Stories of people with dementia who experience word-finding difficulties.

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ABSTRACT

Much research on word-finding difficulties (WFDs) in dementia focuses on quantifying cognitive and linguistic deficits, rather than exploring the ways in which people living with dementia (PLWD) use their existing cognitive and linguistic resources to communicate and share their stories. In addition, little research has focused on exploring the use of non-verbal communication (NVC) and how this is performed through storytelling.

The current research aimed to elicit narratives of PLWD and WFDs. Accounts were elicited from three one-to-one interviews which took place in a community setting. These interviews were videorecorded to explore the use of NVC of both the person living with dementia and the researcher. Narrative analysis of the interviews explored the key narratives told by the participants, and the interactional context between the participant and the researcher within the wider socio-political contexts. In addition, NVC has also been interpreted to demonstrate the ways in which this is used as a resource in storytelling.

By attending to NVC, it was found that even in silences and manifestations of WFDs participants expressed themselves in a multitude of ways which complemented storytelling, showing the capacity to be humorous, engaging, expressive, and moving, even in the absence of words. In privileging the stories of PLWD and WFDs, it was found that the use of NVC is used resourcefully to affirm their identities and personhood despite threats against these. However, participants did story that experiencing WFDs did lead to frustration, anger, shame, and feelings of dismissal from others.

The findings and implications of this study are then discussed, considering their relationship to wider discourses. Findings indicate possibilities for future research and professional practice. The stories presented here may provide ideas for how Clinical Psychologists can improve access to our services at all stages of the dementia journey and promote personhood irrespective of the cognitive and linguistic difficulties experienced by those living with dementia.

1.0. INTRODUCTION

As of December 2021, it is estimated there are 900,000 people living with dementia (PLWD) in the United Kingdom. This is projected to increase to 1.6 million by 2040 (Alzheimer's Society, 2021).

PLWD have life stories which persist despite receiving a diagnosis of dementia. Medical models of dementia sustain a narrative that PLWD are shadows of their former selves (Batra et al., 2015). Kitwood (1997) argues deficit-focused definitions of dementia impact PLWD's opportunities for maintaining personhood[1], particularly when one's sense of self is centred around social roles and relationships (Macrae, 2010).

While cognitions, emotions, and experiences that once defined PLWD and upheld their sense of self are less available (Bryden, 2005), PLWD make attempts to use their cognitive and linguistic resources to affirm and maintain personhood (Batra et al., 2015). This view is jarring in comparison to deficit-based narratives around dementia and elicits questions as to the processes PLWD use to communicate their meaning when they also experiencing communication difficulties. Randall (2009) asserts the retelling of certain stories, while often seen as a memory impairment, may be an attempt to communicate important aspects of the storyteller's identity and preserve these identities even in the latter stages of dementia when words may be lost.

The current chapter will outline my personal interest in this topic and present an overview of the historical and current socio-political contexts surrounding dementia. Following this, I will review the existing literature on the experiences of PLWD who experience word-finding difficulties (WFDs). I will then address gaps in current research and the ways this study aims to address these.

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[1] A term conceived by Kitwood (1997) to illustrate the relational and personal attributes of an individual.

1.1. Defining Terminology

1.1.1. Dementia

The National Institute for Health and Clinical Excellence (NICE) defines dementia as “a progressive, irreversible clinical syndrome with a range of cognitive and behavioural symptoms including memory loss, problems with reasoning and communication, change in personality, and reduction in the person's ability to carry out daily activities.” (2018, p.6). Biomedical constructions of dementia have been criticised for being deterministic, essentialist, and reductionist (Gilliard et al., 2005).

Kitwood (1998) describes dementia as an interaction between neurological processes and the contexts in which these take place, meaning the contexts of PLWD influence how dementia is experienced. Kitwood (1997) proposed harmful social narratives intensified the biological and psychological impacts of dementia and decreased the dignity of PLWD.

I aim to use Kitwood’s (1997; 1998) conceptualisation of dementia in this study and I adopt the view that dementia involves neurological processes which can affect cognitive and functional abilities, within a socially constructed experience.

1.1.2. Word-finding Difficulties In Dementia

Aphasia is a medicalised term referring to language impairment which impacts a person’s ability to comprehend and/or produce speech in written and/or spoken word. Aphasia refers to a complete loss of language and dysphasia refers to a partial loss of language, although aphasia is now used to describe both (NHS, 2018).

Rohrer et al. (2008) found the term word-finding difficulty (WFD) is often volunteered by PLWD and their families to describe impaired language retrieval and output, rather than aphasia, and therefore, will be used throughout. WFDs are present in many types of dementia, including Alzheimer’s dementia (AD) and vascular dementia which Public Health England (PHE; 2019) estimate accounts for 60-70% and 15-20% of all dementia diagnoses in the UK, respectively. WFDs are one of the earliest signs of language impairment in AD (Hodges et al., 1992) and are likely to increase over time presenting growing challenges for PLWD (Nebes et al.,1989).

1.2. Contextualising the Research

1.2.1. Positioning of the Researcher

I wish to challenge the boundaries between my personal and professional self by writing in the first person and being transparent about my personal position. In doing so, I hope to highlight the human interactions between myself and PLWD which have produced this research.

Consistent with a social constructionist view, reflexivity reveals the constitutive nature of research: the inseparability of observer, observation, and their interpretations (Kohler-Riessman, 2015). Krieger (1991) presents ways in which scientific writing seeks to minimise, neutralise, or standardise the personal self of the researcher as it is viewed as a contaminant to the validity of the research. Researchers therefore prefer to place their stories and reflections in the appendices, or reserve personal disclosure for private diaries and fleeting introductory remarks (Kohler-Riessman, 2015).

Afuape (2011) contended that researchers' ideologies are used to make sense of knowledge and our beliefs will inevitably be conveyed directly or indirectly in our written narratives. Van Langenhove and Harré (1999) stated each process involved in the research "can be understood as a tacit and intentional positioning" (p.31) and reveals a glimpse into the person conducting the research.

Gergen (2007) notes issues of power may influence which stories are told or altered. By naming this, I hope it supports my continued reflections on the ways in which I represent myself and 'other' and how this is influenced by my own narratives around dementia. DeVault (1997) noted this transparency in writing is often regarded with suspicion as it can mar the standards of critique and discussion, however, sharing my personal context seems essential to reflexivity.

1.2.2. Personal Context

Many readers will know someone living with dementia and their views about dementia and PLWD will be shaped by their own contexts. In sharing my context and my reasons for researching this topic, I invite the reader to remain curious about their own responses to the research presented. A more detailed personal context summary is available (Appendix A).

I was raised in Ireland in a working-class Catholic family. I would describe myself as a white Irish woman who is well-educated. My Irish identity has become more important to me since moving to Britain in 2016. I have several family members who have been diagnosed with dementia and have witnessed their experiences with health and social care services. I noticed when conversation became difficult, we could find ways of communicating often by using non-verbal communication (NVC) and I wondered how our sense of self is communicated non-verbally.

I have significant experience in working with PLWD in the NHS as a research assistant and as an assistant psychologist. I have delivered Cognitive Stimulation Therapy (CST), life story work, and carer workshops. I felt exclusionary practices were embedded in services, for example, pre-existing exclusion criteria for CST included significant communication difficulties. However, within my work with PLWD, I witnessed and experienced how PLWD adapted their communication style to construct their stories and share their self with others in social contexts and resisted wider narratives around dementia.

My personal and professional experiences led me to wonder about the lived experience of PLWD who experience WFDs and the way in which dominant discourses may shape these?

1.2.3. The Broader Context

Dementia is an object of social knowledge; a set of shared stories which describe it and elicits beliefs and expectations about the behaviour of PLWD (Bosco et al., 2019). Shared stories define our attitude to dementia and PLWD. These narratives may be apparent in social media, news, or in stories we share in everyday conversations (Villar, et al., 2019).

The stories people tell about dementia and the meanings within are constructed through language, metaphors, and NVC: shaped by socio-cultural and historical contexts (Esin et al., 2013). Zeilig (2014) recommends those working with PLWD consider the powerful influence of the wider cultural narratives in which their stories are inscribed. Conceptualisations and cultural meanings attached to dementia are diverse and understood, expressed, or resisted differently by people in their social contexts (Hillman & Latimer, 2017).

1.2.3.1. Socio-cultural and historical contexts

The history of ‘senile dementia’ as a state of insanity in old age originates in Ancient Greece (Berchtold & Cotman, 1998). Later, Romans contended dementia was not a normal part of ageing but rather a result of a life lacking in social and civic engagement. By engaging in an active life, the condition could be reversed (Berchtold & Cotman, 1998). In some ways, this conceptualisation of successful ageing resonates with current concepts of how to slow the progression of dementia, for example, NICE guidelines (2018) recommend cognitive stimulation to improve social functioning.

In the Middle Ages, religious doctrines intensified the stigma associated with dementia and constructed it as an act of divine punishment. PLWD were conceived as sinners, trialled and punished for these sins, even banished, to protect others from their ‘impure spirit’ (Venzmer, 1968).

The nineteenth and twentieth centuries ushered in the categorisation of symptoms into disorders and it is argued this resulted in the objectification of PLWD as merely hosts of a neurodegenerative condition (Henderson, 1986). Framing dementia as a medical condition meant that health services were considered to be responsible for the care of PLWD. Therefore, those who could not be safely managed in the community tended to be placed in medical institutions (Bosco et al., 2019).

Later in the twentieth century, the anti-psychiatry movement challenged the medical model by highlighting the contribution of social factors to mental ‘disease’ (Szasz, 1997) and argued long-term stays in hospitals deprived people of their self-determination (Wing, 1990). Economic drivers and social movements joined to reduce the provision of long-term hospital care for PLWD and shifted care into the community (Davidge et al., 1993).

Kitwood (1997) promoted a care-model which ensured PLWD are central to conversations about their care, to uphold their personhood. Consequently, person-centred care (PCC) came to be regarded as the gold standard for the care of PLWD (Mental Health Foundation UK, 2015). However, medicalisation still permeates the dementia care pathway and may influence the dignity and stigma faced by PLWD (Pinner et al., 2011).

Peel (2014) analysed UK national newspaper articles which revealed modern depictions of dementia are often rooted in catastrophe, for example, describing increasing prevalence of dementia as a ‘tsunami’. They note the juxtaposition between representations of dementia as a catastrophic natural event and the expectation for people to battle or fight against nature which Zeilig (2014) proposed creates both a sense of terror and disempowerment.

These metaphors contribute to findings that 62% of people felt that a dementia diagnosis meant their ‘life was over’ (Alzheimer’s Society, 2016). Bosco et al. (2019) stated even uttering the word ‘dementia’ can create a sense of tremendous dread. Other representations in media refer to dementia as demonic (Willey, 2012) and a ‘scourge’ on society (Van Gorp & Vercruysse, 2012, p.1274). It is unsurprising that a diagnosis of dementia invokes fears of marginalisation/stigmatisation.

PLWD were often conceptualised as existing outside of social norms or acting with deviance (Low & Purwaningrum, 2020). While there are many positive depictions of PLWD these tend to focus on those living well with dementia (i.e., defying fatalistic predictions of dementia) (Low & Purwaningrum, 2020).

Many stories about PLWD are told by proxy informants, reducing the ability of observers to connect emotionally with PLWD and creates a distance between those living with and without dementia (Clarke, 2006; Siiner, 2019). Brookes et al. (2018) noted photographs depicting PLWD often had their gaze facing away from the observer, reducing opportunities for readers to emotionally connect with PLWD.

The Dementia Engagement and Empowerment Project (DEEP) created guidelines for writing about people with dementia, this was produced by 20 PLWD. It was stated certain words raise awareness of dementia and create a sense of urgency for research and funding. However, tendencies to use sensationalistic and depersonalising language like “suffering from” (p.2.) misrepresents dementia and

PLWD. This language referring to suffering gives the impression PLWD are helpless, dependent, and have nothing to contribute. They suggested a preference for using the term “person or people living with dementia” (Dementia Voices, 2015, p.3.) instead of using sensationalistic and dehumanising language.

1.2.3.2. Political and economic contexts

Current UK policy narratives echo those of forty years ago, for example, a 1982 report referred to a ‘rising tide’ of dementia (NHS Health Advisory Service); this foreboding metaphor is echoed in the terms used in government statements and policies which refer to dementia as a ‘crisis’ and a ‘devastation’ (Office of Health Improvement and Disparities, 2022).

Consecutive governments have promised to take action to improve the lives of PLWD. During the 2019 election campaign, the Conservative Party pledged to double funding for dementia research to over £160 million a year. However, there is no strategy or timeline in place to deliver these promises. (House of Commons Library, 2021).

The All-Party Parliamentary Group on Dementia (APPG) was formed in 2013 and is a cross-party group made up of MPs and Peers with an interest in dementia. This group aims to include the voices of PLWD in their meetings and reports, however, methods used to elicit views may be exclusionary. For example, a 2019 report ‘Hidden No More’ included the views of 2,521 survey respondents; only 3% of respondents were PLWD and 80% were carers. This disparity questions whether the stories of PLWD are dispossessed and undervalued. In this report, few direct quotations from PLWD are presented and it seems that other voices were privileged instead, paradoxically hiding the voices of PLWD.

A report by the UK Parliament Health and Social Care Committee (2021) stated that this “horrifying disease” (p.3.) causes a huge strain on health and social care provision and that the associated costs of health and social care for PLWD are expected to triple by 2040. However, two-thirds of care costs are paid by PLWD and their families (Alzheimer’s Society, 2021). This is often referred to by campaigners as a ‘dementia tax’, thus, UK policy narratives unfairly position PLWD as a financial burden to the state.

1.2.3.3. Research

The politicisation of dementia extends into research which then informs health and social care policies. Research priorities may contribute to and maintain particular narratives around dementia and PLWD.

The UK Dementia Research Institute ([UK DRI]; 2022) highlight the “race to find cures for our greatest health challenge: dementia” (p 1.), focusing largely on exploring biological causes, biomarkers, and brain mapping to explore which dementia-related brain changes can be ‘corrected’ by effective cures and/or treatments. The hope and investments in finding a medical cure or treatment for dementia may connect to wider narratives of fighting back against it.

A focus on biomedical aspects and cures for dementia deepen the stigmatisation and objectification of PLWD (Siiner, 2019; Van Gorp & Vercruysse, 2012). These approaches obscure broader social contexts within which PLWD live; they present the PLWD as part of a homogenous group existing within a sterilised and controlled clinical environment where power is afforded to scientists, medical interventions, and institutions (Basting, 2009).

A call to “hear the voices” of PLWD (O’Connor & Purves, 2009, p.16) in dementia research was listed as one of 13 challenges documented in the Prime Minister’s Challenge (Department of Health, 2015). Historically, this group have not always been included as active contributors in research and often their stories were told using proxy informants and observational studies (Innes, 2009).

Patient and Public Involvement (PPI) has been encouraged in government, healthcare, and academic writings. Groups such as DEEP and TIDE (Together in Dementia Everyday) advocated for inclusion of PLWD in research and service development, summed up in the term we often hear today “nothing about us without us” (Parveen et al. 2018, p.992). Join Dementia Research was launched by the National Institute for Health Research, Alzheimer’s Research UK, and the Alzheimer’s Society in 2015. Since its foundation, 69,515 participants have joined a study, although it is unclear how many of these were PLWD or their carers (Join Dementia Research, 2023).

However, Swarbrick et al. (2016) notes a lack of opportunity limits the inclusion of the voices of PLWD in research and service development. Murfield et al. (2011)

wondered whether this may reflect the added complexities of collecting data and obtaining consent, which include adapting to sensory difficulties, physical health problems, and communication difficulties. These barriers have led some researchers to question the validity of including PLWD in research (Murphy et al., 2015). Whilst there is complexity to capacity and communication issues in dementia research, which necessitate appropriate methodologies to maintain an ethical approach (Dewing, 2007), most studies do not appear to assess capacity for inclusion or attempt to enable people to communicate their experiences.

Lepore et al. (2017) found that the views of proxy participants are often privileged over those of PLWD; 77% of studies which use proxy methods of obtaining PLWD’s views did not justify theoretically or pragmatically their reasons for using indirect methodologies (Hughes, 2014). Cottrell and Schulz (1993) argue indirect methodologies can reduce PLWD as akin to objects rather than legitimate contributors.

1.2.3.4. Legislative and healthcare policies

Government and political ambitions have led to increased pressure on healthcare professionals to diagnose dementia (Department of Health, 2015), requiring them to recognise and agree upon the signs of dementia (Innes, 2009). This prompted a focus on prevention of dementia by reducing individual risk factors and encouraging more active lifestyles (NICE, 2018; Public Health England, 2018). Robertson (1990) stated framing dementia as an individual illness is more enticing to policymakers as it produces demonstrable results. For example, Donegan et al. (2017) found there was a significant acceleration in the rate of diagnosis of dementia after the introduction of the UK National Dementia Strategy (2009), with proportions of dementia diagnosis and use of anti-dementia medication doubling.

However, guidelines have also advocated for the implementation of PCC as central to best practice in dementia care, which encourages professionals to engage with the humanity, individuality, and life experiences of people irrespective of cognitive ability, as well as recognising the significant role of relationships in wellbeing (NICE, 2018). However, it has been argued PCC is poorly defined and variable in practice (Dewing, 2008). Davis (2004) criticises the term as it ignores that the implementation of PCC depends upon wider organisational structures and processes.

Moves towards PCC may have followed the inclusion of PLWD in the Human Rights Act (1998), and the Equality Act (2010). Mental capacity is generally defined as the capability to make decisions for oneself, and the Mental Capacity Act (MCA; 2005) provides a statutory framework for protecting those who may not be able to do so.

Boyle (2008) notes despite the MCA (2005) advocating the right to autonomy of people lacking decision-making capacity, the code of practices in the MCA may not comply with the views of service users (Boyle, 2005). This legislation contributes to the social exclusion it sought to address (Boyle, 2010) by transferring power to healthcare professionals to decide whether PLWD have capacity (O’Connor & Purves, 2009).

Mental capacity is inextricably linked to assumed diagnoses; dominant biomedical understandings of dementia and its related impairments can rationalise legal losses of personhood and restrict the definition of capacity and what it means to be human (Behuniak, 2010; Cohen & Eisdorfer, 1986). This can also prevent involvement in research and decision-making (Helgesen et al., 2010; Hernandez et al., 2010).

Having considered the contexts in which the stories of PLWD are constructed, this introduction will further focus on literature pertaining to the experiences of PLWD who experience WFDs.

1.3. Literature Search Strategy

A scoping review was conducted to broadly establish current understanding of the experiences of PLWD and WFDs. Peters et al.’s (2020) guidance on scoping reviews was used to guide this process. To identify relevant papers, the following databases were searched: EBSCOHost, Academic Search Complete, PubMed, PsychINFO and PsychARTICLES. Details of the searches conducted, including search terms, inclusion and exclusion criteria are included in Appendix B.

Overall, most papers returned focused on biomedical explanations or neurological profiling of PLWD who experience WFDs, many studies also focused on quantifying linguistic errors made by PLWD when producing narratives. Excluded papers included those which did not include references to WFDs or make observations of the experiences of PLWD. No papers were found which solely focused on eliciting experiences of PLWD who experience WFDs, therefore, reference lists of relevant papers were also drawn upon to identify articles which may not have populated the database searches, as well as Google Scholar searches to find any grey area literature. A total of nine studies were found which made reference to experiences of WFDs in dementia, although eliciting these experiences was not the main purpose of these studies. The following summary of results and critical review of the literature will be presented in this chapter in narrative form.

1.4. Experiences Of WFDs In Dementia

WFDs are exacerbated when communication attempts by PLWD are overlooked or misinterpreted, which can leave the person feeling misunderstood, thus undermining their sense of self (Ward et al., 2008). These experiences may narrow the opportunities for positive social interactions, increasing social and emotional isolation (Austrom & Lu, 2009).

Olthof-Nefkens et al. (2021) interviewed five dyads of PLWD and their relatives to develop a questionnaire which captured the experienced communication of PLWD. Those with significant communication difficulties were not excluded, as the researchers felt the complexities in communication would contribute to developing a questionnaire which represented the wide range of experiences PLWD have when communicating with caregivers. Participants were supported with visual cues and continual checking for understanding. The questionnaire was not adequately tested for reliability and validity, but did produce items across five subscales that reflected the themes elicited in interviews, including: communication with caregiver, social communication, communication difficulties in daily life, experienced emotions, and conversation quality. Difficulties with communication included: feeling stuck, struggling with pacing of conversations, WFDs, and being misunderstood by others. These experiences elicited emotions such as anger, frustration, sadness. Participants storied that communication difficulties meant they withdrew from conversations or avoided social events more often.

Horst and Hallber (2003) interviewed 11 PLWD about meanings of everyday life while in the early stages of Alzheimer's. The majority (8/11) of participants had caregivers present during the interview, however, the researchers requested caregivers did not intervene when the PLWD was talking. Despite this, family members tended to substitute when they witnessed their family member struggling to remember details or recall words. The PLWD shared their feelings of anger, shame, and sadness towards their difficulties in verbalising their own stories and some described feeling disabled in social situations which led to withdrawal from previously enjoyed activities.

Saunders (1998) analysed data from recordings of neuropsychological assessments of PLWD. Using discourse analysis and discursive analysis, they found PLWD projected their identity in several ways despite the cognitive and communication difficulties experienced during assessment. Several participants who experienced WFDs used object and process metaphors to describe the experience of living with dementia (e.g., describing their brain as being a mistuned piano). Some explicitly named when they could not find the words they were looking for. Saunders (1998) felt communication of their awareness of these difficulties mitigated the threat of further feelings of incompetence which is often felt by PLWD during neuropsychological testing. Participants found ways of constructing and maintaining their identity in interactions with health professionals. These constructed identities were viewed as ways of protecting one's sense of self when threatened, for example, making errors in testing (Saunders, 1998).

Bryden (2015) highlights that everyone communicates non-verbally, relying on others "to see, as well as hear, what we are saying" (p.215.). However, the excerpts from transcriptions included in the above studies only indicate pauses and filler words. I wonder what else was happening in these interactions when there were verbal silences? This absence infers that no other communicative attempts during these pauses occurred and places emphasis on the communication deficits rather than looking out for ability and adaptations or the use of non-verbal communication (NVC).

Those who experience WFDs in dementia are often excluded from interventions designed to support PLWD. Holden et al. (2020) reviewed the inclusion and exclusion criteria for CST in memory clinics across the UK and found 49 of 50 services cited communication difficulties as a reason for excluding PLWD from the intervention. As the only evidence-based therapy for PLWD, the British Psychological Society (2018) called on Clinical Psychologists to improve access to psychological therapies and services for PLWD. This has implications for how researchers and clinicians can increase narrative agency and possession for PLWD in their work.

1.5. Narrative Agency And Narrative Dispossession

Narrative Agency is defined as “the ability and opportunity to author one’s own narrative” (Baldwin, 2005, p.11). Villar et al. (2019) argue opportunities for narrative agency in PLWD are compromised due to three reasons: 1) the linguistic and memory difficulties experienced in dementia make adhering to narrative norms more challenging, 2) cultural stories of dementia promote a negative view of PLWD as having experienced a ‘social death’ (George, 2010), and 3) the merging of these two factors, which endorses practices that do not support storytelling. Therefore, opportunities for constructing and expressing personhood are scarce (Kitwood, 1997).

Some authors (Phinney, 2002) suggest storytelling in PLWD becomes impossible and joint storytelling is appropriate for PLWD given stories are jointly lived, others (Clark-McGhee & Castro Romero, 2015) highlight carer involvement and use of proxy informants in narrative research can position the PLWD into identity constructions which contradict their self-constructs. Baldwin (2006) refers to this as ‘narrative dispossession’. Nygård (2006) felt PLWD are not often included in research as their communication difficulties are viewed as a hindrance. Consequently, how dementia is experienced and managed from the perspective of PLWD is considerably under-researched.

An example of narrative dispossession includes a study by Steeman et al. (2007), who interviewed 20 PLWD and their caregivers. Initial narrative analysis revealed participants shared positive experiences of living with dementia and being valued by others, rather than losing one’s cognition or identity, as central in their experience. These stories were challenged and thought to be told due to “a lack of awareness or as denial due to cognitive loss” (Steeman et al., 2007, p.119). They noted discrepancies between the stories shared by PLWD as being focused on remaining abilities and family members’ sharing stories of loss. These discrepancies led them to re-assess their interpretations that PLWD experienced their situation as positive and they concluded a ‘balance between being valued and being worthless’ was a more accurate story. They remained sceptical about whether living with early-stage dementia was experienced positively.

While stepping back from the data and scepticism are suggested in the Grounded Theory (Glaser & Strauss, 1967) approach used, I wonder whether this contributed to narrative dispossession due to researcher biases and the privileging of family members’ views over the stories of PLWD. The stories shared by participants could have been a way to counteract the stigma they face and retain their dignity. Dooley et al. (2020) used photography to enable five PLWD to share their lived experiences. Participants expressed hope and a brighter future was possible, demonstrating a positive discourse around living with dementia which is often missing in public representations and research.

In the Steeman et al. (2007) study, those with significant aphasia were also excluded from the study without adequate justification, and the descriptions of those who experienced WFDs in the course of the conversations devalue their contributions and highlight deficits in cognitive function, for example, “went off on tangents” (p.124), “repeated the same stories” (p.124). The researchers did briefly attempt reflexivity in the discussion and shared their views of dementia as being a limiting deficit are prevalent throughout their writings despite their perceptions of themselves as deeply appreciative of PLWD and open-minded to the experiences of PLWD.

A study by Fels and Astell (2011) explored joint storytelling in dementia. Of the 22 PLWD who participated, researchers selected 13 stories for analysis and deemed the remainder to be incoherent stories, this devalues the contributions of PLWD who tell their stories through non-verbal means. Interestingly, seven of these stories were positive and this counteracts the idea that dementia is a ‘social death’ (George, 2010). This confers an expectation that PLWD who participate in research should tell the ‘right’ story.

The inclusion of carers who can support storytelling in studies is not always a limitation, Nilsson et al. (2018) interviewed 15 couples where one partner was living with dementia. They found when PLWD were positioned as a third party in the conversation, couples worked together to establish involvement and display joint speakership. PLWD counteracted their exclusion from conversations by making use of various communicative resources such as gaze, and bodily orientation to re-establish their presence in the conversation.

Hydén (2011, 2013) demonstrates how family carers provide ‘narrative scaffolding’ to help the person with dementia tell their story, which allows for the social construction and projection of the ‘self’ into social situations (Sabat, 1991), therefore, the storied self is partly the product of a relational process; the ability to provide positive narrative scaffolding depends on the views of the conversation partner (Sabat, 2001).

Boyle (2014) conducted unstructured interviews and observations with five PLWD who had greater communication and memory difficulties, and found that agency was expressed in a variety of successful ways even without words being used. She suggested despite communication abilities of PLWD being undermined through the constructions of capacity in the MCA (2005), there are several adaptive ways in which people seek to regain their agency in social interactions, termed ‘assistive autonomy’.

Baldwin (2006) highlights the impairments in language and cognition in PLWD can pose threats to narrative agency and narrow conceptions of narration which focus on structural coherent narratives often exclude PLWD. Instead, he highlights the value in the constructing of narratives between PLWD and those without dementia, which can allow seemingly fragmented narratives to be presented meaningfully. This co-construction may allow stories to be presented with shared truth, rather than assumptions of the lived experience of the PLWD.

1.6. Assuming Disability

Assumptions of disability may factor into narrative dispossession and the lack of opportunities for PLWD to tell their stories. PLWD are often viewed through their deficits alone which means they are not given opportunities to nurture their social and communicative abilities (Sabat, 2001) which is exacerbated by dysfunctional social interactions (Sabat, 1994), which Kitwood (1990) termed ‘malignant social psychology’.

Assuming incapacity of PLWD can lead to loss of opportunities to foster existing communication abilities. In a study which videoed conversations in long-term care institutions for the elderly, Ward et al. (2008) estimated PLWD in care homes spent 10% of their time interacting with others, with only 25% of these being interactions with staff and other residents, the other 75% of interactions took place during family visits.

Doyle and Rubinstein (2013) observed professionals working in care homes rarely initiated communication with PLWD outside of their assigned tasks. They were shown to prefer interacting with co-workers even when the PLWD was physically present. In care settings, it is possible the prioritisation of functional tasks constructs the person as an object rather than a capable person who can express their needs and share their perspective of the world. This reduces available opportunities for PLWD to express themselves narratively and construct personal stories, let their voices be heard, and participate in the stories that give meaning to their experiences and link the present situation to their past knowledge and expectations and preferences for their future. Such stories, if they do appear, are controlled by their family or professional caregivers (Villar et al., 2019).

Depersonalisation of PLWD can occur during interactions when conversational partners engage in ‘elderspeak’, for example, using simplified words, using terms of endearment, exaggerating tone, and slowing conversational pace (Brown & Draper, 2003; O’Connor & Pierre, 2004). Elderspeak assumes a lack of competence and can be experienced as stigmatising (Cunningham & Williams, 2007).

Stressing disability over lack of opportunities, reinforces the idea of a complete and despairing decline in narrative agency in PLWD. Firstly, stressing disability disregards the abilities of PLWD which may include non-verbal means of constructing narratives that can be interpreted by an attentive and proactive listener. Secondly, it lessens the responsibility listeners have in sustaining the narrative agency of PLWD. Engaging in storytelling is an inherently social act, and the audience has a crucial role in encouraging (or obstructing) the narrative expression of PLWD encouraging them to continue telling stories can reaffirm their role in the community as active members (Hydén, 2017).

1.7. Storytelling in Dementia

Freeman's (2015) postulation that narratives are part of a universal cognitive toolkit is widely accepted following Bruner's (1991) suggestion that reality is constructed though our use of narratives. However, storytelling is much more than an individual expression, it is an embodied and collaborative social endeavour which can uphold our sense of self and maintain personhood (Kitwood, 1997; Hydén, 2013). Given this, the listener's role, beliefs, and expectations are also central in co-constructing the meaning of these stories; listeners can minimise embodied expressions and dismiss communications which do not follow narrative norms (Guendouzi et al., 2015). Kitwood (1997) describes when PLWD enter "the social arena" (p.14), several processes can erode personhood and make the PLWD invisible while making their perceived cognitive deficits visible.

Despite healthcare professional's collaborative efforts to understand the PLWD's stories, there exists an inherent power imbalance between them (O'Connor & Purves, 2009). Issues of ownership and control form important elements of the storytelling process and provide storytellers with a level of responsibility for their own narrative. However, listeners play an important role in confirming ownership and the validity of stories told. As PLWD may be disempowered and excluded from decisions about their own lives, storytelling opportunities may enable PLWD to reclaim ownership of some aspects of their lived experiences and sustain their sense of self. People can own and control their personal narrative as long as they can fulfil the responsibility of producing a 'tellable' story where 'tellable' is determined by interactive negotiation with their audience. Consequently, listeners may decide a story is untellable if it does not meet narrative norms or counteracts their own narratives of dementia and PLWD.

PLWD seem to engage in the same storytelling processes pre and post onset of dementia. Using storytelling in research can be beneficial as it reduces the expectation for participants to tell the ‘right’ story and allows the storyteller to introduce topics at a pace suiting them, enabling thicker descriptions of their experience of living with dementia (Mishler, 1991). This story may not always be told entirely verbally.

1.8. Non-verbal Communication and Embodiment

1.8.1. Non-verbal Communication

NVC may be defined as behaviours that convey meaning without the use of words (Floyd, 2009, p.9), and are often overlooked in qualitative research; while the figure is contested, much of the meaning-making of conversations is inferred from NVC (Floyd, 2009). NVC conveys core semantic information even in the absence of speech and play a key role in relational aspects of conversations (Knapp & Hall, 2007). Argylle (1988) identified the four primary functions of NVC: expressing emotion, conveying attitudes, presenting one’s sense of self to others, and managing interactions with others.

Omitting NVC in qualitative research can limit the study and threaten the authenticity of the naturalistic inquiry; researchers often find ways of justifying its omission (Begley, 1996). Birdwhistell (1970), emphasises the error in omitting NVC in qualitative analyses, as verbal and non-verbal messages are inseparable when making meaning of our interactions. Kendon (1983) highlights verbal and NVC are so intricately woven and while these communications are presented differently, they are coordinated in their aim of producing a set of actions that support understanding of one’s meaning.

However, several logistical barriers exist in qualitative research, such as a lack of agreement about how these analyses should be conducted, and limited formatting of journals and books (Jones & LeBaron, 2002). Denham and Onwuegbuzie (2013) note some methods of qualitative analysis better suit the inclusion of NVC e.g., latent content analysis (Bales, 1951) and conversation analysis (Sacks et al., 1974).

A systematic review by Denham and Onwuegbuzie (2013) found 76% of qualitative studies (*n* = 227) did not include reference to NVC. In studies which recorded or referred to NVC (*n* = 72), it was found incorporating NVC into data analyses and interpretation was uncommon and underutilised.

1.8.2. Embodiment

Hydén (2013) notes most narrative research about PLWD stresses the conversational and written aspects of stories. As many PLWD experience communication difficulties, these approaches can mean PLWD appear less able and active in conversations. Hydén (2013) argued we should view stories as products and emphasise the performative and embodied aspects of storytelling and highlight the interactive process in which the researcher is also involved.

Thanem and Knights (2019) theorise interviews are embodied encounters as they are shaped by bodily practices, actions and gestures, facial expressions, and are affected by physical dimensions such as proximity and distance. Hence, bodies interact with and are influenced by other bodies, meaning “all bodies involved in the research inquiry are active participants whose meaning-making exists in the moment of encounter” (La Jevic & Springgay, 2008, p.7).

Researchers support the use of visual aids, photos, and sensory adaptations to interviews (Buse & Twigg, 2015; Kontos & Martin, 2013; Tsekleves & Keady, 2021). These approaches typically involve the use of external objects to support exploration of experiences. An embodied approach supports the recognition of the different aspects of communication, connection, and expression.

1.8.3. Embodiment As A Resource

Harwood et al. (2020) videoed 41 interactions between healthcare assistants and 27 PLWD in a hospital setting over a three-month period. The study focused on the refusals of care, and aimed to develop communication guidelines for HCAs to encourage compliance of PLWD when completing task-oriented care. These interactions were transcribed and included some references to NVC if it seemed relevant to the conversation, for example, tone and gestures. They noted even participants whose interactions consisted of only embodied responses continue to display their agency by effectively refusing certain aspects of care.

Fleetwood-Smith et al. (2021) drew upon arts-based practices to explore the significance of clothing to PLWD in care homes. They found videotaping the interactions enabled greater exploration of the varied forms of expressions and interactions which took place which would have gone unnoticed and created otherwise “unknowable” knowledge (Ellingson, p.16, 2017). Hydén (2013) makes the case for video recording and analysis to be a standard method when researching narrative activities, in order to examine embodied behaviour and share the experiences of interactions which consist of verbal and non-verbal interactions (Reavey & Prosser, 2012).

Dowlen, et al. (2021) videoed non-verbal interactions between group members and facilitators in a singing group for six PLWD and four family caregivers. They felt expressive functioning in music and artforms can be used by PLWD with a new sense of purpose. Videorecording facilitated capturing non-verbal embodied moments which led to uncovering less overt moments within the sessions. One group member experienced WFDs and was frustrated by this, however, musical conversations enabled him to share aspects of his personal history by choosing instruments which were specific to his culture and playing in a style that connected him with this. This supported earlier research suggesting creativity can enable embodied reactions and facilitate meaningful interactions for PLWD (Killick & Craig, 2012; Dowlen, 2018; Zeilig et al., 2019).

Kontos et al. (2017) videorecorded interactions in a care home between 23 PLWD and clowns who were delivering a 12-week programme using arts-based approaches. They found even with communication difficulties, PLWD engage in reciprocal communication (verbal and non-verbal) that can serve to initiate affectionate, imaginative, and humorous interactions. Their findings highlighted the often-forgotten capability of PLWD to be deliberately funny, playful, and imaginative rather than being passive receivers of communication from others.

Dominant ideas that language and cognitive ability are essential in conveying ideas about our past and future (Brown, 1998) serve to justify the exclusion of people with communication difficulties, including those with dementia. Sabat (2001) emphasised

PLWD make attempts to use their linguistic resources to affirm and maintain a sense of self through discourse. Often seen as a deficit, the retelling of stories may be an attempt to communicate important aspects of the teller's self and identity and can help to preserve these even in the latter stages of dementia (Randall, 2009).

Sabat (2006) criticised the dominance of the biomedical model and neuropsychological testing in justifying the exclusion of PLWD from research and activities due to their perceived cognitive incapacity and inability to communicate consent, thus privileging biomedical 'truths' over personal truths. In research, ethical concerns, and a dependence upon conventional research methods which privilege recall and verbal expression hinder the inclusion of PLWD in research about them (Fleetwood-Smith et al., 2021). Sabat and Harré (1992), believe these practices lead PLWD to believe they cannot contribute as others do not wish to facilitate their involvement, meaning their stories remain 'locked in' behind perceived cognitive incapacity (Swinton, 2011).

From initial reviews of the current literature, it appears little research has focused on the stories told by PLWD who experience WFDs. The overreliance on conventional methodologies to elicit the views of PLWD also limits the ways in which their stories are told and highlights linguistic and narrative deficits rather than capabilities.

1.9. Research Aims and Questions

This study will aim to encourage the narrative agency of PLWD by supporting and privileging their stories, in whichever way they are expressed. The stories told by participants in this study may inform the work of psychologists and services to improve access for PLWD at all stages of their dementia journey and promote personhood irrespective of the cognitive and linguistic difficulties experienced by those living with dementia.

The following questions are explored in this study:

1) What stories do PLWD share about their experiences of having WFDs in dementia?

2) Within this storytelling, how do people communicate their stories in both verbal and non-verbal ways?

3) How can these stories be understood within the wider context in which they were told?

2.0. METHOD

This chapter will initially outline the epistemological position of the research and the rationale for employing a narrative approach. Following this, the methodology and procedures for recruitment, data collection, and analysis is presented.

2.1. Epistemological Position

Epistemology is a branch of philosophy concerning the ways knowledge is defined and criteria for evaluating claims that something is known, either by individuals or societally (Burr, 2003). This study will view stories told by PLWD and WFDs as influenced by the way in which dementia is defined across personal and sociocultural contexts.

Paradigmatic epistemological approaches are unable to make much sense of our motivations and the social interactions which influence the way in which knowledge is pursued, created, and upheld. For example, a key aim of clinical psychology training courses is to produce reflective scientist-practitioners (British Psychological Society, 2019), an approach which some authors argue favours empirical evidence as truth, adopting a realist position in clinical psychology (Davidson et al., 2007). They also suggest language is a medium for expressing objective truths, thus language is seen to reflect stable and singular meanings (Reissman, 1993). This idea is less applicable for PLWD, particularly those who experience WFDs. McAdams (1993) states the human experience is often ambiguous and cannot be reduced to such tightly reasoned analysis, devoid of rich contextual landscapes.

Due to cognitive and communication difficulties, paradigmatic approaches are less applicable for the research questions, therefore, an alternative epistemological position was used in this study.

2.1.1. Social Constructionism

As previously discussed, there is no objective truth as to what dementia is. This study does not disregard the biological and psychological impacts of dementia; rather it is hoped a social constructionist stance will enable explorations of stories which may resist deficit-focused paradigms of dementia. This study view the stories PLWD tell, and the meanings within, as constructed through language, metaphors, and NVC; these meanings are also influenced by socio-cultural and historical contexts. The ideological views of wider society will influence the ways in which we construct our realities (Esin et al., 2013; Gergen & Gergen, 2008).

A social constructionist approach also allows both the researcher and the reader to consider how their own contexts may influence our interpretations of the stories told in this study. In addition, it invites a reflection of the interactional contexts in which one's reality is constructed, as it encourages the researcher to account for the potential ways in which the stories told may be dependent on the context in which storytelling occurs, and the perceived social functions of storytelling. The study's broader position on narrative allowed further regard of these processes in which narratives were created, known as narrativity (Baldwin, 2006).

Burr (2003) summarised four tenets of social constructionism, which will be used to consider the way in which storytelling, and the knowledge therein, are constructed through interactions between the researcher and participants in their socio-cultural and historical contexts. Burr (2003) states knowledge is constructed through social interactions, people understand the world in relation to socio-cultural and historical contexts, and knowledge and social action are inseparably linked. Finally, she recommends researchers hold a critical stance on knowledge.

2.2. Narrative Analysis

Congruent with epistemological positioning and the research aims and questions, narrative analysis (NA) was employed to explore how PLWD share their experiences of living with WFDs. Several authors have noted there is no single agreed upon definition of NA (Earthy & Cronin, 2008; Andrews et al., 2008). Esin (2011) states NA views stories as the unit of analysis with stories gathered from the accounts of participants. Esin et al. (2013) also suggest NA gives researchers the tools to consider the multiple levels, including the personal and socio-cultural contexts, in which stories are performed and interpreted. Narratives shared by PLWD may not follow linear or chronological expectations, which NA can account for (Willig, 2008), with Earthy and Cronin (2008) explaining shifts in narrative inquiry from explorations of ‘what’ was told to ‘how’ stories were told.

Storytelling can be particularly important for people who are confronting change that risks devaluation and dismissal from society, which seems particularly appropriate for PLWD (Killick & Allan, 2001). As stories are shaped by our sociocultural contexts, the stories we tell may reproduce existing forms of oppression through repeating dominant stories, or they can challenge these by highlighting subjugated stories (Ewick & Sibley, 1995).

NA can take a multitude of approaches; in accordance with the aims of this study, I will integrate approaches which move away from interpretations of storytelling that focus upon operational and sequential features. I will instead focus on the interactional nature of storytelling and the ways in which stories are shared, particularly when language is less accessible.

2.2.1. An Integrated Approach to Narrative Analysis

I followed Riessman’s (2008) guidance to select an approach to NA which was consistent with the research aims. To allow for more nuanced understandings of the ways in which narratives are expressed and the functions of these narratives, I combined different analytical strategies, as recommended by Mishler (1995). I drew upon Stephens and Breheny’s (2013) approach to integrating narratives as told within the immediate context of the interpersonal aspects of the research encounter, and the broader socio-political contexts. To isolate an individual’s story from its context would reduce meaning (Emerson & Frosh, 2009). Integrating analysis across multiple levels could lead to a loss of the PLWD’s voice. Therefore, throughout the results section (Section 3), I attempted to balance this by retaining the storyteller’s voice, as dominant narratives of PLWD dementia can suppress the alternative stories told by them (Murray, 2003).

2.2.2. Key Narratives

Key narratives emerge from the stories we tell, centring around recurrent content or themes, and showing how we make sense of our world (McAdams, 1997; Phoenix, 2008). Boenisch-Brednich (2002) suggests key narratives are established through the events and processes the individual considers to be important, they can reflect established and personal narratives, be repeated a number of times throughout an interview, and demonstrate how the impact of culture is visible in the context of both ‘big’ and ‘small’ stories (Phoenix, 2008).

Bamberg (2006) highlighted debates within NA as to whether analysis should attend to ‘big’ or ‘small’ stories. ‘Big stories’ refer to stories which are shared directly in response to the questions of the interviewer and reflect the most significant narratives of one’s life (Phoenix & Sparkes, 2009). In conversations, ‘small stories’ may appear fleeting, fragmented, and without a beginning, middle or end (Baldwin, 2006; Bamberg & Georgakopoulou, 2008; Phoenix, 2008). I followed Phoenix and Sparkes (2009) guidance which recommends attending to both ‘big’ and ‘small’ stories told in the research encounter.

However, when interviewing PLWD there is a risk that fragmented stories, and repeated re-telling of stories which do not follow chronological order, may be dismissed as simply symptoms of dementia (Guendouzi et al., 2015) and, in this way, key narratives may be overlooked. Returning to the same story or theme can signify the importance of the statement, feeling, or need, so it was important that this be considered in the analysis.

2.2.3. Analysing Narratives in Context

My analysis of key narratives was concerned both with particular accounts of participants’ experiences of living with dementia and WFDS, alongside stories about their broader experiences which may have contributed to how their lives were experienced and storied.

Sarup (1996) conceptualised narratives as being two-part; not only ‘what’ stories are being told but also ‘how’ they are being told. This seems particularly relevant in this study given participants experience WFDs. Though originally outlined for dialogical narrative analysis, Frank (2012), posed some questions which are helpful to consider, for example, in which ways does the storyteller seek to sustain their self or identity in response to wider contexts which may seek to diminish that identity? Frank (2012) also described storytelling as an artful expression through which a person represents the self, this allows a consideration of which resources storytellers use, particularly when they may have difficulties which impede telling 'adequate' stories.

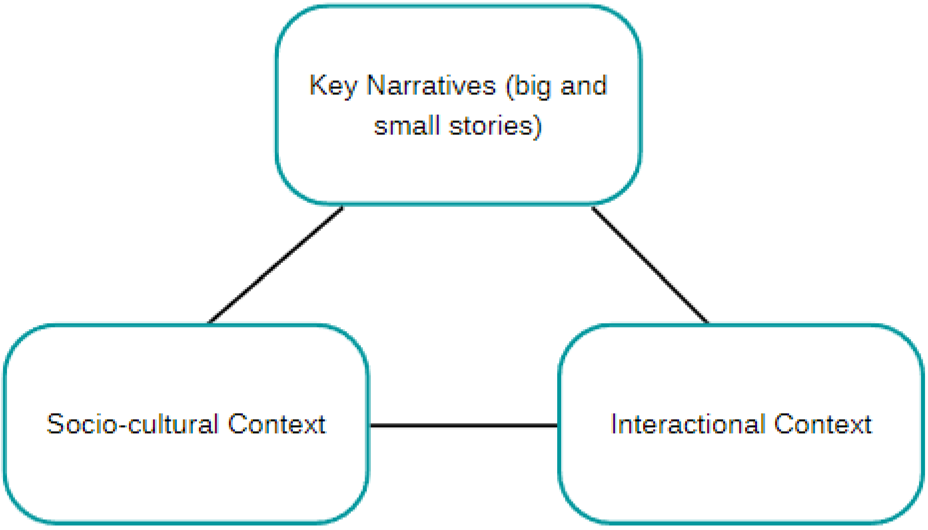
As key narratives may be embedded across personal accounts within different kinds of stories, identifying them required repeated re-reading of each interview in its entirety. Considering the positional levels of storytelling allows acknowledgements of the contexts and functions of wider narratives within interpersonal interactions. It provides opportunities for reflection as to the ways in which certain groups are positioned within society and within research interactions. Positioning may contribute to the way in which identity and experiences are co-constructed (Stephens & Breheny, 2013). Van Langenhove and Harré (1999) posit that positioning is fluid. They make distinctions between the 'self' (a person's beliefs and motivations which enable personal agency), and 'personae' (identities which are produced through wider narratives and in social interactions).

Somers (1994) highlights the storied self can only exist interpersonally. Hence, narratives will also be shaped and co-constructed during the research interview (De Fina & Georgakopoulou, 2008). The ways in which narratives were expressed, and interpreted within our own personal contexts were also important to reflect upon (Tanggaard, 2009; van Enk, 2009). Reissman (2009) notes narratives do not reveal an 'essential' self but, instead, a preferred version of the self. This preferred version is appropriate to the contexts in which stories are told and the social expectations for the storyteller (Stephens & Breheny, 2015).

To integrate these levels of analysis, I combined and adapted Stephens and Breheny's (2013) and Harré et al.'s (2009) analytic approaches, representing the relationship between personal narratives, the interactions between the researcher and PLWD, and the ways in which these interactions were influenced by broader socio-political contexts in which stories were told (seen in Figure 1). To support analysis, a series of questions (Appendix C) were drawn up which related to these levels; these were adapted from several sources (Frank, 2002; Phoenix, 2008; Harré et al., 2009; Stephens & Breheny, 2013). This approach to NA is not step-wise, and each interview transcript was analysed separately. A sample transcript excerpt (Appendix D) alongside the transcription conventions (Appendix E) demonstrate my application of the analytic process built over re-readings.

Figure 1

Summary of Approach to Analysis



2.3. Ethical Considerations

2.3.1. Ethical Approval

Ethical approval was applied for (Appendix F); original ethical approval was granted as were amendments. Ethical approval was granted by the UEL School of Psychology's Research Ethics Committee (Appendix G).

No other ethical approval was needed to conduct the research within non-NHS settings, however, copies of the letter granting ethical approval were provided to organisations so they could make an informed decision as to whether I could recruit through them.

2.3.2. Processural Consent

According to UEL's School of Psychology's Research Ethics Committee definitions (Appendix F), PLWD may be classed as 'vulnerable adults'. Therefore, the processural consent method (Dewing, 2007; Hughes & Castro-Romero, 2015) was used, which is consistent with the Mental Capacity Act (2005). This aids potential participants to make informed decisions, and was used as a framework to guide the consenting process within this study.

A diagnosis of dementia does not necessarily indicate a lack of capacity to consent, as this is contextual and dependent on the complexity of the information provided to PLWD (MCA, 2005; Dewing, 2007). The processural consent method (Hughes & Castro Romero, 2015) is reliant on the researcher's critical reflection and skills in interacting with PLWD, which is supported by my relevant clinical experience in working with PLWD. I kept anonymised field notes to document the consenting process with potential participants. An example is seen in Appendix H. Potential participants were given the opportunity to meet to ask any questions they may have prior to deciding. Participants were informed of their right to withdraw consent, at any point. Those deemed to have capacity to consent were asked to complete the participant consent forms. Carers were provided with a copy of the information sheet and asked for written indication whether they know of any reason their relative would object to participating. In the absence of a relative involved in their care, I consulted with staff to understand the usual ways the person would communicate consent or non-consent and recorded evidence of such in their field notes. This method allowed carers or staff to raise concerns about the PLWD's participation. There were two consent forms, one for participants who have capacity to consent, and one for carers of those who may lack capacity.

2.3.3. Confidentiality, Anonymity and Data Protection

To ensure confidentiality, anonymity and protection of data, a data management plan was developed according to the UEL Research Data Management Policy, and approved by the Research Data Management Officers at UEL (Appendix I).

2.4. Participants

Recommendations for the appropriateness of small sample sizes in dementia research and the level of detail required in undertaking narrative analysis were used to determine how many participants to recruit (Cottrell & Schulz, 1993; Riessman, 1993). The decision to recruit 3 to 4 participants was influenced by the fact NVC was also transcribed, which increased the amount of data produced during interviews.

2.4.1. Recruitment

Local community and charitable organisations were approached via e-mail; confirmation of ethical approval (Appendix F), a poster (Appendix J) and an information sheet (Appendix K), were included. With permission, the study was advertised on dementia-specific online forums; no responses were received to online advertisement, which will later be reflected on (Chapter 4).

Following approaching potential recruitment sites, I received a response from a community organisation in an inner London borough which invited me to attend a lunch club and Memory Café. The centre ran the lunch club every weekday, with the Memory Café taking place once per week after lunch; service users (SUs), their family, or private carers could attend this group.

In my initial visits, my main aims were to introduce myself and to build relationships with SUs and staff. This ensured staff had time to raise concerns about any SUs being approached in relation to the study, for example, concerns about their ability to provide informed consent or known risk issues. Where relevant, I checked with a relative or carer to see if they had any objections to this conversation taking place, in the absence of relatives or carers, I consulted staff members to discuss any potential concerns.

I shared lunch with a variety of SUs, which allowed for less formal conversations. This gave SUs the time to ask me questions about my role and interest in dementia. Engaging in the activities in the Memory Café alongside SUs allowed us to build rapport. This practice gave opportunities to observe how SUs provided consent and allowed me to consider whether partaking in the study would be appropriate (Hughes & Castro Romero, 2015). I also learned more about their preferences for communication and whether they experienced WFDs.

I introduced information sheets and posters to those who had expressed interest and we went through these together. These were created using guidelines for creating dementia-friendly information from the Dementia Empowerment and Engagement Project (Dementia Voices, 2013). SUs provided helpful feedback about readability of the information sheet and made suggestions for changes to wording and background colours which I expressed gratitude for and incorporated (Appendix G).

2.4.2. Inclusion and Exclusion Criteria

PLWD who identify with having WFDs were invited to participate in the study, if interested. While a dementia diagnosis was a prerequisite for this study, many groups may prefer to use other terms. Therefore, preferred terms were used throughout communications with potential participants. An ability to express oneself in English was an inclusion criterion to enable the researcher to carry out a thorough narrative analysis of the transcripts. There was no exclusion based on cognitive ability, if the person wished to participate, and there were no objections from their carers/relatives, which follows the processural consent method, detailed above.

2.4.3. Participant Demographics

Three PLWD participated in the research. Demographic information is shown in Table 1 (p.37). Participant names were pseudonymised.

2.5. Interview Procedure

Those who expressed interest were given updated versions of the information sheets and posters. An initial meeting was then arranged at the centre to discuss the study further. Participants were reminded they could have family, friends, or a staff member present in this conversation, if they wished. While a change in audience can influence storytelling, it is important to ensure PLWD felt safe and comfortable, particularly if they had concerns about their ability to communicate.

Table 1

Participant characteristics

Participant	*Age*	*Gender*	*Ethnicity*	*Anyone else present during interview?*	*Length of Interview* ***HH:mm:ss***
Mike	82	M	White Irish	No	00:44:07
Alfred	88	M	White British	No	01:00:46
Marcela	74	F	White Portuguese	No	01:26:05

2.6. Transcription

Congruent with my approach to data analysis and the research questions, both participant and researcher were included in the transcription with the same transcription conventions being applied to both. This highlights the interactional elements between the researcher and the PLWD and how these were paramount to the storytelling process (Reissman, 2008). It allowed the researcher to consider how stories were embodied, particularly when language and conventional storytelling resources were less accessible. In addition to documenting verbal communication, changes in tone of voice, and facial expressions were transcribed, as recommended by Earthy and Cronin (1998). Consistent with the research aims, I transcribed other aspects of NVC, for example, hand gestures, body posture, and gaze. NVCs were transcribed irrespective of whether language was being produced at the same time, therefore, in moments of silence, I transcribed any NVC occurring in these moments. Transcription conventions (Appendix E) were adapted from a variety of sources (Banister et al., 2013; Frosch & Emerson, 2005; Irvine et al., 2013).

2.7. Validity

The view of narratives as being constructed and contextual poses challenges to existing concepts of validity, which rely on realist positions. Therefore, alternative measures of validity were considered for this study. Polkinghorne (2007) and Riessman (1993) assert qualitative researchers must convince the reader of validity in their presentation of trustworthy analyses and interpretations. Therefore, my analyses and interpretation needed to be transparent and well-established, by presenting evidence such as quotes and literature alongside the analysis, and grounding conclusions in cited evidence (Polkinghorne, 2007).

In addition, Finlay (2002) recommends researchers find ways to be transparent in how personal and interpersonal factors influence the research process. Reflexivity, which guides the researcher to engage in explicit self-aware evaluations of the research process and reflect on the interactions between themselves and the participants. On the same day after each interview, I wrote a reflective log to support transparency, reflections from these logs were used alongside transcripts to analyse the data.

To enhance external validity, invite alternative insight, and assess the soundness of my analysis, I reviewed sections of my analyses and reflective logs with my thesis supervisor, I also ensured participants were provided with summaries of their stories, which provided opportunities for feedback on the analysis and interpretations. Further discussion of validity can be found in Chapter 4.

3.0. RESULTS

This chapter offers a summary of analysis of transcripts from interviews with Marcela, Mike, and Alfred. Each account will be introduced with a short description. Transcription conventions applied are available for the reader (Appendix E).

Consistent with the social constructionist epistemological approach, I acknowledge that my interpretations of the stories presented here are implicitly influenced by own professional and personal contexts (Davis, 2004; Fontana & Smith, 1989).

Stories told by PLWD are often deemed ‘untellable’ if they do not follow narrative norms (Guendouzi et al., 2015). I acknowledge that within this research, I have a role in making stories ‘tellable’ by presenting them in a clear way for the reader. Chase (2003) cautions that narrative researchers should avoid overinterpretation and being overly descriptive. Therefore, I exercise tentativeness in my interpretations and do not make overt knowledge claims or clinical judgements (Riessman, 1993). As recommended by Chase (2003), where interpretations are articulated, these are presented alongside evidence for these interpretations. I have presented direct quotes from the transcripts and aim to be transparent about which parts of the stories I have drawn interpretations from. In doing so, this will allow the reader to decide whether they find these inferences trustworthy, reasonable, and convincing (Riessman, 1993).

Riessman (2008) highlights that the same text can be interpreted in many ways and I invite the reader to consider how their own stories interact with those presented here and be curious as to how these influence their own interpretations.

3.1. Marcela

Prior to this interview, Marcela and I had met on two occasions. I perceived Marcela as polite in interactions, but she preferred being invited into conversations rather than initiating them. She often showed her engagement in conversations through NVC such as smiling, laughing, or nodding. I initiated our first conversation as she was nervous about approaching me; she requested a staff member she trusted approached me first.

Marcela communicated she preferred to use the term ‘memory loss’ instead of dementia and that she would like me to support her to find the words when she experienced WFDs.

3.1.1. “I Started Being Independent As A Young Girl.”

Stories of independence and survival appeared central to Marcela’s narrative; she positioned herself as hardworking and productive. Variations of the word ‘work’ were weaved into her stories 57 times. The lack of financial resources earlier in life persisted when Marcela moved to London over 40 years ago:

> [351-353] …I never done nothing else than *(places hand on table and points finger between two points several times*) work, home, home, work, ◦what else to survive?◦

Marcela’s storying of her independence is that it was hastened by her family’s needs; she began work as a domestic servant alongside her aunt instead of continuing education:

> [428-434] ...I (*uses both hands to gesture towards self? and then outwards*) been taken to this place…Just (*uses right hand to abruptly swipe hand to the right*) 11 years old, a few days before. And erm **(.)** I was then **(.)** from this age (*tilts head and moves forward with more fixed gaze)* working.

Marcela clarified she was academic, but there was some discomfort in narrating these stories in her own voice; her gaze shifted away from me maybe to reaffirm these words were not hers. I wondered if Marcela felt her story was not believable or whether self-constructs made it difficult to tell stories which positioned herself as more intelligent than others. She framed discovering she was intelligent as akin to a revelation. Reflecting on my Catholic upbringing, I wondered if she had been socialised to see pride as sinful, thus, constructed her narratives in a way that restrained from positioning herself above others:

> [624-627] …I am **(…)**, I, I always, always**:::** been <u>shy</u> (Kate nodding) ◦never thought the best of myself◦ (*furrowing brow*) I always feel (*gestures one hand several times towards centre of chest*) always think of myself of nothing always put (*gestures hand above her head*) everyone first than me…
>
> [385-395] Marcela: …this exam, they have erm **(...)** honours (*uses right hand with palms facing upwards in a pushing motion*) (*Kate nods*) and they, they **(.)** found me (*point hands towards self*) erm **(.)** better (*right hand moves to point in semicircle motion from right to left)* from that group (*uses hand to indicate a large circle on table*).
>
> Kate: Oh, ok so you were quite a high (*uses hand with palms facing down and raises it up above the table)* performer?
>
> Marcela: Looks like, I eh **(…)** (*shaking head*) I did not think I was **(…)** I found out I was good in school many years after by a girl who was in the same class as me. She told me years ago and said, (*shifts gaze away from Kate and downwards*) 'oh I remember when you were the best in the class' (*returns gaze to Kate*) I said '<u>really, I never thought' </u>**(↑)**

During this interaction, Marcela experienced WFDs, using NVC to invite me to support her. However, this could have been a way of her embodying the discomfort she feels when speaking highly of herself. In this instance, inviting me to co-narrate the story could have been a means of lessening this discomfort:

> [409-413] Marcela: But, but then what happened was they sent **(.)** invitation for me to go to this college. Because I had been se- se- **(…)** (*Kate nodding up and down)* (*gestures her hand between us in a back-and-forth motion*).
>
> Kate: Selected?**(↑)**

> Marcela: Yes, **(.)** selected (*both smiling)*

As time progressed, she learned being occupied with work provided a distraction and protected her from experiencing difficult emotions and isolation:

> [446-450] …even my aunt she was not talking to me...I would not dare to say, 'I am not ok, you know?' **(…)** and there, that is when I learned to be a hard worker was from (nodding head up and down) this.

> [472-475] …since then *(points towards table*) and ever since then I was trying to be ◦occupied◦ *(leans head forward*) because otherwise (*gestures both hands outwards to the side*) I just felt like to cry**(↑)** (*tilts head to one side)* because I **never(↑)** had toys to play.

Several stories were situated in the contexts of growing up in poverty in rural Portugal in a large family. While Marcela stories her life as one largely devoid of play, there were moments where she felt carefree, in the below example she describes being late for Sunday mass. However, she and her family were shamed by the priest for this. Her decision to not return to church may have been due to shame or may have been her way of distancing herself from her childhood and hastening 'growing up'. She used labour as a bargaining tool to avoid attending church again. Additionally, her dedication to work and caring for her family may have been linked to sense of sacrifice in Catholicism:

> [537-540] …she said, 'come on people are dancing let us go' and a boy much older than me asked me to dance (*sighs out*) I felt (*she adjusts her body posture by placing her shoulders back and sits up taller with head held up higher*) **I grow up** (*both laughing*). I went to dance and had forgotten (*both hands swiping outwards*) all about church (*both laughing*) …

> [556-559] …the priest said how could some mothers let erm **(.)** eh **(.)** their daughters go out and about and not make them go to church. Then it was from that day, I don't want nothing (*nods head side to side and uses left hand in a swiping motion*) to do with the church, <u>especially</u> priests.

> [578-583] Marcela: …I say to Mum I will make the lunch because the **(.)** erm service was like 12 o'clock, and then I would say **<<<** 'you go (*uses both hands in a pushing gesture*), everyone go to church, and I will make the lunch' and my mum did not <u>mind.</u>
>
> Kate: It saved her work (*both laughing*).
>
> Marcela: <u>Exactly</u> (*nodding up and down*) And for me, I <u>was happy</u>, I was **not** going to church.

Marcela storied work as having a protective function, which appeared prevailing throughout her lifespan. Earlier in life, isolation did not seem to be her choice, later in life she told me she felt discomfort in social situations although this dissipated at work.

> [939] "*I never been to socialise, I do not know what to say*"

> [609-610] …yes**:::** and **(.)** like I am quite a <u>shy</u> person and the job I was in I was **(.)** not **(***shaking head*) shy, I was feel in control, you know?

<u>3.1.2."I Just Thought My Brain Is Very Tired It Just Won't Work".</u>

It is unsurprising given the dominance of work in her life Marcela first noticed WFDs and memory in interactions with colleagues:

> [49-51] Erm **(.)**, well, **(.) I (.)** I for a few <u>years,</u> I notice I was erm forgetting <u>words</u>*, (Marcela nods and moves head slightly forward to give emphasis to 'words'*) (*Kate nods*) especially names, names of peoples I been working with over 20 years

She delayed seeking medical advice and tried to find other justifications for these difficulties, perhaps linking to a recognition that if she were diagnosed it would threaten her independence and the sense of control she felt in her working life. When she did seek an assessment and needed time off work, she placed emphasis on her feelings of loneliness and guilt for needing time off, I wonder if the gesture from her heart was a way of connecting me with her honesty:

> [361-363] …and erm **(.)**, for me, I feel so**:::** lonely. It was like I let them down. Even I knew, I want to do this job, but I was feeling **guilt** (*shrugs shoulders and gestures hands from chest outwards with palms facing upwards)* for being sick.

Previous interactions with healthcare professionals led her to delay seeking advice, she storied multiple instances where her concerns had been dismissed. In the silence below, her NVC in our interaction seemed to emulate the timidness she wanted to convey:

> [174-175] I avoid (*nodding head left to right*) all the doctors, I oh**:::** **(…)** (*shifts gaze to her left side and downwards, looks away briefly*) am like a mouse, a mouse
>
> [266-267] …I just thought they **(.)** (*nodding head left to right*) do not believe me it does not **matter(↑)**

Despite receiving a diagnosis of dementia, she continued to work beyond retirement age. It seemed important to position herself as someone who is still busy and productive. I noted she rolled up her sleeves just once and while this seemed natural and coincidental to me in the moment, when transcribing I was struck how this could have been her way of symbolising her readiness for work:

> [134-135] …had to go back to work *(uses right hand to roll up left sleeve*) I stopped working only one year ago *(uses left hand to roll up right sleeve*). I am almost 74 years old**:::**

It may feel necessary to communicate this readiness to preserve personhood and prevent threats to her sense of self, which she may anticipate given wider narratives of PLWD. Marcela often incorporated external narrators; perhaps adapting her storytelling in such a way that presented them as more credible, given her experiences of not being believed by healthcare professionals and wider views of the reliability of stories told by PLWD. This is seen here in relation to her high levels of activity:

> [866-868] I live on my own and I do not (*shakes head*) stop at home (*laughs*). Even the neighbours say, ‘you never stop, always**::** you are doing something’ **(**↑**)**…this is the way I am.

While she views people with dementia (which she refers to as a disability) as more visible in the UK compared to Portugal, she suggested there was still a sense of shame associated with memory loss and WFDs and she would be perceived as ‘less than’ others. While her view of her difficulties was one explained by a biomedical model, she told stories which suggested the experiences of PLWD are hampered by wider narratives around the diagnosis shown in her interactions with others and her sweeping hand gesture suggests a sense of dismissal and marginalisation:

> [819-825] …but before I came to this country now, I could not s-, say I have this problem because this person would be put aside (*simultaneously uses her hand to swipe to the side). You know?* It is not normal (*uses her hand to swipe to the side more abruptly than before*)…one thing I admire in this country is that disabled people do not hide (*shrugging shoulders and shaking head*) at home, they can go out, you know?

> [592-600] Kate: What do you think changes when other people know? <u>What changes</u>, do they **<<<**relate to you differently, do they talk to you differently? What happens? (*folds hand over one another)*
>
> Marcela: It is like I am (*Marcela raises one hand above the table and then moves it up and down)* **(.)** on another level, **<u>not</u>** (*hand used in a sweeping motion swiftly*) to be taken <u>seriously.</u>

It seems Marcela countered her tendency to keep things to herself by telling someone about the diagnosis; I wonder if this was recommended by doctors or friends. Her body language and tone suggest she felt pleased with herself she had told someone, and her different conceptualisations of disability cross-culturally led her to feel this would be more acceptable in the UK. However, her storying of multiple social interactions since expresses her discomfort at the realisation that people are treating her differently because of the diagnosis:

> [924-928] …something happened and I think it was an open door and she came (the neighbour) and I said ‘this (*uses hand to temporarily cover her face*) is not working properly’, I have <u>this</u> problem and I thought (*clenches both fists in shaking motion*) ok **yes** I have said to her, because you <u>have</u> to say to believe you have this. You have to bring yourself to say this problem and I managed to say it…

> [1011-1012] …all of the neighbours know, and I do not feel comfortable**(**↑**)**

Marcela used NVC to mimic how she perceived people changed their responses and communication with her post-diagnosis. She told me how one neighbour started to act more interested in her, while another seemed to ignore her. Her NVC signifies her frustration with their discomfort and her tone when speaking also suggested she felt infantilised by some people’s responses. Her hand gestures may communicate something about her is being lost or ‘thrown away’ when people learn she had memory loss:

> [953-955] …then all of a <u>sudden</u>, she is asking ‘<u>how are you:::?</u>’ *(tone changes to sound empathetic and soft. Marcela tilts her head to the side and leans in with a more fixed gaze)* and I said to myself **ugh** (*sighs, shakes her head and both hands are used in a throwing gesture*) …

> [1223-1226] …the street <u>does not lie</u>. I noticed if I came out to put the rubbish out in the bin, she then would turn her back (*adjusts posture and mimics turning her back*) to me not to say hello (*smiles and wave*s), because before she used to say **(.)** (*waves*) …

She told me she was on a journey to accepting the diagnosis and initially she felt disbelief, but over time she has been trying to come to terms with it. While some people were well meaning, they minimised her difficulties, and she found this made her feel rejected and made her feel she could not be honest about her experiences:

> [1175-1189] …she told me ‘<u>I forget words also</u>’ and **(…)** and then I was not quite sure how to take this, is she not accepting me that I have <u>this problem</u> and is rejecting this or is it to make me feel better?…It is **not** accepting, she only tells me ‘no you are fine’…’others are worse than you’ and it makes me feel like I have nothing (*shaking head*). I think I am still not 100% - sometimes I think I am talking about somebody else…

<u>3.1.3. “I Go Without, You Know, All My Life”</u>

Prior to attending the centre and Memory Café, Marcela had told people of her diagnosis and received responses which she felt had increased feelings of shame. She conveyed feelings of discomfort and reluctance to attend the centre in the first instance, potentially linking to her storying of feeling shamed for being reliant on others for support. She told me this discomfort with needing others was very common in Portugal and often told by her parents that she only visited them to eat their food. Even when Marcela received payment for hard work, she saved this money so she could preserve her independence and self-sufficiency for as long as possible:

> [748-750] …I was always counting pennies and always try <u>look</u> like I am ok (*Kate nodding*), I do not (*shaking head*) need help. Yeah, and it is embarrassment, at least (*points behind her*) back home. It is an embarrassment to show **(.)** you are in <u>need**:::**</u>, you know?

Marcela explained until she started to attend the centre, she would have refused help from others. Her NVC hand gesture potentially indicates giving thanks for this help or praying for words to come. She felt the workers continuing to reach out and provide encouragement, supported her to attend but she noted her hesitancy. Possibly, her experiences of telling others about her diagnosis added to this reluctance:

> [611-615] Marcela: …because I like to go to (the centre) but I think it took 10 months **(…)** to manage to **(…)** *(Marcela abruptly claps her hands together then moves them up and down)*
> Kate: **(.)** Get here? (*smiling and using both hands to point* downwards)
>
> Marcela: (*nodding*) To get here**(↑)**…

Witnessing others receiving care led her to feel more comfortable in accepting support. She storied witnessing someone being frightened on an outing and noted how a small nonverbal gesture indicated volunteers were genuinely caring. She may have used her gaze on the protagonist in this story to communicate feelings she finds harder to express, for example, that she may need or want support too:

> [640-646] I noticed, <u>especially </u>what I notice is that they are so**:::** caring … the guy was scared to get out and was unsure and was stuck. And they give a hand (*gestures her hand out to hold*), they don’t make feel **bad (.)**, just like ‘<u>**hey** you have a hand here</u>’…

She felt initiating conversations with volunteers made her feel as though she was burdening them, she then spoke to a volunteer about this which she felt was a turning point for her in accepting help:

> [787-791] …'anytime Marcela whether I am at work or not'. It was so::; important for me, knowing that…this place for me now is the most important thing in my life (*points to self)* nowadays.

Noting Marcela's storied discomfort with asking for help and support perhaps was her way of inviting me to offer her help, her gaze here may indicate shame:

> [882-885] …(*shifts gaze downwards*). Well, I just accept help since I came to the centre. I **never** accept (*shakes head*) **(…)** I never show anyone I need help anyway (*Kate nodding*). This was putting myself down (*uses hands to gesture downwards*), you know?

Marcela told me staff at the centre helped her to access benefits. While hesitant, it seemed being reminded of her hard work suggested that she felt she needed permission or approval from others to accept this support. While absent from her story, I query whether her medical conceptualisation of dementia gave her validation she was permitted or justified in accessing this support and note how her gesture towards her heart seems to reassure her that receiving help is ok:

> [693-695] …never had benefits in my whole life *(laughs*). Not ever (*shaking head*). I said NO…You are entitled, and you pay tax' (*Kate nodding*) … what he said like 'don't be embarrassed or' **(.)**, he just convinced me *(gesturing hands above head and moves them down and places them on chest)* it is ok

I wonder taking part in this research was an attempt to preserve her perceived value to others, which was previously upheld through work and productivity. Her 'usefulness' to me may counteract the guilt/shame she felt for receiving help and financial support. Interestingly, on this day the meal we had eaten in the café was unexpectedly paid for by the centre and, while absent from her story, I wonder whether her participating was an act of reciprocity, particularly important for elders:

> [807-810] …That is why I am so **(…)** (*uses both hands and shakes them rapidly*) real on this, If I can put my story there (*gestures both hands outward and leans in closer*) and my story can help (*Kate nodding and smiling*) them and you to do research then I am very, very pleased.

3.1.4. Interactional Context

When transcribing, it was apparent that Marcela used NVC alongside verbal communication and was quite expressive. I noticed I used my hands more when talking with her. This mirroring was evident early on, when I went to join Marcela at the table, I adjusted my body language to mirror hers:

> [18-20] Marcela: ***(****Marcela has her hands crossed on the table and is leaning forward towards Kate) (Kate has her hands uncrossed on the table and is leaning slightly forwards).* ***(.)*** I, I don't really mention this::: word (dementia). I **(.)** I, usually tell people that I lost memory *(Kate nods head while Marcela is speaking).*

I noted both Marcela and I often used NVC to pre-empt what we were going to say, this also during silences and WFDs; her NVC often gave an indicator of the word she was looking for. She speaks English as a second language, and may have learned ways of communicating non-verbally to bridge language barriers prior to her experience of memory loss and WFDs:

> [304-305] **…**yes, yes, and I **(…)**, they [employers] went **(…)** *(uses hand to draw out a rectangle and points to different sections of it*), on this date and this date you have been absent…

When Marcela experienced WFDs, she often drew on commonality between us, which seemed natural in the flow of the conversation although could have been a way to redress a power imbalance between us. On other occasions, while she could not recall the word, she described it and invited me to support her. I found these acts interesting and questioned whether these were skills she had developed to lessen the noticeability of WFDs:

> [506-520] Marcela: erm well look after kid and do the housework for some women. And this was to my mum. Yeah, and erm **(…)** erm **(.)** **(**looks away and closes eyes briefly) erm **(...)** (*sighs and laughs*)
>
> Marcela: <Erm **(…)** *(laughs*) >
>
> Kate: <It is ok not to worry> (*smiling*)
>
> Marcela: **(…)** And then **ah** (points to head), what I wanted to (say) … **(…)** it was May and in May, I do not know **(…)** You are Catholic (*pointing to Kate*), yes because you are Irish, no? **(↑)** **(***both laugh*)
>
> Kate: Yes (*nodding*), I am (*smiling*)
>
> Marcela: May is a <<<very important month for the Portuguese **(.)**
>
> Kate: **Oh**, **(.)** the festival of Fatima? (*slightly tilts head to one side*)
>
> Marcela: **Yes** (*pointing hand towards me and smiling*), so you know the story…

Marcela stories herself as someone who is reluctant to speak negatively about others:

> [895]: …I should not criticise…

However, she told me about some of her experiences with mental health professionals. For example, she went to one session of therapy a few years prior to her diagnosis and felt the therapist was dismissive of her. She also felt when she spoke to the nurses at the memory clinic were not listening to her. I wondered how she knew this:

> [1261-1265] Kate: How did you know they were not listening? What were they doing?
>
> Marcela: When you are talking, <u>you can see </u>the way you are looking, you are listening, I **know:::**. Their eyes were like (*she rolls her eyes*); they could not face me, you know?

As the interview was drawing to a close, Marcela was more complimentary, this may have been her way of trying to communicate that she perceived me as different to those who had not listened to her about her concerns:

> [1260] …Looks like I met you a long time ago…

I speculated if Marcela felt speaking in a free-flowing way provided her more relief than time-limited and directive therapeutic methods often used in NHS settings. In addition, Marcela has primarily been offered support in group settings, both in the NHS and in the community, which can be challenging given her unfamiliarity with socialising and her shyness. Interestingly, it was only towards the end of the interview she told me she has a daughter with whom she had a difficult relationship. I wonder given this was an unstructured interview, whether disclosing this was a way to extend our conversation.

After the interview, Marcela and I spoke for another 25 minutes to debrief, as some difficult feelings had arisen especially when speaking about her relationship with her daughter and her experiences of accessing therapy in the past. We spoke about other options for support although she felt she was comfortable with the workers at the centre and would ask them if she needed anything as she had storied earlier:

> [769-771] …I know if something happens to me, I know someone is there for me, (*tilts head sideways*) before I never had (*shakes head*). ◦Never, never had that◦, nothing like…

She was curious to know how she had performed, and I was mindful of what she had said earlier in our conversation in relation to her work:

> [354]: … in a way I wanted to be perfect you know …

I was cautious in my response and iterated I was grateful for hearing her story and that it was lovely to speak more given we had only interacted in group settings prior. She told me she felt great relief for telling her story and was grateful for my time.

3.2. Mike

Mike and I had met on four previous occasions. I perceived him as well-liked and respected, he greeted everyone warmly and typically sat in 'Mike's seat'. Interestingly, there was never an empty seat beside him, and people appeared drawn to him. He was often seen joking with others during group activities and appeared comfortable socially.

Of note, Mike was undergoing investigations for Parkinsonian-like tremors and shaking, therefore, involuntary movements were not transcribed. Mike communicated he preferred to use 'memory problems' or 'difficulties' instead of dementia and the term 'word blindness' instead of WFDs. If he experienced WFDs, he expressed a preference that I allow him time to find the word first and then ask him if he would like me to suggest words to him.

3.2.1. "I Think It Is More Honest For People To Come Clean"

Throughout our conversation, Mike desired to be more honest with his word blindness and, consequently, wanted people to be more honest with him. I wondered if the use of the word ‘clean’ in this context could indicate Mike wishes to relieve himself of a burden or lessen perceived shame associated with memory loss. His body posturing seemed to indicate a readiness to ‘come clean’:

> [148-153] Mike: …rather than saying *(shifts gaze to the side)* “**oh** there is nothing wrong**:::** with me (*pointing to chest),* I am not going to tell (uses both hands shaking gesture) anyone I have got <u>problems</u>”, I have found it easier **for me** and for **(.),** I think it is more <u>honest</u> for people to come clean” (*Mike readjusts body posture in seat, sits upright and forward moving back away from back of chair and moves hands to lap)*

Mike storied people being impatient with him due to word blindness and memory problems. Although laughing this off, his gaze, and tone potentially indicated he finds it difficult expressing this, and acknowledging the way people interact with him has changed:

> [132-133] …I cannot, I cannot remember about what and it **does not matter** but (*Mike looks to one side and focuses gaze elsewhere*) ‘<u>oh bloody hell your memory is crap, isn’t it?’</u> (*Mike uses a softer, almost whisper like tone here*) and (*Mike returns his gaze briefly before looking into his lap*) I said ◦“<u>well yeah, yeah it is:::”◦</u> (*Mike laughs*)…

In sharing, he hoped it would support him to feel less hampered by word-blindness in conversation, by leading people to adjust their communication style and lessen the likelihood he will be patronised or shamed for WFDs:

> [159-162] …I suppose you know as **(.)** me Dad **(…),** me Dad would say a ‘<u>trouble gained is a trouble gold</u>*’* (*Mike laughs*) or something like that (*Kate is nodding and smiling*), you know so get it <u>out there</u>, everybody knows so they are kind of <u>expecting</u>**:::** you to go wrong a bit (*Mike pointing to his head*) and

> they are not as patronising…

Mike utilises his NVC and body language to recount experiences of sharing memory problems; people attempt to comfort him, but he experiences this as silencing and his body language indicates a frustration with this. It appears his body positioning in this interaction gives a sense people cannot tolerate hearing about these difficulties:

> [570-581] Mike: But it is like, **oh yeah** (*looks away and nods*), yeah, '<u>well I have got, I have got memory problems</u>' (*averts gaze as though speaking to someone else*), oh 'yeah, yeah, yeah (*looks down while shaking head*)', as if you know (*he turns his body and uses both hands to indicate sweeping, then uses one hand as though lifting something from the floo*r), as if oh well under the carpet you know? (*returns gaze to Kate*)
>
> Kate: Ok**:::** yeah, so dismissing it? (*uses right hand in a swiping motion*)
>
> Mike: **Oh yeah** (*shaking head and rubbing his knees*)

Mike felt people normalise memory loss and associate it with ageing, Mike did not align with this and saw it as the result of a medical condition:

> [443-447]: **…** I am not **normal bloody hell** (*his expression changes to appear sullen*) …he keeps saying things like 'I know your memory is not as good as it used to', it is very frustrating Kate (*Mike looks down*), it really is…

Mike storied honesty as important for him, but sharing is difficult nonetheless; while in some sense it may provide him a release, his body language and NVC demonstrated a discomfort about doing this in reality:

> [221] …I know (*shakes head and shifts gaze away temporarily*), I

> should not be saying these things but erm **(.)**, I think it is best to get it off me chest…

Mike spoke further about his conflicts about sharing his true feelings with others. He indicated he finds it burdensome to carry emotions alone, but positioned others' burdens as more important than his own:

> [689-693] …I would rather not have it <u>all to me,</u> (*gestures hand towards chest and pats this a few times*), although (*shakes head and looks downwards briefly before returning gaze*) maybe that is a little bit selfish, I do not know, because ok let's say it is awake **(…)** <u>here</u> (*points to shoulders)* and you cannot tell anyone else but by (*moves forward in chair*) telling other people you <u>are putting it on them</u>

While he preferred to know about the future, the idea of facing it 'head on' seemed risky for the potential emotional burden this may bring. Mike cared for his father who had a diagnosis of dementia and who passed away aged 94 which influences his thoughts about being honest with himself about the future. His NVC here seemed to indicate a contradictory desire to keep the future away.

> [618-619] Yeah, yeah. Ok**:::** I, I, I, would like to, **(.)** I do like to know (*uses both hands flattened and facing away from body*) the future is going to bring…

> [171-172] If it was something like what my father had, touch wood it is not (*touches edge of table*), I don't want it **(…)** because I, I, I still miss him a lot

Mike storied how easily he can become preoccupied with worry but this, combined with a desire to know about the future, seemed to lead to confliction within Mike. He noted part of this could be due to his cultural background and a learned inclination to dismiss worries quickly:

> [631-638] Mike: I **(.)**, when I know something is wrong, I tend to sort of (Mike *uses left hand and rotates it repeatedly*) **(…),** worry, worry, worry, worry, that it might be (*Mike uses both hands to point to different areas in front of him*) something else**:::**, you know? (*shakes head and sits back in chair*)
>
> Kate: so, you used that kind of (*imitates Mikes hand gesture*) go round and round, if you were to kind of worry it might be hard to */*
>
> Mike: to yeah (*indicates sweeping gesture* with both hands) get rid of it **oh** and again it is the Irish thing of (*looks away*) 'oh get rid of it' (*uses right hand to mimic throwing something away*)

Mike gave examples researching memory problems and WFDs and how he felt some of what was available on the internet was fatalistic and led him to worry if he had other medical issues. His NVC here seemed to show how difficult he can find it to 'push away' these worries when they arise:

> [598-603] Mike: …so you have got a mild headache and then it is a **bloody brain tumour** (*laughs while sitting back in chair followed by Kate joining in laughter*)…Yeah (*Kate nodding*) and then you think '**oh God'**, so you (*pushes hands against the table and makes grunting noise to indicate exertion*) push it away, yeah (*Mike* l*aughing*)…

Mike had tried to find answers or seek advice from others, but this led to feelings uncertainty in himself and about his future. He described a frustration that his search for honesty had led him to feel more uncertain in himself:

> [588-590] Kate: …so, it sounds like you have received lots of different messages from different places?

> Mike: Oh God (*looks upward as though rolling eyes*), it drives you **mad:::** (*shakes head*), I mean **really:::,** no wonder you get confused with things…

An uncertainty in trying to find answers, both in conversations with other people and researching memory difficulties, has led him to align with the 'Irish way' of dealing with emotional conflicts:

> [618] … do you know what I mean? I would just rather get on with things (*sighs)*

3.2.2. "I Don't Think People Have Actually Got Any Clue At All, I Really Don't."

Mike positioned himself as misunderstood by others and often felt sharing his emotions led to indifferent or uncaring responses; interactions between himself and others seemed to evidence his sense that his emotions may be intolerable to others:

> [558-562] …they don't know what you are **going through,** they **(.)**, they would **like to know,** if you try**:::** to explain it to them **(…)** but they have got **(***holds his hands up again with palms facing towards Kate***),** they have got nothing, they have got no idea (*shaking head*)…

Mike storied while his Mum was his best friend, she also asserted her rules over the family by using physical means. He told of being woken up for mass and being threatened or punished physically if he did not attend; this may be linked to a fear of the family being shamed by the local London-Irish community for his lack of attendance. I wonder if he felt able to share this story with me because of our shared heritage and felt I would understand what he meant. I note in our interaction we both laughed at something which would not be deemed acceptable today:

> [398-405] Kate: And whose accent was that was it your Mam or your Dad?
>
> Mike: Oh erm **(.)** more me Mum, me Dad yes, yes, he was a firm believer and everything else, but it was me Mum (*uses a fist with right hand and places into open left hand*), who **(.)** erm, yeah the (*uses right hand to indicate a rod and slaps into left hand*), <u>the rod of iron (</u>*indicates gesture again) (we both laugh here*)
>
> Kate: I know what you mean
>
> Mike: We will say no more on that one (*indicates right hand in a sweeping motion)*

It seems the relationship he had with her held him together in some way. Without this, it seemed he had lost a grounding and stability in himself:

> [316-319] When me Mum went, again (*shakes head and looks downward*), I was like you know in pieces (*looks towards me*) she was me best friend in the world, so you know so (*lifts hand and mimics throwing gesture*) (*Kate nodding*)

Mike storied himself as empathic and considerate; others seemed comfortable sharing their 'private hell' with him. He used a gesture which suggests he finds it burdensome to carry other peoples' difficulties alongside his own. I wonder if societal gender expectations regarding masculinity and expression may strengthen his reluctance to share emotions. He described the emotions as being situated within his body, in this instance his chest, previously referencing these being 'awake' in his shoulders; maybe indicating that he was expected as a male, particularly one of his generation to show strength:

> Mike: **(…)** well (*tilts head*), perhaps, perhaps they have got their own private hell for want of a better word, erm **(.)**(*leans back*), but you know that (*gestures both hands towards self like wave almost*) they will **tell me::::** *(Kate nodding)*

> **and I have got to (***Mike gesturing both hands towards chest and rests them here)(Kate nodding),* and I do not, you know, I, I, I will take it on, I will take it on board

Mike told that within longstanding friendships, there was a lack of consistency in what he could expect from them. However, his relationship with Catholicism and God became deeper as he aged providing some stability; I also wonder if this filled a void left by his parents' deaths:

> [436-437] …you need somebody constant in your life if it (*raises his hand outward and towards ceiling*), if it is, is not The Lord.

Although his faith was strong, Mike narrated frustration with God using humour, animated tones and NVC. I wonder if he stopped himself in some way from further vocalising this upset by returning to a well-worn story that he just 'gets on with things'. I wondered if when Mike expressed these feelings, he felt the emotions or stress of these in his body, as his NVC appeared to be purposeful to soothe or comfort himself. There is an indication here that, while Mike sees memory problems as being a medical condition, this fate was assigned to him by God:

> [644-649] I mean great (*he looks up briefly*), you know, I mean Dementia **and**::: Parkinson's? I mean <u>**come on**</u> (*Mike looks towards the ceiling with his hands gesturing upwards)*, come, on, I mean "**hello there are other people in this world**" *(laughs and he moves forward in his seat and leans on table*) sort of thing, you know but <u>hey</u>, you get on with it don't you? (*he sits back, looks down and now rubs legs repetitively)*

While readers may interpret Mike as begrudging his ascribed fate, Mike clarified he was not bitter and did not want this to be part of his story. While he stopped short of verbalising it, I wonder if his NVC suggests that, while he does not want to be seen as bitter, he struggles with the emotional experiences linked to his diagnoses and these are difficult for him to tolerate:

> [195-197] …nah (*swipes right hand away*), sorry but do not misunderstand me, Kate. Kate I am (*holds both hands up*) not **bitter::** (*Mike moves his head forward abruptly*) **but (***his hands gesture as though swiping something to the side*) *(Kate nodding)*

3.2.3. "There Are A Lot Of Facets To Who I Am, How I Portray Myself"

Mike storied people enjoying his company, his humour, and his creativity, but he felt who they really enjoyed spending time with was a mask he put on in social situations. He referenced a fictional character who was often portrayed as confident and optimistic, for whom everyone is rooting. He used his NVC below to indicate this character helps him to create a distance between his true self and the outside world:

> [536-543] Mike: …you know trying to be the '**Del Boy'** (*he adjusts his posture here with shoulders upright and chest out and imitates walking with his upper body*) type of thing (*both laughing*)

Below, Mike's NVC communication may suggest that, while he storied a desire to share all the parts of his experience with others and be understood, he appeared uncomfortable in vocalising negative feelings like being annoyed or 'pissed off':

> [481-485] …I **do** put on this façade with people. You know? Oh, I am this (d*ances*) blah, blah, blah, joke (*gestures to table with both hands and points them repeatedly*) **joke, joke, joke,** the whole time, when I am (*averts gaze downwards to the left*) really **(.)**, sort of, completely (*returns gaze*) and utterly 'pissed off' (*he whispers this and then laughs*)

Mike storied his musical abilities were something he was gifted with, but he was guided to play and nurture this ability from his father; these abilities have a durability, persisting despite memory difficulties:

> [249-252] Mike: … oh I think I have always had it; I have <u>always had it</u> (*Kate nodding*), I think that is, I mean, me Dad (*indicates playing instrument with both hands*) played the tin whistle (*both nodding and smiling)*

Throughout his storytelling, Mike appeared to narrate a story akin to that of 'the tortured artist'. His inherent creative talents gave an outlet for all the feelings and parts of himself he fears are less desirable to others. In writing, he could have a space for these feelings, while using his musicality and humour in social situations to portray the parts of himself which people enjoy being around:

> [269-278] Mike: …I was writing poetry…Now they are as dark as the as the as, as, as **(.)** the **(.)** Edgar Allan Poe ones if you like (*laughs then Kate joins in*). But you know, it helps, it helps you through, it helps you through it **(.)** when you (uses *right hand and indicates writing on his left hand which is held out flat*)…

Creativity served a life-long protective function in social situations; being recognised and appreciated for his musical abilities protected him from noticing difficult feelings. He used the word 'famous' several times, describing how it felt to be appreciated by others for his musicality. On one hand, he felt it is wrong to feel prideful for this, on the other hand, this was proof of redeemable qualities and his gestures seemed to indicate this brings a sense of relief. Mike referenced a fragility here; potentially highlighting his conflict in acknowledging the different parts of who he is:

> [296-303] Mike: …I, I know this is going to sound erm ◦<u>really fragile</u>◦, when erm, erm **(.)**, condescending, maybe?

> Kate: It is ok Mike (*softens tone while nodding*)
>
> Mike: But erm **(.)** it is great when erm **(.)** (laughs), when I am walking down (*points out window*), when I am walking down the street (*Mike waves*) when somebody I don't really know shouts out **'Alright Elvis'** (*both laughing and* smiling). Now that is, to me (*lifts his hands wide in open gesture*). You must (*sits upright and leans forward more*), **you must be doing something right** (*both laughing*)

Mike used certain words and contextual information which seemed to further the image that his public and private self were like 'night and day'. He referenced his poetry and inner self as being 'dark'; being alone at night was when he noticed this darkness and fragility the most:

> [522-527] Mike: …but then erm **(.)**, erm, <u>lonely times</u>, when you are in your room, sort of late at night, you go (*he puts his head in hands and covers his face*), you know? (*shaking head and looking downward, his expression sullens*)
>
> Kate: So, noticing this a little bit more when you are alone? (*Mike gestures a pointed finger and shakes this*). Whereas actually, when you are around <u>people:</u> it seems to not be as <u>strong?</u>
>
> Mike: That is right, yeah, yeah, yeah, yeah (*Mike nodding rapidly)*
>
> He storied that not letting people know the real him brought conflicted feelings, shown in his NVC; doing this in social situations was a purposeful act, but he communicated a sense of shame for putting on this façade rather than being his real self. While Mike did wish to share his musical abilities and humour, this comes at the expense of people knowing who he truly is. If he dropped the façade, others may notice his fragility, potentially indicated in the shift in his gaze:
>
> [712-718] I mean the: the real::: me, ◦God I am going to get deep here◦, but

> the real me is not what I **(…)**, very few people know the real me and that is like I said to you before the <u>façade</u>, don't let the world outside (*points both hands to chest*) know what hell you are going through sort of thing , but I think (*sighs*), and then it is like **(...)** when you do the same thing, when you are here in company oh I (*dances, shakes his hips*) and then you think 'oh Christ' (*puts his forehead in his right hand and tuts*), I wish I could you know **(…)**

Mike was unsure about dropping the façade and I wondered whether he had invited me to give an answer, which I was cautious not to do. It seemed Mike was torn between wanting to be himself and an awareness that, without the consistent presence and friendship of his mother, he could 'fall to pieces':

> [489-493] Kate: …you are saying you are really quite shy**:::** and (*Mike nodding along with chin in right hand*), so actually the <u>humour**:::**</u> is suppose, being the joker or the funny man or musician is the way of showing people some parts of you?
>
> Mike: Yeah, maybe, maybe but (*shrugs shoulders*) I have, I don't know whether I should sort of be what I am? (*looks downward into lap*)

<u>3.2.4. Interactional Context</u>

Mike narrated by being honest and 'coming clean' with others about memory and WFDs he was hoping for patience and understanding, although, in actuality, he experienced many people as dismissive, impatient, and patronising:

> [82-87] Mike: …they try throw in a word that, it **might be:: but** (*he uses both hands now to gesture back and forth*), I would rather that than them being oh **(.)** standoffish, if you like or erm **(.)** or erm **(.)** tuts (*shakes his hands rapidly, then right hand only in a pointing gesture towards table shaking, looks up to the ceiling and sighs, clicks fingers*)…
>
> Kate:◦ It is ok Mike◦ (*Kate smiling and nodding*)

> Mike: Or erm (cla*ps his hands together multiple times, looking away from me momentarily*) patronising *(points left hand when he gets this word and relaxes back into seat*)

Mike used gestures to indicate people tend to sweep his concerns under the carpet, dismissing his concerns and contributing to a sense of othering:

> [568-574] Kate: So, for you, it feels like the reality is that nobody can actually understand what it is like?
>
> [569-573] Mike: (*shakes head*) Absolutely, no (*looking down*) but it is like, oh yeah (looks away and nods), yeah, yeah, yeah (inflection), ‘<u>well I have got, I have got memory problems</u>?’ (*Mike averts gaze as though speaking to someone else here*), oh ‘yeah, yeah, yeah (*Mike looks down while shaking head*)’, as if, you know? (*he turns his body and uses both hands to indicate sweeping, then uses one hand as though lifting something from the floor*). As if: ‘**oh well under the carpet, you know**?’ (*Mike returns gaze to Kate*) …

In the beginning of the interview, Mike experienced more WFDs, potentially due to nervousness or uncertainty of how I would respond to him. I wonder if his communication of his difficulties early in the interview was a of inviting me to be patient and understanding:

> [122-123]: I am finding this **(…),** *(Kate nodding*), I am finding this a bit difficult as you can imagine. You can understand where I am coming from.

Mike narrated his sensitivity to not only the words people used but also their tone of voice. He mimics interactions where he experienced WFDs. Mike clearly shifts body posture, gaze, and tone of voice; potentially showing himself as someone who would never speak in this way to another. He used this style of narration several times, and

I wonder if this served as a way of distancing himself from the content of retelling these experiences:

> [99-117] Mike: …oh they will come out with comments like (*he changes his posture and looks away from me*) '**Oh (*shakes head*), well come on, you know**! **What, what?!**' (*he gestures his hand rapidly back and forth to the 'other person'*) (*Kate nodding throughout*) **(…)** (*he shakes his head then slaps his left hand on his knee sharply*)
>
> Kate: So**:::** they are, it is not something they intend to do but <u>how it</u> is said? *(Mike returns his gaze)*
>
> Mike: Yeah. yeah (*nodding*), … I know it is not, trust me I know it is not erm **(.)** erm **(.)** (*shakes hand*), erm **(.)**, (*averts gaze to one side*) m-, m-.m, m- (*he rolls his right hand then tuts*). I think the thing is it is not something that they <u>actually want to do</u>, it is not an intentional thing

Mike used NVC as a tool to add humour to our interactions, sometimes showing me the way in which he may portray the 'Del Boy' persona to others. I wonder whether this comedic ability served him well in social situations when he experienced WFDs, perhaps enabling him to feel that making others laugh is 'doing something right':

> [417-423] Kate: So, faith has been a part of life since young, part of that seems to be enjoying the routine in it but also you have a strong belief in a life after
>
> Mike: Oh god yeah **(.) God!** (*he rolls eyes*) (*both laughing*)
>
> Kate: **<**Sure, it is a figure of speech for the Irish, isn't it? **>**
>
> Mike: **<**Jesus, yeah**>** (*he raises his brows and visibly tightens his lips*) (*both laughing*)

In the latter part of the interview, Mike appeared more complimentary. He used gestures to indicate that I appeared relaxed; he noticed this not only in my words but in my NVC. He was clear to highlight that this was ‘not BS’, which added to his storying of himself as an honest person:

> [654-665] Mike: (*shaking head),* no, no as I have said before you put people so at ease
>
> Kate: (*Kate laughs*) **<Oh**, thank you**>**
>
> Mike: **<**Well, me at least anyways **>** (*points to self)*
>
> Kate: **<**We will see about the others **>** (*both laughing*)
>
> Mike: (*Mike points to his watch*) **Oh is that the time?** Well, must be off *(both laughing*) But yeah (*shaking head and using right hand to shake* it), you have got a <u>very relaxed</u> *(hands to gesture from head to toe*), that makes me relaxed and (*he gestures both hands outward in semicircle motion*)
>
> Kate: Thanks Mike, that is nice to hear
>
> Mike: No, it is good, I mean I don’t <u>BS</u> (*he whispers this word*) (*both laughing*)

I wonder if allowing Mike a space for storying the multiple parts of himself without objection made him feel somewhat understood in this context. I had seen him in a social setting and saw other facets to how he portrays himself. This comment came as the interview was nearing its end. However, the use of words and emphasis on the word ‘might’ summarises his uncertainty that anyone could ever see or understand the ‘real Mike’:

> [726]: …very few people know the real me, I think perhaps you **might**…

After the interview, Mike spoke of grief in losing his parents and sadness in relation to memory problems. He asked whether medication is useful and what helps with memory loss; I reflected that many of the things Mike did already, like attending groups and maintaining a social life, singing, and walking have been shown to be helpful for PLWD. We spoke about how low mood, irrespective of a diagnosis of dementia can lead to difficulties with attention, concentration, and memory.

He felt he could benefit from talking more as he found it helpful to get things off his chest; we spoke about counselling through Age UK, and he consented for me to inform a staff member who could support him further with this. Being mindful Mike often noticed these feelings alone in the evenings, we spoke about Silverline, which he can call 24/7 to speak with someone. I encouraged Mike to speak with trusted workers to guide him in accessing further support in the future.

3.3. Alfred

Alfred and I had met on four previous occasions. I perceived Alfred as a quieter person who seemed to prefer focusing on the activities rather than engaging in ‘chit-chat.’ Alfred had been interested in the research from the first time we met; he and others offered to support me to amend the posters and information sheets, so they were more suited to people attending the Memory Café.

At the beginning of our interview, Alfred communicated he had no preferred terms for memory loss and he asked if I noticed him struggling to find a word that I supported him.

3.3.1. “I Lost My Brilliance”

It seemed important for Alfred to clarify that earlier life experiences led to difficulties with memory, although these have increased with age. His choice of words here seems as though he is letting me in on a secret, possibly ensuring connection early in our interaction:

> [50]: …<u>listen</u>, I may as well you tell you what happened…

Alfred experienced several upheavals earlier in life including the loss of his mother and moving away from London in wartime. Alfred storied his childhood quite quickly, without much interruption, and in a matter-of-fact way, I noted he used non-verbal gestures, which appeared to have a self-soothing quality. The rubbing of his hands and arms was repeated throughout his storytelling when speaking of difficult experiences.

> [51-62] Alfred: …I went to live with an aunt in, in Glasgow (*he moves his hands and places them on his lap with left hand rubbing his arm and hand repeatedly*). A year later, my father went up to Glasgow with a lady (*looks downward and to the side*) and he said (*he returns gaze*) "this is your new mother"
>
> Kate: **<**<u>Oh</u> Alfred, I am sorry**>**
>
> Alfred: **<**Well**:::** a stepmother **>**, she was not exactly pleased**:::** … they did not know much about love (*Alfred laughs*) or anything

Alfred told how he was physically and emotionally abused by his stepmother and, when he told his father, he was silenced. Here, I noticed I mimicked Alfred's self-soothing gesture earlier, perhaps to empathise with him non-verbally, given it was difficult to interrupt verbally:

> [71-77] Alfred: …and sometimes became extremely agitated with this and I took (*he uses both hands in a punching gesture back and forth*), (*Kate starts to rub her left hand repeatedly*) I took the <u>brunt</u> of this (*Alfred sighs*)
>
> **<**Kate: I am sorry, Alfred**>**
>
> **<**Alfred: **(…)** and there were **>** times when erm **(.)**, she would actually swipe me because she thought <u>I was doing wrong</u>: and I defended myself, when my father came home (*he shakes his head*), she had told my father that I had hit her. He hit me (*taps table and points to self*)

Due to these experiences affecting his mental health, he deferred studying medicine. While he could not recall the word, he used NVC to describe Electroconvulsive Therapy (ECT):

> [80-83] …it became **(.),** what is the **(…)**, it became **very bad**, and I, I had to go to a psychiatrist **(.)**. guess what (*Alfred tilts head and has more intent gaze*); he recommended that I went to a mental hospital and have treatment. It was erm ***(…)*** (*taps table rapidly*), with ***(.),*** with (*pointing to sides of head repeatedly*), with sending electrodes through your head…

Receiving ECT created a distance from traumatic memories. However, he highlights his memory was also 'knocked out.' He chooses words and gestures which seem to create distance between him and memory issues:

> [93-99] **…**was obviously a knockout (*Kate nodding*) to my memory (*Alfred tuts*)…the idea of that was to knockout the memory of what, of the fact that my stepmother was beating me and that we, you know, had a <u>**horrible time**</u>, it was supposed to **(.)** (*Kate nodding*), to knock out that…

> [102-104] …this is the background between me and the memory loss (*points to two sections on table*)

At other times, he described memory loss as part of him while reminding me throughout the interview that he once had 'brilliance':

> [89-91] …I was really (*shaking head*) a (*points to head and then moves hand upwards swiftly*) <u>brainless</u> person after that…

> [236-247] …I think I had an IQ of about 130 odd or more…Anyhow, the point is I feel certain that I had an IQ **at one time** *(he laughs*), and then it went (*he uses left hand as though swiping something away*)

Alfred situated intelligence as a key value he held. He described being in awe of technology and how adaptive people are. Although, he externalises the wondrous nature of brains, suggesting memory loss has impacted his view of his own mind:

> [209-211] I think to myself these people are wonderful, it is the same as playing the piano…people have, <u>they</u> have wonderful <u>brains</u>…

Alfred made both positive and negative comparisons to others in his stories. Below, he began to story in the third person how people could make 'fools of themselves,' however, when he experiences WFDs this reminded him of his lost potential:

> [188-201] Alfred:…they may not know the word I am trying to think of, and they may not want to make a <u>fool of themselves (</u>*points left index finger and shakes it, then laughs*)
>
> Kate: So, kind of both ways, sometimes you say they ignore that it happens, what is it like for you when people ignore the difficulties?
>
> Alfred: Eh **(.)** <u>worrying</u>, yeah, yeah (*nodding*) and ◦disappointing◦
>
> Kate: Disappointing (*Kate nodding*) and is that **(.)**, where does that disappointment come from? Is it from other people not supporting you or **/**
>
> Alfred: (*He removes his hand from mouth/chin and points to the side*). Well, erm, I believe that other people are <u>more</u>, are more (*shaking head*), I wouldn't say more brilliant than I am but just brilliant and I (*points to himself*) am not. I wouldn't say people are more brilliant than me because I lost my brilliance (*smiles, laughing, then shrugs his shoulders*)

3.3.2. "I Had To See Everything"

Alfred storied himself as an inquisitive and analytical mind and was clear in storying this. He highlighted his thoughts may be quite abstract, so if he experienced WFDs this should be factored in. I wonder if voicing this protects from feared judgement of his intellect, given the wider narratives around people who forget/struggle to communicate. It may have been a way of adding credence to his stories and safeguarding his personhood in our interaction:

> [24-28] Alfred: I think most of the words I want to come out with might be a bit abstract so maybe I cannot draw it.
>
> Kate: and have you always been someone who has thought like that? (*Kate smiling*)
>
> A: Yeah, well this is a bit more of a (*points to table with left hand and draws circles*) **(…)** scientific background that I have …

Alfred embodied curiosity and desire for knowledge, for example, he highlighted objects in the room he thought were well-designed, referencing Ergonomics. He vocalised the questions that go through his mind and wonderings he has about the world around him. While Alfred is Jewish, and recently returned to the Synagogue, prayer does not align with his scientific mind as it did not provide results, but does trigger his curiosity:

> [358-363] It's not a form of scientific principle **it doesn't work** (*Alfred smiling*), **but**, but it reminds you **(.)** of the (*uses right hand to sweep upwards to the side*), the ◦oneness◦ of God, that's all…(*He looks out the window and starts pointing at different things*). Who made all this? Who made the trees (*shrugging*), who made the cars, who made the atomic bomb? (*returns gaze to Kate*), who made Covid? We do not know, we do not know, it more likely to be what is it called **(…)**, (*uses finger to draw circles on table*), the mother of the earth

To satisfy this curiosity, Alfred attended open lectures at prestigious institutes for many years. Given his earlier experiences and needing to drop out of university, I wonder whether this brought him closer to social and academic circles which he had envisioned for himself as a young man. He laughed and shrugged off that he did not have a degree although this is a point of comparison for him, given the value he places on intellect:

> [453-457] Alfred: … And sometimes (*looks away*), sometimes **(.),** I ask very naïve questions**:::**
>
> Kate: Is that purposeful, to ask naïve questions? Is that to **/**
>
> Alfred: **No:::** most people in audience would have science degrees you see, in fact even when you walk in to sign up they will ask you what your degree is, you see. Well, I haven't got one (*shrugs and laughs*)

Alfred noted his desire to acquire knowledge was hampered by memory difficulties and his NVC suggested a sadness in relation to this loss:

> [410-413] Kate: So, it seems like this has been a constant throughout your life, this search for **(.)** maybe **knowledge?**
>
> Alfred: Yes, yes (*uses left hand to place top of head*) it totally is but the knowledge hasn't stuck (*left hand smacks table*), it is ◦lost◦ …

When Alfred experienced WFDs he even used mechanical terms to substitute the words, for example, replacing the word 'prayers' below:

> [319-320] …in all of the erm **(…)**, cannot remember it (*tilts head downwards towards chest*), the procedures (*lifts head again and returns gaze*)

He also took a technical approach to conversations: he rehearsed conversations or rediverted the conversation towards his interests. I wonder if this approach highlights Alfred's fear that WFDs would lead others to question his intellect and, thus, his worth:

> [143-147] I try to change the sentence or the subject or I don't embark on it full stop (*shakes head and inhales deeply*) although sometimes if I want to mention something (*points left hand towards head*), I will think it over in my mind first **(…)**, for instance, say if we are talking about a certain person and I cannot remember the name, I will (*uses hand to point and slide it around the table*), go through the alphabet in my head, <u>sometimes</u> it jumps out but not always…

Alfred reflected on when he experienced WFDs during a group exercise at the Memory Café. He pointed out some answers did not make sense, but others struggled moreso than him. He previously storied others as 'more brilliant' than him, but something appeared unique in this setting, possibly related to his views of other people with memory difficulties reflecting wider narratives of them being less capable. Being around others with memory loss may help counteract the narrative that he is wholly inferior, as in this setting, he appears to perform better on 'academic' tasks:

> [714-727] Alfred: Well, **last, I was too late today** (*gestures right to swipe away*), to do (*he uses left hand and moves it around table*) **(.)**, (*he looks down*) to do, erm **(.)**, a, a **(.)** little bit (*returns gaze*) of mathematics and then word pairs (*Kate nodding*)
>
> Kate: Yep, that was one of them
>
> Alfred: I <u>can't remember</u> any of the others (*he gasps and puts on a shocked facial expression*), oh there was (*he looks away from me*) what was it erm **(.)**, m**-**, m**-** (*looks back at Kate*)

> Kate: Salt and pepper was one of them, I think?
>
> Alfred: One was wine, and I didn't remember what it was oh it was cheese**:::** and it didn't make sense to me
>
> Kate: **Oh well I said beer!** (*both laughing*)
>
> Alfred: But that was easy for me to (*he uses hand to indicate on table as though moving through a list*), to, once I have the first word, it **(.)**, it triggered the second word, ◦but a lot of the others had difficulties◦

In addition, most attendees were of working-class backgrounds and had limited educational opportunities, Alfred may have picked up on this, as he highlighted the difference between him and others. His NVC below seemed to show the sadness around great loss and, rather than the silence indicating WFDs, he may have decided to stop this storying due to emotional impact of this:

> [224-234] Alfred:…they would not have had the vocabulary (*Kate nodding*), maybe that I have had. You know (*he laughs*), I enjoyed the erm **(…)** (*he taps table*) the <u>dictionaries</u> (*both laughing*)…
>
> K: Yeah, so you had quite a, and you still do Alfred, lots of ways of describing things, a big vocabulary, so are you suggesting in a way that for you there seemed more to lose (*Alfred nodding*) So they do not show the loss as much?
>
> A: ◦Yes, that is right yes◦ (*Alfred nodding*)

<u>3.3.3. "Well, We Are Second Class Citizens"</u>

Alfred storied his wonder at modern technological advances. However, these advances come with the cost of leaving him and older people out, he noted other people who can use technology are 'wonderful', while those who cannot are inferior and second class, particularly those who visibly show memory loss. Given Alfred's story of memory difficulties from earlier in life, this may be a view he has held of himself for sixty-odd years:

> [206-218] Alfred: …with modern technology, smartphones, and tablets which everyone uses, and I **don't** (*shakes head*), and to be able to use your erm (*starts using table to indicate typing*), your erm **(.)**, keyboard which is your **QWERTY** and I think to myself these people are wonderful
>
> Kate: So, something about it feeling a little bit almost /
>
> Alfred: <u>Inferior</u>
>
> Kate: ◦Inferior◦
>
> Alfred: <u>**Second class**</u> (*he returns to earlier pose of covering his mouth with left hand*)
>
> Kate: Is it something that you feel that everyone thinks about people with memory loss, do you think that that is kind of a (*Kate uses both hands and spreads them far apart*) a societal view that people are inferior.
>
> Alfred: People who cannot remember anything are inferior, yes, absolutely. Ok, well maybe not everyone, not necessarily because sometimes people do not <u>show it (</u>*shaking head)*

Alfred's experience of WFDs may out him as being 'inferior' to others. Earlier in life, he protected against losing knowledge by writing, however, this has become more difficult as memory loss has progressed:

> [45-46] … I always insisted that I write things down (*makes writing gesture with left hand on table*), s**-**, s**-** so much earlier in my **(.)** erm life, I was writing things down …

Alfred narrated enjoying being socially and politically active and writing to Members of Parliament and national newspapers. However, difficulties using computers meant he was no longer able to contribute and be a part of political and social dialogue. The advent of technology, while wondrous to Alfred serves to exclude his voice and older people from these conversations:

> [498-500] …I mean even nowadays, I, I, I **(.)** wanted to say something about this erm railway strike but you know, write (*imitates this*), write a letter for the paper but because I cannot **(…)**, I cannot (*imitates typing on the table*)

Alfred storied has never been one to share his feelings or thoughts with others socially. Despite a large vocabulary, he suggested he struggles to apply it socially:

> [633-636] Kate: Have you been someone whom, do you prefer a social life over a quiet one?
>
> Alfred: (*he removes his hand from covering his mouth*) No, no, no, I was never a great one for social life. I don't have **(.)** (*rolls his hands here*) a r**-** r**-** repartee, you know the way I mean (*he shakes his head and looks down*) …

He shared his views of social conversations and noted the rules and methods he should follow for polite conversation. Alfred would like conversations to be deeper rather than surface level but when he has tried openness, he has had disappointing responses and maybe feels inferior in these interactions too. His NVC here may indicate embarrassment if he commits a social 'faux pas':

> [636-657] Alfred: … when people ask, 'Oh how are you?!', (*returns gaze to Kate*) you **do not** start telling people all about your operations (*he smiles and Kate laughs*). You say, <u>"I am well"</u> (*he raises brows*)
>
> Kate: Ok, yes, I see (*Kate nodding*)
>
> Alfred: And then (*he nods and uses left hand to point to the left*) I am supposed to ask them**:::** (*both laughing*), and well, **I forget** (*Kate smiling and nodding*) or**:::** if they start telling me what is wrong with them I get **bored** (*he raises both his hands and covers his face eyes and laughs, he then rests his*

> *head in left hand*)…

He suggested being at the Memory Café is a means of comparison to see how others are coping with memory loss. Alfred acknowledged he has not spoken to many people, so I wondered how he knew they were not coping, potentially this was their performance on more intellectual tasks in the group, like word-matching games:

> [710-712] Kate: … When you started to come to the Memory Café, here, is that for wanting (*gestures hand as though giving something to Alfred)* to speak about memory problems?
>
> Alfred: Yes! (*he raises brows*) and to see how other people (*Kate nodding*) are **coping** (*he repeatedly rubs his left* hand)
>
> Kate: How have you found it?
>
> Alfred: Well (*shaking head*) I haven't talked to many of the people downstairs
>
> Kate: Ah ok, I see**:::**
>
> Alfred: I can see that they are **<<<** not coping**<<<**
>
> Kate: **<<<** ◦Ok◦ **<<<** (*Kate nodding more slowly here*)
>
> Alfred: Or **maybe they are** (*He shakes head*)

Alfred feared that dementia would lead to being isolated at home alone like some of his neighbours and opened conversations with his brother and nephew about his wishes to go into a care home in the future to avoid this. Alfred used an exaggerated facial gesture and tone when referencing a home; it felt as though he was referring to some of the implicit narratives around life in these settings:

> [596-603] Alfred: …I say to him 'oh I am losing memory' he says, "oh well so am I, forget about it". **Oh, come on** (*he scoffs here, leans forward slightly and playfully taps his head with his right hand*) (*both laughing*)

> Kate: Ah ok, so he said, is there a sense that ‘oh it is all fine’
>
> Alfred: Well yeah (*shakes head*), he doesn’t believe it is going to develop into a dementia, nevertheless, I think we are going to be planning, **if** necessary, that if I cannot live on my own, I will have to go into a **home** (*he widens his mouth in a purposefully exaggerated way when saying this word, he then tuts and taps the table*)

While Alfred felt his brother has been dismissive of his concerns about memory loss, he supported him to visit Jewish Care Homes. However, Alfred made clear his views of memory loss are linked to a medical or scientific understanding and, in a care home, while he may be cared for and less isolated, this passivity would hasten memory loss:

> [897-898] … people, they have (*points to head then rests head in hand*) still got their brain but it is just that it does not work**:::** anymore

> [884-888] They were just he <u>sitting </u>in a chair all day long**::** (*Kate nodding*), they had to be **<<< fed, they had to be cleaned, washed, dressed, undressed <<<** And, in terms of the residents, well, you erm (*he shrugs*), you worry (*he smacks his lips*), you (*he scoffs*), well, I (points to self), that I will <u>become like that</u>

Alfred narrated fears for future quality of life although his NVC conveyed a discomfort in voicing these as a sole narrator, suggesting these thoughts are not commonly voiced in the UK. He draws in themes from TV, film, and books, to support him to tell this. He referenced ‘horrible things,’ maybe suggesting his views of memory loss and what it is like to live with the effects of those. I use the word ‘humane,’ revealing some of my own narratives around care homes given my experiences of working with people with memory loss and visiting family members in these settings:

> [906-907] … what’s the word for it? We still keep them alive (*he breathes in through gritted teeth then smacks lips)*

> [919-932] Alfred: ... it is set in the future when horrible things are **(.)**, are, h- h-happening, but you can go (*draws square on table*) a special quarter to go to (*he nods intently*), to pass away
>
> Kate: ◦Ok◦
>
> Alfred: You choose lovely music (*Kate is nodding*), and you have the injection, and you just pass away, **so** (*he laughs*), it sort of feels like that
>
> Kate: So, there is that idea, it comes up maybe that in conversations, and in books, on the radio ***/***
>
> Alfred: **Yeah,** yeah, yeah, yeah
>
> Kate: About the end of life for people who ***/***
>
> Alfred: Who are maybe affected with living the way they are, yeah
>
> Kate: Yeah, and that it can be done in a **<u>humane</u>** (*gestures left hand open palmed facing upwards*), way
>
> Alfred: *(he sighs*) Yeah

Alfred storied feeling inferior and a future in a home may increase this feeling, the Synagogue is a place where he feels valued. Alfred returned to practice his faith following the loss of his father to reconnect with him. Alfred noted others rely on him in the Synagogue; he placed special emphasis on certain words potentially highlighting the important of reciprocity:

> [306-309] …in order to pray you needed at least 10 men, and frequently, I was the 10th one, so **they relied on me,** and they also came when I needed to say prayers, so I realised I should help make up the ten too as often as I could

Alfred storied the ways in which worshippers adapt to difference. He grimaced when communicating he felt he is known for memory difficulties, however, highlighted it is not only people with WFDs who can find conversation difficult. This may be comforting for Alfred, although, he noted this man may be superior to him given his familiarity with technology:

> [328-343] Alfred: … well it is very good (*nodding*) because they do appreciate me and I am, I am well known (*he makes a grimace here*) as being the one who cannot (*points to head*) remember things (*he laughs*), no not quite. Oddly enough we have erm a middle-aged man who is erm, autistic, again it is (*smacks lips*), the word it begins with (*signs letter A with left hand*), it is named after a doctor **(.)**
>
> Kate: Aspergers?
>
> Alfred: Aspergers. And he is also quite, what is the word (*gesturing something towards him with left hand*), **(...)**, r-, respected, **but**. he starts off a conversation…and we cannot see where the link is and we *(inaudible),* as well and there is me as well so (*scoffs*)…also he can use a computer, I can't **so** (*taps table then shrugs shoulder*)

Alfred has donated to Alzheimer's research but expressed frustration that research was not seen a priority for those nearing the end of life:

> [801-802] … and they say for research**:::** (*he taps table*) **but where is it?** (*he sighs, smiles, and shrugs shoulders, he appears to silently laugh)*

> [870-873] Kate: Do you think there is any reason for that? As to why it is not maybe prioritised**:::** or?
>
> Alfred: Yeah, because we are old people and we are going to die off (*he taps the table with right hand and shrugs his* shoulder, *then tenses lips).* There is no point (*Kate nodding*) ◦Oh that is horrible, isn't it?◦

When Alfred and I spoke about what he feels would be useful for dementia, he suggested something similar to ECT. I wonder if it was felt this would act as a catharsis to restore the loss of brilliance and memory he experienced as a result of ECT:

> [828-846] …so, I think we would be going slowly, possibly (*head juts forward*) there might be some electronic gadget that helps you to remember (*he furrows brow*) to sort of stimulate the **brain:::** …all of the computer power and electrics to sort out, **(…)** the wavelengths…

3.3.4. Interactional Context

I noticed the value Alfred placed on science and research and that his desire for contributing to knowledge may be hampered by memory loss and WFDs. I wonder if I wanted to establish his value, knowing that threats exist to his personhood and to try and counter this narrative that he is inferior:

> [122-132] Kate: You have that type of mind where you are looking around to see what works and what doesn't?
>
> Alfred: That is right, that is right (*Alfred nodding*)
>
> Kate: I remember when you were helping me a few weeks ago and you had this idea of "this reads best"
>
> Alfred: (*smiling and nodding*) **Yes**, that is right, that is right yes.

He demonstrated his frustration with experiencing WFDs in NVC throughout the interview, he slammed the table although later counteracting the WFD by asserting he still holds knowledge about the topic:

> [413-421] Alfred:…erm, what is it called? Where the temperature goes (*uses*

> *hand to show increasing levels*)
>
> Kate: **Oh,** global warming?
>
> Alfred: Global warming, this erm **(.)** lecture was all about the melting of the ice caps but cannot remember it all but good
>
> Kate: So, some of the really interesting things stick with you?
>
> A: Yeah, yeah, **but** I cannot remember his name (*slams hands on table*), I know he wrote a book though …

When Alfred experienced WFDs, he would often look away from me then return his gaze when he had found the right word or when he wanted support. I wonder if this made the experience of WFDs easier; if he were to look at another person while experiencing WFDs, this could feel more threatening to his sense of self:

> [13-18] Alfred: … there is a special word for it, I do not have (*taps hand on the table repeatedly and looks down*), many, I do not like describing things **(.)** (returns gaze to me).
>
> Kate: It is ok, (*Kate looking upwards, almost* wordsmith maybe or?
>
> Alfred: (*Points at Kate*) – **<u>That is the word</u>** (*taps both hands on table*) wordsmith, yes, yes, yes, yes. But I, I think in <u>pictures</u> rather than words…

Alfred and I often mirrored each other's NVC, for example, using self-soothing gestures. In this interview, I sat back in my chair, cross-legged, and did so for forty minutes, mirroring Alfred's relaxed posture. This is an unusual stance for me, and I wonder whether this was my way of trying to connect with him to encourage open communication.

Alfred often covered his mouth after saying something which could be considered a 'faux pas'; he did this when speaking about euthanasia. I wonder if below the act of covering his mouth is a way to prevent him making a ‘fool’ of himself, a worry he had narrated throughout the interview:

> [172-181] Alfred: …If I have a question to ask and I cannot really formulate the question **(…)**, correctly, because (*he uses both hands to roll them over each other*), because I might need to bring in other factors in it, you know, it is (*shrugs shoulders*). It is like saying when did you stop beating your wife, that is rhetorical of course, but it is like, **<u>you see, it is so easy to put your foot in it</u>** *(both laughing*)
>
> Kate: Don’t worry at all (*Alfred changes his posture and he rests his head in his left hand while using index and middle finger to cover mouth with index finger in mouth*) …

Alfred did not feel particularly saddened by storying his past and was glad to have contributed to the study. I wonder if him contributing to research was the satisfactory outcome of our conversation. Alfred was curious about the recording equipment; I showed him how to use the videorecorder, while Alfred felt that knowledge does not stick, these interactions seemed joyful and momentarily satisfied his inquisitive mind.

4.0. DISCUSSION

This chapter summarises findings in relation to the research questions and literature regarding the stories told by three PLWD and WFDs, positioned within wider contexts. Taking a reflective stance, I will critically evaluate the research and explore the implications and recommendations from the current research.

4.1. Summary of Findings

The narratives shared by participants reflect the abilities of PLWD and WFDs to story their unique self in interactions with others, particularly when provided with support and facilitation (Hughes & Castro, 2015). Interviews produced a large amount of data, reflecting the rich stories of each participant. The research questions (Section 1.9) provide a general structural framework for analysis and discussion.

4.1.1 What Stories Do PLWD Share About Their Experiences of Having WFDs in Dementia?

A story shared by all participants was their concerns and experiences of memory loss and WFDs were often dismissed, rejected, or minimised by others. These responses led to disappointment, sadness, anger, and frustration. All participants storied interactions which suggested others had changed their ways of interacting with them. This is similar to the concept of ‘elderspeak’ (Brown & Draper, 2003; O’Connor & Pierre, 2004), which involves using simplified words, terms of endearment, exaggerating tone, and slowing the pace of conversation when communicating with older people.

These experiences seem to suggest PLWD may be viewed in terms of their deficits, not given the opportunities to nurture their existing social and communicative abilities and express their feelings in relation to memory loss, leading to a range of depersonalised interactions (Sabat, 2001). Ward et al. (2008) found overlooking or misinterpreting communication attempts of PLWD can leave the person feeling misunderstood, undermining one’s sense of self - most prevalent in Mike’s storytelling.

Similar to findings in a study by Olthof-Nefkens et al. (2021), participants storied their experiences of feeling stuck, not being able to find the right words, and being misunderstood by others. For example, Alfred storied WFDs often led him to avoid or withdraw from certain conversations or implement strategies to lessen WFDs, rather than risk being viewed as defective by others, which poses a threat to his personhood.

Other stories centred around loss and fears of future losses, particularly loss of autonomy. For example, Marcela storied her fierce independence and how living with dementia and WFDs had made it more likely she would need to depend on others. Alfred storied a loss of brilliance, partly storied as due to the memory loss associated with ECT, which has been well documented (e.g., Robertson & Pryor, 2006). However, this had been further exacerbated by WFDs posing a threat to his identity within social interactions. Alfred also storied future losses of independence if he would need to go into a care home. Mike storied losses regarding narrative agency (Baldwin, 2005), exacerbated by other people’s responses to expressions of his experiences of living with dementia.

I observed times when my conversation style changed, for example, speaking more quickly, led to increases in WFDs or shorter responses. While participants did not explicitly story these changes, my observation shows storytelling for PLWD and WFDs is impacted by the conversational style of the partner. Lack of awareness of how to support those with WFDs to share their experiences narrows opportunities for positive social interactions, potentially increasing risk of social and emotional isolation (Austrom & Lu, 2009).

Opportunities for constructing and expressing personhood are scarce in PLWD (Kitwood, 1997), participants in this study took the opportunity to author their own stories when the opportunity arose and resisted stigmatised identities in their storytelling.

4.1.2. Within This Storytelling, How Do People Communicate their Stories In Both Verbal and Non-verbal Ways?

Excluding NVC from research can erroneously lead PLWD to appear less able and active in conversations. By emphasising the performative and embodied aspects of storytelling (Hydén, 2013), this research confirmed previous findings that PLWD and WFDs make both verbal and non-verbal efforts to use their cognitive and linguistic resources to affirm and maintain their personhood (Batra et al., 2015).

When experiencing WFDs during our interactions, participants used embodiment as a resource to strengthen their storytelling, even in silences, they used gestures to support me to understand the words they were looking for. There were several instances where posture and body positioning changed, which seemed a purposeful act which strengthened their storytelling. For example, Mike's moving forward seemed his way of placing emphasis on important aspects of his story.

Retelling of stories is often dismissed as a symptom of dementia which leads to key narratives being overlooked. In this study, it was noted the retelling of stories emphasised important aspects of their identities. For example, Marcela storying her hardworking nature was present from the beginning to end of our interaction, Alfred told several stories about his scientific and inquisitive mind, and Mike storied his musical and social abilities as key aspects of his identity.

Other nonverbal aspects of storytelling used were gaze, tone, facial expressions, and use of gestures. All participants averted their gaze from me when they were recounting interactions with other people and quoting others. This may have been a way of distancing themselves from the words of others and being clear the words they had spoken belonged to someone else. This could have also ensured their projected self was not altered by other voices.

All participants used changes in tone to convey various messages. For example, Marcela used an infantilising tone when she recounted experiences of speaking with people who were aware of her memory difficulties and alluded to emotional impact of these infantilising interactions. In addition, facial expressions were used to emphasise certain points or add humour to storytelling, like Mike raising his eyebrows in an exaggerated fashion when being ironic. Several gestures seemed to convey feelings which would not have otherwise been verbalised. For example, Alfred often covered his mouth after saying something which could have been considered a ‘faux pas’, while it seemed this was an aspect of his humour, his NVC may have suggested he was somewhat repentant about some of his storying. Marcela often used hand gestures to imply something about her is being lost or ‘thrown away’ when people learnt of her memory loss, and Mike gestured sweeping something under the carpet when he tried to share his experiences.

Similar to findings from a study Kontos et al. (2017) this study finds when communication difficulties are experienced in dementia, PLWD engage in reciprocal communication (verbal and non-verbal) which initiates creative and humorous interactions. They highlighted the capability of PLWD to be deliberately humorous and resourceful, rather than being passive receivers of communication from others, demonstrating that, even when words are difficult to retrieve, PLWD and WFDs are active and collaborative storytellers.

4.1.3. How Can These Stories Be Understood Within The Wider Context In Which They Were Told?

Storytelling can be particularly important for people who are confronting change that risks devaluation and dismissal from society, such as PLWD (Killick & Allan, 2001). As stories are shaped by our sociocultural contexts, stories told here may replicate existing forms of oppression through repeating dominant sociocultural narratives in relation to dementia (Ewick & Sibley, 1995). For example, Alfred storied his view that people who cannot remember are inferior, and older people are second-class citizens. This belief may be related to dominant ideas that language and cognitive ability are essential in conveying ideas, and those who have difficulties in doing so are seen as ‘less than’ (Brown, 1998).

Stories of connection with others, independence, belonging, and intelligence, seemed to resist stigmatised identities. The use of emotionally charged metaphors and use of proxy narrators rather than PLWD, can mean the public struggle to connect emotionally with PLWD (Clarke, 2006; Siiner, 2019); this seems to link with the participants’ experiences of people not knowing what to do or say when they shared their experiences of living with dementia and WFDs.

Robertson (1990) stated framing dementia as an individual illness is enticing as it produces demonstrable results. Participants related to dementia as a medical condition; sadly, medical models can sustain narratives that PLWD are shadows of their former selves (Batra et al., 2015). Additionally, cultural stories of dementia often promote a negative view of PLWD and lead to many experiencing a ‘social death’ (George, 2010). All participants storied an awareness that a diagnosis would lead them to be treated differently by others, even ostracised. For example, Marcela noting a neighbour turning her back on her.

Current research is largely focused on exploring biomedical markers of dementia, biological causes, and brain mapping to explore the brain changes that can be ‘corrected’ by effective cures and/or treatments (UK DRI, 2022). However, Alfred felt progress is slow due to the narratives around older people, particularly those with cognitive issues, being less worthy of investment. The hope and investments in finding a medical cure or treatment for dementia may connect to wider narratives of fighting back against it. Language used in public campaigns such as ‘Fightback’ (Alzheimer’s Research UK, 2016), seem to place onus on individuals to defy the odds. This may have been reflected in all participants seeking advice after the interview as to how to manage living with dementia, and the Memory Cafes’ activities often focusing on cognitive stimulation.

4.2. Critical Review

4.2.1. Validity

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

4.2.1.1. Trustworthiness of analysis

As outlined in Section 2.2., Riessman’s (1993) framework for narrative research suggested evaluating the data in terms of coherence¸ persuasiveness, correspondence, and pragmatic use. The final area will be presented when considering the implications and recommendations of the research (Section 4.3).

- Coherence: considers how meanings linked across multiple levels (Riessman, 1993) through the use of staged narrative analysis considering experiential, interactional and wider narrative levels. Being transparent about the analysis in providing excerpts (Appendix D) enables the reader to see the processes involved in narration, analysis, and interpretation.

- Persuasiveness: This considers the credibility of interpretations presented in the current study. While attempts were made to strengthen persuasiveness, through use of direct quotes and summarising existing theoretical and research claims, persuasiveness is mostly dependent on reactions of the reader (Riessman, 1993). Interpretations demonstrated a transparent link to wider socio-cultural, political and research contexts, which interact with participant narratives. In addition, I reflected on ways in which my communications both verbal and non-verbal may have impacted on narrative construction and potentially influenced the stories told here. This transparency supports the reader to remain open to other interpretations of the excerpts, beyond my perspective, and consider how their own contexts may influence which stories persuade them most.

- Correspondence*:* This concerns how linked the narrative I presented in analysis is aligned with narratives of participants. Providing summaries of analysis with participants and requesting their feedback aimed to ensure their narratives were accurate in my representation. While feedback was not forthcoming, providing summaries was important as consent was re-sought to produce the stories told in this write-up. As suggested, corresponding the analyses to existing knowledge, for example, academic literature and dementia policy narratives allows room for a broader range of interpretations of key concepts (Riessman, 2008).

4.2.2. Methodological Limitations

4.2.2.1. Recruitment

I contacted several third-sector organisations and advertised the research in relevant online forums, only one centre invited me to advertise the research in-person. I had anticipated recruitment would be challenging given previous evidence of gatekeeping by professionals for PLWD (Nygård, 2006; McKeown et al., 2015). I found limited responses to requests to advertise the study possibly evidenced barriers which hamper PLWD's opportunity to contribute to research, particularly when they experience communication difficulties.

I attended the Memory Café on eight occasions for recruitment (and on one occasion following recruitment to provide summaries of analyses). Three participants were recruited. While this allowed these narratives to be studied in depth, narratives from many others remain unheard.

While others expressed interest in the study, I noted many PLWD from minoritised groups seemed to seek advice from me in informal conversations and highlighted the ways in which they and their families felt let down by NHS services. Sadly, they did not wish to partake in research interviews, which meant their stories remain unheard in this research context. Sasidharan and Hickey (2021) explored the barriers to minority group participation in research and considered what could be done to address these. Of relevance to this research is that my inclusion criteria stated people needed a proficient level of spoken English, this may have inadvertently given a message that people from minoritised groups may not be able to articulate their points for reasons other than WFDs (Sasidharan & Hickey, 2021). Developing relationships prior to the start of a research project was identified as an important part of creating a more equitable relationship and enabling communities to have meaningful input and shape research ideas so the topic being researched is relevant to their interests. However, recruiting in this way, particularly for a time-limited study, proves a resource issue, as developing these relationships within the community is a lengthy process (Sasidharan & Hickey, 2021).

4.2.2.2. Data collection and analysis

A limitation of this study is that single interviews were used to collect data, these interviews may have been limited in their scope and only captured how the participants felt in that moment (Riessman, 2002). Stories collected over several visits could have provided richer accounts and a greater refinement of my ability to respond to NVC of each participant and scaffold their stories.

Narrative research with minimum questions is idealised to minimise researcher influence (Riessman, 2008), however, it was necessary to respond to people in their preferred ways (e.g., supporting them to find a word, or repeating their last used phrases to prompt them) as requested, to ensure their comfort and minimise potential distress.

I was conscious of the authority I held in choosing excerpts to analyse and present to the reader. This may have been influenced by my own positioning in the world, views of PLWD and my experiences of having several relatives who have lived and are living with dementia and WFDs. Therefore, I largely included extended excerpts to allow the reader to be in closer proximity to the stories told by participants.

Denham and Onwuegbuzie (2013) found incorporating NVC into data analyses and interpretation was uncommon and underutilised. In including NVC in this study, I hoped to enable thicker descriptions and interpretations of the stories of PLWD who experience WFDs. For transparency, I included NVC of the participant and myself in all excerpts. However, limited word-count impacted on my scope to comprehensively address NVC. Jones and LeBaron (2002), highlighted linear formats of academic theses, and journals are additional barriers in including NVC in research.

As discussed in Section 2.6. there is no universal way of transcribing NVC, this meant I had to combine recommendations from various authors. Further, my recognition and interpretation of NVC will be shaped by my own cultural and personal contexts (Tanggaard, 2009; van Enk, 2009). Transcription was a lengthy process, possibly due to my unfamiliarity with transcription and inconclusive agreements on transcribing NVC, it is important this be considered in future research endeavours for feasibility.

4.2.3. Reflexivity

In line with my stance, I hold that the observer, observation, and the interpretations are inseparable (Kohler-Riessman, 2014). Academic writing often seeks to minimise, neutralise, or standardise the 'self'; researchers prefer to place their stories and reflections in the appendices, or reserve personal disclosure for private diaries and fleeting introductory remarks (Kohler-Riessman, 2014). The personal self of the researcher is often viewed as a contaminant to the validity of the research (Krieger, 1991). However, in line with my research aims, it is important to reflect that my 'self' was projected in the research encounter in several ways.

Due to my own cultural background, I have been exposed to stories told in a different language but also stories which follow alternative narrative norms. Ireland has an established history of sharing stories in the oral tradition and 'seanchaithe' meaning 'bearers of old lore' are storytellers who use draw on our folklore, history, and legends as an adjunct to storytelling. The distinctive role and craft of the seanchaí is particularly associated with the Gaeltacht (the Irish-speaking areas of Ireland) where my family are from; local storytellers were considered craftsmen who honed their art by trialling various styles of speech, gestures, and storytelling conventions. I wonder if my exposure to stories told through a different cultural lens enabled me to be more perceptive to stories told by PLWD which incorporated various gestures, styles of speech and alternative storytelling conventions; my interpretations of these are implicitly informed by my own cultural and societal expectations (Davis, 2004).

In my conversations with carers of minoritised PLWD who attended the Memory Café, they spoke of the lack of care they received from the NHS and their frustration that there had been little follow-up post diagnosis. This led to feelings of abandonment, and they noticed barriers in accessing additional support or social care for the PLWD. While PLWD and their carers, particularly those of Afro-Caribbean heritage shared stories of the similarities between them and Irish people in Britain and seemed comfortable to engage with conversations in the social setting of the Memory Café, I am mindful that I also was representing the NHS in this context. While some expressed interest in the study, I wonder if my dual role as an NHS professional and a researcher was a barrier for participation, they may not have trusted me enough to share their stories in an individual context as I represent an organisation which has been evidenced to provide differential treatment to PLWD from minoritised backgrounds (Tsamakis et al., 2021). I wonder if there was an understanding that I would have interpreted their stories according to Western norms and misrepresented their experiences, re-enacting some of the existing issues they face when accessing healthcare.

I believe that the decision to spend several days in the Memory Café before and after interviews supported me to draw on contexts outside of the interview itself to contextualise the stories told, furthering the validity of the interpretations. In addition, during the interviews, participants used their prior knowledge of me and drew on this when they were inviting me to scaffold their stories or support them when they experienced WFDs; for example, Marcela noted I was Catholic, which gave me a clue to the word she was looking for. These instances would not have been possible had I interacted only with participants during the research interview.

It is important to note that psychologists undertaking qualitative research hold dual roles, as clinicians and researchers, and need to distinguish between the purposes of the therapeutic encounter and the research encounter (Thompson & Russo, 2012). Therapeutic skills lend themselves well to qualitative interviews and are useful in managing the emotions and potential clinical risks associated with exploring sensitive areas of a participant's life (Thompson & Russo, 2012). However, these skills can also be misused, albeit unconsciously, to gain access to information which a participant may not have intended to disclose (Kvale & Brinkmann, 2009). I was mindful of this in my interactions with PLWD, both in the Memory Café and in research interviews. In line with this consideration, my interview schedule contained a single opening question, and mainly detailed how I would ensure comfort and respond to signs of distress (Appendix I). This decision allowed participants to decide which stories to share, even if they were perceived to be unrelated to the initial question. My role was to scaffold these stories and share my ongoing reflections and interpretations to ensure understanding, rather than challenge or counter these stories in a way that a psychologist might in some therapeutic interventions.

Within the context of interview interactions, I am aware that my views on dementia may have impacted the stories told by the participants. While, it may have been helpful to take a strengths-based approach, which can help to foster positive social interactions for PLWD (Sabat, 2001), I wonder if at times I was more curious about stories which counteract dominant narratives. This may have impacted the storied self projected in the interaction. However, in other ways, positive narrative scaffolding may have been provided in my flexibility in responding to the needs of each participant, and asking for preferences for support regarding WFDs at the beginning of the conversation (Sabat, 2001).

Riessman (2009) notes narratives do not reveal an ‘essential’ self but, instead, a preferred version of the self. This preferred version is appropriate to the contexts in which stories are told and the social expectations for the storyteller (Stephens & Breheny, 2015). I was mindful that I had the power to choose which data and stories to present to the reader (Fontana & Smith, 1989), and in doing so I would also be presenting a preferred version of myself as a professional in the research context. To balance this, I aimed to include quotes which showed interactions between myself and participants, and noted times where my views were more reflective of my personal contexts. For example, Alfred had mentioned euthanasia in relation to PLWD; I noted that in my own response I shared that this was ‘humane’ (p.80). Conversations about death, dying, and future losses permeated stories told by all participants and I was mindful that, as I have witnessed several PLWD as they approached the end of life, I had observed care that felt inhumane, at times. While this is not something I would have shared in a therapeutic context, I wonder if this was my way of expressing that I could tolerate these narratives around death and dying to support scaffolding of these stories. While, it would have been useful for the reader to have been presented with more of these interactions between myself and participants, limited word-count meant that I chose to privilege the stories of participants in line with my research aims and questions.

4.2.4. Ethics

I used the processural consent method, which incorporates a broader construction of capacity, encompassing compassion, balancing the rights and wishes of PLWD alongside their protection (Dewing, 2007; Hughes & Castro Romero; 2015). This enabled documentation of decision-making regarding consent, including consenting post-data collection to the inclusion of contributions in the analysis and written report.

As part of this method, rapport building with all participants was possible prior to consenting.

Despite following ethical guidelines, this research may have reproduced existing power relationships for PLWD through researching a group to which I do not belong. I gained significantly in using participants' narratives for my doctoral thesis, akin to the concept of 'narrative economy' (Hillman et al., 2018). While participants expressed they felt the research interview was beneficial and they were glad they had contributed for various reasons, their long-term benefits are unknown. To address this, another member of my cohort and I have agreed to support the organisation with funding applications, as they felt our professional power and knowledge may prove beneficial to ensuring the longevity of the work they do, in a climate of funding cuts. However, this ongoing relationship is not something the participants are aware of, and I may have inadvertently enacted previous findings which showed minoritised groups often feel academics only access certain groups of people when they needed something (Sasidharan & Hickey, 2021).

Birt et al. (2016) found receiving summaries of interview analyses helps to ensure the research remains meaningful for participants and can support them to feel validated and that their contribution is of worth. Riessman (2008) suggested feedback on the analysis should be sought both as part of good ethical practice and to ensure validity of the findings. The provision of feedback was optional and at the time of write-up of this study, has not been received. This may reflect findings that participants often privilege the interpretation of the researcher, which may be why feedback has not been forthcoming (Estroff, 1995), limiting this study's validity claims. However, this could be rectified in future by researchers allowing more time to meet with participants following data-analysis.

To ensure this research is meaningful, I aim to disseminate my findings in academic, professional, and lay settings, aiming not to privilege academic endeavours over meaningful findings for PLWD and WFDs.

4.3. Implications and Recommendations

4.3.1. Clinical Practice

The therapeutic relationship is imperative for CPs and other professionals to consider when working with PLWD. The current study highlighted the role, both, PLWD and professionals hold in constructing identities through embodied interactions. Attending to NVC alongside verbal communication showed that, while the participants do experience WFDs, they communicated their stories in adaptive ways, which served a function of maintaining and upholding personhood.

My previous experiences of delivering interventions for PLWD seemed to reflect wider narratives which encouraged stigma against PLWD and served to treat them as a homogenous group of individuals (Castro Romero, 2016). Importantly, given many PLWD and WFDs are excluded from interventions if they have communication difficulties (Holden et al., 2020), the diverse stories shared by participants counteract the perceived homogeneity of this group, and showcase their adaptive abilities to share their stories despite experiencing WFDs.

The British Psychological Society (2018) called on CPs to improve access to psychological therapies and services for PLWD, as within existing therapeutic interventions for PLWD, there seems to be little opportunities for those who experience WFDs to explore their emotional responses to a diagnosis. The lack of provision of therapeutic interventions was noted by all participants. CPs should aim to create more inclusive therapeutic approaches which account for the ways in which people embody their stories, and emotions, and how embodiment is a resource that exists even when people experience significant communication difficulties.

Creativity can enable embodied reactions, facilitate meaningful expression of stories, and increase positive social interactions for PLWD and communication difficulties (Killick & Craig, 2012; Dowlen, 2018; Zeilig et al., 2019; Dowlen et al., 2021). This approach was helpful in supporting those who lacked confidence in verbal communication, as their participation was not dependent on this. CPs could consider how creativity could be used in therapeutic interventions to support narrative scaffolding and enable people to tell their stories in ways which strengthen their narrative agency.

4.3.2. Service Provision

CPs are trained in neuropsychological testing and are often involved in the diagnostic process for PLWD. It is important CPs consider a nuanced approach to working in settings which privilege bio-medical explanations. CPs have a role in contextualising these diagnoses within the wider context of the person's life; while a label may be helpful for some, it could prove a threat to identity for others (Saunders, 1998). Working psychologically with groups and systems is a key role of CPs in the NHS (BPS, 2007), hence, it is important the CPs provide spaces for alternative stories of PLWD to be shared in team settings.

Holden et al. (2020) reviewed the inclusion and exclusion criteria for CST in memory clinics across the UK and found 49 of 50 services cited communication difficulties as a reason for excluding PLWD from the intervention. As shown in this study, there are several ways that PLWD can express their stories and preferences for care. Psychologists should consider how adaptive ways of communicating with PLWD could be embedded in services and to support staff to engage with these.

Advocating for PLWD as 'experts by experience' (Barnes, 2009), could promote their involvement in service and policy design (British Psychological Society, 2016). Having worked with the North Thames Faculty for the Psychology of Older People, we aimed to develop long-term partnerships with local charitable organisations and research institutions. Our research showcases and events invited experts by experience and privileged research which was co-produced by elders or PLWD. These acts ensured that professionals could engage with views and research which otherwise may have been hidden by dominant medical narratives (Martín-Baró, 1994; Mental Health Foundation, 2015).

Pressures faced by all health and social care professionals in the NHS and in charitable organisations may limit capacity to implement these suggestions, which encourage the humanity, individuality, and life experiences of PLWD, as well as recognising the significant role of relationships in wellbeing (NICE, 2018). However, Davis (2004) notes the onus on healthcare professionals to carry out PCC creates undue pressure on individuals, rather than leading to change in wider organisational structures and processes.

4.3.3. Sociocultural and Political

Participants storied dementia as a biomedical condition which had several negative associations with it; these negative stories seemed to be exacerbated by interactions with others who held negative views of PLWD and internalisation of bleak biomedical explanations. For example, all participants storied being treated differently following diagnosis. However, their choice to contribute to this study and storying of their self in our interactions resisted some of these stigmatised narratives.

DEEP (2015) explored how words which raise awareness of dementia and create a sense of urgency for research and funding for dementia appear sensationalistic and depersonalising. They referred to use of words such as 'suffering from' as 'curl up and die' words, which sustain stereotypes about PLWD and lead the public to believe a life with dementia is not worth living; Alfred also storied this in his referencing to euthanasia, relating to the suffering he envisions if dementia progresses to an advanced stage.

Sensationalistic language referring to suffering gives the impression PLWD are helpless, dependent, and have little to contribute. Dementia activism groups such as DEEP and TIDE have adopted the tagline 'Nothing about us without us,' which is a strong indication people with this diagnosis wish to be seen as active agents in their own lives (Mental Health Foundation, 2015). Marcela, Alfred, and Mike, by their participation, seemed to embody this idea they have something to contribute and have narrative agency. However, Charlesworth (2018) noted that even when PLWD do contribute, professionals and researchers may use their knowledge and power to question the validity and representativeness of these stories.

As previously discussed, wider contexts in which PLWD and WFDs navigate contain influential stories about dementia which often go unchallenged. However, the homogeneity of stories which influence government policies may be linked to the inappropriate methods used to elicit views of PLWD. For example, in 'Hidden No More,' an online survey received 2,521 responses; only 3% of which were from PLWD (APPG, 2019). In this report, other voices were privileged instead, paradoxically hiding the voices of PLWD.

CPs can contribute to sharing of alternative stories in settings which are more accessible and frequented by PLWD, this would follow on from recommendations to create dementia-friendly communities (DoH, 2015). Such enterprises can be supported by CPs consulting on policy developments and, within this, creating contexts and spaces which seek and privilege the contribution of PLWD and WFDs.

4.3.4. Future Research

Historically, PLWD have not been active contributors in research and often their stories were told using proxy informants and observational studies (Innes, 2009). The omission of narratives of PLWD may relate to wider beliefs that PLWD may not produce ‘tellable’ stories, particularly if they experience WFDs and other communication difficulties, which means their story deviates from narrative norms.

In the present study, a way of counteracting this was by videorecording interactions and reporting on all aspects of communication in the research encounter, which yielded thicker descriptions and interpretations. Even when participants experienced WFDs, their verbal and NVC were inseparably woven and appeared to be synchronised even in moments of silence which supports understanding of their stories. Omitting NVC may impact the way in which we make meaning of the stories told in narrative research (Birdwhistell, 1970).

It is recommended future studies consider ways of privileging stories of PLWD and consider consenting processes which have more nuanced constructions of capacity. Embracing processural consent methods (Dewing, 2007; Hughes & Castro Romero, 2015), and inclusion of all forms of communication in research with PLWD, promotes an ethical and inclusive practice which can enable stories, often deemed as ‘unknowable’, to be known and shared in a variety of contexts meaningful to PLWD and their families.

Join Dementia Research (2023) has increased the numbers of people participating in dementia research, although it is unclear how many of these are PLWD. Although the information on these studies is hosted online, when advertising this study, despite many views on my online advertisements, there were no expressions of interest from PLWD. This may speak to technological barriers for older populations, particularly those who experience cognitive difficulties; something which was storied by one participant was he felt ‘left behind’ despite his interest in research and contributions to knowledge.

Additionally, this research embodied a social constructionist approach and showed ways in which interactional aspects of research, and the subjectivity of analyses and interpretation of participant stories, were influenced by conceptualisations of dementia across several contexts: personal, interactional, and socio-cultural. Seeking objective truths can often obscure the rich contextual landscapes that influence human experiences, and how experiences are storied in diverse ways by individuals, which upholds their own personal truth (McAdams, 1993).

4.4. Conclusion

Engaging in storytelling is an inherently social act, and the audience has a crucial role in encouraging (or obstructing) the narrative expression of PLWD; encouraging them to continue telling stories can reaffirm their role in the community as active members (Hydén, 2017). I hope this study has shown supporting and privileging the stories of PLWD and WFDs, in whichever way they were expressed, adds justification for including their voices in future studies, policy developments and in the public sphere.

I emphasised communication attempts of PLWD are multi-faceted, and PLWD and WFDs maintain their ability to tell stories and uphold personhood despite threats against these. Even in silences and manifestation of WFDs, participants expressed themselves in a multitude of ways which complemented storytelling, showing the capacity to be humorous, engaging, expressive, moving, and unique even in the absence of words.

Importantly, while people storied their self and upheld their personhood in several ways, they also storied lives of hardship which had impacted their emotional wellbeing. This wellbeing seems to be further impacted following a dementia diagnosis. Professional practices may exclude people with communication difficulties from therapeutic spaces and re-enact narratives that their stories are less knowable and understandable. The stories told here may provide ideas for how CPs can improve access to services at all stages of the dementia journey, promoting personhood irrespective of cognitive and linguistic difficulties experienced by those living with dementia.

5.0. REFERENCES

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6.0. APPENDICES

APPENDIX A: Personal and Professional Contexts

Many readers will know someone living with dementia and their views about dementia and PLWD will be shaped by their own contexts. In sharing my context and my reasons for researching this topic, I invite the reader to remain curious about their own responses to the research presented.

I grew up in Ireland and moved to London in 2016 to pursue a career in Clinical Psychology. Both my parents grew up in rural Ireland, in large Catholic farming families. I was raised Catholic in a working-class family and I am considered well-educated. My mother is from a Gaeltacht (an Irish speaking region) and Irish is her first language; I was raised bilingual. I noticed the Irish words or descriptions of dementia held with them cultural stories of how dementia had traditionally been viewed. For example, the word ‘néaltrú’ meaning dementia literally translates to ‘the third cloud or haze (of one’s life)’, insinuating that effects of ageing are an inevitable course in one’s life, rather than an illness or condition requiring intervention.

Before the urbanisation of Ireland, PLWD were mostly cared for at home by their family with the support of the local community. Elders were held in high esteem for the knowledge they held, shared through traditional storytelling. However, the privileging of biomedical explanations in modern times has meant what was once viewed in Ireland as an expected part of ageing is now considered an illness, thus requiring assessment and treatment from healthcare professionals (O’Malley et al., 2022).

I have several family members who have been diagnosed with dementia and witnessed their experiences with health and social care services. For example, I visited a relative while they were in hospital for respite care and due to WFDs in English, they primarily spoke through Irish. This made being understood by others very challenging. I witnessed how busy staff would often not have the time to wait for a response or would interpret their silences as disinterest or symptomatic of the progression of his ‘illness’. However, upon spending time with them, we found ways of communicating with each other, often this was by using non-verbal communication. It appeared their sense of self was being communicated non-verbally by repeating certain hand movements which seemed to reflect their former work as a skilled tradesperson or were reminiscent of them playing the accordion.

Throughout my professional career, I have had significant experience in working with PLWD. I worked as an NHS research assistant for two years working on studies which aimed to either cure or slow down the progression of dementia. I then spent two years working in a Memory Service as an Assistant Psychologist and facilitated Cognitive Stimulation Therapy (CST), life story work, and delivered carer workshops. I also sat on the North Thames Faculty for the Psychology of Older People, where we facilitated events aimed at sharing innovative clinical practice.

In facilitating CST, many PLWD felt the activities and aims of the group upheld wider narratives which encouraged stigma against PLWD and served to treat them as a homogenous group of individuals (Castro Romero, 2016). However, I noted how people resisted some of the narratives around dementia, for example, refusing to sing outdated songs, or play games which they perceived as infantilising. Some PLWD voiced they would have preferred a group which focused on sharing their emotional responses to receiving a diagnosis of dementia.

It appeared exclusionary practices were embedded in services, for example, pre-existing exclusion criteria for CST included significant communication difficulties. This meant PLWD and WFDs were further stigmatised by the services which were intended to support them. However, within my work with PLWD, I witnessed and experienced how PLWD adapted their communication style to construct their stories and share their self with others in social contexts.

These experiences led me to wonder about the lived experience of PLWD who experience WFDs and the way in which dominant discourses may shape these?

APPENDIX B: Literature Search Strategy

The following search terms were used:

Alzheimer’s OR Alzheimer’s dementia OR Alzheimer’s disease OR dementia OR Lewy body dementia OR dementia with Lewy bodies OR vascular dementia OR frontotemporal dementia OR dementia in Parkinson’s disease AND word finding difficulties OR word finding difficulty OR word finding problems OR word finding deficits OR word finding impairments AND stories OR experiences OR narratives

The following criteria were applied for review:

Inclusion Criteria:
1) People diagnosed with dementia or identify with diagnosis
2) English language

Exclusion Criteria:
1) Studies focusing on cognitive functioning or biomedical symptoms of dementia primarily
2) People with a diagnosis of dementia not included in study
3) Studies focusing on WFDs in strokes or Mild Cognitive Impairment or other medical conditions
4) Study only focusing on carer experiences
5) Studies which attempt to elicit the view of the PWLD by proxy
6) Book reviews
7) Duplicates

Results:

- An initial inclusion of the word aphasia in search terms was removed as it returned results primarily related to communication difficulties as a result of a stroke.
- 1112 studies were returned, and titles and abstracts reviewed for relevance.
- 259 were identified for further exploration of full-texts.
- 9 studies were found which referenced the experience of WFDs in dementia. It is noted that none of these studies were designed to elicit the views of PLWD or assess their experiences of WFDs. However, these experiences were either observed or commented upon in the body of text.

APPENDIX C: Narrative Analysis Questions

Areas of Focus:

- Content (Key narratives)
- Context
- Performance
- Interactions between the participant and researcher

Questions to consider for analysis:

- What is being said?
- How is the narrator trying to communicate their story?
- What is the story designed to do? What is being performed? Why? - What other stories are being drawn upon?
- What cultural and socio-psychological influences are acting upon the narrator and the researcher?
- In what context is the narrative placed?
- How is the narrator constructing their identity? Does the researcher do anything to uphold or oppose this?
- What is being forgotten/excluded?
- What big and small stories are being repeated?
- In which ways has the researcher contributed to the narrative?
- If a family member was present, in which ways did they contribute to the narrative
- How do the researcher’s responses (verbal and non-verbal) support or dismiss attempts to share both big and small stories?
- What resources is the PLWD using to tell their story?
- When the PLWD experience WFDs, what other modes of communication do they use? How do these support storytelling?
- How does the researcher respond to non-verbal communicative attempts? Does the researcher dismiss these attempts or respond to them?
- Given the professional power held by the researcher, consider the possibilities that certain stories are being told for other functions other than expressing the self and identity, for example, to receive support from a professional?

APPENDIX D: Sample Analysis Excerpt

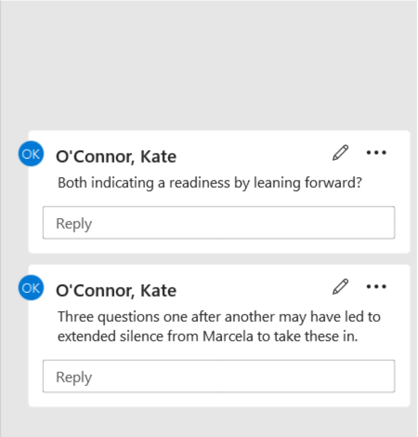
Green: NVC of researcher

Blue: NVC of participant

Kate Are you ok to go ahead?

Marcela: Yes *(Marcela has hands crossed facing towards their body. They are leaning forward towards Kate and nodding while Kate speaks)*

Kate: *(Kate has hands on table moving while talking. Leaning slightly forward)* So. We spoke a little bit earlier about your experiences with WFDS and dementia or memory loss. What terms do you prefer? Do you prefer to call it memory loss? Do you use the word 'dementia'? *(Marcela has hands crossed facing towards their body. They are leaning forward towards Kate and nodding while Kate speaks).*


O'Connor, Kate

Both indicating a readiness by leaning forward?

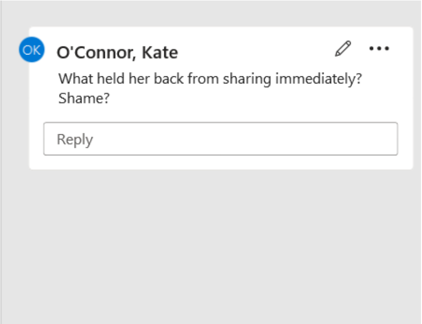
O'Connor, Kate

Three questions one after another may have led to extended silence from Marcela to take these in.

Marcela: (…) I don't really mention this::: word (dementia) *(Kate nods their head). I* ***(.)*** *I, recently tell people that I lost memory*

Kate: Memory, OK. So, will I **<**use tha..? **/>**

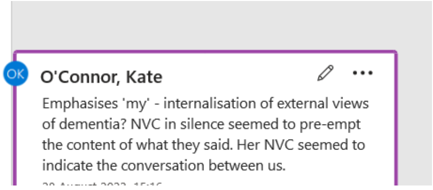
Marcela: **<**So I think it sink in**>** (*Marcela uses their right hand to gesture towards their head and their hand then moves to their chest in a single movement. They then cross their arms to return to same position as earlier) (Kate nods head up and down while Marcela is speaking and hands now interlocked on table)*


O'Connor, Kate

What held her back from sharing immediately? Shame?

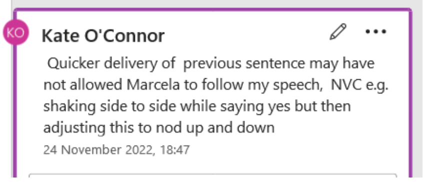
Kate: °OK° so will we use memory loss instead?

Marcela: Yes, that is what I use. **(…)** *(Marcela in this silence uses their hand which is opened with palms facing upwards to gesture towards me and back to themselves three times).* When I tell someone my: problem **(…)** I try to say **(.)** eh memory loss


O'Connor, Kate

Emphasises 'my' - internalisation of external views of dementia? NVC in silence seemed to pre-empt the content of what they said. Her NVC seemed to indicate the conversation between us.

Marcela: **<**Yes**>** (*Marcela nods their head sideways and then up and down*)


Kate O'Connor

Quicker delivery of previous sentence may have not allowed Marcela to follow my speech, NVC e.g. shaking side to side while saying yes but then adjusting this to nod up and down

24 November 2022, 18:47

APPENDIX E: Transcription Conventions

(.) Pause or silences

(…) extended pauses or silences

underline Underlining used to mark words or syllables which are given special emphasis of some kind

bold Words or parts of words spoken loudly marked in bold

˚ ˚ Encloses talk which is produced quietly

s::: Sustained or stretched sound; the more colons, the longer the sound

(Laugh) Non-verbal communication, used alongside verbal communication or in silences,

[Inaudible] Inaudible

cu- Cut-off word or sound

... Lines or words of transcript have been excluded

<[K]: text> Brief interjection/overlapping talk

(↑) Marks high pitch

/ Interruption

>>> Marks speeding up delivery

<<< Marks slowing down of delivery

[19-23] Transcription line numbers

APPENDIX F: Amended Ethics Application Form

UNIVERSITY OF EAST LONDON

School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL

FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

(Updated October 2021)

FOR BSc RESEARCH;

MSc/MA RESEARCH;

PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

Section 1 – Guidance on Completing the Application Form
(please read carefully)

1.1	Before completing this application, please familiarise yourself with: ▪ British Psychological Society's Code of Ethics and Conduct ▪ UEL's Code of Practice for Research Ethics ▪ UEL's Research Data Management Policy ▪ UEL's Data Backup Policy
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will look over your application and provide feedback.
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for review.
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection must **NOT** commence until your ethics application has been approved, along with other approvals that may be necessary (see section 7).
1.5	Research in the NHS: ▪ If your research involves patients or service users of the NHS, their relatives, or carers, as well as those in receipt of services provided under contract to the NHS, you will need to apply for HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of Psychology for ethical clearance. ▪ Useful websites:

	https://www.myresearchproject.org.uk/Signin.aspx https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/ ▪ If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required. ▪ HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example. ▪ The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
1.6	If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login You may also find the following website to be a useful resource: https://www.gov.uk/government/organisations/disclosure-and-barring-service
1.7	Checklist, the following attachments should be included if appropriate: ▪ Study advertisement ▪ Participant Information Sheet (PIS) ▪ Participant Consent Form ▪ Participant Debrief Sheet ▪ Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5) ▪ Permission from an external organisation (see section 7) ▪ Original and/or pre-existing questionnaire(s) and test(s) you intend to use ▪ Interview guide for qualitative studies ▪ Visual material(s) you intend showing participants

Section 2 – Your Details

2.1	**Your name:**	**Kate O'Connor**
2.2	**Your supervisor's name:**	**Dr. Maria Castro**
2.3	**Name(s) of additional UEL supervisors:**	**Dr. Lorna Farquharson**
		3rd supervisor (if applicable)
2.4	**Title of your programme:**	**Professional Doctorate in Clinical Psychology**
2.5	**UEL assignment submission date:**	**23/05/2022**
		Extension being applied for

Section 3 – Project Details		
Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.		
3.1	**Study title:** Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	Stories of people with dementia who experience word-finding difficulties.
3.2	**Summary of study background and aims (using lay language):**	This study aims to address several issues. In part this will involve recognising and privileging symbolic and/or non-verbal expression in the stories of people with dementia and word-finding difficulties (Hyden, 2013). The term word-finding difficulty (WFD) is a term often volunteered by people with dementia (PWD) and their carers to describe impaired language output (Rohrer et al., 2008) and are present in many types of dementia. WFDs are likely to increase over time presenting growing challenges for the person (Nebes, Brady, & Huff, 1989). It is estimated that 850,000 people are living with dementia in the UK (Public Health England, 2019). Cognitive stimulation therapy (CST) is the only non-pharmacological evidence-based intervention for dementias. Since 2006, CST has been recommended for use by the National Institute for Health and Clinical Excellence (2018). Approximately 90% of memory clinics in the UK offer CST (Royal College of Psychiatrists, 2016). A systematic review has shown that CST can improve cognition, wellbeing, and quality of life, amongst other benefits (Woods, Aguirre, Spector, & Orrell, 2012). Holden, Stoner, and Spector (2020) reviewed the inclusion and exclusion criteria for CST in memory clinics across the UK and found that 49 of 50 services cited communication difficulties as a reason for excluding PWD from the intervention. The British Psychological Society (2018) called on clinical psychologists to improve access to psychological therapies and services for people with dementia. The stories told by participants in this study may provide knowledge of ways in which psychologists and the services they work in can improve access to therapies at all stages of the dementia care pathway. It is hoped that these stories may provide us with information relevant to clinical psychology and provision

		of care for people with dementia and word-finding difficulties.
3.3	**Research question(s):**	What stories are told by people with WFD in dementia?
3.4	**Research design:**	The research is qualitative and will use a narrative framework to guide data collection and analysis.
3.5	**Participants:** Include all relevant information including inclusion and exclusion criteria	Those who have a dementia diagnosis and identify with having word-finding difficulties will be invited to participate in the study, if interested. The researcher notes that while a dementia diagnosis is a prerequisite for this study, that many groups may prefer to use other terms to describe dementia. Therefore, preferred terms will be used throughout communications with potential participants. Approximately four to six people will be interviewed, following informed consent being obtained. An ability to express oneself in English is an inclusion criterion to enable the researcher to carry out a thorough narrative analysis of the transcripts. There will be no exclusion based on cognitive ability, should the person wish to participate and there be no objections from their carers/relatives which follows the processural consent method, detailed below.
3.6	**Recruitment strategy:** Provide as much detail as possible and include a backup plan if relevant	Participants will be recruited through community support groups for people with dementia and/or their carers and in online forums. Initial contact with these services has been made, and permission to recruit from these services is granted, following receipt of ethical approval. Should the recruitment take place in person, the researcher plans to provide a brief overview of the study at the end of these support groups alongside information sheets to those interested, there will also be posters available on site. The proposed poster has been attached alongside the information sheet. The information sheet will be adapted visually to align with the poster and make the information easier to read, in line with guidelines by Allan (2001), although the written content will remain the same. In the online forum, the researcher will post an advertisement for the study and include the proposed poster.
3.7	**Measures, materials, or equipment:** Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	The researcher requires a video recorder for face-to-face interviews, alongside a locked backpack to transport the recordings, signed consent forms etc. until they are uploaded to UEL's One Drive for Business. The researcher will keep an anonymised, confidential field diary as per informed consent procedure.

3.8	**Data collection:** Provide information on how data will be collected from the point of consent to debrief	If there are no objections from carers/staff, those who express interest in the study will be invited to meet with the researcher to discuss the study further. The participants in this study are classed as vulnerable adults, therefore, the process of informed consent is seriously considered. The processural consent method (Dewing, 2007; Hughes & Castro-Romero; 2015) is consistent with the Mental Capacity Act (2005) which will aid potential participants to make their own decisions and will be used as a framework to guide the consenting process within this study. A diagnosis of dementia does not necessarily indicate a lack of capacity to consent, as capacity to consent is largely contextual and dependent on the complexity of the information provided to the PWD (MCA, 2005; Dewing, 2007). The processural consent method (Hughes & Castro-Romero, 2015) is reliant on the researcher's critical reflection and skills to interact with the PWD, which in this proposal is supported by the researcher's relevant clinical experience in working with PWD in NHS dementia services and dementia research over the course of four years. The researcher will keep anonymised, confidential field notes to document the consenting process with potential participants. Potential participants will be given the opportunity to meet with the researcher to ask any questions they may have prior to making a decision. The participant will be informed of their right to withdraw consent, at any point. Those who are deemed to have the capacity to consent will be asked to complete the participant consent forms. Rather than obtain proxy consent on behalf of participants, carers will be provided with copy of the information sheet and asked for written indication whether they know of any reason why their relative would object to discussing the research or participating. In the absence of a relative involved in the care of the person with dementia, the researcher may consult with staff to understand the usual ways the person would communicate consent or non-consent and record evidence of such in their field notes. This method will allow carers or staff to raise any concerns they have about their loved one's participation, which will be considered as part of the informed consent process. There are two consent forms, one for participants who have the capacity to make a decision regarding the study and one for carers of those who may lack capacity to make this decision. Interviews will be

		video recorded as this may add richness to the stories of people with dementia and WFDs as non-verbal communication and gestures can also be documented (Hyden, 2013). Interviews will be video recorded If they take place in person or recorded via Microsoft Teams if they take place remotely. While the telling of stories through digital means can be rewarding for people with dementia it does present additional challenges as PWD have increased difficulties in accessing technology. The latest research or guidelines on communicating with PWD via online platforms will be consulted closer to the time of data collection and relevant adaptations will be made. Those who consent to the study will be invited to bring any aids or objects e.g., photos which the feel would support them to tell their story. Interviews will be conducted with those who provided informed consent and may last up to one hour. The researcher will provide pens/markers and paper should the person wish to write or draw responses if they are experiencing significant WFDs. The interviews will entail conversations following a conversational prompt to elicit the stories of the person with dementia and word-finding difficulties. While there are no formalised questions as part of this interview, a suggested interview schedule is provided at the end of this document and will include suggested ways of introducing/setting up the conversation and ending the interview and transitioning to the debriefing process. The researcher has previously worked with PWD and will provide summaries and reflections to check their understanding of continued interpretations. Additionally, gentle reminders and reassurance will be provided, if requested or required by the participant to minimise potential distress. In the interviews, the researcher will observe verbal and non-verbal cues for indicators of distress, agitation, or confusion etc. When these signs are witnessed, the researcher will ask the participant if they would like to continue the interview, have a break, or reschedule for another time. They will be reminded about their right to withdraw. After the interview, there will be time for the person to ask questions or raise any concerns they may have. A debrief letter will also be provided. The researcher will also keep confidential, anonymised field notes to support interpretation of the data. It is also important to note that prior to face-to-face interviews, the researcher will take a lateral flow

		test and ensure that distance is maintained throughout the interview, if advised by government guidelines. In addition, the researcher will bring medical masks and wear these if requested by the participant.	
3.9	**Will you be engaging in deception?**	**YES** ☐	**NO** ☒
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	If you selected yes, please provide more information here	
3.10	**Will participants be reimbursed?**	**YES** ☐	**NO** ☒
	If yes, please detail why it is necessary.	If you selected yes, please provide more information here	
	How much will you offer? Please note - This must be in the form of vouchers, not cash.	Please state the value of vouchers	
3.11	**Data analysis:**	A constructionist approach to narrative analysis provides the researcher with useful tools to understand the range and levels involved in stories, instead of handling those stories merely as clear and unified entities (Esin et al., 2013); this analysis appears to be congruent with epistemological stance and the research question.	

Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

If a Research Data Management Plan (RDMP) has been completed and reviewed, information from this document can be inserted here.

4.1	**Will the participants be anonymised at source?**	**YES** ☐	**NO** ☒
	If yes, please provide details of how the data will be anonymised.	Please detail how data will be anonymised	
4.2	**Are participants' responses anonymised or are an anonymised sample?**	**YES** ☒	**NO** ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during transcription, pseudonyms used, etc.).	Interviews will be recorded via video recorder in person or via Microsoft Teams if the interview takes place remotely. Participant data will be pseudonymised at the point of transcription. An anonymisation log will be created in a password protected Excel file and uploaded to UEL's OneDrive for Business, then deleted from the	

		laptop. This file will be kept in a separate folder to the recordings and transcriptions etc. Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g., names, day centre locations, job location, identifiable scenarios) anonymised in the transcripts. Interviews that are recorded on Microsoft Teams will be auto transcribed. The auto-transcriptions will be reviewed and edited by the researcher in Microsoft Word, and then uploaded to UEL's OneDrive for Business and deleted from the laptop. Printed and electronic consent forms will be used to document consent. If paper format, these will be transported securely in a backpack with a lock and stored in a locked room in the researcher's private residence until these can be scanned and uploaded to UEL's OneDrive for Business. Following this, the paper copies will be shredded and disposed of in a confidential waste bin. Consent forms e-mailed will be uploaded to UEL's OneDrive for Business and deleted from email inbox.
4.3	**How will you ensure participant details will be kept confidential?**	As conversations will be video recorded, it will be ensured that these are stored securely on UEL's OneDrive for Business. When the recordings are transcribed, names and any identifiable information will be removed to ensure anonymity. The researcher will maintain confidentiality within the limits of their ethical obligations throughout the study. Confidentiality will be broken if the researcher has concerns about the safety of a participant or others. This will then be brought to discussions with the researcher's supervisor and relevant safeguarding procedures followed, if necessary. Every effort will be made to keep the PWD informed of this process. This will be communicated in the information sheet.
4.4	**How will data be securely stored and backed up during the research?** Please include details of how you will manage access, sharing and security	If the interviews take place in person, the video (with accompanying audio) recordings of interviews will be transferred from the researcher's recording device onto the researcher's private laptop immediately after the interview and saved onto the researcher's personal drive on UEL OneDrive for Business. Any copies on the researcher's private laptop will be deleted. Microsoft Teams recordings will be stored on the Stream Library, a backup will be stored on UEL's OneDrive for Business, and any files downloaded to the researcher's laptop will be deleted. Each audio/video file will be saved with the date on interview. Each participant will be assigned a participant number in chronological order of their

		interview date. This number will be assigned to their transcripts, when saved. Transcripts will be stored on UEL's OneDrive for Business and copies deleted from the researcher's private laptop. No list of names linking the participant numbers with identifiable information will be stored on the researcher's laptop. These labelled recordings will then be transferred to the researcher's private laptop and uploaded immediately to UEL's OneDrive for Business and recordings will then be deleted from the laptop. Video recordings will only be viewed on the laptop during transcription. Otherwise, recordings will be stored on UEL's OneDrive for Business. The consent forms will be scanned and uploaded to UEL's OneDrive for Business. Paper versions of consent forms will then be shredded and destroyed, and electronic versions will be uploaded to UEL's OneDrive for Business and deleted from the laptop. Data will be uploaded to the researcher's OneDrive account on the UEL server. Scanned consent forms will be saved in a separate folder on OneDrive to other research data. Once data have been backed up on UEL servers it will be deleted the laptop. Video/audio files will only be accessible to the researcher and anonymised transcripts will be available to their supervisor and examiners. The supervisor will be given access to the transcripts on UEL's OneDrive for Business via a secure link.	
4.5	**Who will have access to the data and in what form?** (e.g., raw data, anonymised data)	The raw data will only be accessible to the researcher. Anonymised transcripts will be shared with the supervisor via secure links on OneDrive. Excerpts from anonymised interviews will be included in the thesis and resulting dissemination. However, no full transcripts will be available via the UEL repository	
4.6	**Which data are of long-term value and will be retained?** (e.g., anonymised interview transcripts, anonymised databases)	Anonymised transcripts will be kept to support dissemination of the research.	
4.7	**What is the long-term retention plan for this data?**	Following completion of studies, transcripts will be deleted from the researcher's OneDrive for Business, and these will be transferred to an encrypted folder on the researcher's private password-protected folder and kept for up to three years.	
4.8	**Will anonymised data be made available for use in future research by other researchers?**	**YES** ☐	**NO** ☒

	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐
4.9	**Will personal contact details be retained to contact participants in the future for other research studies?**	**YES** ☐	**NO** ☒
	If yes, have participants been informed of this?	**YES** ☐	**NO** ☐

Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with 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.

5.1	**Are there any potential physical or psychological risks to participants related to taking part?** (e.g., potential adverse effects, pain, discomfort, emotional distress, intrusion, etc.)	**YES** ☒	**NO** ☐
	If yes, what are these, and how will they be minimised?	There is the potential for some distress if the subject matter is upsetting, however, researcher will use their clinical experience of working with people with dementia to check in with verbal and non-verbal cues that the person is experiencing distress and the interview will be paused to check if the person still wants to continue, they will be reminded of right to withdraw. A debriefing conversation will take place with the researcher after the interview. Should there be a risk indicated to the participant or others, relevant parties will be informed to ensure their safety, in line with their best interests according to MCA (2005).	
5.2	**Are there any potential physical or psychological risks to you as a researcher?**	**YES** ☒	**NO** ☐
	If yes, what are these, and how will they be minimised?	If disclosure of information which would indicate risk to person, the impacts of this on the researcher would be minimised by conversations with the research supervisor.	
5.3	**If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that**	**YES** ☒	

	you have attached a GRA form as an appendix:			
5.4	**If necessary, have appropriate support services been identified in material provided to participants?**	**YES** ☒	**NO** ☐	**N/A** ☐
5.5	**Does the research take place outside the UEL campus?**	**YES** ☒	**NO** ☐	
	If yes, where?	In private rooms booked through local community organisations.		
5.6	**Does the research take place outside the UK?**	**YES** ☐	**NO** ☒	
	If yes, where?	Please state the country and other relevant details		
	If yes, in addition to the General Risk Assessment form, a Country-Specific Risk Assessment form must also be completed and included (available in the Ethics folder in the Psychology Noticeboard). Please confirm a Country-Specific Risk Assessment form has been attached as an appendix. Please note - A Country-Specific Risk Assessment form is not needed if the research is online only (e.g., Qualtrics survey), regardless of the location of the researcher or the participants.	**YES** ☐		
5.7	**Additional guidance:** ▪ For assistance in completing the risk assessment, please use the AIG Travel Guard website to ascertain risk levels. Click on ‘sign in’ and then ‘register here’ using policy # 0015865161. Please also consult the Foreign Office travel advice website for further guidance. ▪ For on campus students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Director of Impact and Innovation, Professor Ian Tucker (who may escalate it up to the Vice Chancellor). ▪ For distance learning students conducting research abroad in the country where they currently reside, a risk assessment must also be carried out. To minimise risk, it is recommended that such students only conduct data collection online. If the project is deemed low risk, then it is not necessary for the risk assessment to be signed by the Director of Impact and Innovation. However, if not deemed low risk, it must be signed by the Director of Impact and Innovation (or potentially the Vice Chancellor).			

	▪ Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

Section 6 – Disclosure and Barring Service (DBS) Clearance

6.1	**Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)?** If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project	**YES** ☒	**NO** ☐
	* You are required to have DBS or equivalent clearance if your participant group involves: (1) Children and young people who are 16 years of age or under, or (2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or 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 with your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible.		
6.2	**Do you have DBS or equivalent (for those residing in countries outside of the UK) clearance to conduct the research project?**	**YES** x	**NO** ☐
6.3	**Is your DBS or equivalent (for those residing in countries outside of the UK) clearance valid for the duration of the research project?**	**YES** x	**NO** ☐
6.4	**If you have current DBS clearance, please provide your DBS certificate number:**	**REDACTED**	
	If residing outside of the UK, please detail the type of clearance and/or provide certificate number.	Please provide details of the type of clearance, including any identification information such as a certificate number	
6.5	**Additional guidance:** ▪ If participants are aged 16 or under, you will need two separate information sheets, consent forms, and debrief forms (one for the participant, and one for their parent/guardian).		

	- For younger participants, their information sheets, consent form, and debrief form need to be written in age-appropriate language.

Section 7 – Other Permissions

7.1	**Does the research involve other organisations (e.g., a school, charity, workplace, local authority, care home, etc.)?**	**YES** ☒	**NO** ☐
	If yes, please provide their details.	**NAMES REDACTED** both provided permission to recruit from their services, following receipt of ethical approval. E-mails with these organisations are included as attachments.	
	If yes, written permission is needed from such organisations (i.e., 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). Please confirm that you have attached written permission as an appendix.	**YES** ☒	
7.2	**Additional guidance:** - Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as ‘my’ or ‘I’ with ‘our organisation’ or with the title of the organisation. This organisational consent form must be signed before the research can commence. - If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC 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.		

Section 8 – Declarations

8.1	**Declaration by student. I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor:**	**YES** ☒
8.2	**Student's name:** (Typed name acts as a signature)	Kate O’Connor

8.3	**Student's number:**	U1945522
8.4	**Date:**	11/02/2022
Supervisor's declaration of support is given upon their electronic submission of the application		

I: Participant Consent Form

Participant Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Stories of people with dementia who experience word-finding difficulties

	Please initial
I confirm that I have read the participant information sheet for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data from the study.	
I understand that the interview will be recorded using a computer programme called Microsoft Teams or an audio/video recorder.	
I understand that my personal information and data, including audio/video recordings from the research will be securely stored and remain confidential, as far as is possible. Only the research team will have access to this information, to which I give my permission.	
Where possible, participants' confidentiality will be maintained unless a disclosure is made that indicates that the participant or someone else is at serious risk of harm. Such disclosures may be reported to the relevant authority.	
It has been explained to me what will happen to the data once the research has been completed.	
I understand that short, anonymised quotes from my interview may be used in material such as conference presentations, reports, articles in academic journals resulting from the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant’s Name (BLOCK CAPITALS)

…………………………………………………………………………………………………

Participant’s Signature

…………………………………………………………………………………………………

Researcher’s Name (BLOCK CAPITALS)

…………………………………………………………………………………………………

Researcher’s Signature

…………………………………………………………………………………………………

Date

……………………..………………………………………………………………………….

II: Carer/relative consent forms

Form for Carers or Relatives

-

UNIVERSITY OF EAST LONDON

Research study: Stories of people with dementia who experience word-finding difficulties.

Please fill in your name (BLOCK CAPITALS)

……………………………………………………………………………………

Please fill in the name of the person who is interested in the study (BLOCK CAPITALS)

……………………………………………………………………………………

What is your relationship to the person who would like to participate in the study?

…………………………………………………………………………………..

Please answer the questions by ticking either yes or no.

I have been given a copy of the information sheet given to my relative about the project and have had the opportunity to read this.

YES ☐

NO ☐

I understand that I can ask for questions or for more information from Kate.

YES ☐

NO ☐

I confirm that I do not know of any reason why my relative would object to being approached to take part in the project.

YES ☐

NO ☐

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

YES ☐

NO ☐

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

YES ☐

NO ☐

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

YES ☐

NO ☐

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

Signature.. Date......................................

Thank you for your time. It is greatly appreciated.

III: Participant Debrief Sheet

PARTICIPANT DEBRIEF LETTER

Thank you for participating in my research study which explores the stories of people with dementia who experience word-finding difficulties. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided:

- All of the information you provide will be kept safe on a secure online platform called OneDrive.
- The only person who has access to these recordings is the researcher. The recordings of our conversations will be stored securely in a password-protected folder on this online platform which will be accessible only to the researcher.
- The researcher will then produce an anonymised written record of the conversation. This means that the researcher will not reveal your name when writing about our conversation.
- Once the researcher has a written record of the video recording, it will be deleted. This will be no later than six months after our conversation.
- The researcher will keep anonymous notes of all her contact with people involved in the research. These notes may only be seen by the researcher, their supervisors, and exam board.
- The anonymised records will be kept for up to three years as they may be used to write summaries of this research to share with others, for example, a journal article may be written.

- This summary might include some of the things you have said in the conversation with the researcher but it will not refer to your name or any information which could identify you.

- Given the above, you may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

Your Memory Service: (to be filled in by researcher and participant after interview).

Telephone:
E-mail:

AGE UK

Website: www.ageuk.org.uk

Telephone number: **0800 678 1602**. It is free to call 8am – 7pm 365 days a year

Your local AGE UK (to be filled in by researcher and participant after interview):

Telephone:

E-mail:

Alzheimer’s Society:

Website: www.alzheimers.org.uk

General Enquiries; **0330 333 0804** available 8am to 10pm every day (except Christmas Day).

Dementia support: **0333 150 3456** available 8am to 10pm every day (except Christmas Day).

Silver Line:

The Silver Line is the only free confidential helpline providing information, friendship and support to older people, open 24 hours a day, every day of the year. Call anytime on

0800 4 70 80 90

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Name: Kate O'Connor
E-mail: u1945522@uel.ac.uku1945522@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor Dr. Maria Castro. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: m.castro@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email:t.patel@uel.ac.uk)

IV: General Risk Assessment Form template

UEL Risk Assessment Form

Name of Assessor:		**Date of Assessment**	**08.02.22**
Activity title:	**Research interviews**	**Location of activity:**	**Local community organisations**
Signed off by Manager (Print Name)		**Date and time (if applicable)**	

Please describe the activity/event 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 and last for up to one hour with a person with dementia and their carer, if relevant. These interviews will take place in local community organisations through which recruitment is taking place.

Overview of FIELD TRIP or EVENT:

Interviews conducted in local community organisations with participants and carers.

Hazards attached to the activity

Hazards identified	Who is at risk?	Existing Controls	Likelihood	Severity	Residual Risk Rating (Likelihood x Severity)	Additional control measures required (if any)	Final risk rating
Use of camcorder and tripod may increase risk of trips/falls	Researcher /participant/ carer	Tripod is set-up after participant is seated safely and located beside the researcher to minimise trips hazard.	1	2	2		2
Conducting interviews in unfamiliar settings may mean researcher is unfamiliar with layouts/exits etc.	Researcher/ participant/ carer	To ensure that the researcher discusses the plans for emergencies on site and is shown the exit routes, in case of emergency	1	1	1		1

Potential distress arising from discussing potentially upsetting subjects	Researcher/ participant/ carer	Risk management will always be discussed with supervisor. A debriefing letter is provided to each participant and discussed with the researcher. Clinical experience of the researcher will support decision making in relation to risk.	2	2	4	Should any risk issues arise, the researcher will use their clinical judgement and also liaise with their supervisor to ensure the participant is directed to the correct supports and signposted appropriately. Relevant people involved in the person's care will also be informed if any risk is indicated.	4
Potential distress to the researcher from hearing upsetting stories	Researcher	The researcher works in the NHS in mental health settings and is familiar with risk procedures and management. While some subject matter may be upsetting this is not outside the researcher's profession and they have mechanisms in place to manage this.	1	1	1		1
Slip or trip hazard due to posters, information sheets etc. falling	Researcher/ participant/ carer	Be vigilant on the day to make sure that all stray papers etc. are picked up off the floor.	2	1	2	Regular monitoring when on sites advertising study.	1

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)	3-4 = 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)

APPENDIX G: Ethical Approvals: Original and Amended

University of East London

School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details

Reviewer:	**James Walsh**
Supervisor:	**Dr Maria Castro/Dr Lorna Farquharson**
Student:	**Kate O'Connor**
Course:	**Prof Doc in Clinical Psychology**
Title of proposed study:	**Stories of people with dementia who experience word-finding difficulties**

Checklist

(Optional)

	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)	☐	☒	☐
Detailed account of participants, including inclusion and exclusion criteria	☒	☐	☐
Concerns regarding participants/target sample	☐	x	☐

Detailed account of recruitment strategy	☒	☐	☐
Concerns regarding recruitment strategy	☐	x	☐
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	☒	☐	☐
Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	x	☐	☐
Clear and detailed outline of data collection	☒	☐	☐
Data collection appropriate for target sample	x	☐	☐
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point	☐	☐	☒
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	☒	☐	☐
Concerns regarding data storage (e.g., location, type of data, etc.)	☐	☒	☐
Concerns regarding data sharing (e.g., who will have access and how)	☐	☒	☐
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)	☐	☒	☐
If required, General Risk Assessment form attached	x	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	x	☐	☐
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	☒	☐	☐
If required, Country-Specific Risk Assessment form attached	☐	☐	☒
If required, a DBS or equivalent certificate number/information provided	☒	☐	☐
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	☒	☐	☐
All relevant information included in the participant information sheet (PIS)	☒	☐	☐
Information in the PIS is study specific	☒	☐	☐
Language used in the PIS is appropriate for the target audience	☒	☐	☐
All issues specific to the study are covered in the consent form	☒	☐	☐
Language used in the consent form is appropriate for the target audience	☒	☐	☐
All necessary information included in the participant debrief sheet	☒	☐	☐
Language used in the debrief sheet is appropriate for the target audience	☒	☐	☐
Study advertisement included	☒	☐	☐
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	☒	☐	☐

Decision options

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.
APPROVED - BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES	In this circumstance, 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 at the end of this form once all amendments have been attended to and emailing a copy of this decision notice to the supervisor. The supervisor will then forward the student's confirmation to the School for its records. **Minor amendments guidance:** typically involve clarifying/amending information presented to participants (e.g., in the PIS, instructions), further detailing of how data will be securely handled/stored, and/or ensuring consistency in information presented across materials.
NOT APPROVED - MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED	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. **Major amendments guidance:** typically insufficient information has been provided, insufficient consideration given to several key aspects, there are serious concerns regarding any aspect of the project, and/or serious concerns in the candidate's ability to ethically, safely and sensitively execute the study.

Decision on the above-named proposed research study

Please indicate the decision:	APPROVED

Minor amendments

Please clearly detail the amendments the student is required to make

Major amendments
Please clearly detail the amendments the student is required to make

Assessment of risk to researcher		
Has an adequate risk assessment been offered in the application form?	**YES** ☒	**NO** ☒
	If no, please request resubmission with an **adequate risk assessment.**	
If the proposed research could expose the researcher to any kind of emotional, physical or health and safety hazard, please rate the degree of risk:		
HIGH	Please **do not approve a high-risk** application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.	☐
MEDIUM	Approve but include appropriate recommendations in the below box.	☐
LOW	Approve and if necessary, include any recommendations in the below box.	☒
Reviewer recommendations in relation to risk (if any):	Please insert any recommendations	

Reviewer’s signature

Reviewer: (Typed name to act as signature)	**James Walsh**
Date:	**11/04/2022**

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology 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 Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL’s Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

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

Student name: (Typed name to act as signature)	Please type your full name
Student number:	Please type your student number
Date:	Click or tap to enter a 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

School of Psychology Ethics Committee

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

For BSc, MSc/MA and taught Professional Doctorate students

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology

Note that approval must be given for significant change to research procedure that impact on ethical protocol. If you are not sure as to whether your proposed amendment warrants approval, consult your supervisor, or contact Dr Trishna Patel (Chair of School Ethics Committee).

How to complete and submit the request

1	Complete the request form electronically.
2	Type your name in the 'student's signature' section (page 2).
3	When submitting this request form, ensure that all necessary documents are attached (see below).
4	Using your UEL email address, email the completed request form along with associated documents to Dr Trishna Patel: t.patel@uel.ac.uk
5	Your request form will be returned to you via your UEL email address with the reviewer's decision box completed. Keep a copy of the approval to submit with your dissertation.
6	Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

Required documents

A copy of your previously approved ethics application with proposed amendment(s) added with track changes.	**YES** ☒
Copies of updated documents that may relate to your proposed amendment(s). For example, an updated recruitment notice, updated participant information sheet, updated consent form, etc.	**YES** ☒
A copy of the approval of your initial ethics application.	**YES** ☒

Details

Name of applicant:	**Kate O'Connor**
Programme of study:	**Professional Doctorate in Clinical Psychology**
Title of research:	**Stories of people with dementia who experience word-finding difficulties.**
Name of supervisor:	**Dr. Lorna Farquharson**

Proposed amendment(s)

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Change to photograph, minor structural changes, and changes to the wording of the information sheet. Provide the option of a black and white information sheet also. (Appendix A, p.16)	I attended a dementia cafe and lunch club. Based on my interactions with service users when discussing the study, they provided feedback about the information sheets and posters which could make them more appropriate to the population group. I wrote down these suggested changes. Service users generally suggested some changes to the wording and a desire for the information to be more concise and clear. As per my previous ethical approval, I had stated I would change the background and layout of the information sheet at a later date to be similar to the poster, which was included for reference. However, I would like to make minor amendments to the content to respond to service users comments. Some of the amendments include changing 'participate' to 'take part' removing referring to my name in the document and saying 'I' instead, changing the wording to refer to 'people living with dementia' rather than 'people with dementia'. Some headings were also changed to be more straightforward. As it is a PDF file, I included it in the document as changes to it were made on Canva which could not be tracked in Word.
Change to photograph and wording of poster (Appendix E, p. 35)	As above
Proposed amendment	Rationale for proposed amendment
Proposed amendment	Rationale for proposed amendment

Confirmation

Is your supervisor aware of your proposed amendment(s) and have they agreed to these changes?	**YES** ☒	**NO** ☐

Student’s signature

Student: (Typed name to act as signature)	**Kate O’Connor**
Date:	**25/05/2022**

Reviewer’s decision

Amendment(s) approved:	**YES** ☒	**NO** ☐
Comments:	Please enter any further comments here	
Reviewer: (Typed name to act as signature)	**Trishna Patel**	
Date:	**27/05/2022**	

APPENDIX H: Field Notes – Processural Consent Example

Process stages	Notes
Permission to access	At the time of approaching in relation to the study, **NAME REDACTED** and I had met on two occasions as part of the Memory Café and had had several interactions before this conversation and I also joined in in activities as part of the dementia café and also ate lunch with several attendees as part of their lunch club. This meant that I had had several informal interactions with them prior to speaking with him about the study. Previously, staff had identified them as someone who would be good to speak to as they have noticed he experienced word-finding difficulties and felt that he may be interested in contributing to research. Staff had no concerns about **NAME REDACTED** or capacity to communicate preferences. They lives with a friend and have one sibling, but they are rarely in touch, therefore, no relatives or carers were contacted regarding consent. However, upon observing and interacting with **NAME REDACTED** as part of the group, I monitored usual ways of consenting and also spoke to staff about this.
Usual way of consenting – speak to staff, relatives	Staff felt that **NAME REDACTED** could communicate their wishes verbally although sometimes as he struggles to find the right words they would sometimes use gestures to indicate agreement or disagreement e.g., nodding, shaking their head, using hands to 'shoo' away if they did not wish to have some of the food on offer. **NAME REDACTED** seemed well engaged with others in conversation and used a combination of verbal and non-verbal ways of communicating. Throughout our initial interactions, I did not have concerns about their ability to consent or to express their wishes.

Initial consent meeting	**NAME REDACTED** and I met over two occasions for consenting. The initial meeting took place after the Memory Café and we went through the information sheet together and went through any questions they had. As part of this conversation, I showed **NAME REDACTED** the camera and audio recorder as they were interested in seeing these and how they work before they consented to interview. **NAME REDACTED** also told me how they found their experience of WFDs a challenge especially as there was nothing on offer through the NHS to support with this. We spoke about meeting again the following week to revisit the conversation and they said that "for now it is a yes (to participating)", I let them know that they could change their mind by next week and that it would be no problem. The following week, I returned to the lunch club and was sat at a different table to NAME REDACTED he initiated contact by gesturing me over to the table, and I went to have a chat. **NAME REDACTED** told me they would like to participate, and we arranged a time that day that would suit. This was before the music session so that they could still participate in this. **NAME REDACTED** and I met in a private room on site, and we went through the consent forms together. When we got to question 4 "I understand that if I withdraw from the study, my data will not be used" – they said they wanted me to use their story for research so that the situation for PLWD could improve. I again showed them the video and audio recorder which I set up on a tripod – I did a practice recording so that they could see how it worked. This was then deleted straight away.
Ongoing consent monitoring	Before our meeting, we agreed a gesture to use during the interview should they wish to stop or not be able to find the word. In the interview, I also monitored for signs of distress. For example, on one occasion they spoke about their experience of caring for their father which was upsetting – I asked whether they needed a break or would like to

	stop. However, they indicated they comfortable to continue the conversation.
Consent upon completion	After we finished the interview, **NAME REDACTED** and I chatted about how they found the process and what their thoughts were about allowing their data to be used now that the interview had been completed. They indicated that they were happy for me to use our interview for analysis and would like me to come back to the service again with a summary of the findings. I also will be attending the memory café again on 3-4 occasions, this will give **NAME REDACTED** and opportunity to discuss the study again if they wish.
Consent to collect group level demographics	Provided – I also reminded **NAME REDACTED** that acronyms would be used throughout the study and any identifying information would be removed.
Feedback	**NAME REDACTED** would welcome a short summary of the findings would be welcomed, I will return to the centre following analysis and give this summary to **NAME REDACTED.**

APPENDIX I: Data Management Plan

UEL Data Management Plan

Completed plans must be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Kate O'Connor
PI/Researcher ID (e.g. ORCiD)	
PI/Researcher email	u1945522@uel.ac.uk
Research Title	Stories of people with dementia who experience word-finding difficulties.
Project ID	N/A
Research start date and duration	6 months Proposed start date December 2022

Research Description	The proposed study aims to address gaps in previous literature in accounts of people with dementia and word-finding difficulties. The proposed study will explore the narratives of people with dementia who experience word finding difficulties (WFDs). Previous research has suggested that these are seldom told. Narrative dispossession often occurs when the contributions of professionals and carers to the story results in a narrative with does not reflect the person's lifelong self-constructs. Non-verbal contributions of those with WFDs are rarely included in data collection and analyses; these communication attempts may be ways to convey important aspects of one's reality when verbal communication is hindered. Thus, much research has not accounted for the alternative strategies that people with dementia use to tell their stories when experiencing word finding difficulties. The researcher proposes a method which would allow for the verbal and non-verbal aspects of storytelling to be documented and interpreted using narrative analysis. This study aims to address these gaps by interviewing four people with dementia who experience word-finding difficulties. These interviews will be open-ended and video recorded to allow for transcription of verbal and non-verbal communication.
Funder	N/A: part of professional doctorate
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	19/08/2021

Date of last update (of DMP)	07/12/2021
Related Policies	e.g. Research Data Management Policy
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
What data will you collect or create?	It is hoped that four people with dementia who experience word-finding difficulties will be interviewed by the researcher. Interviews will be up to one-hour long and open-ended. All interviews will be audio/video recorded and transcribed by the researcher. Transcriptions in Microsoft Word format only Video recordings will be saved in .mp4 format for both Microsoft Teams and video recordings. Personal data will be collected on consent forms (names) and prior to the interview (email address and/or telephone number for purposes of arranging the interview, via the researcher's UEL email address). Video recordings will contain identifiable information; however, the researcher has developed procedures to ensure these are only accessible to the researcher when transcribing the data. No further data will be created in the process of analysing the transcripts.

How will the data be collected or created?	Interviews will be recorded via video recorder in person or via Microsoft Teams if the interview takes place remotely. Participant data will be pseudonymised at the point of transcription. Each participant will be given a participant number in chronological order of their interview date. All identifiable information (e.g. names, day-centres, locations, identifiable scenarios) will be anonymised in the transcripts. Interviews will be recorded on Microsoft Teams and will be auto-transcribed. The auto-transcriptions will be reviewed and edited by the researcher in Microsoft Word, and then uploaded to UEL's OneDrive for Business and deleted from the laptop. Each participant will be given a participant number (in interview chronological order) and all identifiable information (e.g. names, day centre locations, job location, identifiable scenarios) anonymised in the transcripts. Printed and electronic consent forms will be used to document consent. If paper format, these will be transported securely in a backpack with a lock and stored in a locked room in the researcher's private residence until these can be scanned and uploaded to UEL's OneDrive for Business. Following this, the paper copies will be shredded and disposed of in a confidential waste bin. Consent forms e-mailed will be uploaded to UEL's OneDrive for Business and deleted from email inbox.
Documentation and Metadata	

What documentation and metadata will accompany the data?	- Consent forms - Information sheets for participants - Debrief forms. - Participant contact information and anonymisation process of data. An anonymisation log will be created in a password protected Excel file and uploaded to UEL's OneDrive for Business, then deleted from the laptop. This file will be kept in a separate folder to the recordings and transcriptions etc. Data and documentation files will be kept in separate folders, and folders will be organised according to research activity e.g. interviews. File names will be labelled using a brief descriptor of the content, the participant number, date, and version number, if relevant. An underscore will be used to separate elements in the file name. The formatting used will be consistent across files. No codes/themes will be created from the data collected as narrative analysis will be used.
Ethics and Intellectual Property	
Identify any ethical issues relating to the data and/or data collection and how these will be managed	The researcher has considered that limiting research to online recruitment may make it less accessible to those from lower socioeconomic backgrounds and to people who have difficulties and/or do not have support to use technology required to participate. Participants must have a reasonable level of proficiency in English, to allow the researcher to complete a comprehensive narrative

	analysis of the data; therefore, this study may be inaccessible for many PWD who access services. As participants in this study are classed as vulnerable adults, the process of informed consent is seriously considered. The processural consent method (Dewing, 2007; Hughes & Castro-Romero; 2015) is consistent with the Mental Capacity Act (2005) which will aid potential participants to make their own decisions and will be used as a framework to guide the consenting process within this study. The processural consent method (Hughes & Castro-Romero, 2015) is reliant on the researcher's critical reflection and skills to interact with the PWD, which in this proposal is supported by the researcher's relevant clinical experience in working with PWD in NHS dementia services and dementia research over the course of four years. Potential participants will be given the opportunity to meet with the researcher to ask any questions they may have prior to making a decision. The participant will be informed of their right to withdraw consent, at any point. Information sheets will be provided to carers of PWD who are interested in the study. This will allow carers to raise any concerns they have about their loved one's participation, which will be considered as part of the informed consent process (Appendix E). In the interviews, the researcher will observe verbal and non-verbal cues for indicators of distress, agitation, or confusion etc. When these signs are witnessed, the researcher will ask the PWD if they would like to continue the interview, have a break, or reschedule for another time. They will be reminded about their right to

	withdraw. After the interview, there will be time for the person to ask questions or raise any concerns they may have. A debrief letter will also be provided. As conversations will be video recorded, it will be ensured that these are stored securely on a password-protected computer in a locked room. When the recordings are transcribed, names and any identifiable information will be removed to ensure anonymity. The researcher will maintain confidentiality within the limits of their ethical obligations throughout the study. Confidentiality will be broken if the researcher has concerns about the safety of a participant or others. This will then be brought to discussions with the researcher's supervisor and relevant safeguarding procedures followed, if necessary. Every effort will be made to keep the PWD informed of this process. This will be communicated in the information sheet.
Identify any copyright and Intellectual Property Rights issues and how these will be managed	N/A
Storage and Backup	
How will the data be stored and backed up during the research?	If the interviews take place in person, the video (with accompanying audio) recordings of interviews will be transferred from the researcher's recording device onto the researcher's private laptop immediately after the interview and saved onto the researcher's personal drive on UEL OneDrive for Business. Any copies on the researcher's private laptop will be deleted. Microsoft Teams recordings will be stored on the Stream Library, a backup will be stored

	on UEL’s OneDrive for Business and any files downloaded to the researcher’s laptop will be deleted. Each audio/video file will be saved with the date on interview. Each participant will be assigned a participant number in chronological order of their interview date. This number will be assigned to their transcripts, when saved. Transcripts will be stored on UEL’s OneDrive for Business and copies deleted from the researcher’s private laptop. No list of names linking the participant numbers with identifiable information will be stored on the researcher’s laptop. These labelled recordings will then be transferred to the researcher’s private laptop and uploaded immediately to UEL’s OneDrive for Business and recordings will then be deleted from the laptop. Video recordings will only be viewed on the laptop during transcription. Otherwise, recordings will be stored on UEL’s OneDrive for Business. The consent forms will be scanned and uploaded to UEL’s OneDrive for Business. Paper versions of consent forms will then be shredded and destroyed, and electronic versions will be uploaded to UEL’s OneDrive for Business and deleted from the laptop. Data will be uploaded to the researcher’s OneDrive account on the UEL server. Scanned consent forms will be saved in a separate folder on OneDrive to other research data. Once data have been backed up on UEL servers it will be deleted the laptop.

How will you manage access and security?	As conversations will be video recorded, every step will be taken to ensure these are stored securely. Access to the researcher's OneDrive is made through multi-factor authentication from a password-protected laptop. Using participant numbers, anonymised transcripts will be shared using secure links via OneDrive for Business with the researcher's supervisor.
Data Sharing	
How will you share the data at project end	Excerpts from anonymised interviews will be included in the thesis and resulting dissemination. However, no full transcripts will be available via the UEL repository.
Are any restrictions on data sharing required?	Video/audio files will only be accessible to the researcher and anonymised transcripts will be available to their supervisor and examiners.
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	. Video recordings will be deleted from UEL servers upon examination of the research and anonymised transcripts will be kept for a maximum of three years to allow for dissemination.

What is the long-term preservation plan for the data?	Following completion of studies, transcripts will be deleted from the researcher’s OneDrive for Business and these will be transferred to an encrypted folder on the researcher’s private password-protected folder.
Responsibilities and Resources	
Who will be responsible for data management?	The researcher
What resources will you require to deliver your plan?	Private laptop
Review	
	Please send your plan to researchdata@uel.ac.uk **We will review within 5 working days and request further information or amendments as required before signing**
Date: 10/12/2021	Reviewer name: Penny Jackson Research Data Management Officer

Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: **researchdata@uel.ac.uk**

Administrative Data

Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (https://repository.uel.ac.uk) or a subject repository. How long should data be retained?

APPENDIX J: Poster

University of East London

Are you a person living with dementia and experience word-finding difficulties? Would you like to take part in research to share your experiences?

What is involved? :

I will ask you to meet with me just once for up to one hour. However, we can stop the conversation whenever you wish to.

If you wish, a trusted person e.g. a friend or relative can sit in on this conversation.

This conversation can take place in person or online via a video call. The conversation will be recorded. If we meet in person, we will ensure we are socially distanced.

It is your choice as to whether you wish to take part, I will also consider whether your relative has any objections to you taking part.

The researcher:

My name is Kate O'Connor.
I am training to become a Clinical Psychologist.

I am in my third year of a professional doctorate at the University of East London.

I am interested in speaking to people about their experience of having word-finding difficulties and living with dementia.

If you take part, I will ensure to use your preferred terms for dementia.

Interested in taking part or have any questions?

You can e-mail Kate O'Connor (Trainee Clinical Psychologist) at **u1945522@uel.ac.uk** for further information.

This research is being conducted as part of a Clinical Psychology doctorate at the University of East London.
Should you have any concerns about this research, please contact the School of Psychology Ethics Committee via Dr. Trishna Patel at **t.patel@uel.ac.uk**

APPENDIX K: Information Sheet

University of East London

PARTICIPANT INFORMATION SHEET

Stories of people living with dementia who experience word-finding difficulties.

You are being invited to participate in a research study.

The purpose of this document is to give you the information you need to decide whether you would like to take part in the research.

Please take time to read the following information carefully.

If you have any questions, please speak with Kate (the researcher).

Who is the researcher?

My name is **Kate O'Connor.**

My e-mail address is: **u1945522@uel.ac.uk**

I work in the NHS as a Trainee Clinical Psychologist.

I am completing a Professional Doctorate in Clinical Psychology at the University of East London.

As part of my studies, I am conducting research which you are being invited to take part in.

What is the research about?

I am interested in speaking to people about their experience of having word-finding difficulties and living with dementia.

Previous research has shown that this group can have limited opportunities to share their experiences.

This study can provide useful information about your experiences so that psychologists can take these into consideration when planning services for people living with dementia.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Why have you been asked to take part?

You have been invited to take part in my research as I am looking to involve people living with dementia who also experience word-finding difficulties,

If you experience word-finding difficulties, you may notice that words are often on 'the tip of your tongue'. Other examples of this are difficulties in recalling someone's name, or the name of an object. Some people also notice it is harder to read or write in the way they used to.

Taking part is your decision

Reading this information sheet does not mean that you have to take part in the research.

You are free to decide whether to participate in this research. If you do not wish to take part, you do not have to provide a reason.

Regardless of your decision, you will be treated with respect and your decision will not affect any help or care you receive.

What would taking part involve?

If you choose to take part, you will be asked to sign a consent form.

You will be asked to have a conversation with me about your experiences of living with dementia and word-finding difficulties. We can have this conversation in person or online. We can meet for up to one hour.

The conversation will be video, and audio recorded by the researcher.

If we meet in person, I will ensure we follow the latest government guidelines on coronavirus (COVID-19), and I will take a lateral flow test before we meet.

If online, this would require that you already have access to a computer with a webcam, microphone, and internet access. I cannot provide these.

Sometimes people may find using new technology challenging. If interested, you will be given instructions on how to access the video call. If you require any adaptations to make the conversation easier for you, please let me know.

If you would require support from relative, friend or carer to take part, I will give them an information leaflet too.

I cannot provide payment for taking part in the study.

What would happen during the conversation?

The conversation would start with a general question about your experience of living with dementia and word-finding difficulties. From then on, what we talk about will be decided by you.

If you choose, you may show photos or other items which help you to tell your story.

If you need breaks throughout the conversation or any adaptations, you can let me know.

We can meet on more than one occasion if this would be easier for you.

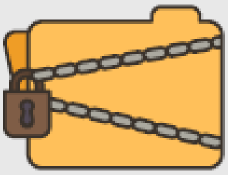
Confidentiality

All the information you provide will be kept safe in an online secure folder called OneDrive.

Recordings and written versions of our conversations will be kept safe. The recordings will be deleted following examination of the research. Records will be made anonymous and will be kept for up to three years. The records may be used to write summaries of this research to share with others, for example, a journal article may be written or I may provide a presentation about the study.

I will write anonymous notes of all my interactions with people involved in the research. These notes will only be seen by myself, my supervisor, and my exam board.

What will happen to the information that you provide?



If you participate, you will be asked to sign a consent form. After I read this, I will make a note of your name and contact details in a protected folder. I will be the only person who has access to these details. If you e-mail me a consent form, this e-mail will be deleted.

The conversation will be recorded. This is so that I can carefully consider all aspects of our conversations. The recordings of our conversations will be stored securely in an online folder called OneDrive. I am the only person who will view these recordings.

I will then write a record of the conversation and I will ensure this is anonymous. This means that I will not reveal your name or location when writing about our conversation. The video recordings will be deleted after examination of the thesis.

I will write a summary of our conversation so that I can let other people know what I have learned from your experiences.

This summary might include some of the things you have said in the conversation, but it will not refer to your name or any information which could identify you.

Safety

Before you participate, I will consider if anyone else has concerns about you participating in this study e.g. a relative or staff member.

It is important to let you know that if you say something which would lead me to be concerned about yours, or someone else's safety, I may need to share this with other people to make sure you and others are safe.

I will do my best to let you know if I have to share information about you to keep you safe. However, if this is the case, the information would only be shared with my supervisor or health/social care professionals such as your GP.

What if you change your mind?

If you choose to take part and later change your mind or wish to stop the conversation that is perfectly ok. If you change your mind you can let me, a staff member or a loved one know.

You are free to withdraw from the research study at any time, without providing a reason.

You can also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

Whatever your decision, this will not affect the support you receive.

Contact Information

The researcher's contact details:

My name is **Kate O'Connor** and if you would like further information or have any questions you can send me an e-mail. My e-mail address is **u1945522@uel.ac.uk**

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor, **Dr. Lorna Farquharson**. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: l.farquharson@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: **Dr Trishna Patel,** School of Psychology, University of East London, Water Lane, London E15 4LZ.
Email:t.patel@uel.ac.uk

Thank you for your time. It is greatly appreciated.

APPENDIX L: Interview Schedule

<u>Setting up and introducing the conversation:</u>

Researcher: to reintroduce self at this point and thank the participant for agreeing to meet.

Await participant response

Researcher: is there anything that would help you to feel more comfortable during our conversation today e.g., lighting, seating, hot drinks etc.?

Await participant response

Researcher: before we begin, it might be helpful to discuss what will happen today. As you can see, I have a video recorder set up (if in person), which is not yet recording our conversation. When we agree, I will turn this on to record a conversation about your experiences of having dementia/memory difficulties (use preferred term) and word-finding difficulties. We can talk for up to one hour but there is no obligation to do this, we can stop the conversation when you wish to. As you can see, I have brought pens/paper as some people prefer to draw/write if they cannot find the word they are looking for, so please feel free to do this. I may also write in my notebook as we speak to support me when I analyse the data. Do you have any questions about this?

Await participant response

Researcher: Is there anything else that would support you to communicate during this interview? Or is there anything I need to do to support you e.g., speaking slowly, more loudly, allowing you more time to respond etc.?

Await participant response

Researcher: if at any point, you would like to stop the interview, or you need a break please let me know. For example, some people may wish to raise their hand to show that they would like to stop or need a break (display gesture). How would you let me know if you wanted to stop the conversation?

Await participant response

Researcher: Thank you for letting me know. Before we begin do you have any questions or concerns about the interview and what happens afterwards?

Await participant response

Beginning the interview:

Are you happy to begin recording now?

Opening question:

I was wondering if you could tell me about your experiences of having memory difficulties/dementia (use participant's preferred term) and word-find difficulties?

Note:

The researcher will provide summaries and reflections to check their understanding of continued interpretations throughout the interview. Additionally, gentle reminders and reassurance will be provided, if requested or required by the participant to minimise potential distress

In addition, the researcher will observe verbal and non-verbal cues for indicators of distress, agitation, or confusion etc. and respond appropriately. The researcher will ask if the participant would like to continue the interview, have a break, or reschedule for another time. They will be reminded about their right to withdraw from the study.

Ending the interview:

When the conversation comes to a natural end or the participant wishes to stop the interview, the researcher will summarise the conversation and thank the participant for sharing their story. The video recorder will be turned off at this point.

Transitioning to debriefing:

Researcher: thank you again for speaking with me. I am aware that sometimes speaking about your experiences may bring up difficult feelings. I am wondering if you have any concerns after this conversation?

Await participant response

Researcher: It may be helpful if we look at some supports available to you both in your local area and online and ensure that you have their contact details. (to introduce debriefing letter).

Ending conversation: to thank the participant again for participating and to remind them of how to contact the researcher should they have any queries or concerns or would like to withdraw their data etc.