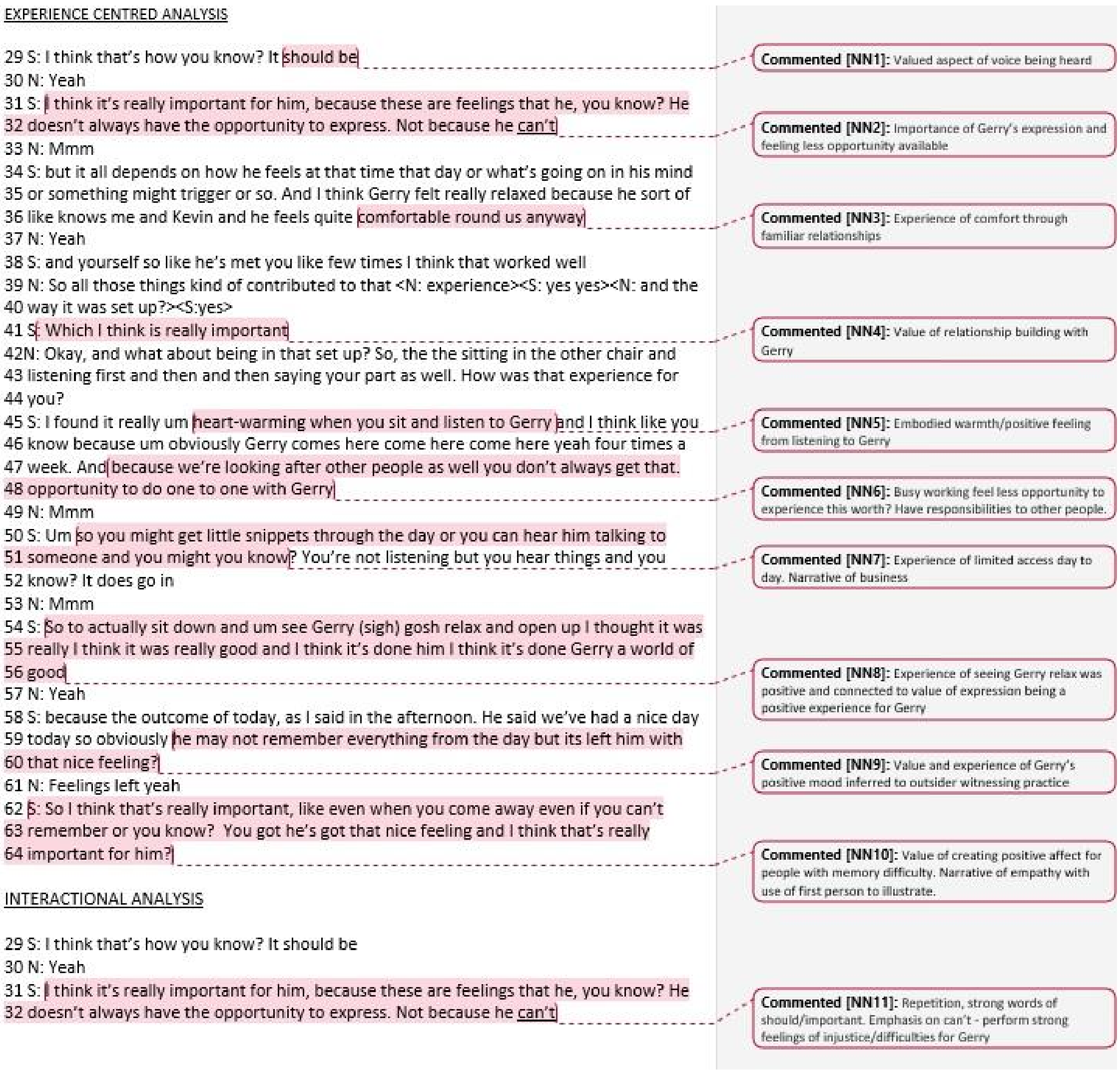
1/4/19

Interviewed XXXXX this morning, I approached him as he sat with [Male member] at the table, I asked if he wanted to take part in my project today and he agreed to, I showed the PIS again and he remembered being shown this. I stated 'I couldn't remember if I had shown him', I wanted to normalise memory difficulties and took a one down position. I also did not wanted to make him anxious before taking part. I asked XXXXX who would be taking part, I remember feeling like an inconvenience last visit, they were short staffed and were not willing/able to give someone up for the OWP. I agreed for XXXXX to attend alone, which she was happy to do. We sat in the activity room while people played Kalooki outside. I set up the interview and XXXXX grew inpatient I felt, asking me 'ask me a question' and 'carry on'. When I asked my first questions he would respond with short responses and then 'pass'. Including follow up questions. I grew worried he was not happy to engage but it soon became a bit of a game, I remembered his approach had left me anxious the first time I saw him and additionally, I was a little embarrassed. Probably as my power was undermined in front of XXXXX and I felt reflected on my competency as a trainee, so worked harder than with XXXXX. As the interview progressed XXXXX told stories he felt comfortable with if he didn't want to answer something would say 'pass'. I would move on, after all it was his preferred story. Cues were in the form of typical milestones etc. There was a couple points in the interview XXXXX would reflect on his ability and compared himself to others who attended, he looked at XXXXX to confirm if he was okay. I felt the need to move on and explore other parts of XXXXX instead. Once he didn't want anymore questions he would start asking me to ask XXXXX instead, once I moved on XXXXX would also interject his thoughts and opinions. He would confirm what XXXXX had witnessed as his intentional identity/values and back with stories/examples. It appeared to be less pressure than the one to one. He did state on one occasion 'nobody knows me', this was a strong self image for XXXXX it seemed, being a private man and having control of what he tells/doesn't tell. He thanked me for the interview and left.

5/4/19

Met with XXXXX for her interview, XXXXX was alone and I sat with him. I felt slightly sad for him, no one else was here and XXXXX was not well who did XXXXX have to talk to? He asked me how the interview writing was going and stated he was very interested in hearing what I had to say about him. I told him it would take two-three weeks. He asked me about my engagement and how he thought I was Jewish before, we spoke about the local area and an Indian restaurant he knew of. He struggled to name it so I took my phone out and showed him a picture, he told me that was the restaurant and recommended I went. XXXXX was in a meeting, once it was over I spoke to XXXXX who has a cold and was going to go home, but agreed to take part. During this time XXXXX reflected on her image of XXXXX, she told after the interview he had asked her if he had done alright (reassurance?) and he noted him saying something out of context which he never normally did. It appeared to represent the illness progressing which was sad to witness for XXXXX. She reflected on conversations with his wife about how shut down XXXXX is. I was wondering how much of that narrative had transpired into her view of him at the centre. She admired his drive and related to that aspect of him greatly. I asked her to compared her experiences of OWP with XXXXX and XXXXX. She drew on her relationships with them both and how she had to be a different person with each gentleman. XXXXX was safer to be emotional with than XXXXX.

APPENDIX O - Analysis Examples



EXPERIENCE CENTRED ANALYSIS

S: I think that's how you know? It should be

Commented [NN1]: Valued aspect of voice being heard

N: Yeah

S: I think it's really important for him, because these are feelings that he, you know? He doesn't always have the opportunity to express. Not because he can't

Commented [NN2]: Importance of Gerry's expression and feeling less opportunity available

N: Mmm

S: but it all depends on how he feels at that time that day or what's going on in his mind or something might trigger or so. And I think Gerry felt really relaxed because he sort of like knows me and Kevin and he feels quite comfortable round us anyway

Commented [NN3]: Experience of comfort through familiar relationships

N: Yeah

S: and yourself so like he's met you like few times I think that worked well

N: So all those things kind of contributed to that <N: experience><S: yes yes><N: and the way it was set up?><S:yes>

S: Which I think is really important

Commented [NN4]: Value of relationship building with Gerry

N: Okay, and what about being in that set up? So, the the sitting in the other chair and listening first and then and then saying your part as well. How was that experience for you?

S: I found it really um heart-warming when you sit and listen to Gerry and I think like you know because um obviously Gerry comes here come here come here yeah four times a week. And because we're looking after other people as well you don't always get that opportunity to do one to one with Gerry

Commented [NN5]: Embodied warmth/positive feeling from listening to Gerry

Commented [NN6]: Busy working feel less opportunity to experience this worth? Have responsibilities to other people.

N: Mmm

S: Um so you might get little snippets through the day or you can hear him talking to someone and you might you know? You're not listening but you hear things and you know? It does go in

Commented [NN7]: Experience of limited access day to day. Narrative of business

N: Mmm

S: So to actually sit down and um see Gerry (sigh) gosh relax and open up I thought it was really I think it was really good and I think it's done him I think it's done Gerry a world of good

Commented [NN8]: Experience of seeing Gerry relax was positive and connected to value of expression being a positive experience for Gerry

N: Yeah

S: because the outcome of today, as I said in the afternoon. He said we've had a nice day today so obviously he may not remember everything from the day but its left him with that nice feeling?

Commented [NN9]: Value and experience of Gerry's positive mood inferred to outsider witnessing practice

N: Feelings left yeah

S: So I think that's really important, like even when you come away even if you can't remember or you know? You got he's got that nice feeling and I think that's really important for him?

Commented [NN10]: Value of creating positive affect for people with memory difficulty. Narrative of empathy with use of first person to illustrate.

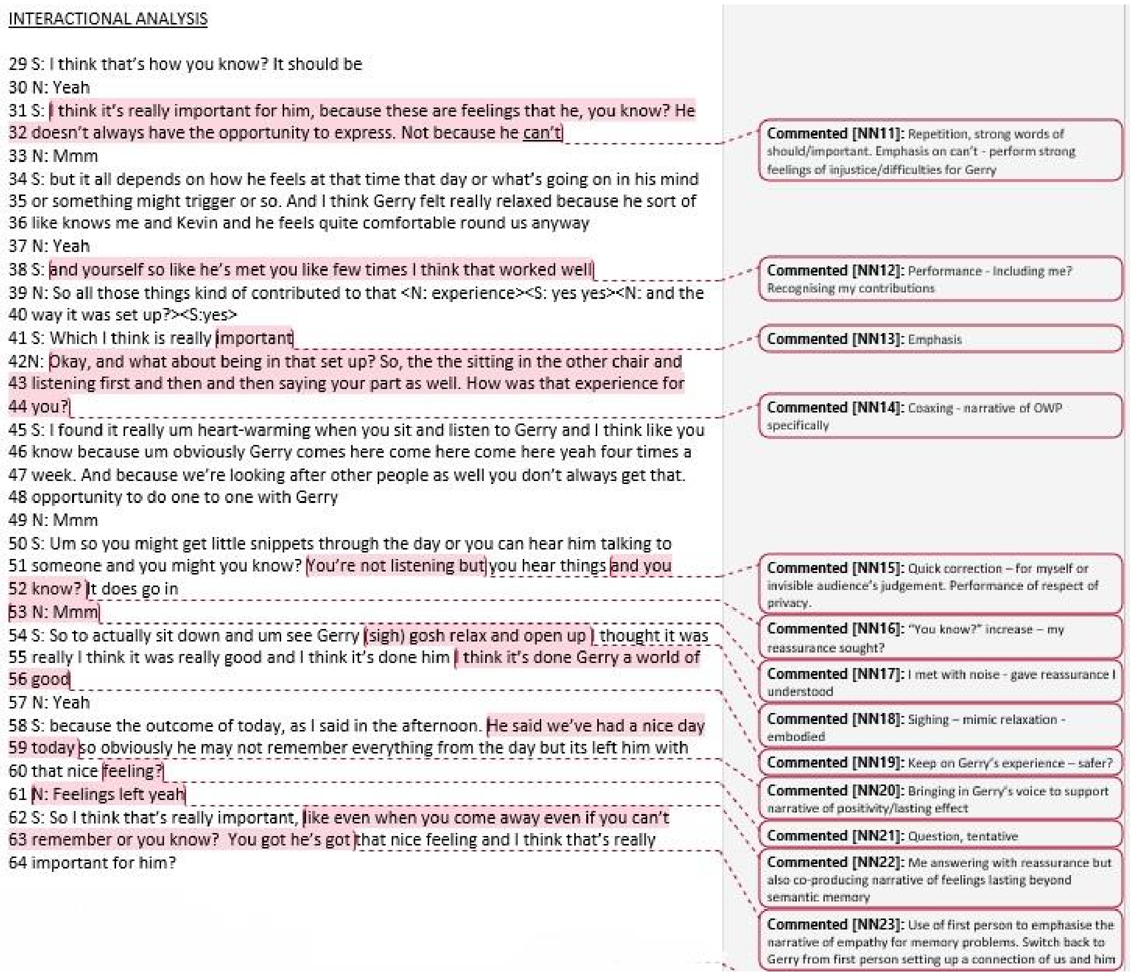
INTERACTIONAL ANALYSIS

S: I think that's how you know? It should be

N: Yeah

S: I think it's really important for him, because these are feelings that he, you know? He doesn't always have the opportunity to express. Not because he can't

Commented [NN11]: Repetition, strong words of should/important. Emphasis on can't - perform strong feelings of injustice/difficulties for Gerry



INTERACTIONAL ANALYSIS

29 S: I think that's how you know? It should be
30 N: Yeah
31 S: I think it's really important for him, because these are feelings that he, you know? He
32 doesn't always have the opportunity to express. Not because he can't
33 N: Mmm
34 S: but it all depends on how he feels at that time that day or what's going on in his mind
35 or something might trigger or so. And I think Gerry felt really relaxed because he sort of
36 like knows me and Kevin and he feels quite comfortable round us anyway
37 N: Yeah
38 S: and yourself so like he's met you like few times I think that worked well
39 N: So all those things kind of contributed to that <N: experience><S: yes yes><N: and the
40 way it was set up?><S:yes>
41 S: Which I think is really important
42N: Okay, and what about being in that set up? So, the the sitting in the other chair and
43 listening first and then and then saying your part as well. How was that experience for
44 you?
45 S: I found it really um heart-warming when you sit and listen to Gerry and I think like you
46 know because um obviously Gerry comes here come here come here yeah four times a
47 week. And because we're looking after other people as well you don't always get that.
48 opportunity to do one to one with Gerry
49 N: Mmm
50 S: Um so you might get little snippets through the day or you can hear him talking to
51 someone and you might you know? You're not listening but you hear things and you
52 know? It does go in
53 N: Mmm
54 S: So to actually sit down and um see Gerry (sigh) gosh relax and open up I thought it was
55 really I think it was really good and I think it's done him I think it's done Gerry a world of
56 good
57 N: Yeah
58 S: because the outcome of today, as I said in the afternoon. He said we've had a nice day
59 today so obviously he may not remember everything from the day but its left him with
60 that nice feeling?
61 N: Feelings left yeah
62 S: So I think that's really important, like even when you come away even if you can't
63 remember or you know? You got he's got that nice feeling and I think that's really
64 important for him?

Commented [NN11]: Repetition, strong words of should/important. Emphasis on can't - perform strong feelings of injustice/difficulties for Gerry

Commented [NN12]: Performance - Including me? Recognising my contributions

Commented [NN13]: Emphasis

Commented [NN14]: Coaxing - narrative of OWP specifically

Commented [NN15]: Quick correction – for myself or invisible audience's judgement. Performance of respect of privacy.

Commented [NN16]: "You know?" increase – my reassurance sought?

Commented [NN17]: I met with noise - gave reassurance I understood

Commented [NN18]: Sighing – mimic relaxation - embodied

Commented [NN19]: Keep on Gerry's experience – safer?

Commented [NN20]: Bringing in Gerry's voice to support narrative of positivity/lasting effect

Commented [NN21]: Question, tentative

Commented [NN22]: Me answering with reassurance but also co-producing narrative of feelings lasting beyond semantic memory

Commented [NN23]: Use of first person to emphasise the narrative of empathy for memory problems. Switch back to Gerry from first person setting up a connection of us and him

WIDER NARRATIVES

S: I think that's how you know? It should be
N: Yeah
S: I think it's really important for him, because these are feelings that he, you know? He doesn't always have the opportunity to express. Not because he can't
N: Mmm
S: but it all depends on how he feels at that time that day or what's going on in his mind or something might trigger or so. And I think Gerry felt really relaxed because he sort of like knows me and Kevin and he feels quite comfortable round us anyway
N: Yeah
S: and yourself so like he's met you like few times I think that worked well
N: So all those things kind of contributed to that <N: experience><S: yes yes><N: and the way it was set up?><S:yes>
S: Which I think is really important
N: Okay, and what about being in that set up? So, the the sitting in the other chair and listening first and then and then saying your part as well. How was that experience for you?
S: I found it really um heart-warming when you sit and listen to Gerry and I think like you know because um obviously Gerry comes here come here come here yeah four times a week. And because we're looking after other people as well you don't always get that. opportunity to do one to one with Gerry
N: Mmm
S: Um so you might get little snippets through the day or you can hear him talking to someone and you might you know? You're not listening but you hear things and you know? It does go in
N: Mmm
S: So to actually sit down and um see Gerry (sigh) gosh relax and open up I thought it was really I think it was really good and I think it's done him I think it's done Gerry a world of good
N: Yeah
S: because the outcome of today, as I said in the afternoon. He said we've had a nice day today so obviously he may not remember everything from the day but its left him with that nice feeling?
N: Feelings left yeah
S: So I think that's really important, like even when you come away even if you can't remember or you know? You got he's got that nice feeling and I think that's really important for him?

Commented [NN24]: Political and the personal

Commented [NN25]: Less opportunity for PDwD to express themselves than others.

Formatted: Highlight

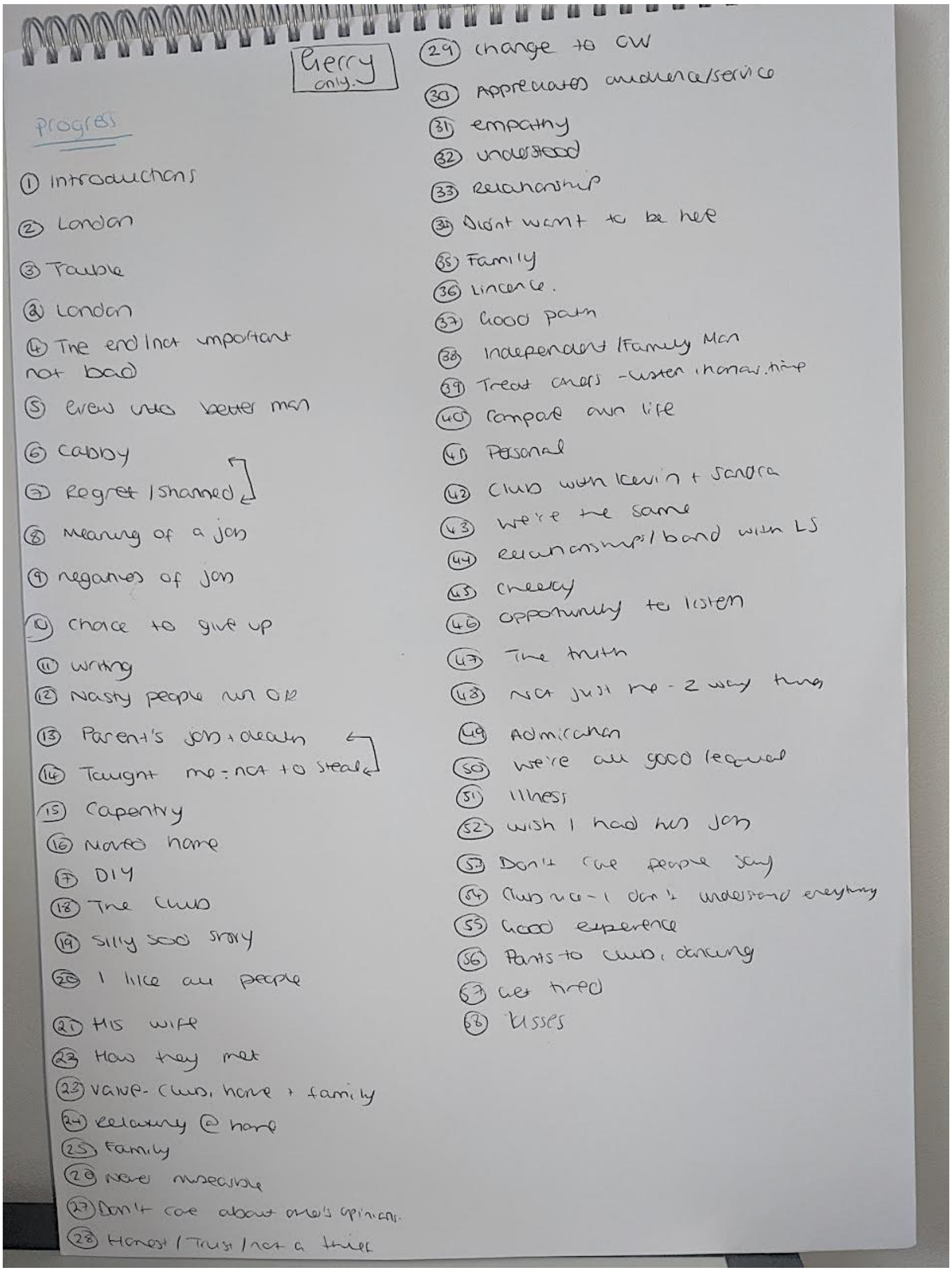
Commented [NN26]: Eluding to dementia narratives of sun downing, triggering memory

Commented [NN27]: Individualised. Person centred considerations

Commented [NN28]: Less opportunity for care staff to engage in one on one do to workload/other more pressing responsibilities other than one to one conversation

Commented [NN29]: Valuing respect and privacy of people

Experience centred – whole narrative view

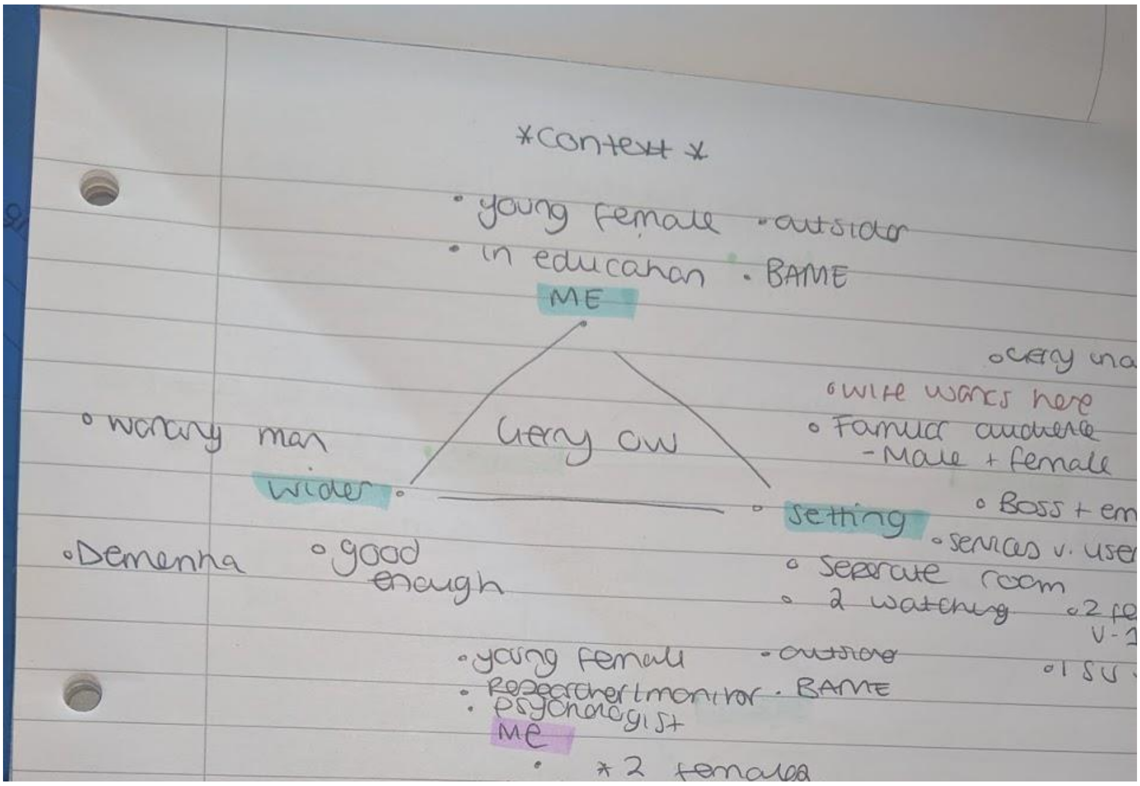


Gerry
only.

Progress

① introductions
② London
③ Trouble
② London
④ The end / not important
not bad
⑤ Grew into better man
⑥ Cabby
⑦ Regret / shamed
⑧ Meaning of a job
⑨ negatives of job
⑩ chance to give up
⑪ writing
⑫ Nasty people are OK
⑬ Parent's job + death
⑭ Taught me = not to steal
⑮ Capentry
⑯ Moved home
⑰ DIY
⑱ The club
⑲ Silly sod story
⑳ I like all people
㉑ His wife
㉓ How they met
㉓ value - club, home + family
㉔ relaxing @ home
㉕ Family
㉖ never miserable
㉗ Don't care about other's opinions.
㉘ Honest / Trust / not a thief
㉙ change to CW
㉚ Appreciates audience/service
㉛ empathy
㉜ understood
㉝ Relationship
㉞ Didn't want to be here
㉟ Family
㊱ Lincence.
㊲ Good path
㊳ Independent / Family Man
㊴ Treat others - listen, honour, time
㊵ Compare own life
㊶ Personal
㊷ Club with Kevin + Sandra
㊸ We're the same
㊹ relationship / bond with LS
㊺ cheeky
㊻ opportunity to listen
㊼ The truth
㊽ Not just me - 2 way thing
㊾ Admiration
㊿ We're all good / equal
(51) Illness
(52) Wish I had his job
(53) Don't care people say
(54) Club nice - I don't understand everything
(55) Good experience
(56) Parts to club, dancing
(57) Get tired
(58) Kisses

Wider Narrative – Context Maps



Emerging Narratives Over Time