Alternative Narratives of Dementia: Healthcare Professionals Witnessing Blogs from People Living with Dementia

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ABSTRACT

Background: People with dementia are increasingly becoming involved in advocacy to seek change in the ways that dementia is understood by individuals, organisations, and society. A growing number of studies have explored the experiences and motivations of people with dementia who advocate, however they have not explored the impact of advocacy within a healthcare context.

Aims: The aims were to explore the personal blogs of people with dementia who advocate, and to investigate the impact of these blogs on healthcare professionals who work alongside people with dementia.

Methods: Two people with dementia and four healthcare professionals took part. The narrative practice of outsider witnessing was used to connect the blog entries of each person with dementia to two healthcare professionals. Following this group meeting, healthcare professionals were also interviewed individually. A Dialogical Narrative Analysis was used to explore blog posts and the narratives that were elicited from healthcare professionals pertaining to the impact of these blog posts.

Analysis: Blog posts suggested that being diagnosed with dementia could initially be associated with loss. However, they also suggested that through a process of psychological acceptance and adaptation to symptoms, it was possible to continue living a full and meaningful life with dementia. Healthcare professionals reported that hearing blog entries from people with dementia enabled them to develop a greater insight into the experience of dementia, challenged their preconceived ideas about dementia, and incentivised them to change their practice.

Conclusions: The findings provided initial support for the value of including advocacy by people with dementia (through their blog entries) into approaches to training and educating healthcare professionals. However, the effects of advocacy need to be explored further by studies which employ more rigorous methodologies. Moreover, there is a need for healthcare professionals and training providers to be open and receptive to involving people with dementia in service delivery.

CONTENTS

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1. INTRODUCTION

1.1. Overview

I will begin this chapter by outlining the terminology that is often used to describe people with dementia. I will also provide a brief overview of some of the common conceptualisations of dementia, and I will situate dementia within the current social and political context. Next, I will narrow the focus to explore dementia within a healthcare context, focussing specifically on person-centred care and the involvement of people with dementia in service delivery.

The second part of the chapter will focus on the topic under study which is advocacy by people with dementia, and the impact of advocacy on healthcare professionals. I will review the literature pertaining to advocacy by people with dementia and outline the theoretical framework that is used to conceptualise advocacy within this study. Then, I will review literature that has focussed on the involvement of people with dementia in healthcare training and education. Finally, I will state the aims, research questions, and rationale for the study.

1.2. Language and Terminology

I will use language such as “person with dementia,” and “people living with dementia” to describe individuals who have been given a dementia diagnosis. This language is in line with guidelines that have been created by people with dementia who are part of the Dementia Engagement and Empowerment Project (DEEP; DEEP, 2014).[1] Within the guidelines, it is recognised that the language used to talk about dementia directly impacts the ways in which people with dementia see themselves, and how they are perceived by others (DEEP, 2014). The guidelines suggest that respectful language which emphasises the person rather than their condition should be used to describe individuals (DEEP, 2014). Although considering people with dementia as one group can be helpful in terms of the fight for equal rights, it is also acknowledged

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[1] DEEP is an organisation that brings people with dementia together into local networks to share experiences, support each other, and strive for positive social change in issues that surround people with dementia.

that there will be great variation in peoples' experiences within this group based on characteristics such as age, gender, class, culture, and ethnicity. Moreover, the language used in this research may not resonate with all people with dementia.

1.3. Conceptualising Dementia

The ways in which dementia is conceptualised influences the wellbeing and treatment of individuals who live with it (Milne, 2020). Therefore, I will briefly review and critique two of the most common ways of understanding dementia; the medical model, and the psychosocial model. The models are presented under distinct headings because they represent different paradigms. However, in clinical practice, each paradigm operates alongside each other and can be considered as being of equal importance in constructing understandings of dementia.

1.3.1. The Medical Model

Under medical models, dementia is a classified disorder within the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2022). It is classified into different types however, the most common types are Alzheimer's disease and vascular dementia (Alzheimer's Society, 2022). Each type of dementia is said to have a distinct neuropathological cause. For example, Alzheimer's disease is thought to be caused, in part by an accumulation of Beta-amyloid plaques (i.e., abnormal clusters of protein fragments) and tangles (i.e., a protein that forms part of dead nerve cells) in the brain (Mehta & Schneider, 2021). The accumulation of these proteins interferes with the signalling between brain cells which can lead to symptoms such as a deterioration in memory, thinking speed and language (Mehta & Schneider, 2021). In practice, neuropathological changes in the brain are usually identified using brain scans such as Computed Tomography (CT) scans (National Institute on Aging, 2022). These scans use radiation to produce images of the brain which can show shrinkage of brain regions that can occur in dementia, as well as other potential sources of disease such as infections or blood clots (National Institute on Aging, 2022). Alongside the use of scans, the clinical features of dementia such as problems with memory, language, thinking speed, and visual perception can be identified using clinical interviews with service users and their loved ones (i.e., "informants"). During these interviews, the service user's history is taken to shed light on the possible aetiology of the disease. Moreover, during interviews, individuals are asked questions to ascertain information about any changes in service user's day-to-day functioning which may provide evidence of an underlying cognitive impairment (Cooper & Greene, 2005). In some cases, in-depth neuropsychological testing can be performed to generate a cognitive profile for service users, providing further evidence of the aetiology of the disease (Prado et al., 2019). Medical treatments work to alleviate symptoms and usually involve medications such as Memantine and anticholinesterase inhibitors which aim to slow down the progression of disease, but cannot cure it (NICE, 2018).

Scholars working within the field of dementia have increasingly challenged biomedical models (Milne, 2020). For example, research has found that the brains of people with Alzheimer's disease that were studied post-mortem showed biological markers that were thought to be the hallmarks of other types of dementia (Nelson et al. 2012; Mehta & Schneider, 2021). This evidence suggests that separating dementia into types based on neurological changes can be problematic because individuals with one diagnosis may have brain differences that are suggestive of other diagnoses. Similarly, brain related changes that are indicative of Alzheimer's disease have been found in autopsies of individuals who showed no outwardly identifiable symptoms (Terry, 1992), suggesting that symptoms cannot always be explained by neurological changes alone. Taken together, these findings suggest that although the medical model of dementia is widely accepted, its legitimacy as a standalone approach to understanding dementia can be contested.

1.3.2. The Psychosocial Model

Over the last decades, understandings of dementia have shifted away from a purely biomedical approach to acknowledge the influence of social and psychological factors in the development and maintenance of symptoms (Milne, 2020). The psychosocial model stems largely from the pioneering work of Tom Kitwood (1997) who applied the theory of personhood to understand dementia. The term "personhood" is often used interchangeably with "selfhood" and "identity" and can be defined as the "standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect, and trust" (Kitwood, 1997, p. 8). In other words, according to the theory of personhood, the symptoms experienced by people with dementia are affected by the ways in which they are treated by others. Indeed, research has suggested that when others act in ways that disempower, label, stigmatise and invalidate people with dementia, their symptoms can be exacerbated (Kitwood, 1997). Alternatively, when the actions of others successfully meet the needs of people with dementia, a process of "rementing" (Kitwood, 1997) can occur whereby individuals can recover some of their cognitive abilities (e.g., Chenoweth et al. 2009; Ballard et al. 2018).

The psychosocial model has been praised for widening our understanding of dementia to include the influence of social and psychological factors (Milne, 2020). Thus, it could be suggested that the model promotes an understanding of dementia as a lived experience that is impacted by a multitude of factors, rather than solely as a set of structural and chemical changes that take place in the brain. By focussing on the person as well as the difficulties associated with their diagnosis, the model suggests that individuals are worthy regardless of their cognitive impairment (Sabat, 2021). The implication that people with dementia are valuable regardless of extrinsic factors is core to this research because it suggests that the knowledge and expertise of people with dementia should be respected, learned from, and acted upon.

1.4. Political Context

Exploring the political context surrounding dementia is important because policies are likely to be powerful in influencing dementia care and understandings of dementia at a societal and individual level (Broda et al. 2017).

Finding ways to support people with dementia has been considered a health and social care priority in the United Kingdom (UK) for many years (Department of Health; DoH, 2012). A brief review of key policy documents highlighted several areas that have been targeted by UK governments including raising awareness of the symptoms of dementia, tackling stigma, promoting earlier diagnosis, and improving dementia services. For example, in 2009 the Labour government led by Gordon Brown released its National Dementia Strategy which was entitled "living well with dementia" (DoH, 2009). This strategy pledged to increase public and professional knowledge about the symptoms of dementia and to promote earlier diagnosis (DoH, 2009). Following this, a series of policy documents entitled "Challenges on Dementia" were released. The first policy document, which was developed under a coalition government between the Conservative Party and the Liberal Democrats set out plans to develop "Dementia Friendly Communities" by 2016 (DoH, 2012). This community programme aimed to encourage organisations, including places such as supermarkets and banks to share responsibility for supporting people with dementia to live independently and without the need for formal support from services (DoH, 2012). The second "Challenge on Dementia" document which was released under the Conservative government led by Theresa May continued to focus on establishing "friendly" communities (DoH, 2016). Moreover, the document set out plans to diagnose people earlier and to tackle societal and workforce stigma before 2020 (DoH, 2016).

Despite these drivers to reduce stigma and raise awareness, results from a recent survey found that 98% of people with dementia felt that they were being treated differently in comparison to people with other health conditions (Alzheimer's Society, 2016). Therefore, it could be suggested that existing policies are not sufficient to meet the needs of people with dementia. In support of this view, some researchers have suggested that concepts such as "dementia awareness" and "dementia friends" are weak and fail to recognise that people with dementia are a minoritised group who face exclusion and oppression (Shakespeare et al. 2019). Instead, some researchers have highlighted the importance of laws to protect people with dementia, for example the Equality Act (2010) which makes it illegal to treat an individual with dementia less favourably because of their diagnosis (Hare, 2016).

1.5. Sociocultural Context

The way that dementia is understood socially and culturally is likely to shape the experiences of people who live with the illness. Therefore, I will now explore some of the common meanings that are attached to dementia in British society.

Dementia as a concept has evolved and changed over time depending on historical milestones and the beliefs and attitudes that were acquired because of them (Bosco et al. 2019). Historically, the illness has been related to sin (Berrios, 2008), and insanity (Hill & Laugharne, 2003). Since the emergence of dementia as a disease in the late 1970s and 1980s, the biomedical model has been suggested to dominate public narratives and knowledge (Milne, 2020). This biomedical dominance has been shown to have a variety of implications for the ways that dementia is understood by lay people. For example, one systematic review article explored how the construct of dementia had changed over time (Bosco et al. 2019). The article suggested that by focussing on disease, the medical model resulted in the "objectification" of people with dementia meaning that individuals became viewed in terms of their diagnosis and symptoms, rather than as people (Bosco et al. 2019). Another study which explored articles in British newspapers in the years before 2013 found that the media often depicted people with dementia as "empty shells" and "zombies" (Zeilig, 2013). This representation could be seen as reflecting a societal belief that people with dementia lacked a sense of identity. Similarly, findings from survey research which explored the views of 9,116 lay people who were over the age of 50 suggested that dementia was the most feared illness above that of illnesses such as cancer and diabetes (Saga, 2016). This highlights the anxiety and fear that surrounded (and arguably still surrounds) the condition.

In recent years there has been a shift in societal constructions of dementia whereby people with dementia are being increasingly recognised as people, rather than as "empty shells" or "patients" (Parker et al. 2020). This shift is suggested to be related to several factors such as the inclusion of people with dementia under the Equality Act (2010) which has been seen as a step forward in recognising the worth of individuals (Bosco et al. 2019). Moreover, some people with dementia have started to speak publicly about their experiences of dementia, for example by publishing books, speaking on the radio, and talking at conferences (Seetharaman & Chaudhury, 2020). Studies that have explored the motivations of people with dementia who speak publicly suggest that individuals aim to promote an understanding of dementia as an illness that people can adapt to, and continue to live well with (Bartlett, 2014b).

In a paper that explored societal narratives of dementia (McParland et al. 2017), the authors suggested that the societal shift towards more positive notions of dementia had been necessary in terms of reducing the stigma associated with the condition. However, they suggested that there was now a divide between views of dementia as *either* being a tragedy, *or* an illness that one could live well with (McParland et al. 2017). They suggested that this dichotomy is problematic because it risks disenfranchising the most vulnerable individuals, who, through no fault of their own may not be able to “live well” with the condition. They argued that there is a need for society to develop a more nuanced narrative which accepts the complexities of living with the condition rather than understanding it as a dichotomised experience of “tragedy” or “living well” (McParland et al. 2017).

1.6. Person-Centred Care

I will now narrow my focus to consider dementia within a healthcare context, focussing on how care is provided alongside people with dementia at an individual level. I will focus specifically on person-centred approaches to care because these are universally considered to be the “gold standard” way of working alongside people with dementia (Downs & Lord, 2017).

1.6.1. Definition and Principles

Person-centred care refers to a variety of approaches that involve supporting people in a unique way depending on their preferences, likes, dislikes, hobbies, and interests (Manthorpe & Samsi, 2016). In the context of dementia, person-centred approaches are seen as being rooted in psychosocial theories of personhood which recognise the importance of relationships and social context in wellbeing (Kim & Park, 2017). Best practice guidelines on dementia outline four key components of person-centred care (NICE, 2018). The first component involves recognising and acknowledging the human value of people living with dementia regardless of their cognitive abilities. The second is to respect the individuality of people with dementia including the impact of their life experiences and personality on their response to illness. The third component highlights the importance of the person’s perspective in decisions related to their care. In line with theories of personhood in dementia (Kitwood, 1997), the fourth component involves the development of relationships and social environments that enable people to live as well as they can (NICE, 2018). Although the NICE guidelines (2018) refer to the need to involve people with dementia in decisions about their care, older frameworks (e.g., Brooker, 2006) do not appear to state the need to include people in decision-making. One interpretation of this discrepancy between older and newer frameworks could be that until recently, people with dementia have not been recognised as individuals who are able, despite their symptoms, to communicate their preferences (Cheston et al. 2000).

1.6.2. A Review of Some Evidence on Person-Centred Care

I will now briefly review some of the literature that has explored the use of person-centred care in services that care for people with dementia. Li and Porock (2014) undertook a narrative review of findings from 24 papers across three different countries to explore the effects of person-centred care that was provided in a residential setting (Li & Porock, 2014). Person-centred interventions included pet therapy, gardening projects, and strategies to increase opportunities for individuals to highlight their preferences. Across the studies, staff reported that people with dementia demonstrated improvements in their mood, quality of life, and their ability to undertake tasks such as eating, dressing, and washing, thus suggesting the benefits of providing person-centred care. The authors highlighted several issues with the studies under review. For example, they suggested that each study adopted a different definition and understanding of person-centred care, and that limited information was provided about the interventions that were used. Both issues could be said to limit the comparability and replicability of the findings which means that it is unclear as to whether person-centred care does in fact reliably lead to the benefits to wellbeing that have been stated. This may mean that services are less inclined to apply the principles of person-centred care in practice. Therefore, although person-centred care appears to represent a promising approach to practice, further research with greater methodological rigour is needed.

Using a global survey on attitudes towards dementia, it was suggested that 40% of people with dementia felt ignored by healthcare providers (Alzheimer's Disease International, 2019) which runs counter to the principle of person-centred care to involve people with dementia in decision-making. The exclusion of people with dementia by healthcare professionals was evidenced in quotes from survey respondents such as “my neurologist ignored my presence when my diagnosis was discussed with my husband” (Alzheimer’s Disease International, 2019 p. 3). Although it is not clear which countries those who felt ignored received care from, findings from the report could be seen as evidence that, in practice person-centred care is not provided. Similarly, in a recent systematic review, Marulappa et al. (2022) explored the use of person-centred care within outpatient and community settings. The review authors found that across the four studies which explored the extent to which person-centred care was provided in practice, all showed that person-centred care was inadequate (Marulappa et al. 2022), thus providing further evidence that in practice care is often insufficiently person-centred.

1.7. Service User Involvement in Healthcare Delivery

I will now focus on the ways in which people with dementia have been involved in service delivery, highlighting some important legislation and research.

Service user involvement in service delivery involves the active participation of a person with lived experience of health challenges in planning, commissioning, designing, and overseeing health services (Millar, 2016). Although participation should be embedded into all aspects of services, specific activities may include recruiting and selecting staff, workforce training, and gathering feedback regarding what a service needs to improve on (Miller, 2016). A variety of legislative frameworks have been developed to mandate service user involvement in service delivery, for example the NHS and Community Care Act (1990), and the National Health Service Act (2006). Service user involvement in service delivery was also a key aspect of the government’s National Dementia Strategies (e.g., DoH, 2016), and is recommended in current best practice guidelines on working with people with dementia (NICE, 2018). These frameworks highlight the importance of supporting people with dementia to participate in the planning and delivery of services.

An executive summary paper that was developed by Northumbria University sought to review initiatives for good practice in including people with dementia in service delivery (Cantley et al. 2005). The authors used a case study approach to review how people with dementia were involved in the delivery of 16 dementia-related organisations across the Northeast. They highlighted the benefits of involvement for those who were involved, suggesting that people with dementia often reported improved self-esteem and confidence arising from their sense that their perspectives were valued by services (Cantley et al. 2005). Another study was carried out on behalf of the DEEP (Williamson, 2012) to understand how people with dementia who were involved in 162 DEEP groups across the UK had been contributing to service delivery. Results from surveys suggested that there were only a small number of groups who were invited by organisations to take part in service delivery (Williamson, 2012). Therefore, although involvement is a legal requirement that produces many benefits, opportunities for meaningful involvement of people with dementia may be inadequate.

1.8. Dementia Self-Advocacy

Having provided an overview of the conceptual, political, social, cultural, and healthcare contexts surrounding dementia, I will now narrow my focus to explore the topic under study which is advocacy by people with dementia. Advocacy could be suggested to be at the core of many issues surrounding people with dementia. For example, it could be seen as being a central part of person-centred care, and the involvement of people with dementia in healthcare delivery because advocating involves speaking up for oneself and one's needs and rights. I will begin this section by defining self-advocacy, before undertaking a review of the evidence base pertaining to advocacy by people with dementia.

1.8.1. Definition of Self-Advocacy

Advocacy by people with dementia has been defined in different ways. According to Dixon et al. (2020), advocacy "*of*" people with dementia (otherwise termed "self-advocacy," or "cause advocacy") describes "a process by which one or a number of people seek justice or social change in relation to a specific issue" (p. 4). On the other hand, advocacy "*for*" people with dementia (or "case advocacy") is where someone such as a healthcare professional or family member speaks on behalf of an individual to ensure that the individual's needs and rights are met (Schichtanz et al. 2018). Examples of self-advocacy may include a range of activities such as lobbying the government, writing letters to policymakers, public speaking, and “posting” online on social media platforms (Dixon et al. 2020). Although advocates can often be involved in activism, the terms advocacy and activism are seen as being slightly different. Advocates are said to hold specialist knowledge about an issue such as dementia, which they share to address problems, whereas activists engage in protests, marches and events that are intended to make others listen to the expertise of advocates (The US Institute of Diplomacy and Human Rights, 2021). Thus, the terms “self-advocacy” and “people who self-advocate” are selected because these terms reflect the topic under study.

I will now carry out and present the findings from the first of two literature searches. This first review of the literature aimed to explore the existing evidence base on advocacy by people with dementia and to identify any gaps that this study could explore.

1.8.2. Literature Search Strategy

The literature search was carried out electronically using EBSCOhost (PsychInfo, CINAHL Complete, and Academic Search Ultimate) in November 2022 (see Appendix A). The literature was searched using the terms: (dementia or Alzheimer’s) and (“social movement” or advoca* or activis*). Across all databases, the search yielded 639 results, of which 10 were of direct relevance to this review. The high number of excluded studies perhaps reflects the wide use of terms such as “activism” and “advocacy,” as suggested in a previous systematic review (Weetch et al. 2022). The reference lists and the “cited by” function on Google Scholar were also searched to identify missing or grey literature.

1.8.3. Inclusion and exclusion criteria

Studies were included if they focussed on people with dementia who were involved in self-advocacy. Studies that pertained to solely to case advocacy (i.e., where a third-party advocates on behalf of the person with dementia) were excluded because this research is focussed on advocacy *of* people with dementia, rather than advocacy *for* people with dementia (Dixon et al. 2020). Studies that sought the perspectives of people with dementia and others such as carers were included.

1.8.4. Overview of Studies

I will start by providing an overview of the studies that were included in the review to orient the reader to the existing literature. The literature was all qualitative. Six studies focussed on the motivations for, and experiences of engaging in advocacy, though they did not focus on the experience of taking part in specific advocacy activities (Bartlett, 2014a; Bartlett, 2014b; McConnell et al. 2020; Schicktanz et al., 2020; Russell et al. 2020; Hillman et al. 2018). On the other hand, three studies focussed on participants' experiences of engaging in specific advocacy activities such as "blogging" (i.e., sharing written blogs online; Brooks & Savitch, 2022), creating short video diaries for a project called Dementia Diaries[2] (Lazar & Dixon, 2019) and posting about the experience of dementia on Twitter[3] (Talbot et al. 2019). Two studies (Kannaley et al. 2019; Talbot et al. 2021) explored the content of materials that were produced by people with dementia (e.g., blog posts and tweets, respectively) to understand the experience of dementia.

The following sections are structured according to the key themes that were derived from previous research to shed light on the content of self-advocates' accounts.

1.8.5. A Sense of Purpose Derived from Engaging in Advocacy

Two studies found that involvement in campaigning brought people with dementia a sense of purpose (Bartlett, 2014a; Talbot et al., 2019). For example, Bartlett (2014a) carried out interviews over two years with 16 people with dementia to understand their lived experiences of advocacy. Examples of advocacy included writing letters to papers, blogging, and attending campaign meetings. Participants suggested that campaigning brought them a sense of purpose and meaning arising from their feelings that their work was important to the lives of others. However, they reported

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[2] Dementia diaries is a UK project that supports people with dementia to share their stories and perspectives online."

[3] Twitter is a microblogging platform where people share written "tweets" that are less than 280-characters in length with wide audiences (i.e., "followers").

that campaigning was often challenging due to the negative effects of dementia such as fatigue and memory loss. Moreover, many participants reported experiences of having their diagnosis questioned by others. The researchers suggested that this happened because advocates appeared to be healthy, competent, and articulate, and thus did not meet societal expectations of people with dementia.

Bartlett's (2014a) findings were limited because the sample was predominantly white British, involved people who were highly educated (i.e., people who had previously worked in professional or managerial roles), and who were young and relatively healthy. These critiques apply to many of the other studies included within the review (e.g., Bartlett, 2014a; Brooks & Savitch, 2019). The lack of diversity within existing research (and perhaps advocacy generally) could be seen as problematic because the characteristics of research participants are likely to be unrepresentative of the demographic of people with dementia in society. This represents a form of epistemic injustice (Fricker, 2007) because the knowledge produced is likely to misrepresent the experiences of those from diverse backgrounds in terms of ethnicity, age, and ability. This may have a negative impact on the wellbeing of these individuals because they may not have access to the knowledge needed to understand their experiences.

1.8.6. Developing a Collective Identity

Two studies suggested that being involved in advocacy supported individuals to develop a sense of "collective identity" (Bartlett 2014b; McConnell et al., 2020). Bartlett (2014b), drawing on a definition provided by Della Porta and Diani (2006) defined collective identity as a person's "identification of identifications with and attachment to some collective in cognitive, emotional, or moral terms" (p. 20). Using interviews, Bartlett (2014b) found that engagement in advocacy enabled people to gain respect and status for themselves, but also for other people with dementia. Similarly, research by McConnell et al. (2020) sought to develop a theory of "what works, for whom, in what circumstances when implementing empowerment initiatives" (p. 6). To develop this theory, McConnell et al. (2020) observed and interviewed 15 people with dementia, three staff members and two board members who were part of an advocacy organisation in Northern Ireland. In line with findings from Bartlett (2014b), participants in McConnell et al.'s (2020) study suggested that their involvement in the organisation created a sense of belonging, shared identity, and collective strength. These aspects of group membership were suggested by participants to help them to overcome feelings of isolation and supported them to overcome issues with their identity that had been caused by being diagnosed with dementia (McConnell et al. 2020).

1.8.7. Living as Well as Possible with Dementia

Three studies provided insights into the experience of dementia, as well as the experience of campaigning (Kannaley et al. 2019; Talbot et al. 2021; Hillman et al. 2018). For example, Kannaley et al. (2019) explored blog posts from 19 people with dementia and 44 informal carers using thematic analysis, to understand the experience of dementia from each perspective. Blog posts conveyed both a sense of the challenges associated with dementia (e.g., feelings of uncertainty, fear of the unknown, and loss) as well as accounts of pleasurable experiences such as feeling connected to others, and individuals' appreciation of nature (Kannaley et al. 2019). Whereas blog posts seemed to portray a combination of pleasant and distressing experiences of dementia, tweets from people with dementia which were analysed by Talbot et al. (2021) were suggested to almost solely portray the message that participants were living well despite their diagnosis. Indeed, only one out of the 12 account holders in Talbot et al.'s (2021) study were suggested to discuss the challenges associated with their symptoms of dementia, suggesting the differences in perspectives that are shared through different forms of advocacy.

Participants in a study by Hillman et al. (2018) also predominantly shared experiences of living well with dementia. The researchers analysed interviews with five people with dementia and four informal care partners who were members of an advocacy organisation. Participants' accounts were conceptualised by the researchers as "illness narratives" (i.e., personal accounts of illness that aim to revise and maintain the identities of those who are sharing the narrative; Frank, 1995). The researchers drew upon the concept of "narrative economies" (Burchardt, 2016) which seeks to understand how narratives of illness can be valuable to society due to their ability to shape meaning of a condition. Hillman et al. (2018) suggested that participants' narratives served two purposes, the first being to support individuals to maintain their identity in the face of difficulties associated with dementia, and the second being to shape knowledge about dementia at a societal level (Hillman et al. 2018).

Findings from Hillman et al. (2018) and Kannaley et al. (2019) were limited because the researchers in both studies pooled the analysis from people with dementia and carers together meaning that it was not possible to distinguish which findings were relevant for which group. Moreover, in Kannaley et al.'s (2019) research, the number of participants was heavily weighted towards care partners (i.e., 19 people with dementia and 44 care partners) which risks privileging the perspectives of care partners over the perspectives of people with dementia. The overreliance on caregivers' narratives is a feature of a lot of research on dementia (Morbey et al. 2019) and highlights the need to prioritise the voices of people with dementia themselves.

1.8.8. Raising Awareness of Dementia and Tackling Stigma

Participants in five studies suggested that they were motivated to become involved in advocacy by a drive to reduce the stigma associated with dementia (Schichtanz et al. 2020; Russell et al. 2020; Brooks & Savitch, 2022; Lazar & Dixon, 2019; Talbot et al., 2019). For example, Schichtanz et al. (2020) compared the aims of people with dementia, carers and board representatives who were involved in dementia advocacy groups in Germany and Israel using semi-structured interviews. For people with dementia in Germany and Israel, the main driver for involvement in advocacy was to improve the public's awareness of dementia and to reduce stigma. However, Schichtanz et al.'s (2020) findings were limited because the socio-political context surrounding dementia, and thus the experience of dementia in Germany and Israel is likely to be different compared with in the UK. Thus, findings cannot be reliably transferred to the UK context.

Research by Brooks and Savitch (2022) was carried out in the UK and produced similar findings to Schichtanz et al.'s (2020), thus providing support for the finding that people with dementia are motivated to engage in advocacy by a wish to reduce stigma. Brooks and Savitch (2022) carried out interviews with six people with dementia who shared blogs as part of their advocacy work. Like participants in other research (Russell et al. 2020; Bartlett, 2014b), bloggers were motivated by a desire to educate others, such as healthcare professionals about dementia to raise awareness and challenge the stigma associated with their illness. Moreover, participants suggested that blogging as a format for sharing one’s experience was helpful because it enabled them to overcome difficulties that were associated with “speaking off the cuff” (Brooks & Savitch, 2022 p. 2407). This highlights the importance of allowing people with dementia to have time to prepare their advocacy work; a finding that will be considered further when highlighting the aims of this research.

Overall, the literature highlighted within the review suggested that a key goal of self-advocates (and indeed the definition of advocacy) was to bring about positive changes for other individuals, organisations, and groups. However, none of the studies sought to explore the impact of self-advocates’ work on others, thus it is not clear whether their work is making the difference that individuals intend. This highlights a gap in the literature which this study intends to explore. Indeed, other dementia advocacy researchers also highlight the need for additional research to explore the impact of advocacy, and to understand the ways in which advocacy creates change (e.g., Lazar & Dixon, 2021).

1.9. Conceptualising Self-Advocacy: Stories and Narrative

I will use the concept of stories (used interchangeably with “narrative”) to explore how advocacy may influence individual advocates, and those who are exposed to advocacy. The concept of stories is drawn upon because narrative theory is well-established in research (McAdams, 2018), and literature within the field of dementia has provided support for the existence of a narrative identity in people with dementia (e.g., Surr, 2006; Mills, 1997). Furthermore, narrative theory could be suggested to provide a way of understanding how advocacy by people with dementia may influence the identities and experiences of those who advocate (i.e., the “storyteller”) but also how their advocacy may influence those who are exposed to their work (i.e., the “audience”). Both aspects are integral to this study’s aims. I will now provide a brief overview of narrative theory before exploring some of the research that has conceptualised advocacy as personal stories and used this framework to explore its effects.

Stories can be defined as “the effort to communicate events using words (prose or poetry), images, and sounds, often including improvisation or embellishment. Stories are creative and value laden, usually revealing something important about the human condition” (Haigh & Hardy, 2007, p. 408). We use stories to construct our sense of selfhood because they allow us to integrate past, present, and future experiences as well as different aspects of our identity such as our social roles, values, and attitudes (McAdams, 2018). Importantly for this research, stories not only influence storytellers, but they also influence the mood, knowledge, and attitudes of others (Heritage, 2005). This role of stories in influencing audiences has been suggested to make stories particularly important in the field of advocacy which is intended to persuade individuals, organisations, and society (Austin & Connell, 2019).

I will now present some of the research that has conceptualised advocacy as “stories.” One article explored the use of personal narratives to communicate science with non-expert audiences (Dahlstrom, 2014). The article suggested that personal stories encouraged audiences to empathise with those who were in the story, the stories were easier to understand and recall, and they produced greater engagement when compared with factual information (Dahlstrom, 2014), thus demonstrating that stories may help to effectively communicate messages to influence change. Moreover, Boswell (2013) highlighted the role of personal narratives within the political domain. He suggested that stories are particularly useful because they enable people to engage in political issues and because they simplify complex information in a way that is compelling to audiences (Boswell, 2013). Finally, Johnson et al. (2013) explored the use of personal narratives that had been written by women who identified as Arab-Muslim. The researchers found that when readers were given a story that included the women’s personal dialogue, readers were more empathetic and demonstrated more positive attitudes towards the Arab-Muslim community, compared with those who were given a simple summary of the women’s experiences. Although none of these studies were involved people with dementia, they suggest that personal stories can be powerful in promoting empathy, shifting attitudes, and communicating information for those who are exposed to them. This could be seen as highlighting the importance of stories within the field of advocacy.

1.10. The Effect of Personal Stories from People with Dementia on Healthcare Professionals

The first literature review highlighted that people with dementia who self-advocate intended for their work to be seen by, and influence healthcare professionals (e.g., Brooks & Savitch, 2022). However, the review highlighted the absence of literature that has sought to explore the effect of advocacy by people with dementia in any context, or in the context of healthcare. Thus, a second literature review was carried out in a sequential manner following the first review. This second review aimed to provide a fuller understanding of how involving people with dementia in workforce education and development impacted professionals. Although individuals within this body of research may not identify as advocates or share experiences that may be conceptualised as “stories,” arguably the function of involvement from people with dementia in training and education, and the function of advocacy is similar. Indeed, both intend to generate changes in aspects such as healthcare professional’s knowledge, attitudes, and beliefs that are driven by the perspectives of people with dementia.

1.10.1. Literature Search Strategy

A second literature search was carried out electronically using EBSCOhost (PsychInfo, CINAHL Complete, and Academic Search Ultimate) in March 2023 using the terms (dementia or Alzheimer’s) and (story or storytelling or narrative) and (education or training or learning; see Appendix B). Across all databases the search yielded 1,265 results, of which two were relevant to this study (Jack-Waugh, 2023; Morris, 2014). The large number of excluded studies could be suggested to reflect the paucity of approaches to improving practice that directly involved people with dementia (Marulappa et al. 2022). The reference lists and the “cited by” function on Google Scholar were also searched to identify missing or grey literature. The reference list search highlighted another relevant study (Schrimpf Davis et al. 2021), however the participants were older adults rather than people with dementia. Due to the small number of studies included in the review, this paper was included to provide findings for comparison in my discussion section.

1.10.2. Inclusion and Exclusion Criteria

Studies that explored approaches to education and training that involved a person or people with dementia sharing their experiences or perspectives as part of the programme were included. Individuals could have been involved either directly (e.g., through talking about their lived experience of dementia to professionals), or indirectly (e.g., resources that they had created such as videos, or written accounts may have been shared as part of the training). Studies were excluded if they explored approaches to training that did not involve people with dementia, or if they involved simulations of the experience of dementia.

1.10.3. Exploration of Studies

I will now review each of the studies in turn. Schrimpf Davis et al. (2021) paired 1251 medical students with older adults in the United States. Each student interviewed the older adult about their perspectives on aspects of care such as the doctor-patient relationship and ethical issues. Thus, the students were learning directly from the patients' perspectives. After the interview, students discussed their experiences in groups of 10-12 people before completing an evaluation using a mixed-methods survey. Findings highlighted how "eye-opening" the interviews with older adults were because they provided insights into the patients' experiences. Students reported that they learnt about person-centred care, felt hopeful and inspired by the positivity of older adults, and became knowledgeable about older adults' needs, priorities and their expectations of service providers. The findings could be seen as providing initial support for the potential of stories from people with dementia who advocate to influence practice. However, the use of a survey to gather the perspectives of students appeared to limit the depth of understanding regarding the impact of older adults' narratives. Furthermore, the content of the older adults' narratives was not explored, meaning that their valuable perspectives on how care should be provided could not advance research in the field, or thereby generate recommendations for improving practice.

The second study (Jack-Waugh, 2023) aimed to construct a theory to understand the experiences of 524 professionals who were taking part in a Dementia Champion (DCs) education programme in Scotland. DCs are registered professionals, such as nurses who are trained to lead on the improvement of care for people with dementia (Banks et al. 2014). The programme involved five face-to-face study days and a series of written assignments which took place over eight months. The training was delivered by a multi-professional team which included people with dementia and their family carers, although it was not clear what the roles of people with dementia were. The authors presented three core theoretical concepts to understand DCs experiences before, during and after the training programme. Prior to training, it was suggested that because of factors such as stigma and a lack of knowledge on the part of DCs, they were pre-determined to inadequately meet the needs of people with dementia. The training programme itself was suggested to support DCs to "take on the role of the other" (i.e., to understand the perspectives of people with dementia, carers, and other DCs). Post-training experiences were characterised by a process of self-reflection whereby the self-concepts of DCs were re-defined, and their preconceived assumptions about people with dementia were challenged. Although the authors suggested that being with people with dementia supported the changes noted in DCs, it was not clear what the roles of people with dementia were. Thus, it was not clear whether the changes were attributed specifically to people with dementia, or whether they were an artefact of other parts of the programme.

The third study by Morris et al. (2014) sought to understand the influence of first-person accounts of dementia on mental health nursing students. Thirty-six students were each shown five different media resources with the aim of facilitating learning about the lived experience of dementia. The resources included a feature film portraying the experience of dementia, a television documentary from the first-person perspective of someone with dementia, and an autobiography written by a person with dementia. After being shown each type of media, students completed a questionnaire and took part in focus group interviews to discuss their perspectives on each resource. The interviews were analysed using grounded theory, and the questionnaires were analysed descriptively. On the questionnaire, participants selected the television documentary as the "most impactful" resource in terms of the level of understanding that it promoted and the emotional impact that it had. All students responded that they either “strongly agreed” or “agreed” that the media resources increased their appreciation of the internal experience of dementia.

Although this body of literature (Morris et al. 2014; Jack-Waugh, 2023; Schrimpf-Davis et al. 2021) could be suggested to provide some support for the potential for advocacy (or “hearing the voices of people with dementia”) to be beneficial in educating healthcare professionals, none of the research was carried out within the context of advocacy specifically. Moreover, the accounts of people with dementia and older adults did not appear to have been conceptualised as “stories.” Given that people with dementia who self-advocate appear to have specific motivations (e.g., Bartlett, 2014b; Brooks & Savitch, 2022), and that stories are particularly effective in creating change (e.g., Boswell, 2013), the effects of advocacy on healthcare professionals could perhaps be different. This demonstrates the need for further research.

1.11. Aims, Justification and Rationale

1.11.1. Aims

The study draws upon the concept of stories to explore the personal blogs of people with dementia who engage in advocacy, and to investigate the impact of these blogs on healthcare professionals who work alongside people with dementia.

1.11.2. Justification and Rationale

Exploring blogs by people with dementia who advocate intends to shed light on their experiences and perspectives, with the aim of using their perspectives to inform clinical practice. Furthermore, it could be seen as important to explore blog narratives themselves, prior to exploring their impact on professionals, to understand the content of the narratives that are suggested to be generating the effect. Blog narratives are explored as opposed to other forms of advocacy because individuals have suggested that using personal blogs to advocate enables them to carefully prepare their story (Brooks & Savitch, 2022). Furthermore, narratives that are well-practiced are suggested to be the most effective in influencing change because they allow the storyteller to appear confident and genuine (Austin & Connell, 2019).

It is important to explore the impact of advocacy so that people with dementia who advocate, and advocacy organisations can continually improve (Austin & Connell, 2019), however the effects of advocacy in previous research have not been explored. This study looks specifically at the impact of advocacy on healthcare professionals because healthcare professionals are one group that people with dementia aim to influence through their work (e.g., Brooks & Savitch, 2022).

1.11.3. Research Questions

1) What stories do people with dementia who are involved in advocacy share in their online blog entries?

2) How does hearing blog entries from people with dementia affect healthcare professionals?

1.11.4. Clinical and Research Relevance

The research begins to merge the fields of advocacy by people with dementia and healthcare practice. Studies have shown that in practice, care for individuals with dementia is often not sufficiently person-centred (Alzheimer’s Disease International, 2019), and that despite the requirement to involve people with dementia in service delivery, individuals are still often excluded (Williamson, 2012). Exploring the impact of advocacy on healthcare professionals may be a starting point for understanding how the voices of people with dementia (through advocacy) could be centralised within approaches to workforce training and development. This is important given the requirement for the voices of people with dementia to be embedded in all aspects of service delivery (e.g., NICE, 2018; National Health Service Act, 2006). The study also intends to advance the small body of literature that has explored the experiences and motivations of people with dementia who advocate by beginning to consider the impact of their work.

2. METHODOLOGY

I will now outline the methodology that I used to meet the aims of the project. I will begin by outlining my epistemological position, before providing an account of the process of patient and public involvement, recruitment, and data collection.

2.1. Epistemological and Ontological Position

The study adopted a social constructionist epistemological position. Constructionism posits that there is no absolute truth and that instead knowledge is generated through the language used during social interactions, and within social, historical, and cultural contexts (Burr, 2003). Therefore, constructionist approaches see research as a form of social action because it produces new understandings and ideas about the world (Riessman, 2008). This meant that the current study could be conceptualised as part of the social movement to revise the ways in which people with dementia have been socially and culturally positioned, and to de-stigmatise the illness (Bartlett, 2014). Understanding research as a form of socially and culturally bound knowledge production also encouraged me to critically reflect on how the study constructed people with dementia and healthcare professionals, and the potential impact of these constructions on individuals. The aim of this was to produce knowledge that was responsible, and considerate of the needs of those who the research was intended to be useful for.

The position taken by constructionism that reality only exists through dialogue has been criticised for reducing issues which are hugely impactful on peoples' lives, such as dementia, to the effects of language (Burr, 2003). To avoid denying or minimising the material reality of brain changes associated with dementia, the study adopted the ontological position that material changes may exist, however that we cannot necessarily know what these changes are because language may only be able to partly capture their nature (Nightingale & Cromby, 2002). In line with constructionist positions, the research assumed that the language we use to talk about dementia generates the reality of living with it (Burr, 2003).

2.2. Patient and Public Involvement

Members of the public and people with dementia were involved at different stages of the project. The decision to include stakeholders was consistent with national policy guidelines on involving people with dementia in research (DoH, 2016). Internet forums such as Dementia Talking Point (Alzheimer's Society, 2022), Twitter, and dementia advocacy projects were explored to begin to understand what the priorities of people with dementia were. This search of different forums highlighted a theme that people with dementia felt that they had been denied a voice, and it shed light on the ways in which they were advocating to get their voices and stories heard.

Several online meetings were held with a person with dementia who is involved in advocacy (herein referred to as the "consultant"). The consultant provided support in shaping the focus of the project, as well as the data collection procedure. For example, he highlighted the need to develop relationships with people with dementia ahead of the witnessing practices, to offer breaks, and to use jargon-free language. He also provided feedback on the information sheets and consent forms for people with dementia.

2.3. Participants

2.3.1. Recruitment of People with Dementia

Individuals who authored online blogs were recruited by the consultant through his personal networks. This method meant that the project did not have to rely on social media recruitment which often excludes many people with dementia (Phillipson et al. 2016). The consultant approached potential participants with dementia, and following this I emailed them the information sheet (see Appendix C) and consent form (see Appendix D). As recommended by the consultant and multiple scholars (e.g., Dewing, 2002), a preliminary meeting was held on Microsoft Teams to discuss the information sheets and to begin the process of rapport-building.

2.3.2. Recruitment of Healthcare Professionals

Healthcare professionals were recruited from my professional networks, and snowballing was used to increase the number of participants. Information sheets (see Appendix E) and consent forms (see Appendix F) were sent to them via email.

Informed consent was ascertained from all participants, the process of which is outlined further in section 2.5.2.

2.3.3. Inclusion Criteria

People with dementia had to meet the following criteria:

- Have a diagnosis of dementia (any type)
- Be the author of a publicly available blog about their experiences of living with dementia
- Speak English
- Be able to independently use, or be supported to use Microsoft Teams
- Have the capacity to consent to take part in research

Healthcare professionals had to meet the following criteria:

- Communicate verbally in English
- Work with people with dementia
- Be able to use Microsoft Teams

People who lived with any type of dementia were included because the project was concerned with the psychological and social impact of having a label of dementia, rather than with a more epistemologically realist understanding of specific symptoms of each diagnostic category. This was also in line with other research exploring dementia narratives which did not exclude participants based on their dementia diagnosis (e.g., Hillman et al. 2018). For feasibility of data collection and to widen the pool of participants from different geographical locations, all participants needed to be competent in using Microsoft Teams.

2.3.4. Participant’s Demographic Information

Overall, two people with dementia and four healthcare professionals were recruited. Both participants with dementia had a diagnosis of young-onset Alzheimer’s disease and had been authoring blogs since the time that they were diagnosed. Healthcare professionals were all female and worked in varied professional National Health

Service (NHS) roles alongside people with dementia. Participants' full demographic characteristics are presented in Table 1 with pseudonyms to increase anonymity.

Table 1

Demographic information for healthcare professionals and people with dementia.

Pseudonym	Dementia diagnosis	Age	Gender	Ethnicity	Job Role	Age at time of diagnosis
Sue	Young-onset Alzheimer's disease	58	Female	White British	N/a	54
Louise	N/a	51	Female	White British	Trainee Clinical Psychologist	N/a
Mandy	N/a	43	Female	White British	Associate Practitioner	N/a
Gavin	Young-onset Alzheimer's disease	71	Male	White British	N/a	63
Ruth	N/a	28	Female	British Asian	Assistant Psychologist	N/a
Sharon	N/a	24	Female	White British	Rare Dementia Support Advisor and PhD student	N/a

2.4. Procedure

This section will outline the method of data collection, beginning with explaining how blog posts were selected from people with dementia.

2.4.1. Selection of Blog Posts from People with Dementia

Previous research exploring blogs from people with dementia who were involved in advocacy selected five of participants' most recent blog entries for their analysis (Kannaley et al. 2019). In the current study, people with dementia were invited to select two blog posts, with over ten lines of text, and from any point in time to share with the healthcare professionals. The purpose of allowing participants to choose their own entries was to give them agency and control over what they shared with healthcare professionals and the identities that they wished to perform. This was particularly important given the lack of power held by people with dementia, owing to dominant narratives, to define their identities in their own ways (Baldwin, 2006). It is recommended that longer interviews with people with dementia should be avoided to reduce fatigue (Cridland et al. 2016). Therefore, the number and length of blog posts aimed to balance the need to have enough material for the purposes of the analysis, but not so much material that lengthy outsider witnessing practices were required.

2.4.2. Outsider Witnessing Practices: Explanation and Rationale

The narrative practice of outsider witnessing was used in this research as a methodology to gather participants' narratives and enable exploration of the research questions. Outsider witnessing is a storytelling practice that is widely used in narrative therapy (i.e., a type of psychotherapy that is used in mental health contexts). Its use in this research provided a framework for connecting blogs from people with dementia to healthcare professionals, to understand the content of the blogs, and their impact. Moreover, outsider witnessing practice is theoretically grounded within social constructionism and narrative theories which meant that it fitted with the study's theoretical and epistemological position.

During outsider witnessing practices, clients are invited to tell their stories whilst witnesses listen and respond in ways that acknowledge the storyteller's worth, strength, and resources (Carey & Russell, 2003). Therefore, in line with the narrative theories, the focus is shifted away from disempowering stories that focus on symptoms, towards stories of strengths and resilience which are intended to encourage personal growth. The audience (or "witnesses") are required to respond to the story according to four categories (White, 2007) which are: (1) identifying the expression; (2) describing the image; (3) embodying responses; and (4) acknowledging transport. The purpose is to accept the legitimacy of the person's experiences and to draw out alternative stories which are given meaning through their interactions with the audience. There are several limitations of using this approach which are outlined in the critical review (see section 5.3.1).

2.4.3. Briefing Healthcare Professionals about their Role as Outsider Witnesses

Healthcare professionals were briefed about their roles as outsider witnesses ahead of the witnessing practices. Considering research which highlights that healthcare professionals can hold negative beliefs about people with dementia (e.g., Keogh et al. 2020), this was particularly important. Taking time to brief witnesses was also in line with recommendations for inviting witnesses into therapy conversations in clinical practice as doing so aims to make that their involvement as helpful as possible to the storyteller (Carey & Russell, 2003).

2.4.4. Outsider Witnessing: Procedure

Two outsider witnessing practices were held, each lasting for an hour. When Sue read her blog entries, she was “witnessed” by Louise and Mandy, while Gavin's reading of his blog entries was “witnessed” by Ruth and Sharon. Groups were formed based on the order that people were recruited. Data was gathered using the following procedure, adapted from White (2007). A more detailed guide can be found in Appendix G.

1. Participant’s consent was re-checked. They were reminded about the structure and purpose of the group and asked to keep their discussions confidential.
2. The person with dementia read their blog entries aloud to the healthcare professionals.
3. Healthcare professionals were asked to reflect on what they had heard by asking them questions from the four categories of enquiry (White, 2007). These questions were centred on (a) identifying the expressions or images; (b) describing the image; (c) embodying responses; and (d) acknowledging transport.
4. The person with dementia was invited to share their reflections on what the healthcare professionals said.

2.4.5. Individual Follow-Up Interviews

Healthcare professionals were interviewed individually for 30 minutes about their experience of taking part in the outsider witnessing practice. The rationale was to elicit further dialogue regarding the impact of hearing blog entries from people with dementia. A narrative interviewing style was used, enabling interviews to follow the lead of participants in terms of the direction and content of the conversations (Anderson & Kirkpatrick, 2016). During the interviews I asked one broad question which was “what impact did hearing the blog entries read by (either Sue or Gavin) have on you?” I also asked several follow-up questions which aimed to prompt further dialogue (see Appendix H). Following each individual interview, participants were provided with the de-brief sheet (see Appendix I). Figure 1 shows a visual summary of the process through which data was collected, from the start of the outsider witnessing practices, to the end of the individual follow-up interviews.

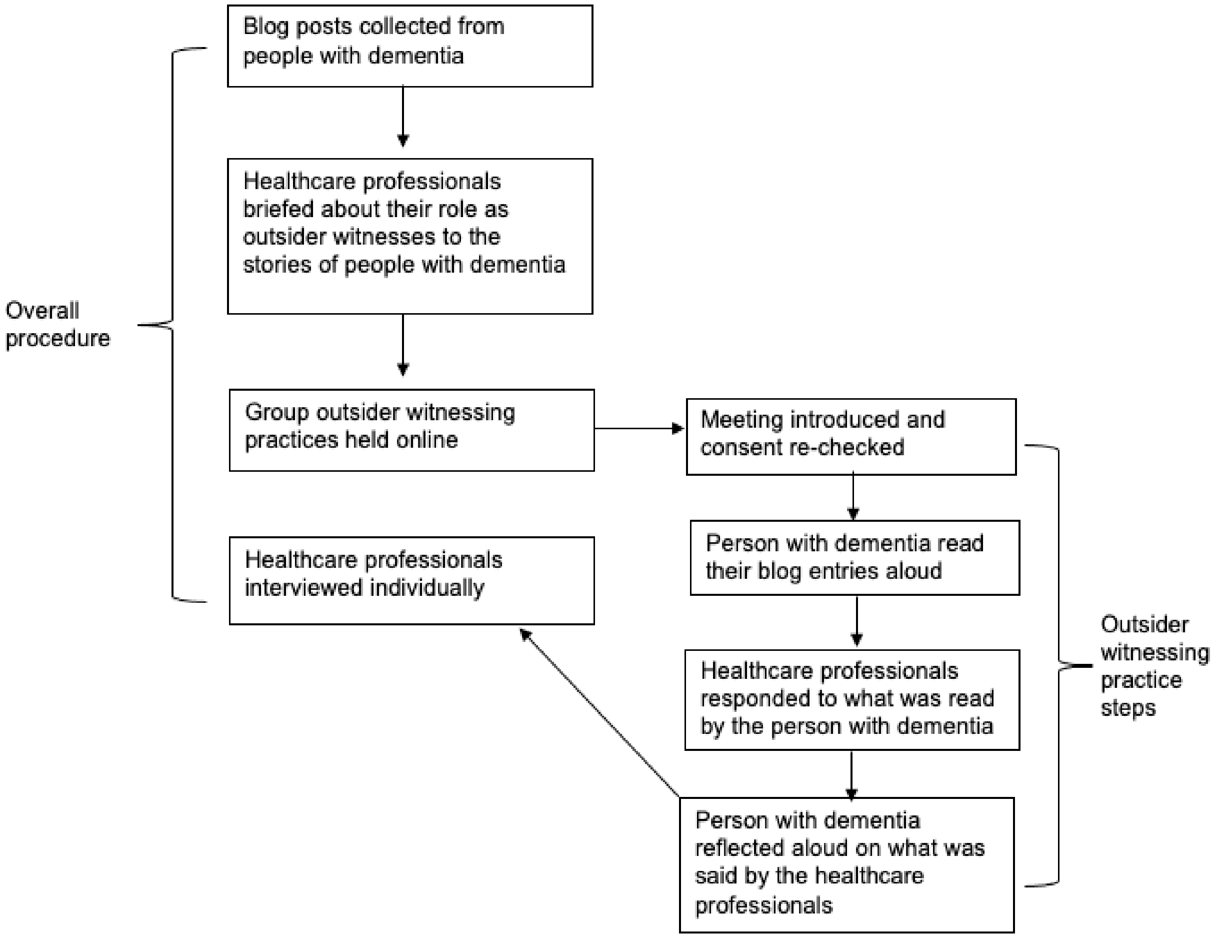

Figure 1

Visual map of the process of data collection.

2.5. Ethical Considerations

This section will outline the ethical issues considered during the process of the research. This was particularly important given that carrying out research alongside people with dementia poses unique ethical and legal issues (Chandra et al. 2021).

2.5.1. Ethical Approval

Ethical approval was applied for (see Appendix J) and granted by the School of Psychology Research Ethics Sub-Committee at UEL (Appendix K). NHS ethical approval was not required because healthcare professionals were recruited through my professional networks, rather than through NHS services.

2.5.2. Establishing Informed Consent

I will now detail how informed consent was sought from all participants, paying particular attention to this process for people with dementia. Providing informed consent requires that potential participants have the “mental capacity” to make the decision to take part. Capacity is demonstrated by people showing that they can understand the information provided, retain it, weigh it up, and then communicate their decision with the assessor (MCA, 2005). However, for people with dementia, issues with memory, comprehension, and language can impact their capacity, and in turn their ability to give informed consent (Chandra, 2021).

In line with good practice guidelines, the study assumed that people had capacity unless there was evidence to suggest that it was compromised (MCA, 2005). Consent was regarded as an ongoing process which was sought at all stages of the research (Hughes & Castro Romero, 2015) because capacity could have fluctuated over the months of data collection. For example, initial consent was ascertained from people with dementia by asking them to sign a consent form. Consent was checked again using verbal questions (i.e., “are you happy to go ahead?”) at the start of the outsider witnessing practice and checked again frequently throughout the practice by monitoring for non-verbal signs of distress. All participants were deemed to have capacity throughout the data collection procedure and provided consent each time consent was checked.

2.5.3. Ensuring the Psychological Safety of Participants

There was a potential risk for people with dementia to become distressed by comments that were made by the healthcare professionals during the outsider witnessing practices. Briefing healthcare professionals ahead of the practices and setting up the practices sensitively served to reduce this risk. The potential to experience distress was discussed with people with dementia prior to ascertaining consent, and they informed me about how they would present if they were distressed and how they would like me to respond should this happen. Participants' verbal and non-verbal communications were monitored for signs of distress throughout the data collection procedure.

2.5.4. Confidentiality and Anonymity

There has been debate amongst blog researchers about whether bloggers should be accredited for their work, or whether the norms within research of protecting participant's anonymity should be followed (Hookway, 2008). Like other researchers that have researched works of art (e.g., Hookway, 2008; Bruckman, 2002), I prioritised protecting participants' identities over accrediting the authors. Thus, full copies of the blog entries from people with dementia are not provided in the appendices, the blogs are not referenced, and pseudonyms are used throughout the report. This decision was made because research requires participants to be anonymous (Wiles, 2008), and it was not expected that authors would be disadvantaged in any way by protecting their anonymity. Although all efforts were made to protect anonymity, people with dementia were informed that they could not remain fully anonymous because their blogs were publicly available online and extracts from their blogs would be presented in the thesis. They were required to state on the consent form that they understood the limits of anonymity. All participants were informed that they were required to keep the personal details of other participants confidential.

2.5.5. Right to Withdraw

Participants were informed that they could withdraw without giving an explanation any time within three weeks of the individual interview.

3. ANALYTIC PROCEDURE

This chapter will outline the method of Narrative Analysis (NA) that was used to explore the outsider witnessing practices and individual interviews. Within the context of approaches to NA, the term “narrative” can be defined in multiple ways. This study uses the term narrative to define a storyteller’s “connection of events into a sequence that is consequential for later action and for the meanings that the teller wants listeners to take away from the story” (Riessman, 2008; p. 3). The terms, narrative and story are also used interchangeably, as suggested by Riessman (2008).

3.1. Dialogical Narrative Analysis: Explanation and Rationale

NA is an umbrella term which is used to describe a variety of ways that narratives can be explored to interpret how individuals make meaning in their lives (Smith, 2016). This study used the approach of Dialogical Narrative Analysis (DNA; Frank, 2010, 2012), which is concerned with the ways in which talk is interactively (or “dialogically”) produced and performed between speakers. The researcher asks “who” a story is aimed at, “when” and “why” it is directed towards them, and for “what” purpose (Riessman, 2008, p. 105).

DNA was adopted for several reasons. For example, it was particularly suited to exploring both how storytellers positioned themselves in relation to their social context (e.g., dominant narratives, conceptualisations of dementia in healthcare, and the immediate storytelling situation), and the ways in which they constructed identities for themselves and of others (Riessman, 2008). Both aspects were important in understanding how participants’ stories drew-upon, added to, and countered dominant ideas about people who live with dementia. Using NA in general also enabled me to access rich layers of information to promote a more in-depth understanding of participants’ points of view (Constantine & Ponterotto, 2006). In line with the study’s epistemological aims, this unique perspective was intended to offer consumers of the research a deeper understanding of the views of professionals and people with dementia that they could draw upon to improve their practice.

DNA is unique from other methods of NA because it is concerned with both the content of stories, and the functions or effects of stories for the storyteller and on listeners (Frank, 2010). In terms of a story's function, DNA assumes that during dialogical interactions storytellers actively work towards generating a change in aspects such as knowledge, mood, or identity in themselves and others, the nature of which can be explored in the analysis (Heritage, 2005). Emphasising the function of stories was helpful in answering the second research question which sought to explore how participants were *impacted* on account of hearing the stories that were shared during the outsider witnessing practices. This is because it helped to shed light on the ways in which participants sought to move their audience.

Other qualitative methods, such as Thematic Analysis, and Interpretative Phenomenological Analysis were considered however, they were ruled out because they did not allow for as much consideration of how stories were socially and culturally embedded or produced during interactions with others.

3.1.1. Deciding What Constitutes a Story: Big or Small Stories

There has been much debate about what constitutes a story suitable for NA. The current study conceptualised the interviews as small stories which can be defined as tellings of ongoing events, or shared events in everyday interactions, through which people make sense of themselves and others (Bamberg, 2004). Small stories research departs from more traditional narrative research which privileges the analysis of long, relatively uninterrupted, and fully formed teller-led accounts of past experiences, or "big" stories (Georgakopoulou, 2015).

The decision regarding how to conceptualise the data posed a dilemma because in practice, distinguishing between big and small stories can be challenging (A. Frank, personal communication, November 14, 2022).[4] However, a small stories approach was better suited to this research for several reasons. For example, healthcare professionals were asked specific questions during the outsider witnessing practices (i.e., questions about expression, images, resonance, and transport) which meant

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[4] I had an email exchange with Arthur Frank when considering the fit of his approach to the aims of this research.

that their narratives were interrupted and produced in response to specific questions. Therefore, they were not uninterrupted, teller-led accounts as are traditional narrative interviews. Furthermore, participants’ narratives were relatively short, and detailed their experiences of what was happening “in the moment,” rather than their experiences of past events (i.e., professionals responded to hearing the blog posts of people with dementia at the time that they were read), providing another reason why participants’ narratives fitted better with definitions of small stories, rather than of traditional big stories.

3.2. Analytic Steps

The analysis was adapted from existing heuristic guides to undertaking a DNA (e.g., Frank, 2010; Smith & Monforte, 2020). Using a guide aimed to balance the need for the method to be rigorous and replicable, whilst also allowing for flexibility of thought (Frank, 2010). The analysis involved undertaking a series of readings of the data and developing a detailed analysis memo at the end of each one. The process was cyclical and iterative, as opposed to linear and fixed (Smith & Monforte, 2020). Each part of the outsider witnessing practice (i.e., the blog reading and the professionals’ responses) and each follow-up interview was considered as a narrative. Therefore, there were eight narratives in total; four were elicited from the outsider witnessing practices, and four were elicited from professionals’ follow-up interviews.

3.2.1. Transcription of Interviews

All interviews were transcribed automatically by Microsoft Teams software and transferred to a Microsoft Word document. Audio and video recordings of the interviews were used to correct errors in the transcription and add information about non-verbal utterances. The symbols used to transcribe these details were adapted from Frosch and Emerson (2005) and are shown in Appendix L. Each participant’s dialogue was transcribed in a different colour to draw attention to each story.

3.2.2. First Reading: Identifying the Thematic Content

The first reading focussed on identifying the key themes which made up each person’s narratives. The themes were marked onto the transcripts using the comments feature in Microsoft Word. The aim of this step was to familiarise myself with the content of the narratives so that the key stories that I chose to focus on could be interpreted within this context.

In traditional “big” stories research, the first reading of transcripts often involves consideration of the narrative’s structure to explore its general trajectory (Smith & Monforte, 2020). However, because participants were required to give their accounts “in the moment” and in response to specific questions, they were not classified as big stories (see Section 3.1.1.), thus, exploration of other aspects of the narratives were prioritised. I will now describe these aspects in more detail.

3.2.3. Second and Third Readings: Asking Dialogical Questions

In the second and third readings of the narratives, several sets of dialogical questions were posed, and reflections were marked on the transcripts (Frank, 2010). Dialogical questions can help to open what was unnoticed about the story (Smith & Monforte, 2020). Questions can pertain to what narrative resources are used by storytellers, who their stories are likely to connect with, how stories give rise to identities, how they generate a bodily feeling, and how they may function in the storytellers’ and listeners’ lives (Frank, 2010, 2012). This research focussed on questions which were considered to highlight something that was helpful in answering the research questions.

During the second reading, I posed a set of questions about narrative resources. Resource questions are those which ask *what* was told in participants’ stories but also *how* they were comprised from other resources that were available to the storyteller (Pheonix et al. 2010). Questions about *how* the narratives were comprised relates to DNA’s assumption that one’s story is never fully their own and are always comprised from a greater stock of narrative resources (Frank, 2010). Stories are polyphonic when they draw upon the voices of individuals, and heteroglossic when they draw upon the voices of communities (e.g., medical or activism communities) or dominant narratives (Frank, 2010). DNA suggests that the resources that one has available to them to tell their stories have the potential to either constrain their selfhood or enable it to flourish (Frank, 2010).

During the third reading, I asked questions about identity and function to highlight how the stories of participants were dialogically produced and performed in interactions with others (Frank, 2010). Identity questions explored how people with dementia constructed identities for themselves and of healthcare professionals, and how clinicians constructed identities for themselves and of people with dementia. Alternatively, questions about function analysed how the stories of people with dementia served them or shaped the conduct of healthcare professionals. Conversely, they sought to explore how the stories of healthcare professionals functioned in the lives of people with dementia. Examples of each type of question that was used, and their purpose are presented in Table 2.

Table 2

Description of the dialogical questions asked, including examples and explanation of the purpose of each. The table is adapted from Caddick (2016).

Type of question	Examples	Purpose
Resource	What narrative resources do people with dementia and healthcare professionals draw upon to construct their stories? Which storytellers have access to which resources? What other resources might lead to different stories?	To understand how people with dementia and healthcare professionals were able to tell their stories, and where these stories came from.
Identity	How are the identities of people with dementia shaped by the stories that they are telling? How do people with dementia construct identities for healthcare professionals? How do healthcare professionals construct identities for people with dementia?	The purpose of asking identity questions was to understand how the stories told by people with dementia and healthcare professionals constructed their own identities and the identities of others.
Function	How do the stories of people with dementia serve their own life, and how do they serve the lives of professionals? How do the stories of healthcare professionals serve themselves, and the lives of people with dementia?	To understand what function the stories of people with dementia had in their own lives and the lives of healthcare professionals, and what function the healthcare professionals' stories had in their own lives and the lives of people with dementia.

3.2.4. Fourth Reading: Selecting Key Stories for Further Analysis

The selection of material for further analysis from the transcripts was based on phronesis, defined as those stories from the total collection which “call out as needing to be written about” because of the wisdom gained throughout the research process (Frank, 2010, p. 43). Other research using DNA has also used phronesis to identify stories for analysis (e.g., Blix et al., 2013; Warmington et al. 2022). What was learned during the research process was the result of the data itself, but also from fieldwork, including conversations with the consultant, knowledge about the priorities of people with dementia who campaign for social change, and my clinical work in dementia services.

Stories were more likely to be selected if they occurred numerous times in the narratives of those who were part of the same outsider witnessing practice, because repetition was thought to suggest that a story was particularly influential. However, the stories presented in the report represented only a few of many possible alternatives, the selection of which would have constructed different representations.

For each story that I selected, the immediate narrative context was considered to make my contributions to the stories told explicit (Emerson & Frosch, 2004). For example, I considered how the stories told were guided by the parameters of the outsider witnessing practices, and the questions that I asked. Narrative context was also a primary focus of previous research with people with dementia and healthcare professionals (Warmington et al. 2022), and providing context is a key feature of evaluating the quality of narrative research (Riessman, 2008). An example of an annotated transcript can be found in Appendix M, and an example analysis memo containing my reflexive considerations and each reading of the narratives is shown in Appendix N.

3.2.5. Member Checking

It is important that after a story has been analysed and thus reconstructed by a researcher, it is sent back to the participant to be “re-authored” (i.e., checked and validated). This ensures that the participant is given the opportunity to check their story and add any nuance details (Birt, 2016). Allowing participants with dementia to re-check their analysis was particularly important considering that it was not possible to fully maintain their anonymity. Therefore, alongside understanding what details could be added to their narratives, it was important to re-check their consent for their narratives to be presented in the report and published online. Participants with dementia were emailed with the analysis of their individual narratives and requested to respond via email to explain any nuances or changes that they wanted to make. They were also given the opportunity to have a conversation about their analysis over Microsoft Teams if this was preferred, however neither participant with dementia wished to make any changes.

3.3. Reflexivity

This section will outline how reflexivity was integrated into data collection, analysis, and presentation stages of the study. Reflexivity refers to a researcher's honesty with themselves, their research, and their audience about their subjective values, biases, and inclinations, detailing how these may have impacted the knowledge that was produced (Tracy, 2010). For example, the narratives that were generated from the interviews would have been influenced by the questions that I asked, my social positioning as a young, white female healthcare professional, and participants' beliefs about what I might have expected from the research. To attend to this, I wrote a reflexivity note on the analysis memo for each participant which noted my emotional interactions and considered mine and the participants' intersecting identities (see Appendix N). I also kept a journal throughout the study which detailed my reflections on the experience of being with each participant and my general observations about their appearance, behaviour, narrative style and affect. An example from my journal can be found in Appendix O.

4. ANALYSIS

I will now present my analysis of the two outsider witnessing practices and four individual follow-up interviews, all of which took place online. Narrative research that conceptualises interviews as “big” stories often presents the analysis of participants’ interviews as one long narrative for each person (Riessman, 2008). However, since the interviews in this study were conceptualised as “small” stories (Bamberg, 2004), the analysis is instead structured in line with the process through which the data was collected. Presenting the analysis in sections, rather than as a long account for each participant intended to ensure that the analysis was situated within the context of the interview situation including the questions that I asked participants.

To provide context and orientate the reader, I will outline some details about each participant’s background and the interview circumstances at the start of section of the analysis. I will also clarify the meaning of each transcription symbol in the footnote as they are used in the text, however a full key can be found in Appendix L. Line numbers are provided at the start of each long excerpt which correspond with the line numbers on the transcripts and each excerpt is numbered.

4.1. Sue’s Story

The first outsider witnessing practice involved Sue (a person living with dementia), Mandy, and Louise (healthcare professionals). Sue read two of her blog entries and I invited Mandy and Louise to respond to what they had heard. The first blog entry that Sue read (dated December 2020) detailed her experience of attending a memory service, and her initial reactions to receiving her dementia diagnosis. Part of this first blog entry was read as a poem. In Sue’s second blog entry (dated May 2022), she talked about the ways in which her identity had changed following her diagnosis. Thus, although Sue’s blog entries were dated some time apart from each other, she read them at the same time, one after the other for the purposes of the outsider witnessing practice.

4.1.1. The Memory Clinic

Sue’s narrative captured her unpleasant experience of the assessment, diagnosis, and treatment process that she went through when attending a memory clinic. Whilst reading her first blog entry, she explained that it took around seven months for her to receive her diagnosis. In excerpt 1 which captured Sue’s reading of part of her poem, Sue told Louise, Mandy, and me the story of what happened when she attended the memory clinic to find out the outcome of the doctor’s cognitive assessment. In the following excerpt, “he” refers to Sue’s doctor:

> [95-103] He clasps his hands together, he leans back in his chair
> He taps his notes together and flicks aside his hair
> I'm sorry, Mrs Smith we have to tell you this
> We've looked at all your tests and eventually come up with this
> Your memory has deteriorated in these categories
> You have cognitive impairment, it's Alzheimer’s disease.
>
> I have the diagnosis, it's Alzheimer's disease
> This is truly flooring… now it's time to leave.

<u>Excerpt 1</u>

Sue seemed to highlight her sense of despair on being told that she had Alzheimer’s disease. Her narrative appeared to draw upon the voice of the doctor to reconstruct the way in which the doctor gave her the diagnosis. Words such as “deteriorated,” “impairment” and “disease” within her narrative could be said to align with the negative and pessimistic framings of dementia that have been suggested to dominate societal narratives. It could be suggested that by constructing her narrative from notions of dementia as being an impairment or disease, Sue was perhaps likely to come to see herself as being impaired or diseased. Sue’s dialogue in excerpt 1 was marked by a heavy moment in the outsider witnessing practice. I wondered how her narrative had been constrained by medical framings and dominant narratives of dementia, and how her story would have been different had her doctor conveyed the diagnosis in a more hopeful way.

After sharing her experience of receiving her diagnosis, Sue made a plea to professionals to “please, please understand, you need to keep us going!” Sue’s request to “keep us going” seemed to make the implicit message of the poem (i.e., that professionals should promote a sense of hope when diagnosing someone with dementia) explicit because she reiterated her perspective. Her narrative perhaps suggested that Sue used her distressing experiences at the memory service as motivation to engage in advocacy which involved her using her voice to share her ideas about how professionals could improve their practice.

4.1.2. Changing Identity

Sue’s narrative also constructed the ways in which her identity changed during her “journey” with dementia. Excerpt 2 captured how she introduced her second blog entry during the outsider witnessing practice to Louise and Mandy:

> [142-145] Sue: … and then this year, I wrote one which (2 secs)[5] it was about finding me. Because when you get a diagnosis, you seem to lose who you are and you've lost your job, you've lost, you've lost everything, really. Everything that that you was used to doing. So I wrote this blog.

Excerpt 2

Sue explained that being diagnosed with dementia lead to a loss of her selfhood, in part because she lost her job. Her narrative seemed to align with dominant sociocultural narratives of dementia which convey the idea that dementia leads to a loss of identity. The statement “so I wrote this blog” as the conclusion of Sue’s account suggests that the act of writing blogs may have served as an initial catalyst for the reconstruction of her identity.

In excerpt 3 Sue seemed to reflect on the impact of her friends’ attitudes and beliefs about her identity which, as she suggests lead to lose valuable relationships:

---

[5] This symbol represents an extended pause, and the number inside the brackets refers to the length of the pause.

> [205-216] Sue: Some friendships that I, I really cherished ended due to my dementia. Friends believing that I am no longer the same person that I used to be. That's how some people see dementia.[6]
>
> What is an important thing to remember is that I still cherish those severed friendships along with the experiences because I was lucky enough to have them in my life.
>
> The reality was that these people were unable to see me. They only saw the me they wanted me to be.
>
> The people that have accepted me, I am happy to say that our friendships/relationships are stronger.

Excerpt 3

Sue suggested that the stigmatising attitudes held by her friends meant that her friends no longer wanted to be friends with her. Her suggestion that "some people" held negative beliefs and attitudes towards dementia could be seen as implying that contrary to how other people saw her, Sue *did* in fact see herself as being the same person. Therefore, Sue's narrative in excerpt three and excerpt one appeared contradictory. In excerpt one she suggested that she had lost her identity, whereas in excerpt three she explained that she was still the same person. This contradiction could be understood by considering the time at which she wrote each blog post because excerpt one is taken from an earlier blog post than excerpt two. Perhaps when Sue was first diagnosed, she felt stripped of her identity, however, as time passed, she perhaps found ways of re-constructing her selfhood. Sue also suggested that when others accepted her, their relationships were strengthened, thus her narrative highlighted that when others held favourable attitudes towards her, dementia could bring about positive changes as well as losses.

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[6] A solid line underneath the text represents words that are emphasised.

Towards the end of her blog narrative, Sue's story appeared to reach a high point where she suggested that she had learned to "accept" her illness:

> [196-199] The experience that I have taken with me over the last three years has <u>empowered</u> me to be the person that I am today.
>
> "£[7] acceptance and appreciation are the key to being me.
>
> <u>Excerpt 4</u>

In excerpt 4, Sue's narrative suggested that her previous experiences had enabled her to construct new parts of her identity, and that attributes such as acceptance and appreciation were core to who she was. Considering the function of her narrative, and in line with narrative theories which suggest that the stories we tell shape who we are, perhaps Sue's story about her personal transformation helped her to continue living as well as she could with dementia, enabling her start with what she described as her "new chapter" in life.

At various points during the outsider witnessing practice Sue seemed to draw upon the collective voice of the dementia community. For example:

> [162-166] Sue: Why should I try and fit in! Mould myself into something I'm not comfortable with.
>
> I have realized it's not about fitting in… It's about being me.
>
> When you are being yourself, everything comes from your heart, usually unfiltered, we just go with our first thoughts.
>
> <u>Excerpt 5</u>

---

[7] A £ sign represents that participants are talking in a smiley voice or using suppressed laughter.

In excerpt 5, Sue’s narrative constructed her realisation that life, to her was not about following normative expectations about how she should behave. Instead, she suggested that she valued being able to be her authentic self. Sue’s narrative appeared to change from using individual terms (e.g., “I” and “me”) to describe herself, to using collective terms as she suggested that “*we* just go with our first thoughts.” It could be hypothesised that her use of the term “we” referred to the wider community of people with dementia, thus her narrative seemed to draw upon the collective voice of the dementia community. Her narrative perhaps functioned to teach others of the value of being different, and thus perhaps to improve societal attitudes towards people with dementia.

4.2. Witnessing Sue’s Story

After Sue read her blog entries, I invited Louise and Mandy to respond to what they had heard using the four categories of questions used during outsider witnessing practices (White, 2007). Mandy is an Associate Practitioner who worked in a memory clinic and Louise is a Trainee Clinical Psychologist, who, at the time of data collection was working in a specialist dementia assessment service. I will re-construct some of the key stories that were elicited from Louise and Mandy during the outsider witnessing practice.

4.2.1. Expressions

The first question that I asked Louise and Mandy was “what expressions caught your attention or captured your imagination?” Louise was struck primarily by Sue’s insight into her experience at the memory clinic, and particularly by her expression about the sound of her feet “stomping” down the corridor:

> [249-267] Louise: What stood out was from that first poem (.) was it the sound of the feet stomping down the corridor, because I have recently been through something similar with my father and (.) and it's very it was very evocative, and I went into goosebumps because seeing it from the other angle-

> Hannah: Can you tell me a bit more about the feet stomping, what did it evoke?
>
> Louise: Uhm (.) going to the memory clinic and there’s a sort of parade, they said, oh there’s a lot of you because my step mums very frail and she's got her walking stick. My dad, he’s sort of bouncing around but doing his own thing and then so it's a trail of the psychiatrist, my step mum hobbling along, my dad is thinking about whatever he’s thinking, and then me and it was just going down that long corridor. That’s what I meant. Evocative about (.) what is that like, the experience of going into these places from the other side.

Excerpt 6

This extract captured how Sue’s blog entries enabled Louise to understand the experience of going to a memory service from her father’s “angle” or “side.” Thus, Sue’s story and Louise’s story seemed to connect because they had both experienced attending a memory service. Despite holding the identity of a healthcare professional within the outsider witnessing practice, Louise shared a personal story which highlighted her identity as a daughter as well as a clinician. In sharing this personal perspective, she seemed to challenge ideas about professionalism within relationships between service users and clinicians whereby clinicians are expected to hold “boundaries” and not disclose personal information. Louise’s story seemed to balance the power dynamic between Sue as a service user and myself, Mandy, and Louise as clinicians, which created a space which appeared to me as being open, warm, and respectful.

4.2.2. Images

The second question that I asked related to the “images” that were evoked by listening to Sue’s blog entries. Louise described a metaphorical image of Sue as a maypole:

> [403-424] Louise: …I guess if there's an image, its Sue at the centre of this core family and people who matter to her right in the middle and actually

> making decisions where decisions before have kind of been taken away from her.
>
> Mandy: Yeah
>
> Louise: (.) and it feels hopeful (2 secs) … £ It's like a maypole. Sue can be a maypole.

Excerpt 7

Louise seemed to draw on ideas related to personhood and person-centred care as she noticed how Sue's identity changed from someone who had been excluded from making decisions, to someone who was now at the "centre" of her family. The image that she constructed brought her a sense of hope. Her reference to a maypole perhaps reflected her identity constructions of Sue as someone who was resilient and strong which was in direct contrast with dominant narratives if dementia, for example the narrative that people with dementia are a burden to others and society.

Similarly, Mandy explained how Sue's blog entries led her to construct the image of an "epic" (i.e., a genre of narrative characterised by a heroic adventure). Mandy's dialogue was marked by laughter and smiling which created a fun and light-hearted tone:

> [295-309] Mandy: So it's almost like an epic. So at the beginning of the story there's this (.) disaster. And then as it goes on, Sue kind of shows that no, this isn't gonna be the, the be all and end all for me. I am still this person. I can still do xyz. I'm still this. I'm still a mum, grandma. All those lists that she said, I'm still all of those. So at the end it's almost a triumph over this nasty little thing that tries to ruin everything. [1 sec] that's how I see it anyway (h).[8]
>
> Hannah: Determination?

---

[8] This symbol represents laughter within the dialogue.

> Mandy: Yeah, definitely.
>
> Hannah: Can you say a bit more?
>
> Mandy: She's a fighter. She’s not taking it lying down, not accepting it, and if she doesn't like it, it’s not gonna happen (h).

Excerpt 8

In expert 8, Mandy’s narrative highlighted her interpretation of Sue’s story, as one which started with the “disaster” of being diagnosed and ended with Sue’s “triumph” over dementia at the end. She reconstructed Sue’s story using various master narratives. For example, her narrative appeared to align with models of person-centred care because she demonstrated that she had not lost sight of Sue’s identity, and she affirmed Sue’s identity as a “mum,” and a “grandma.” Mandy focussed on Sue’s strengths by stating her view of what Sue could still do, rather than on what she could no longer do. Therefore, at this point, Sue’s narrative perhaps influenced Mandy’s to convey a hopeful story of dementia.

My dialogue in this excerpt also shaped how Mandy’s dialogue unfolded. I responded to Mandy by questioning whether Mandy was referring to Sue’s determination, and this led Mandy to share imagery about Sue as a “fighter,” thus demonstrating the power that I had as the researcher in shaping and influencing participants’ narratives.

4.2.3. Resonance and Transport

I asked Louise and Mandy how Sue’s blog entries “resonated” with them in their own personal or professional lives, and how they had been “moved” on account of hearing Sue’s story. Mandy shared how witnessing Sue’s story reminded her of the importance of keeping people who are living with dementia at the forefront of her mind during her professional interactions:

> [593-599] Mandy: I think it is like Louise just said, just trying to keep the person at the forefront of your mind when you are on your sixth person of the day and you're knackered, it's not that sixth person's fault that you're knackered, it's you know, you still have to treat them as if they are the first one of the day or the first one back from holiday and you're completely refreshed and on the ball and, everything's good. You need to treat <u>everyone</u> like that. So I'm gonna have to (.) yeah keep it in mind yeah at the beginning when I knock on that door.

<u>Excerpt 9</u>

It is not clear what Mandy meant by "keeping the person at the forefront of [her] mind." She could have been referring to ideas about personhood whereby clinicians are required to consider people (i.e., their multiple identities) first before their diagnosis, or alternatively she could have meant that she wanted to display empathy even when she was feeling tired. Either way, Mandy appeared to highlight how expectations from her service in terms of how many appointments she was expected to do in a day provided a barrier to her being able to practice in the ways that she wanted to.

For Louise, Sue's blog entries led her to consider the relationships between professionals and people with dementia in healthcare:

> [531-538] Louise: Yeah, uhm, in terms of change for me, I'm I'm I'm, I couldn't tell you right now what the change will be. I know that I keep, just in terms of memories of people I've come across almost like a treasure box in my head, so it will go in my treasure box of sort of experiences and hearing this and it'll be brought up again. I think what it was a really good reminder of something, you know (.) what the the ideal when working with someone is uhm (.) I bring my experience, they bring in their experience and actually we're holding hands and we're walking together towards something uhm I'm not tugging a person along, and they're not tugging me along. We're actually on the journey together and just keeping that in mind because each journeys gonna be different(.)

Excerpt 10

Louise explained that she was unsure of how witnessing Sue's blog entries would change her, however she referred to her memory of Sue as something that she would "treasure." She reflected on what she saw as "the ideal" when working with people with dementia which she explained meant that she and the person were on a journey side by side each other. She highlighted the reciprocity in the relationship whereby she felt that both parties brought important knowledge and experience, and in doing so suggested that power should be shared. Louise's analogy of professionals and service users "holding hands" resonated with my own understandings of professional relationships which I acknowledged by nodding and smiling when Louise spoke.

4.3. Louise's Experience of Hearing Sue's Blog Entries

I will now construct some of the key stories from Louise's follow-up interview which took place a week after the initial outsider witnessing practice and explored her experience of "witnessing" Sue's blog entries with Mandy.

4.3.1. Challenging Prior Assumptions of Dementia

Louise begun her individual interview by suggesting that she had expected Sue to present with more cognitive difficulties than in fact she did. She highlighted her surprise that she had made this assumption:

> [7-15] Louise: I'll be honest, I, I thought that, I thought that Sue would be more cognitively compromised than she was. It could have been anyone just sitting there talking to us and, and I'm surprised at myself because that prior assumption is not something I would say I'd make, but I had made it and I thought it's gonna be, that there might be some silences or that she might not be able to sort of engage in conversation, but actually, from the get go when she joined the screen it was a completely normal conversation. So just aware that I had made some assumptions.

Excerpt 11

Louise’s narrative reflected her expectation that Sue may have found it difficult to converse with Mandy and Louise or speak fluently without silences. Her suggestion that her story was “honest” seemed to reflect a sense of guilt or shame about her prior assumptions that were possibly not reflective of the professional that she saw herself as. Her narrative perhaps reflected the power of normative expectations of what someone living with dementia “should” be like which, to her surprise, led her to hold inaccurate preconceptions. Louise went on to suggest:

> [20-22] Louise: “The funny thing is, that’s never been my experience of working with people with dementia, all my interactions have been lively.”

Excerpt 12

Louise appeared to further convey her sense of surprise that, despite her experiences of working with people with dementia often being lively, she had assumed that Sue would have presented with greater difficulties than she did.

4.3.2. The Importance of Listening, Humanity and Warmth

Witnessing Sue’s blog entries brought Louise to consider the importance of peer support, humanness, listening, and warmth in healthcare and her own practice:

> [220-224] Louise: If we listen enough to people we could, things could be put in place that actually that were appropriate for them. Uhm yeah well rather than, like, rushing in to fix this bit, this bit, actually saying, well, what's helpful for you (.) I do know peer support is helpful, is probably the most helpful thing is voices together and yeah, listening (.) listening to the person about what they want to happen.

Excerpt 13

Louise highlighted her frustration and exasperation at the healthcare system for providing interventions which she felt were inappropriate, implying her sense that the support Sue received was unhelpful because clinicians had not listened to her. Moreover, in excerpts 14 and 15, Louise talked about how she wanted to pass on what she had learnt from Sue to other people in her service:

> [173-176] Louise: It’s consolidating that, and I think if- (.) because I have a complete aversion of anything leadership or managery, just don't like it but if it was one thing I ever wanted to teach or pass onto people, it’s warmth, how to do warmth because you establish trust baseline.
>
> Excerpt 14

> [191-195] Louise: Her blog, or her speaking uhm was motivating because it it says these things need to happen, this humanity needs to be encouraged. You know, people need to be supported and and and it's actually motivating. This is a good reason to actually in the future at some point step into a senior role because you are able to make this happen and encourage it.
>
> Excerpt 15

In excerpts 14 and 15, Louise shared her values of warmth and “humanness,” and her belief in the importance of listening to people. She suggested that Sue’s story inspired her to consider applying for more senior roles in the future so that she could support others to practice in this way. Through telling stories about how she had learned from Sue, she seemed to position Sue as someone who she valued and respected, a position which is strikingly different to dominant ideas of people with dementia as dependent, vulnerable, or lacking capacity. Louise’s suggestion that Sue’s blog was “actually” motivating suggested that her drive to take on leadership positions was surprising to her, perhaps because it did not fit with her usual constructions of her own identity.

4.4. Mandy’s Experience of Hearing Sue’s Blog Entries

I will now re-construct some of the key stories from Mandy's follow-up interview which took place two weeks after the outsider witnessing practice.

4.4.1. Adopting a Listening Position

When asked about Mandy's experience of being an outsider witness, her narrative captured her appreciation of being able to listen to Sue's story, particularly because it was different to the stories that she usually heard from service users:

> [192-211] Hannah: How did find being an outsider witness? So, taking on the role that you took within the group?
>
> Mandy: See I, I lead quite a lot of groups and meetings, so to be part of the, well, not the main character was quite nice because I got to listen to listen to someone else's story, which is one of my favourite things about my job, that you hear all of the fantastic things that people have done. So, yeah, someone needs to make a movie about her (h)
>
> Hannah: Mmm so listening to Sue's story, how was that?
>
> Mandy: So listening to not only what happened, because you hear a lot of that, you hear the facts. So in October I noticed that I was forgetting things for shopping. In November, I went to the doctor. In January, I had the scan and it wasn't that, it was, it was those things. But then it's like… <u>and this made me feel like,</u> and this is what I said to my husband, and this is how it felt for my family when we were talking about it, so all those extra little snippets that aren't just fact based there, what's the word? Call it qualitative, yeah, whatever it is, yeah.
>
> <u>Excerpt 16</u>

Mandy suggested that being able to adopt a listening position (rather than a speaking position) during the outsider witnessing practice brought a welcome change from her usual role at work. Her narrative also suggested that Sue's "qualitative" insights were different to the "facts" that she often heard during her clinical practice, as Sue's dialogue was more focussed on her feelings. This discrepancy perhaps reflects something about Mandy's context as a healthcare professional who was expected to see many people in a day, as perhaps she did not have time to hear any more than the "facts." Mandy appreciated the depth of Sue's narrative as she felt that it gave her a greater insight into the experience of dementia.

4.4.2. Taking Action

Sue's narrative appeared to function in Mandy's life by inspiring her to update the resources that she shared with people with dementia who were younger, livelier, and busier:

> [157-162] Mandy: Yeah, and one of the other things I have done is I've got a pack of activities and different resources in each of the towns and villages that I work in and I have planned, cause I'm over in those villages quite often, just to sort of maybe find a spare half an hour and look at the community boards again and just see if there's anything a bit more, uhm yeah (.) lively for the younger ones or the busier ones, rather than the same old, same old.

Excerpt 17

Her narrative highlighted her wish from hearing Sue's story to act by updating her resources for service users with new information about "what's on" in the community. Her reflection that she wanted to find some spare time to improve the care that she provided suggested both the lack of time that she had, but also the value of time in improving practice. At one point, Mandy explained that she had already been to look at the community boards, but another point she said that she had only planned to look, she had not already looked. It was not clear whether Mandy had or had not looked yet, however, the contradiction perhaps reflected her desire to perform her identity to me in ways that she thought I wanted, for example by suggesting that the outsider witnessing practice had led her to change.

4.5. Gavin’s Story

I will now present the analysis from the second outsider witnessing practice involving Gavin (a person living with dementia), Sharon, and Ruth (healthcare professionals). Gavin read two of his blog entries and I invited Sharon and Ruth to respond to what they had heard. Gavin’s first blog entry was constructed in July 2021. In his blog, he suggested that it had been written following a conversation with his friends who were also living with dementia, and he suggested that the entry detailed their “thoughts and feelings about [their] disease.” His second blog entry (dated January 2022) portrayed Gavin’s experience of living with dementia over the Christmas period. It is important to note that often, Gavin’s blog entries used collective terms such as “we” and “our,” suggesting that his stories often aimed to represent not only his experience, but also the experiences of the wider community of people living with dementia. Therefore, I will switch between using singular and collective terms throughout the analysis to reflect the language that Gavin used in his entries.

4.5.1. The Negative Effects of Dementia

Gavin’s narrative frequently detailed his experience of how he and his friends were affected by dementia. For example, in excerpt 18 below which was taken from his reading of his first blog entry, he described their experience of living with dementia using imagery and metaphor:

> [12-20] Gavin: This brain disease is like that. It hiccoughs the automatic sequencing that you have done all your life. Everything you learned from birth. Little bits get lost or don’t work, so the chain is broken and you do things wrong.
>
> Pour your drink over your supper.
>
> Talk to the invisible visitors that come and go.
>
> Make tealess tea.
>
> Be unable to tie shoelaces.

> Lose words.

Excerpt 18

Gavin outlined the ways in which he and others conceptualised their illness, suggesting that they understood dementia primarily as a “disease” that disrupted and boke the usual cognitive processes in the brain. Thus, Gavin’s narrative seemed to reflect the dominant medical and scientific way of conceptualising dementia within healthcare services and society. He used a series of metaphors which outlined how the changes in their brains impacted their day-to-day lives, leading them to “lose words,” for example. Therefore, in this excerpt his story suggested that he and others felt a sense of sadness and loss due to their illness. Considering the ways in which Gavin’s story may have served his identity and life, it could be suggested that telling stories about his problems risked constraining Gavin’s identity by promoting a sense of himself as deficient or defective. However, his story regarding the negative effects of dementia was also accompanied with a request to the audience:

> [58-61] Gavin: So remember, those of you who meet us and talk with us, or paint or draw or sew or cook or carve with us…be ready to lend us an arm to lean on. Watch out for the signs, the morse code messages we send out.
>
> Our faces may not signal any change, but our silence might.

Excerpt 19

In excerpt 19, Gavin directly asked people to be aware of the signs that a person with dementia was distressed and to be prepared to offer them support. This request seemed to mark an ending to his story in excerpt 18 which portrayed the negative effects of dementia. Therefore, his story which begun in excerpt 18 by outlining the challenges of dementia perhaps served to promote empathy and understanding amongst others (i.e., readers of his blog).

Another struggle associated with dementia portrayed through Gavin’s narrative was related to the experiences of him and other people with dementia at Christmas:

> [123-129] Forgive us, please, that we can no longer join in. I promise, we would if we could. We would love to.
>
> But when you have to stand still for five seconds before putting your leg into your trousers, to make sure you get it right and don't fall over, believe me, you don't have much spare capacity.
>
> When it takes five seconds to work out what someone said, and another five to decide how to reply, quick fire, multi-person dialogue is not really a starter.

<u>Excerpt 20</u>

He seemed to convey the sense of exhaustion and exasperation felt by people with dementia due to the challenges associated with managing every-day tasks such as getting dressed and trying to "keep up" with conversations with others. He suggested that despite their wish to "join in" at Christmas, taking part in celebrations was often challenging, and he asked for the audience's forgiveness at this loss of ability. Gavin's narrative seemed to capture the difference between how people with dementia wanted to act, and the actions that were possible given the challenges associated with dementia. I felt sad upon hearing this, and Sharon's and Ruth's facial expressions during this part of Gavin's narrative also suggested that they shared my sense of sadness. However, immediately after, Gavin went on to read:

> [130-132] Gavin: And for goodness' sake don't start down that other road: 'well if he can write that he can't have dementia!' My intellect is unimpaired, <u>mate.</u> It's the speed and method of using it that are declining.

<u>Excerpt 21</u>

He imitated the voice of someone else who appeared to believe that because Gavin was writing blogs, he could not have been living with dementia, and he responded to this voice within his narrative by arguing that dementia had not impaired his intellect. Gavin's narrative seemed to reflect the stigmatising beliefs that were hold by this other person about how people with dementia *should* present (i.e., as someone who could not write). His use of sarcasm and humour which was strengthened by his emphasis on the word “mate” perhaps demonstrated that he strongly rejected this pejorative suggestion. By rejecting the identity of someone who did not have dementia in his blog, Gavin perhaps sought to protect his identity as a person with dementia and get readers of his blog “on side” so that they could learn about the negative impact of stigma.

4.5.2. Coping with Dementia

Gavin’s narrative frequently constructed the ways in which he had learned to cope with the effects of his illness, and this story positioned alongside those which portrayed the challenges of living with dementia. His story about coping was marked using personal pronouns such as “I” rather than collective pronouns, perhaps suggesting that the ways in which one manages dementia is personal and varied. For example, in excerpt 22 which was taken from the reading of his first blog entry, Gavin presented a series of questions which he seemed to have been asked previously by other people:

> [21-31] Gavin: How do these chain breaks make you feel?
>
> Do you get angry when they happen?
>
> Do you imagine your future?
>
> Do you weep at the loss of skills or memories?
>
> I do, indeed, think frequently about my disease and its effects, but not often in a fearful way.
>
> I have grown accustomed to living with physical defects since I my 20s and I developed a bone disease on my lower spine. It stopped me from playing sport and became disablingly painful at times.

> Other illnesses and diseases have got me as the years rolled by, so I just live with whatever symptoms I have at any time. Take the pills!
>
> Excerpt 22

In excerpt 22, Gavin presented the questions that he had been asked by others about how he managed his illness, before providing answers to them. The questions that he (re-)presented appeared to reflect societal expectations about how people with dementia should feel (i.e., angry, fearful, and sad about their illness). Such ideas perhaps arise from sociocultural notions that dementia is synonymous with a “living death,” “tragedy,” or “catastrophe.” However, Gavin’s response seemed to counter these dominant expectations because he suggested that he did not in fact feel frightened of his illness, or angry about it. He reflected that his previous experiences of coping with illness had helped him to be able to live alongside symptoms of dementia. Therefore, he seemed to frame his experience in line with narrative resources of “living well” with dementia. His narrative, which could be seen as challenging prevalent societal norms perhaps serves his life by enabling him to foster a sense of peacefulness and acceptance. Thus, he did not appear to get entangled within a battle with his illness. Later in his narrative he talked about the future and said “what will be will be” which also seemed to convey a sense of acceptance owing to a lack of personal control over his future.

4.6. Witnessing Gavin’s Story

I will now reconstruct some of the key stories that were generated from the online outsider witnessing practice with Sharon (an Assistant Psychologist who works in an NHS care home support service), and Ruth (a Support Advisor and PhD student who works in a rare dementia service). During the outsider witnessing practice, Sharon and Ruth “witnessed” Gavin’s blog entries by responding to the four categories of questions (i.e., questions of expression, image, resonance, and transport) proposed by White (2007).

4.6.1. Expressions

The first question I asked was about which “expressions” caught the healthcare professionals’ attention. Both were struck by Gavin’s use of language which they said enabled them to better understand the experience of dementia:

> [155-172] Sharon: … I umm was thinking about the same sort of powerful language that was used like bite and lost and even tealess tea and invisible visitors. It was very, very powerful and it really paints that picture for us to show us how clearly this might be umm envisioned by by Gavin, and (.) yeah, just helps me see what that might be like for someone with dementia.
>
> Hannah: When you say Sharon, when you say it gives you an idea of what it might be like for someone living with dementia, can you tell me a bit more about that?
>
> Sharon: I suppose hearing it being described with such powerful language like this, it just (2 secs) opens my eyes a bit more (.) umm and I suppose using that language you can see emotion attached to it as well.

Excerpt 23

In excerpt 23 Sharon suggested that Gavin’s use of powerful language, particularly his references to making tealess tea and seeing people that were not there helped her to gain an insight into Gavin’s subjective world. Her narrative seemed to portray a sense of empathy for Gavin which Sharon used to empathise with, or consider the perspectives of other people with dementia. From Sharon’s account, it appeared that she had not encountered narratives that offered such an evocative understanding of dementia prior to this. This difference in the insights provided by Gavin and the level of insight that she was used to hearing could perhaps be explained, in part by her occupational context. Indeed, Sharon worked with people with dementia in a care home setting who were perhaps more likely to communicate non-verbally, therefore, she may have had less exposure to service users who portrayed their emotions using such expressive and figurative language.

Similarly, Ruth was also struck by Gavin’s examples of how dementia impacted his daily life. In excerpt 24, Ruth suggested that she was struck by how normal Gavin’s descriptions of making “tealess tea” and talking to “invisible visitors” seemed to him, however, for her his expressions were shocking:

> [239-248] Ruth: …And so it's not shocking for you to read, for Gavin to read that list, whereas for us to hear it it is, so that really struck me of the difference of how we just see people getting on with their day and don't think much of it but there's so much going on behind the scenes that we're unsure of.
>
> Excerpt 24

Ruth suggested that the discrepancy between how she perceived Gavin’s challenges and how Gavin perceived them made her consider the difference between what people (i.e., outsiders such as healthcare professionals) saw when they spoke to someone with dementia, and reality of what the person experienced “behind the scenes.” She suggested that it was not possible to know entirely what someone else’s experiences were which seemed to serve as a reminder to be curious and empathetic in her practice. Considering the context of the group interview, Ruth corrected herself when she said “for you to read, for Gavin to read” to align with the instruction that I gave at the start to refer to Gavin in third, rather than first person. Her correction reminded me of the influence of the practices’ parameters on the stories that were constructed.

4.6.2. Images

When asked about the “images” that Gavin’s story evoked, Ruth constructed a vivid image of Gavin at the centre with different materials moving in front of him and then away again, but not impacting his central position:

> [272-281] Ruth: It might sound quite odd but rather than sort of a static image, I very much have an image of of Gavin in the centre, a very strong character because I feel like the presence, the way that Gavin is able to express himself through the blogs, it does feel like a a very strong voice and presence and a

> very important presence, but almost with blobs kind of moving in front of the picture and shifting away as these different challenges arrive. So, it's more of a fluid movement of the things that dip in and touch George and affect his life and then they kind of step back as he might move through the different emotions that he's described in the blog posts.

Excerpt 25

Ruth suggested that she perceived Gavin as having a “strong voice and presence” which she felt had remained unchanged despite the challenges that he experienced (represented in her image by moving “blobs”). Thus, her dialogue appeared to challenge the dominant narrative that dementia leads to a loss of identity, and instead she conveyed her sense of Gavin as a strong and resilient man. Her perception of his strength seemed to come from “the way that Gavin [was] able to express himself through the blogs.” Though it was unclear how Gavin’s expressions influenced her perception of his identity, she could have been referring to aspects such as his use of language, his tone of voice, or the fluency with which he spoke. Whilst these aspects led her to construct a positive image of Gavin, her narrative could be seen as reflecting her implicit assumption that a person with dementia was perhaps less likely to speak in this way.

4.6.3. Resonance and Transport

Ruth and Sharon were asked how Gavin’s story “resonated” with their own life experiences, and how they had been “moved” on account of hearing Gavin’s blog entries. Ruth explained that she interpreted a sense of desperation in parts of Gavin’s blogs due to people’s lack of understanding about dementia. In excerpt 26, she suggested that this sense of desperation was something that she connected with:

> [421-426] Ruth: I think it really connected with kind of the desperation in in parts of the blogs where you just want people to understand and you almost wanna shake them and be like, look, it's not that difficult. There's lots of different ways that dementia can kind of manifest.

Excerpt 26

Ruth suggested that she felt similarly frustrated about people's lack of understanding of dementia; a frustration and exasperation which she conveyed by emphasising the words "you just want people to understand." It is not clear which part, or parts of Gavin's story led Ruth to conclude that people did not understand dementia. However, her suggestion that there were many ways for dementia to manifest perhaps fitted with Gavin's story about other people not believing that he had dementia. In contrast to Ruth's suggestion in excerpt 25 that she was not aware of what could be happening "behind the scenes" for a person with dementia, in excerpt 26, she appeared to position herself as someone who in fact did understand dementia. This discrepancy could be interpreted by considering the guidelines that were provided for healthcare professionals as part of briefing them about their roles as outsider witnesses. Perhaps in excerpt 26, Ruth wanted to affirm Gavin's identity by positioning herself alongside him as someone who acknowledged and stood against stigmatising narratives of dementia.

When asked about how Sharon and Ruth felt that they had been "moved" on account of hearing Gavin's blog entries Ruth commented on how "generously" Gavin had shared his story which she said reminded her that people with dementia often wish to share their perspectives:

> [517-521] Sharon: Often people do want to talk about their experience and share, so it's about us as healthcare professionals perhaps creating the opportunity for them to do that.

Excerpt 27

Ruth's dialogue could be seen as reflecting her implicit assumption, or her understanding of other peoples' implicit assumptions that people with dementia do not want to talk in detail about their experiences. However, she suggested that listening to Gavin's blog confirmed that in fact people with dementia do want to share their experiences. Her narrative seemed to align with psychosocial models of dementia and person-centred care which emphasise the importance of the social environment in enabling or disabling opportunities for people with dementia to have their voices and perspectives heard. Indeed, she placed the onus on healthcare professionals, rather than people with dementia, to ensure that she and other professionals created opportunities for individuals to speak and be heard.

4.7. Ruth's Experience of Hearing Gavin's Blog Entries

This section reconstructs some of the key stories from Ruth's individual interview about her experience of hearing Gavin's blog entries.

4.7.1. Emotionally Connecting with Gavin's Blog Entries

Ruth's narrative frequently described an array of different emotions that she felt on account of hearing Gavin's blog entries. She explained that Gavin's narrative resonated with her experience of her dad who lived with dementia, which meant that she could connect with his experience "quite deeply." For example, she suggested that hearing Gavin's honest reflections about the challenges of living with dementia at Christmas made her feel less "alone" and less "guilty" for having similar mixed feelings about the event. Ruth also reflected on the positive emotions that were brought about by hearing Gavin read his blog entries in his own voice:

> [91-93] Ruth: …having it sort of narrated for you, if you like, it was, I was able to almost let go of the idea of I have to find something to say and simply just relax and enjoy, enjoy the story from somebody else.
>
> Excerpt 28

Ruth suggested that being able to listen to Gavin's blog entries made the experience feel relaxing and enjoyable because it reduced the pressure on her to speak. Her narrative seemed to imply that she saw her professional role as being to impart knowledge or to have "something to say" that was helpful to her clients, rather than to listen and validate people's experiences. She suggested that speaking about dementia in a more "vulnerable way" which acknowledged her own feelings and Gavin's feelings represented a way of interacting with people with dementia that she was not used to:

> [144-147] Ruth: I think that was something that kind of caught me off guard a little bit. It wasn't a way of speaking about dementia that I have been used to, but it was actually very refreshing to kind of remind myself that not every conversation has to come with a scientific add on. Some can just be, you know, a conversation or just hearing how someone's feeling or trying to manage something at the moment, even if that's completely unrelated to their dementia.
>
> Excerpt 29

In excerpt 29, she highlighted her sense of surprise perhaps at how different the conversation was in comparison with the conversations that she appeared to have been "used to." However, she suggested that the way of talking about dementia within the outsider witnessing practice was pleasurable and interesting. Her narrative suggested that Gavin's blog entries encouraged her to see that conversations with service users did not always have to involve providing scientific knowledge, rather, they could be focussed on how the person is feeling, or about aspects of their identity of lives beyond their experience of dementia.

4.7.2. Gaps in Knowledge

Gavin's blog entries seemed to remind Ruth that her experience of caring for her dad who lived with dementia did not mean that she knew everyone's experience of dementia because "every single person's experience is different." Rather than feeling disheartened, frustrated, or upset by her gaps in her knowledge, she suggested that she welcomed the opportunity to learn more:

> [27-29] Ruth: Actually, it was quite nice to see that it's not about knowing it all, [and that] it's about being able to accept that you have flaws and gaps in your knowledge and instead build on those.
>
> Excerpt 30

Ruth appeared to highlight her sense of pleasure and acceptance about the inevitable gaps in her knowledge as she suggested that not knowing everything instead brought an opportunity to learn and discover more. Her narrative seemed to counter ideas about the roles of clinicians and service users under medical models of care because under medical models of care professionals could be seen as being expected to “know” about the experience of dementia. Instead, she suggested that working with people was as much about listening to, and learning from people’s experiences as it was about providing knowledge and information. Ruth’s story therefore positioned her as someone who was open, curious, and willing to learn from Gavin which perhaps enabled her to adopt this attitude in her practice.

4.8. Sharon’s Experience of Hearing Gavin’s Blog Entries

I will now present some of the key stories that were weaved throughout Sharon’s follow-up interview that captured her experience of “witnessing” Gavin’s blog entries.

4.8.1. Getting to Know the Person Beyond their Diagnosis

Sharon’s narrative captured how Gavin’s blog entries led her to consider the importance of understanding the people with whom she works, including their values and interests as a priority before understanding the impact of their psychological “problems.” She told me about a new client with whom she had started to work, and I asked her how she thought her first meeting with this client had been different to usual, on account of hearing Gavin’s story:

> [100-113] Hannah: I wonder how you would have gone into the meeting having not heard Gavin, and how things would have been different?
>
> Sharon: Yeah, that’s a good question. I think before my primary focus would be just focusing on the depression, but now that I’ve heard Gavin, I want to take my time with this new patient and I feel that time is needed to just let her feel even more comfortable with me because usually I can build rapport quite easily and in the first couple of sessions, but considering how depressed she is, I think it’s going to be much more difficult and so I think I need a lot more time with them (2 secs). So I think yeah, just time and having normal

> conversations with her, doesn't have to be therapeutic, well talking can be therapeutic, but yeah just having normal conversations and just getting to know her as a person rather than primarily focusing on the depression, which is what I would have done, sort of gone in guns blazing, so now I think I just take a lot more time.

Excerpt 31

Sharon suggested that prior to witnessing Gavin's blog entries, her focus with her client would have been on making sense of her client's depression, however, since hearing Gavin's story, she instead wanted to focus on getting to know her as a person. Her narrative seemed to reflect a change in her identity from someone who perhaps used to draw upon medical models of care, to someone who now aligned herself more with person-centred care principles within the context of her work with her client. However, my framing of the question about how her approach would have been "different" had she have not heard Gavin's blog entries was perhaps leading because I did not leave space for Sharon to tell me that her approach had not been different. This perhaps reflected my wish for Sharon (and the other healthcare professionals) to value Gavin's blog entries and act upon his advocacy efforts.

Sharon's wish to have "normal conversations" with her client seemed to relate to her aim of using principles from person-centred care to better understand her client's identity. However, she suggested that she perceived having "normal" conversations (i.e., those which focused on the person rather than their problems) as not being therapeutic, thus highlighting her conflict between which approach to care she wanted to align herself with. Sharon corrected herself when she said, "well talking can be therapeutic" suggesting her resistance to her initial idea that having "normal conversations" could not be helpful to clients.

5. DISCUSSION

This final section will discuss the insights gained from the analysis and consider how they relate to previous literature. The limitations of the study are discussed within a critical review, and implications are drawn alongside recommendations for future research.

The study was the first to explore the impact of self-advocacy by people with dementia on healthcare professionals. To meet this aim, I drew upon the concept of narrative to explore two blog entries from two people with dementia, and the impact of these blog entries on healthcare professionals. The research questions were:

1) What stories do people with dementia who are involved in advocacy share in their online blog entries?

2) How does hearing blog entries from people with dementia affect healthcare professionals?

5.1. The Stories of People with Dementia who Self-Advocate

This section will respond to the first research question.

5.1.1. The Experience of Receiving a Diagnosis of Dementia

Sue's stories provided an account, in the form of a poem of her experience of attending a memory service. She suggested that the way in which her diagnosis was communicated by her doctor (i.e., using language of deficit and deterioration) contributed to her sense of despair and hopelessness. In line with narrative theories, the stories that we hear from others can become integrated into our sense of identity (McAdams, 2018). Thus, it could be suggested that the way in which Sue's doctor communicated her diagnosis to her perhaps led Sue to come to see herself as being impaired and deficient. Similarly, she suggested that her diagnosis led to a loss of her sense of identity; an experience that has been found in previous literature pertaining to the experience of receiving a dementia diagnosis (Naue & Kroll, 2009).

However, in line with theories of personhood which highlight the impact of social and psychological factors in shaping experience (Kitwood, 1997), her loss of selfhood did not appear to be related to the symptoms of dementia. Rather, it appeared to be connected to social factors such as the loss of her job. The impact of employment loss on identity for people with dementia has been highlighted in previous research (e.g., McCulloch et al. 2016). Moreover, research exploring the experiences of people with dementia who self-advocate suggests that engaging in advocacy can be experienced as identity-affirming because it can relocate people back into the world of work (Bartlett, 2014a). Indeed, this finding by Bartlett (2014a) is in line with Sue's suggestion that through blogging (i.e., engaging in advocacy), she attempted to regain her sense of identity.

5.1.2. The Experience of Symptoms of Dementia

Whereas Sue's blog entries were primarily focussed on the psychological and social challenges associated with dementia, Gavin's blog entries focussed on his and others' experiences of the biological symptoms of dementia. He appeared to conceptualise dementia as a disease of the brain that caused issues with cognitive functioning. Therefore, his narrative was often embroiled within biomedical narratives of "disease" and "deficit." The alignment of his narrative with disease models of dementia could be understood using narrative theory which suggests that personal narratives do not just appear from nowhere and are instead comprised of the voices of multiple individuals, and wider communities and institutions (Frank, 1995). In previous research exploring the experiences of those with dementia who advocate, some participants were found to conceptualise their illness in biomedical terms (Bartlett, 2014a). This could be seen as demonstrating the power of biomedical stories in shaping the personal stories (and thereby the identities and experiences) of people with dementia.

Speaking on behalf of himself and other people with dementia, Gavin also referred to the ways in which the symptoms of dementia could influence daily life. It appeared that the function of describing his symptoms was to educate others about the challenges of dementia to encourage them to be compassionate and kind towards individuals. He often drew upon metaphor and imagery to construct these parts of his narrative, for example he referred to his experience of making “tealess tea” and talking to “invisible visitors.” A key feature of persuasive narratives has been suggested to be emotionality which can be promoted by using visual imagery (Neimand, 2018). Indeed, Gavin’s descriptions of his symptoms were suggested by Sharon and Ruth (the “witnessing” healthcare professionals) to be particularly insightful. Thus, it could be suggested that Gavin perhaps had some understanding of what constituted a persuasive story, hence his use of imagery and metaphor.

5.1.3. The Negative Effects of Stigma

Common to Sue’s and Gavin’s narratives were experiences of stigma and the detrimental impact that stigma had on their identity. For Sue, stigma was enacted by friends who rejected her, whereas for Gavin, it was enacted through other people questioning the validity of his diagnosis because he did not present in line with common stereotypes of dementia. Experiences of stigma arising from normative expectations have also been widely documented within the literature pertaining to the experiences of self-advocates (e.g., Bartlett, 2014; Talbot et al., 2021). For example, in previous research, one participant described feeling awkward and guilty for still being able to function well with dementia, and another participant also reported an experience of having his diagnosis questioned (Bartlett, 2014a). Such experiences have been suggested to lead to feelings of anger, frustration, and hurt (Talbot et al. 2021), thus demonstrating the impact of stigma on wellbeing.

5.1.4. (Re)constructing Selfhood

Gavin’s and Sue’s blog entries seemed to reflect and construct their sense of self through narrative. Sue’s blog entries conveyed how, after her loss of identity following her diagnosis, she was able to develop a new sense of identity. She suggested that acceptance, appreciation, and authenticity were key parts of her reconstructed sense of self. Similarly, Gavin’s blog entries seemed to suggest that he had been able to assimilate dementia into his existing sense of identity. Similar accounts of the ways in which selfhood is reconstructed following a diagnosis have been cited elsewhere in the advocacy literature. For example, Hillman et al. (2018), drawing on the concept of narrative, suggested that participants used storytelling during the research interview encounter to reassess their sense of identity. The researchers suggested that the process of narrating during the interview supported participants to develop a coherent and structured narrative of their lives, which in turn served to uphold their selfhood. Similarly, it could be suggested that through blogging, Gavin and Sue were able to continuously revise and shape their identities in the light of new information or challenges, thus suggesting the effects of blogging on identity.

Sue’s and Gavin’s stories of identity frequently appeared to be constructed from the voices of the wider community of people with dementia who self-advocate. Whereas Gavin’s stories were almost all marked by the collective voice, Sue seemed to draw on the voice of other people within her community when sharing parts of her identity that portrayed strength, acceptance, and appreciation. For example, she moved between using first-person pronouns to using terms such as “we” and “us” when describing how she had regained her identity following her diagnosis. Thus, for Sue particularly, it could be suggested that the narrative resources provided by the dementia advocacy community served her identities in ways that were enabling, suggesting the community’s positive influence on her. The role of advocacy in supporting the development of a collective identity has been explored elsewhere in the literature. For example, in McConnell et al.’s (2020) research, people with dementia suggested that advocacy gave them a sense of collective strength which enabled them to overcome feelings of isolation and marginalisation. These findings could be suggested to demonstrate the positive impact of engaging in advocacy for individuals.

5.1.5. Stories of Adaptation and Coping

Finally, Gavin’s and Sue’s blog entries captured the ways in which they had learned to adapt and cope with the challenges of dementia. For Gavin, his past life experiences were instrumental in shaping his current ability to cope, whereas for Sue learning to accept challenges and appreciate what she had in her life was important. Their accounts of coping all resonated with the social and political framing of “living well” with dementia (DoH, 2009) as they suggested that despite their challenges, they were still able to live a meaningful life. Similar stories of adaptation and coping have been shown in the self-advocacy literature (e.g., Talbot et al. 2021). Hillman et al. (2018), drawing on the concept of narrative, suggested that stories of adaptation and coping served two purposes. The researchers suggested that the first purpose was to support individuals to maintain their narrative identity in the face of difficulties associated with dementia. They suggested that stories of coping also served to counter the dominant narrative that dementia represents a “tragedy” or “catastrophe,” thereby helping to shift societal meanings of the illness at an individual, organisational and societal level (Hillman et al. 2018).

Overall, Gavin and Sue shared a variety of stories in their online blogs. Despite only exploring two blogs from each person, their posts did not suggest that they experienced dementia as either solely a “tragedy” or as an illness that they could simply “live well” with (McParland et al., 2017). Rather, their accounts suggested that dementia is a complex experience that could involve both ends of this dichotomy at different times.

5.2. The Impact of Self-Advocates’ Stories on Healthcare Professionals

This section will respond to the second research question by providing a summary of findings which detailed the ways in which healthcare professionals (Louise, Mandy, Ruth, and Sharon) were affected by Gavin’s and Sue’s blog entries. Since there was overlap between the accounts of healthcare professionals, I will synthesise the key stories from the analysis into common themes which capture these overlaps.

5.2.1. Insight into the Subjective Worlds of People with Dementia

Central to all professionals’ stories were accounts of how Gavin’s and Sue’s blog entries provided valuable insights into the subjective worlds of people living with dementia. This finding is also echoed in previous research that exposure to first-person accounts increased awareness of dementia and enabled people to “take on the role of the other” (Schrimpf Davis et al. 2021; Jack-Waugh, 2023; Morris, 2013). Despite working within healthcare services alongside people with dementia, both Sharon and Mandy reflected that hearing such an in-depth insight into the experience of dementia was not something that either of them was familiar with. This discrepancy could be understood in several ways. For example, Gavin and Sue were perhaps more able and willing to describe their internal emotional experience when compared with others with whom Mandy and Sharon had worked. Alternatively, it could reflect the ways of working in which Sharon and Mandy were familiar. Indeed, it has been suggested that healthcare services are often set according to business models which emphasise profit and service priorities such as managing waiting lists (Castro-Romero, 2017). Thus, Sharon and Mandy may not have had time to gather such an in-depth insight from service users before or may not have seen value in doing so. However, understanding the lived experience of dementia is likely to be a fundamental part of delivering person-centred care that conveys empathy, compassion, and respect (Morris, 2013). Therefore, that healthcare professionals reported having a greater insight into dementia because of hearing Gavin's and Sue's blog entries is perhaps promising in terms of considering the role of advocacy in training and educating healthcare professionals.

Healthcare professionals reported feeling emotional on account of hearing Gavin's and Sue's blog entries. For example, they reported feeling moved, hopeful, and inspired which they suggested was linked to the depth of insight into lived experience that the blogs provided. Inherent within Louise's narrative was also a sense of guilt arising from her preconceived ideas about people with dementia, a reaction that was also highlighted by participants in previous research (Jack-Waugh, 2023), and guilt has been suggested to be particularly motivating (Neirdeppe et al. 2008). The emotional impact of blog entries within this study could be understood using the concept of narrative. Within literature that has explored the role of stories within political contexts, it has been suggested that the extent to which one is "transported" into a story (i.e., they are cognitively absorbed in it) influences the level of emotion that is experienced when being exposed to it (Green & Brock, 2000). Thus, the emotional impact of Gavin's and Sue's blog entries perhaps suggests that the healthcare professionals were particularly "transported" into them. Since transportation is associated with changes in knowledge, attitudes, and behaviour (Green & Brock, 2000), this response to the blog entries could perhaps help to explain why healthcare professionals reported having a greater insight into the experience of dementia.

5.2.2. Challenging Assumptions and Biases

Healthcare professionals also detailed various ways in which their preconceptions about people with dementia had changed on account of being exposed to Gavin's and Sue's blog entries. For example, Louise's narrative suggested that Sue's blog entries directly challenged her preconceived ideas about what people with dementia "should" be like, as Sue did not fit into the "usual" stereotype. Louise's reflection mirrors findings from previous research that people with dementia who campaign for social change often did not behave in ways that one might "expect" (Bartlett, 2014). The finding that personal narratives can challenge stigma has been shown in previous research. For example, students in Schrimpf Davis et al.'s (2021) study reported that hearing the stories of older adults helped them to challenge their preconceived ideas about older people. Moreover, participants in Johnson et al.'s (2013) study who were exposed to stories of lived experience from Arab-Muslim women reported more positive attitudes towards this community compared with those who were exposed to a factual summary of their experiences. This could be seen as highlighting the potential for advocacy to challenge healthcare professionals' pre-conceived ideas about people with dementia.

Exposure to Gavin's and Sue's blog entries led healthcare professionals to perceive Gavin and Sue as strong and resilient individuals. Highlighting advocates' strengths and resources, as opposed to their weaknesses or failures is seen as being a key aspect of the outsider witnessing practice procedure (White, 2007), and the issues associated with directing professionals to talk in particular ways are explored in section 5.3.1. However, findings from previous research also support this study's findings regarding the suggestion that exposure to personal narratives from people with dementia promotes the construction of positive identities. Indeed, the students in Morris's (2014) study used terms such as "humourous," "resilient" and "engaging" to describe the person with dementia who they saw in a documentary (Morris, 2014). Drawing on narrative theory which proposes that identity is constructed through the stories that we tell (McAdams, 2001), it could be suggested that telling stories of strength may lead healthcare professionals to see people with dementia as being strong, resilient, or humourous, for example. These identities could be suggested to be in opposition to dominant ideas of people with dementia as being passive, or lacking a sense of self (Zeilig, 2013). Thus, it could be suggested that exposure to advocacy through blog entries may have a role in challenging the stigma associated with the condition amongst healthcare professionals, thereby potentially improving care for people with dementia (Evripidou, 2017).

5.2.3. Blogs as an Incentive to Professionals to Provide Person-Centred Care

Healthcare professionals discussed the ways in which they intended to act differently on account of hearing Gavin's and Sue's blog entries. For example, Sharon explained that Gavin's blog entries had motivated her to take time to understand the identity of a client with whom she was working, beyond the client's "problems." Similarly, Louise's narrative highlighted how she had been motivated to adopt more senior roles in the future so that she could embed the qualities and skills of listening, humanity, and warmth into healthcare services. The actions that Sharon and Louise seemingly wished to take could be seen as being actions which if taken, may either directly or indirectly facilitate person-centred care (NICE, 2018). The influence of blog entries on professionals' motivations to change their practice could possibly be considered within the context of advocacy literature that has explored what makes a "good" advocacy story. For example, stories with storytellers who share similar social identities to their audience have been suggested to be the most persuasive (Green, 2004; Neimand, 2018). Although Louise who had witnessed Sue's blog entries was like Sue in terms of age, ethnicity and gender, Sharon (who witnessed Gavin's blog entries) differed from Gavin in all these aspects. Thus, although holding similar social identities may help to explain the impact of Sue's narrative on Louise, it cannot explain why Sharon reported that she had intended to change based on hearing Gavin's blog entries. Moreover, although professionals reported their intentions to change their practice, it was not clear whether they did in fact act.

5.3. Critical Review

5.3.1. The Use of Outsider Witnessing as a Methodology

The research used the narrative practice of outsider witnessing (White, 2007) to provide a way of connecting blog entries from people with dementia to healthcare professionals. This creation of a storytelling situation was necessary to answer the research questions, and using outsider witnessing enabled me to simultaneously explore the stories of both groups. Although using novel methods could be seen as a strength, the use of outsider witnessing also raises several issues. For example, in line with the outsider witnessing procedure, healthcare professionals were requested to respond to blog posts from people with dementia by affirming their identities and acknowledging their strengths and resources (White, 2007). Thus, the outsider witnessing practice created a highly artificial situation and it was not possible to determine whether the impact of blog entries on healthcare professionals was generated by the stories of people with dementia, or by factors relating to the nature of the outsider witnessing practice. Indeed, professionals' stories were often idealistic. For example, Louise referred to her memory of Sue as "treasure" and suggested that she saw Sue as inspiring. The specific requirements of the practice may have meant that healthcare professionals were deterred from, or unable to tell other stories and particularly those that constructed less favourable accounts of the impact of hearing self-advocates' blog entries. Therefore, the findings constructed were likely to have overemphasised the impact of advocacy on healthcare professionals.

The presence of the person with dementia within the group interviews would have also impacted the stories that were constructed by healthcare professionals. Indeed, research within the field of student education warns of the dangers of using storytelling amongst student groups because counter stories (i.e., those that resist or work against the dominant story) can remain unspoken due to real or implied sanctions associated with sharing them (Abma, 2003; Garrett, 2006). The same could be said for this study. Indeed, in the presence of Sue and Gavin, healthcare professionals were perhaps unlikely to say that they had not learned anything from their blog entries, thus their accounts may not have been authentic representations of their experiences. Despite this, the findings from this research did appear to align with findings from previous studies that explored the impact of advocacy in different contexts (e.g., Dahlstrom, 2014), and findings from studies that explored the impact of first-person narratives within educational settings (e.g., Schrimpf Davis et al. 2021), which could be suggested to give the findings greater credibility.

5.3.2. Issues with the Sample

The study used a small sample size including two people with dementia and four healthcare professionals. In line with approaches to Narrative Analysis (e.g., Riessman, 2008), the recruitment of a small number of individuals sought to prioritise the in-depth exploration of participants' narratives which valued their subjectivity and uniqueness. Thus, the findings were not intended to be generalisable. Rather, readers are encouraged to evaluate the "transferability" of findings by considering how the concepts used within the research may apply to their own context (Josselson, 2011). For example, researchers who are interested in exploring the impact of advocacy by people with dementia may consider using narrative theory as a conceptual framework to underpin their work, or healthcare professionals may consider the ways in which they could incorporate service user narratives into their individual work or service delivery.

People with dementia who agreed to take part in this research were both white British and had both been diagnosed with young-onset dementia (i.e., dementia that is diagnosed in individuals who are under the age of 65; American Psychiatric Association, 2022). At the time of participation in the study, Sue was aged 58 and Gavin was aged 71, and both presented themselves as being relatively fit and healthy. Therefore, it could be suggested that Gavin and Sue are people with certain characteristics in terms of their social identities; characteristics that are unlikely to be unrepresentative of the broader population of people with dementia. Indeed, people with young-onset dementia only account for eight percent of all dementia diagnoses (Prince et al., 2015) and dementia disproportionately effects people from black and minority ethnic backgrounds (Dementia UK, 2023). Issues relating to a lack of diversity within research samples is also a key critique of previous research (e.g., Bartlett 2014a; Bartlett 2014b; Hillman et al. 2018) and are problematic because the voices of people with dementia from marginalised groups (e.g., older people and people from racialised groups) remain unheard. Thus, this research and other dementia advocacy research is privileging the worldviews of younger white people with dementia, over the views of those from minoritised backgrounds which may have negative implications for the wellbeing of already minoritised people.

Healthcare professionals who took part in this research also had certain characteristics. For example, Louise and Ruth both had personal experience of a relative who lived with dementia. Previous research has suggested that having experience of a family member with dementia is associated with clinicians holding more favourable attitudes towards people with dementia (Cheston et al. 2016). It could be suggested that healthcare professionals who held more favourable attitudes towards dementia would have been more likely to agree to participate than those who held less favourable views. Thus, healthcare professionals already appeared to hold largely positive views towards people with dementia meaning that it was unsurprising that they were open and receptive to listening to and learning from Gavin’s and Sue’s blog entries. Research has suggested that healthcare professionals often hold negative views about people with dementia (Evripidou et al. 2017), thus had these individuals been part of the sample, the effects of advocacy on professionals may have been less promising.

5.3.3. Ethical Considerations

It was not possible to maintain the anonymity of participants with dementia in the research because the blog entries from people with dementia are publicly available online, and quotes from them were presented in the report. Therefore, readers of the study may have been able to identify who Gavin and Sue were through searching for their blogs online from the quotes that were presented in the analysis. This may have left Gavin and Sue open to criticism or negative comments from others who, without seeing my report, would not have been aware of and therefore able to respond to their blog entries. To address this, participants were required to sign the consent form, and the analysis for each person with dementia was sent to them to ensure that they consented to my analysis being available online.

Presenting the analysis from the follow-up interviews with healthcare professionals also raised an ethical dilemma regarding what to include, considering that the final report would be available to the participants with dementia. For example, in her individual interview, Louise (healthcare professional) explained that Sue (person with dementia) did not present in the way that she had expected, owing to her expectations of what people with dementia should be like. Indeed, research has shown that others’ expectations can result in upset and anger for people with dementia (Bartlett, 2014), therefore highlighting the potential for Sue to become distressed should she have read the report. The decision was made to include Louise’s story because it highlighted how personal accounts could help to challenge stigma, which was felt to be important for the wider dementia community.

A further ethical issue arose due to the method of recruiting participants that was selected for the project. Participants with dementia were selected via the research consultant’s networks for several reasons. For example, people with dementia who have written blogs are a very specific population to recruit and the consultant was expected to have personal connections through which participants could be accessed. However, aside from the inclusion and exclusion criteria that were shared with the consultant (detailed in section 2.3.3.), it was not clear how the consultant selected potential participants. It is possible that he selected individuals that he felt were particularly eloquent or who authored online blogs that, in his view, were “good” or “important.” Therefore, other potential participants may have been overlooked and denied of the opportunity to have their voices heard.

5.3.4. Quality of the Analysis

When judging the quality of the data analysis, narrative research considers “trustworthiness,” rather than realist definitions of validity and reliability (Riessman, 2008). In line with social constructionism and narrative theories, trustworthiness refers to what is accomplished through storytelling, rather than whether the findings represent the “truth” or “accurate” depictions of events (Gubrium & Holstein, 2000). The quality of analytical interpretations can be evaluated using the criteria of persuasiveness, correspondence, coherence, and pragmatic use (Riessman, 1993).

Persuasiveness is demonstrated when interpretations are “reliable and convincing” (Riessman, 1993: 65). Persuasiveness was achieved by using direct quotes from participants, by including a consideration of the situational context through which the narratives were produced, and by providing an example analysis memo to outline the process of the analysis (see Appendix N). Correspondence considers how analytic interpretations align with the meanings held by research participants, and it was increased by checking my analysis with participants and adding nuances based on their feedback.

For a narrative to be coherent it should contain information about the context of the storytelling situation and details regarding the temporal order in which different actions relating to the storytelling event took place. Coherence was sought by providing a clear account of the methodology used to gather participants' narratives and by providing an example excerpt from my study journal (see Appendix O). Moreover, the analysis was presented in the temporal order that events took place, for example the blog narratives from people with dementia were presented first, followed by healthcare professionals' narratives from the outsider witnessing practice, then their individual interviews. Finally, findings were intended to be pragmatic (i.e., applicable across different contexts) by considering the effects of advocacy within a healthcare training and education context, to ensure that findings were relevant to clinical practice.

5.3.5. Reflexive Considerations

Since it is important to embed reflexivity throughout the entire research process (Riessman, 2008), I will now consider some of the ways in which my identities and experiences perhaps influenced the stories that were elicited from participants and the ways in which I interpreted the findings. Further reflexive considerations can be found in Appendix N and Appendix O.

When writing up the analysis, I had to decide upon which stories from the group and individual interviews to select. In line with the method of DNA, the decision was based on "phronesis" which meant selecting stories based on those that "called out as needing to be written about" (Frank, 2010). When selecting stories from Gavin's and Sue's blog entries, I was careful to select excerpts that were representative of their whole narrative (or "gestalt") across each person's two blog entries. For Gavin and Sue, their entries seemed to simultaneously convey a sense of hope, acceptance, and coping as well as a sense of loss, despair, and exhaustion. Thus, I selected entries that I felt captured this range of experience. As someone who considers themself to be critical of using biomedical models and diagnostic categories to conceptualise distress, I was perhaps more likely to construct stories that reflected the disempowering impact of biomedical paradigms on Gavin's and Sue's experiences. However, I was surprised that for Gavin, although he conceptualised dementia a "disease" of his brain, he was nevertheless able to adapt and cope well with his illness. This served as a reminder that understanding dementia as a disease category may not be disempowering for every individual with dementia.

During the interviews, I was required to balance my role as a researcher and as a trainee clinical psychologist. Although outsider witnessing was used as the methodology, I was also familiar with outsider witnessing as a therapeutic practice within my clinical work. This issue related to my role was particularly pertinent when deciding how to respond to what participants said during the outsider witnessing practices. I was aware of my natural disposition to summarise and validate (in line with my role as a psychologist), however, I recognised that doing so would have influenced participant's dialogue in line with my own position, more so than if I had simply asked a follow-up question. Thus, although there were times that I did use therapeutic skills, where possible I tried to respond to participants' responses with open-ended follow-up questions to elicit more dialogue.

5.4. Implications and Recommendations

This section discusses the implications of the study and recommendations are made for people with dementia who self-advocate, clinical practice, approaches to workforce development, and future research.

5.4.1. People with Dementia who Advocate and Dementia Advocacy Organisations

Findings that blog entries improved professionals' understandings of dementia, led them to question their preconceived ideas about dementia, and incentivised them to change their practice suggests that blogging may be a promising form of dementia advocacy, particularly within a healthcare context. However, for blogs and other forms of advocacy to be effective in generating changes in practice outside of this study, services must be aware that they exist. Increased awareness could be achieved in several ways. First, people with dementia may post links to blogs and other advocacy efforts on social media, or they could accept invitations to take part in television or radio interviews where they may discuss their work. They could also inform professionals or researchers with whom they encounter, about their work and the work of other advocates. It is likely that over time these actions will have a snowball effect, increasing the number of people who advocate and the number of individuals and organisations who are aware of their efforts. One barrier is perhaps that many people with dementia will not have the skills or confidence to speak publicly, post on social media or share blogs, and individuals may be deterred by the risk of being negatively impacted by the effects of societal stigma (Bartlett, 2014a). To overcome this, advocacy organisations may consider coaching people with dementia to improve their confidence, or they may consider alternative ways through which individuals can advocate. For example, the use of assistive digital, visual, and photo-based technology in dementia settings has received increased research attention (e.g., Rincon, 2022), and represent potential ways in which advocacy could be made easier and more accessible.

5.4.2. Clinical Practice

Although person-centred care is the gold standard way of working with people with dementia (Downs & Lord, 2017), Sue's experience at a memory clinic suggested that her diagnosis was portrayed in line with medical models of care. Sue recommended that healthcare professionals should communicate a more hopeful message about dementia when sharing service users' diagnoses with them. Indeed, given the role of language in shaping one's view of themselves, and their illness (Frank, 2010), healthcare professionals should be aware that using language such as "impaired" or "deteriorated" when giving a diagnosis may be experienced as distressing, and thus language like this should perhaps be avoided. Moreover, it is likely to be important to hold in mind common beliefs about dementia, for example the belief that receiving a diagnosis would mean that one’s life was over (Saga, 2016), and to tell individuals that many people continue to live a meaningful and fulfilling life with dementia. Moreover, in line with person-centred approaches to care (NICE, 2018), professionals should consider each person with dementia as an individual and strive to understand and use language that aligns with individuals’ own internal frameworks for understanding their difficulties. Such frameworks may be based on religious, spiritual, or cultural ideas, and it should be noted that biomedical models represent only one way of understanding dementia, and that there are many (equally valuable) other ways of understanding the illness.

Professionals may consider signposting people to dementia advocacy organisations like the Dementia Engagement and Empowerment Project which is an organisation which runs groups in different areas across the UK. For Sue, her involvement in advocacy seemed to support her to reconstruct her identity following her diagnosis and for others, engaging in advocacy can reduce feelings of isolation (McConnell et al. 2020). Encouraging people to blog, journal, or record their experiences in some capacity may help people to remember important experiences and life events (Brooks & Savitch, 2022) and thus revise and maintain their narrative identity (Hillman et al. 2018). Blogging may be adapted to involve photographs, shorter sentences, or paintings depending on the individual’s experience of using computers, their ability to write, or their level of concentration.

Another tentative suggestion may be to signpost people with dementia to blogs by people with dementia, or to other material such as “the 4 amigos” (i.e., an online video blog in which four people living with dementia talk together about their experiences of dementia and provide support to each other). Although further research is needed regarding the impact of advocacy on people with dementia who are exposed to advocacy materials, it is possible that for some people, hearing about the experiences of others may support them to feel less psychologically alone in their difficulties. However, in line with person-centred models of care (NICE, 2018), individuals’ preferences, reaction to their diagnosis and personal attributes should be considered and the potential benefits and risks of engaging in, or exposing themselves to advocacy should be explored collaboratively.

5.4.3. Professional Training and Education

The findings provide some initial support for the potential for advocacy (specifically blogs) by people with dementia to improve professionals' understandings of dementia, to challenge their preconceived ideas about those who live with it, and to provide motivation to deliver person-centred care. Under national legislation (i.e., the Mental Health Act, 2006) and guidelines on working with people with dementia (NICE, 2018), services are required to embed service user involvement into all aspects of service delivery, including in approaches to training and development. Research has suggested that existing dementia training programmes rarely involve collaboration with people with dementia (e.g., Marulappa et al. 2022) which perhaps contributes to findings that they are often ineffective in driving changes to practice (Parveen et al. 2020). Within healthcare settings, incorporating blogs from people with dementia into training, team reflective practice meetings, multi-disciplinary team meetings, or individual or group supervision, may help to educate professionals based on the priorities and experiences of people with dementia. Moreover, universities may consider incorporating blog entries, video diaries, or other advocacy stories into part of their training programmes for prospective healthcare professionals. However, the use of blogs as a resource to aid professional development is not enough to constitute true service user participation in educational programmes. Rather, people with dementia (as opposed to simply their blogs) should be invited to work collaboratively with healthcare services and other training providers to co-develop and co-deliver training programmes.

There are several issues that need to be explored when considering including blogs or other advocacy stories as a means of training or educating professionals or students. For example, there is a need to include a sufficient breadth of narratives to ensure that professionals do not become fixed on one viewpoint (Drumm, 2013). Research has shown that people with dementia who identify as LGBTQ+ (Smith et al. 2022) and individuals who are from racially minoritised backgrounds (Moriarty, 2015) are more likely to experience discrimination and poor treatment in healthcare services. Furthermore, research has suggested that healthcare professionals hold less favourable views towards people with dementia who are in the more advanced stages of the illness (Evripidou et al. 2017). Although this suggests the need to incorporate a diverse range of perspectives, further research is needed to explore whether advocacy by people with dementia who face marginalisation within society serves to reduce stigma, or whether in fact advocacy may have unintended consequences such as increasing stigma.

Incorporating blogs within a healthcare educational context as a source of knowledge is likely to involve disrupting traditional power hierarchies. By respecting the blogs of people with dementia as an important source of knowledge, those with dementia become positioned as active “insiders” and professionals become positioned as passive “outsiders” (Baines et al., 2019); the latter which could be seen as being a role typically held by people with dementia when they access services. Although professionals within this study appeared to be open and willing to learn from Gavin’s and Sue’s blog entries, in practice the disruption of traditional power roles is unlikely to be respected and accepted by all. Therefore, learning from advocacy by people with dementia could be met by some level of resistance amongst educators and healthcare professionals. To overcome this resistance, existing staff within teams could take on the roles of “practice facilitators” (Manley & McCormack, 2003) to embed advocacy into practice from a ground-level (i.e., from healthcare professionals upwards, rather than from management downwards), and a continual process of feedback and reflection with teams would be required.

5.4.4. Recommendations for Further Research

Exploring the effects of advocacy has been suggested to be particularly difficult because large societal shifts are difficult to evaluate (van Wessel & Ho, 2018). However, seeking to understand the impact of advocacy within healthcare specifically is perhaps more straightforward, and doing so has the potential to generate positive changes in practice. There is a need for future research to use methodologies that allow for greater flexibility in healthcare professionals’ responses regarding the impact of advocacy than was possible to achieve in this research due to the use of outsider witnessing. This would ensure that the suggested impact of advocacy is a result of the advocacy itself, rather than being a facet of the data collection procedure. The advocacy efforts, and impact of these efforts from individuals from diverse backgrounds in terms of age, gender, ethnicity, and sexual orientation should be explored to ensure that the knowledge generated through research is transferable across the dementia community, and that all voices are valued. Furthermore, a range of advocacy efforts such as video diaries and tweets, as well as their impact could be explored using a range of approaches such as mixed-methods questionnaires, focus groups or interviews, to understand which forms of advocacy are the most influential to professionals. Doing so would support healthcare services to understand what types of advocacies they could include in approaches to reflective practice, or training for example. Furthermore, it would enable people with dementia who advocate and advocacy organisations to adapt their efforts to achieve maximal change.

5.5. Conclusion

This was the first study to explore advocacy by people with dementia (via their blog posts) and the effects of advocacy on healthcare professionals. The use of outsider witnessing as a methodology was novel and enabled the simultaneous exploration of blog posts *and* their impact. The findings provided initial support for the value of advocacy in the education and development of professionals. Indeed, professionals reported to have gained a deeper insight into the lived experience of dementia, their accounts suggested that some of their assumptions about people with dementia had been challenged, and they clearly stated their intentions to act upon their learning to improve their practice. However, further research that has greater methodological rigour is required to progress our understanding of how advocacy by people with dementia can be valuable in healthcare contexts. There is also a need for healthcare professionals to be open and willing to advocacy, and to see the value in involving individuals. I am hopeful that with the ongoing hard work of individuals with dementia, and the efforts of healthcare professionals who are passionate about listening to, and learning from people with dementia, positive change can be achieved.

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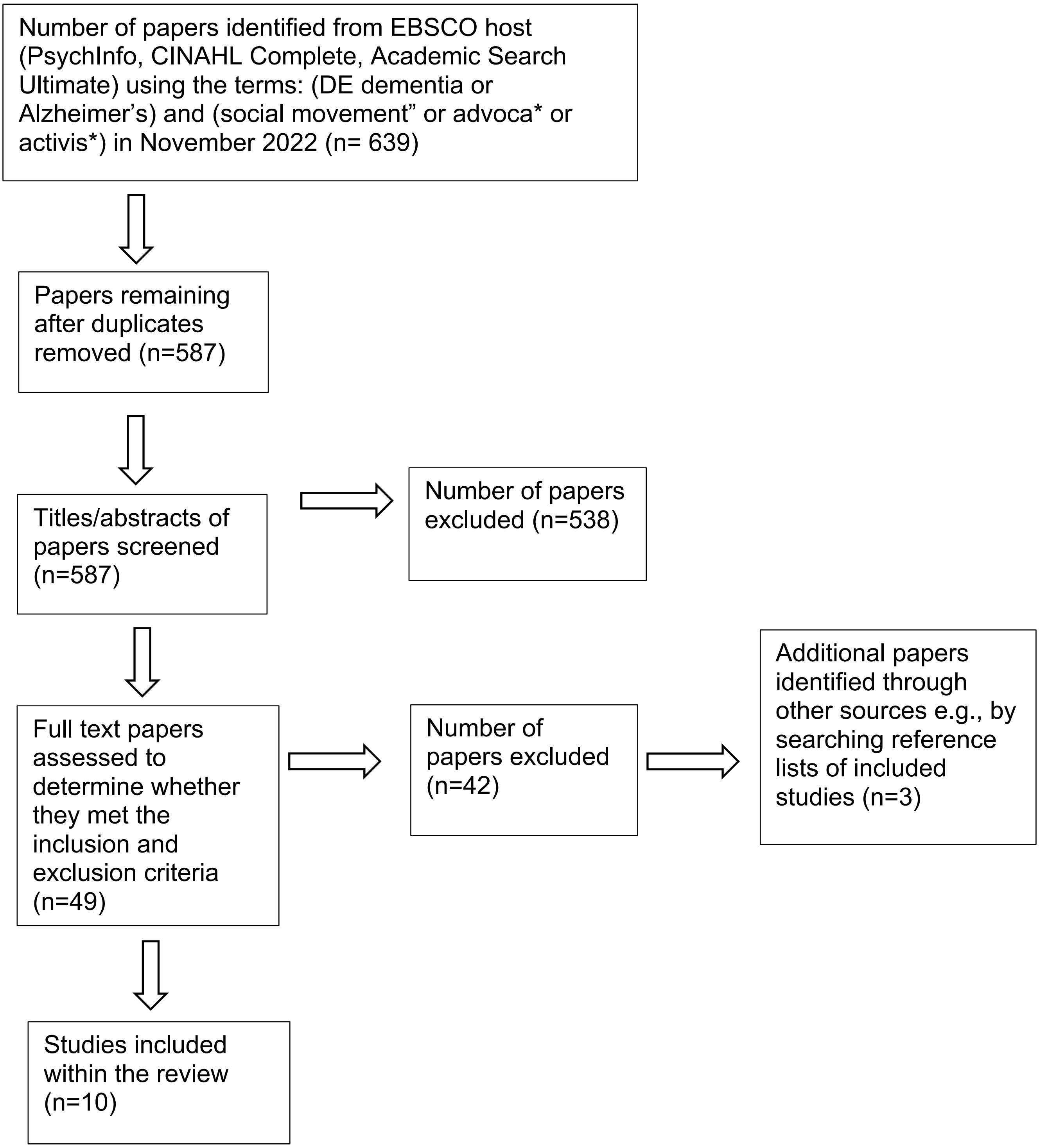
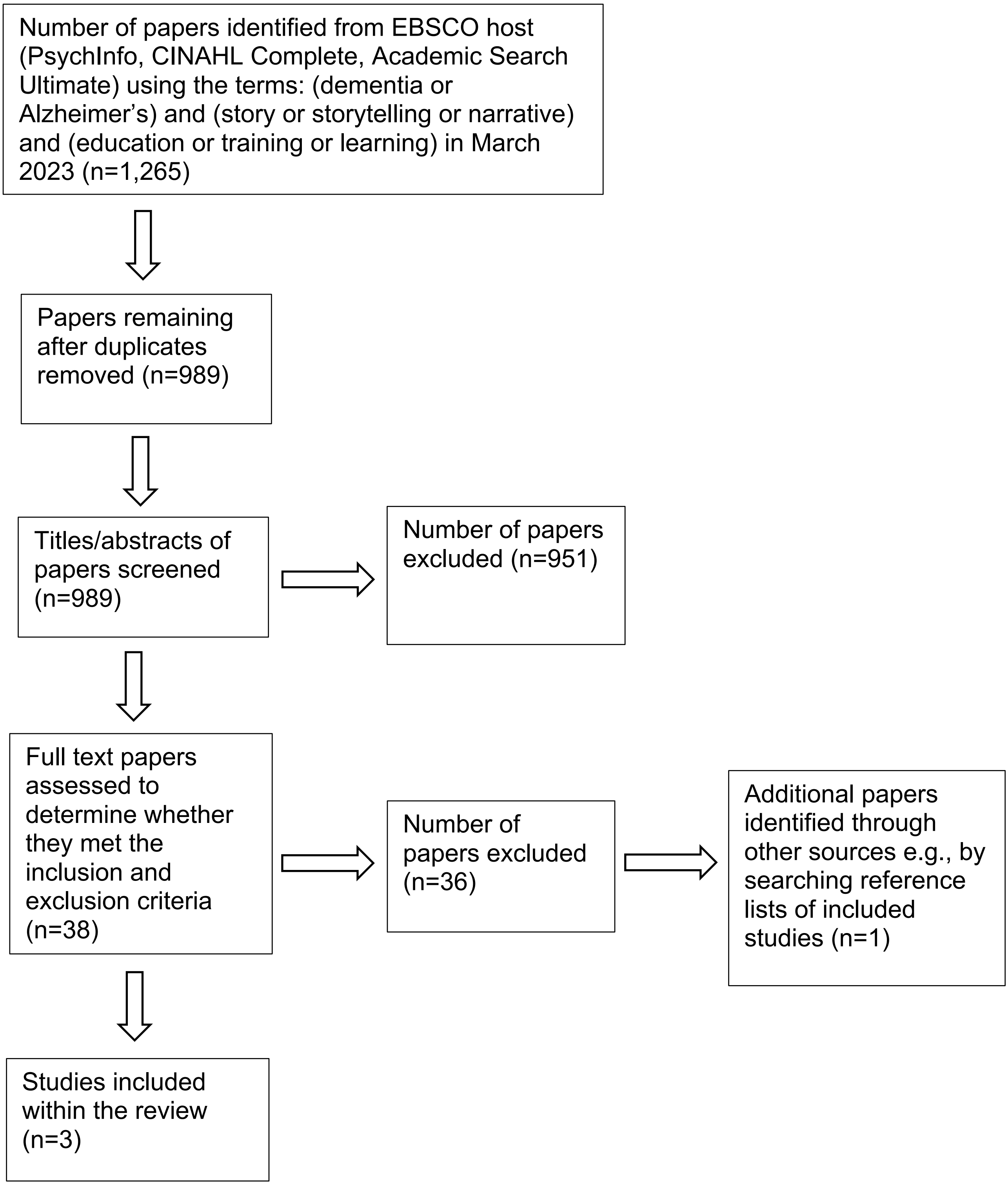
7. APPENDICES

Appendix A: Literature Search One Strategy



Appendix B: Literature Search Two Strategy



Appendix C: Information Sheet for People Living with Dementia

Witnessing Blogs from People who Live with Dementia

Who am I?

Hello, my name is Hannah. I am a Trainee Clinical Psychologist working in the NHS. I am carrying out this research as part of my professional doctorate in Clinical Psychology. I go to the University of East London.

My email address is U2075219@uel.ac.uk

I will arrange to meet you to speak about the information that is in this document, so that you have chance to ask any questions.

What is the research?

I am interested in the experiences of living with dementia that you **share in your blog.** I would also like to understand how hearing your blog impacts **healthcare professionals** who work with people with dementia.

This is important because although people who are living with dementia are sharing their experiences more and more, research has not yet explored what effect they have on others.

The research will be carried out **online** via Microsoft Teams videocall.

Why have I been invited to take part?

I am inviting people who are living with Dementia or Mild Cognitive Impairment to take part.

To take part you need to:

- Have an online blog with **multiple entries** in which you share your **personal** experiences of living with dementia.
- Consider yourself to be an **activist or advocate** for people who live with dementia.
- Be able to use **Microsoft Teams** or be supported to do so by a friend or relative.
- Speak **English.**

What will happen?

I will arrange to meet with you online to **explain** the study.

If you decide to take part, I will invite you to an online meeting with me and two healthcare professionals who are also participants.

I will ask you to read a blog entry **of your choice** out loud (or I can do this if you'd prefer). Then, I will ask the healthcare professionals questions such as "what words or phrases from the blog that you heard caught your attention?" The questions that I ask are intended to **validate and affirm** your experiences.

I will ask you to share your reflections about what they said. If you wish, you can **write or type** some notes as you are listening. You can **share as much or as little as you like.** The group will **last about an hour.**

After the group meeting, I will chat with you individually about your experience of the group. This will take no longer than **30 minutes.**

Both meetings will be recorded. Only I will be able to listen to the recordings.

What happens if I feel upset during or after the interviews?

I have done everything that I can to make participation a positive experience. However, if you do feel upset because of our meetings you can contact:

- Dementia Support: Telephone number: 01243 888 691, email address: info@dementiasupport.org.uk
- Alzheimer's Society: Telephone number: 0333 150 3456, website:

What happens to my answers afterwards?

I will analyse a **selection** of your blog entries to understand what experiences you share and how you made sense of them.

I will also type up everybody’s answers from the group interviews, read them and write up the report.

I will ask you if you want to **check** that what I have written is accurate. It is your choice whether you do this or not.

I will write parts of what you said in your blog entries, and interview in my doctoral thesis. I will not use your real name. However, I cannot guarantee that readers would not be able to identify you because readers would be able to use quotes from my thesis to find your online blog. **The thesis will be publicly available online.**

How will my responses be kept safe?

The other members of the group will know your first names, but they will be asked to keep your details and responses **confidential.**

Your responses will be stored safely in a **password protected computer.** Only me and my supervisor will be able to see them. They will be deleted once my thesis has been marked and passed.

Your personal details will be kept confidential. However, if I felt worried about your safety or the safety of anyone else, I might have to break this confidentiality. I would always try to talk to you about this first.

What happens if I change my mind?

It is completely **your choice** whether to take part or not.

If you would like to withdraw, please **let me know at any time** within three weeks of the second interview. After this time, I will have started to analyse the interviews and retain the right to use what you have said. It would still not be possible to identify you (i.e., the quotes will be anonymised).

What do I do if I want to know more?

If you would like to know more about the research, please contact:

Hannah Muir (Trainee Clinical Psychologist): u2075219@uel.ac.uk

If you have any **concerns** about the research, please contact:

Dr Maria Castro Romero (supervisor): m.castro@uel.ac.uk, or Dr Trishna Patel (Chair of Research Ethics Committee): t.patel@uel.ac.uk

Appendix D: Consent Form for People Living with Dementia

University of
East London

CONSENT FORM

Witnessing Blogs from People Living with Dementia

Researcher: Hannah Muir
Email address: U2075219@uel.ac.uk

I have read and understood the information sheet that explains the study and I have been given a copy to keep. ☐

I have had the opportunity to ask questions about the project. ☐

I understand that it is my choice to participate and that I can withdraw at any time within three weeks of the last interview. ☐

I understand that if I withdraw, my responses will not be used. ☐

I understand that the interviews will be recorded. ☐

I understand that my personal information will be stored securely and be kept confidential. ☐

I understand that only me and my supervisor will be able to look at the data, and I give my consent to this. ☐

☐

Hannah has explained to me what will happen after the research has been completed.

I understand that quotes from by blog entries, and from the interviews will be used in my report. Hannah has explained that she will use a false name in her report. ☐

I understand that even though I will take steps to make it difficult for people to identify you, it would still be possible. This is because readers could match the quotes from your blog entries used in my report with your entries that are available online. ☐

I would like to receive a summary of the study findings. I am willing to provide contact details for this to be sent to. ☐

I hereby agree and fully consent to take part in the study. ☐

Participant's name (BLOCK CAPITALS)

……………………………………………………….

Participant's signature

…………………………………………………..

Researcher's name (BLOCK CAPITALS)

………………………………………………………..

Researcher’s signature

……………………………………………………………..

Date: …………………..

Appendix E: Information Sheet for Healthcare Professionals

Witnessing Blogs from People Living with Dementia

Who am I?

Hello, my name is Hannah. I am a Trainee Clinical Psychologist working in The NHS. I am carrying out this research as part of my professional doctorate in Clinical Psychology. I go to the University of East London.

My email address is U2075219@uel.ac.uk

I can talk to you about the information that is in this document, so that you have chance to ask any questions.

What is the research?

I would like to know how you are affected both personally and professionally by hearing blog entries that have been written by people with dementia.

This is important because people are increasingly sharing their experiences of what it is like to live with dementia online via blogs. However, research has not yet explored the ways in which people are affected by reading them.

I will carry out the research **online** via Microsoft Teams.

Why have I been invited to take part?

You have been invited because you are a health care professional who works with people who are living with dementia.

To take part you need to be able to:

- Use Microsoft Teams
- Speak English

What will happen?

You will be invited to attend an **online group** with one other professional, and a blogger who writes about their experiences of living with dementia. Blog entries will be **read aloud** to you, and I will ask questions to prompt you to have a **conversation** with each other about what you have heard. The blogger will listen and be given the opportunity to **respond** to what you said.

The group will take **around 1 hour**.

After the group meeting, I will interview you individually about your experience of the group. This will last for around **30 minutes.**

I will record all our conversations, however only I will be able to listen to them.

How will my responses be kept safe?

The other members of the group will know your first name, but they will be asked to keep your details and responses **confidential.**

The audio-recordings will be stored safely on a **password protected computer.** They will be deleted once my thesis has been marked and passed. The typed-up versions of the recordings will be kept for **three years** but any information in them that might identify you (e.g., names of people and places will be changed).

Your personal details will also be kept **confidential.** However, if I felt worried about your safety or the safety of anyone else, I might have to break this confidentiality. I would always try to talk to you about this first.

What happens to my answers afterwards?

After the group and individual meeting, I will type up everyone's answers, read them and write up the report.

I will ask you if you want to **check** that what I have written is accurate. It is your choice whether you do this or not.

What happens if I change my mind?

It is completely **<u>your choice</u>** whether to take part or not.

If you would like to withdraw from this study, please **let me know at any time** within three weeks of the interview. After this time, I will have started to analyse the interviews and retain the right to use what you have said. It would still not be possible to identify you (i.e., the quotes will be anonymised).

What do I do if I want to know more?

Please contact:

Hannah Muir (Trainee Clinical Psychologist): u2075219@uel.ac.uk

Or if you have any concerns about the project, please contact:

Dr Maria Castro Romero (supervisor): m.castro@uel.ac.uk, or Dr Trishna Patel (Chair of Research Ethics Committee): t.patel@uel.ac.uk

Appendix F: Consent Form for Healthcare Professionals

University of
East London

CONSENT FORM

Witnessing Blogs from People Living with Dementia

Researcher: Hannah Muir
Email address: U2075219@uel.ac.uk

I have read and understood the information sheet that explains the study and I have been given a copy to keep. ☐

I have had the opportunity to ask questions about the project. ☐

I understand that it is my choice to participate and that I can withdraw within three weeks of the last interview. ☐

I understand that if I withdraw, my responses will not be used. ☐

I understand that the interviews will be recorded. ☐

I understand that my personal information will be stored securely and be kept confidential. ☐

I understand that only me and my supervisor will be able to look at the data, and I give consent for this. ☐

☐

Hannah has explained to me what will happen after the research has been completed

I understand that quotes from what I say during the interviews will be used in my report. They will be written in a way that does not identify who I am. ☐

I would like to receive a summary of the study's findings. I am willing to provide contact details for this to be sent to. ☐

I hereby agree and fully consent to take part in the study. ☐

Participant's name (BLOCK CAPITALS)

…………………………………………………………….

Participant's signature

…………………………………………………….

Researcher's name (BLOCK CAPITALS)

……………………………………………………………..

Researcher's signature

……………………………………………………………..

Date: ……………………..

Appendix G: Procedure for the Outsider Witnessing Practices

Adapted from Michael White's (2007) definitional ceremonies

1. Introduction to the practice

Hello, thank you for agreeing to take part today. Just to say, before we start that I will be audio and video recording our group so that I can listen back to it later to transcribe it. Is this ok with everyone?

[Name of person with dementia] has chosen two of their blog entries. In a moment I will ask them to read these out loud to you. Afterwards, I will ask [names of healthcare professionals] questions to prompt a conversation between you. Whilst you are talking, [name of person with dementia] will stay silent and listen. When you have finished, [name of person with dementia] will be invited to share their perspective on what you said.

[Names of healthcare professionals] what you say should be about your own thoughts and feelings in response to hearing [name of person with dementia] story, drawing out their strengths, values, and personal qualities. It should be shared in a way that is helpful to them. Please try to talk about [name of person with dementia] in third person.

Please all talk openly and without judgement, there is no right or wrong answer.

I hope that afterwards you might want to share some of the themes and results from our conversation today, but please keep people's names and any identifying details confidential.

Remember you can leave at any point by pressing the "leave" button without having to give any explanation.

Does anyone have any questions?

2. **<u>Invite [name of person with dementia] to read their blog entries</u>**

3. **<u>Invite healthcare professionals to reflect on what they heard</u>**

Identifying the expression (personal qualities, strengths, achievements)

- As you were listening to [name of person with dementia] blog, what expressions caught your attention, or captured your imagination?
- What touched or moved or inspired you?

Describing the image

- What images of [name of person living with dementia] life, their identity, and the world more generally did these expressions evoke?
- What did [name of person living with dementia] story suggest to you about their purposes, values, beliefs, hopes, dreams and commitments?

Embodying responses

- What is it about your own life or experiences that accounts for why these expressions struck a chord for you?

Acknowledging transport

- Where has hearing [name of person living with dementia] story today taken you, that you wouldn't have arrived at, if you weren't here today?
- In what ways have you changed on account of witnessing [name of person living with dementia] story, and responding to it in the way that you have?

4. **<u>Invite reflections from the person living with dementia</u>**

- What felt significant for you from what [names of healthcare professionals] said, and why?

5. **<u>Close and invite questions</u>**

Appendix H: Interview Guide for the Individual Interviews with Healthcare Professionals

Introduction

We’re meeting again today to talk about your experiences of hearing [name of participant with dementia] blog entries? We have about half an hour. As you know, I will be recording the conversation so that I can look back at it later, is this ok with you? Do you have any questions, or shall I start the recording now?

Key Questions

If you can think back to the last time we met with [names of the other participants], what were your thoughts before we started?

What impact did the hearing the stories of [name of participant with dementia] have on you?

Prompts

- Could you give an example?
- Please could you say a bit more about that?
- What was that like for you?
- Is there anything else that you would like to add?

Debrief

- Thank you for your time
- How did you feel about our conversation?
- Is it still ok for me to write up our conversation and use parts of what you said in my report?
- Do you have any questions?

Appendix I: Debrief Sheet

Witnessing Blogs from People Living with Dementia

Researcher: Hannah Muir
Email address: U2075219@uel.ac.uk

Thank you for taking part in the research. I wanted to provide some more information about the study's aims and what will happen next.

What was the study about?

The group interview that you took part in was called an 'outsider witnessing practice.' This is a method that we use in psychological talking therapies to enable people to tell stories that are often silenced or not heard. People living with dementia often report the experience of being excluded and ignored.

Over the last decade, people living with dementia have come together to campaign for change in the ways that they and others are treated in society. Some people have started to write publicly available blogs to make sure that their voices are heard. The research aimed to understand what stories people living with dementia were telling in their blog entries. It also hoped to explore how hearing these stories was valuable for healthcare professionals who work alongside people living with dementia.

How will my data be managed?

I will hold your data securely and in line with the GDPR and Data Protection Act 2018. You can find more details in the information sheet that I gave to you when you agreed to take part.

What will happen to my responses?

I will write up your responses in my report which will be submitted for an assessment. Your responses will be written in a way that does not identify you. If you were a person living with dementia taking part in the study, I won't use your real name or any personal details to refer to you. However, because your blog is publicly available online, and I will use quotes from them in my report, I cannot garuantee that readers will not be able to identify you. Findings may be shared at conferences, in talks and in journal articles. I will also ask you if you want to receive a summary of the study's findings once I have completed it. Your responses will be held securely for three years, and then they will be deleted.

What if I feel upset by the study?

I have done everything that I can to make taking part an enjoyable and useful experience. However, if you feel upset by the study you can contact:

Dementia Support

- Telephone number: 01243 888 691
- Email address: info@dementiasupport.org.uk
- Address: Dementia Support Hub, Sage House, City Fields Way, Tangmere, Chichester, West Sussex, PO20 2FP.

Who can I contact if I have any questions or concerns?

If you would like more information, or have any questions please contact me:

Hannah Muir (Trainee Clinical Psychologist): u2075219@uel.ac.uk

Or if you have any concerns about how the research has been conducted, please contact:

Dr Maria Castro Romero (supervisor): m.castro@uel.ac.uk, or Dr Trishna Patel (Chair of Research Ethics Committee): t.patel@uel.ac.uk

Appendix J: Ethical 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:	Hannah Muir
2.2	Your supervisor's name:	Dr Maria Castro Romero
2.3	Name(s) of additional UEL supervisors:	Dr David Harper
		3rd supervisor (if applicable)
2.4	Title of your programme:	Professional Doctorate in Clinical Psychology
2.5	UEL assignment submission date:	Initial submission date
		Re-sit date (if applicable)

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	Alternative Narratives of Dementia: Healthcare Professionals Witnessing Blogs from People Living with Dementia
3.2	Summary of study background and aims (using lay language):	The project aims to explore (a) the experiences that are shared by dementia activists via online blog entries and (b) the impact of reading these blogs on healthcare professionals (HCPs).
3.3	Research question(s):	What stories do activists who are living with dementia tell in their online blogs? What is the impact of reading these entries for HCPs?
3.4	Research design:	The research will qualitatively analyse the activist's blog entries. Then, a series of group and individual interviews will be carried out to explore HCPs experiences of reading them.

		Following the group interviews, participants will be interviewed individually about their experiences of the groups. All group and individual interviews will be facilitated by myself. The research has been designed alongside a co-researcher who lives with dementia and who is also an activist and blogger. Blog entries and interviews will be analysed qualitatively using Narrative Analysis.
3.5	Participants: Include all relevant information including inclusion and exclusion criteria	It will recruit activists who have a diagnosis of dementia and who share blog entries online. They must be 18+, have a diagnosis of dementia or mild cognitive impairment, be able to communicate verbally in English, be able to use Microsoft Teams videocall software, and be able to listen and respond to what a small group of people have said. Healthcare professionals must be over 18, speak English and work with people with dementia. A small sample size (11) is required because the analysis is focussed on individual narratives.
3.6	Recruitment strategy: Provide as much detail as possible and include a backup plan if relevant	Plan A for recruiting bloggers: Bloggers will be recruited through the co-researcher's network. The co-researcher informed me that he has several people in mind that he believes would fit the inclusion criteria. The co-researcher will seek their consent for their contact details to be passed to me, then I will contact them to ask if they would like to receive the information sheet. After this, if they are still interested in taking part, an initial meeting will be held to talk more about the study and gain informed consent. Plan B: The study advert for bloggers (see appendix A) will be shared via the Dementia Engagement and Empowerment Project website. The co-ordinators from DEEP have agreed to share this. Plan C: Permission to use blogger's blog entries can be sought from the blogger however they will not be required to be part of the interview process. HCPs will be recruited through my online and personal networks. They will not be recruited directly via their employing NHS trust, therefore HRA approval/NHS approval will not be required. The study advertisement (see appendix B) will be sent via personal email/social media/phone numbers.
3.7	Measures, materials or equipment:	Publicly available blog entries which are on private websites owned by the activists. Permission will be sought from the activist to

	Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	use these and share them with the focus group members. The project will require a computer with access to MS Teams and a Dictaphone. A field diary which will be adapted from Hughes and Castro Romero (2015) will be used to document the consent process (see below). An interview guide will be used to guide the questions asked in the focus group and follow-up individual interviews. This is shown in the appendix.
3.8	Data collection: Provide information on how data will be collected from the point of consent to debrief	An initial unhurried meeting will be held with the activists to explain the project, share and explain the information sheet, and for them to ask any questions. A family member/relative can also be present in the meeting. If they wish to take part, informed consent will be gained from all participants electronically. From here, a process consent methodology (Hughes and Castro Romero, 2015) will be used for people with dementia. This means that their consent will be checked at each stage of the process i.e., at the start of the group interview, during it, after it, and during the individual interviews. Checking will take place verbally i.e. asking them “are you happy to continue or would you like to stop?” I will also monitor for non-verbal cues which might indicate distress. HCPs will be asked to sign an electronic informed consent form. Participants will attend an online group interview via MS Teams. The process of the focus groups will be explained and consent for people with dementia will be re-checked. I will read the activist’s blog out loud and the other participants will be asked to have a discussion guided by the interview questions in the appendix G. I will ask follow-up questions to prompt for more information. The activist will stay quiet and listen. When the discussion has stopped, the activist will be invited to share their reflections on what was said. Participants will be provided with a spoken de-brief and reminded of their upcoming individual interview slots. Individual interviews will take place via MS Teams in the week following the group interview. This will last 30 minutes and be about

		participant's experiences of the group. Participants will then be provided with a written de-brief (see appendix E).	
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:	Activist's blog entries will be analysed using Narrative Analysis which is qualitative method. All group and individual interviews will be recorded using MS Teams inbuilt software, and a dictaphone as a back-up. MS Teams software will be used to transcribe the interviews. Personally identifiable information will be changed to maintain confidentiality. Participants will be assigned a number e.g. P1, P2, P3 so that I know who said what. All interviews will be analysed using Narrative Analysis. Participants will be given the opportunity to check the analysis for accuracy.	

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.		
4.2	Are participants' responses anonymised or are an anonymised sample?	YES X	NO ☐
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed during	Participants will be allocated a number e.g. P1, P2. The details of which number represents which participant will be saved securely in the researcher's UEL One Drive. Although the	

	transcription, pseudonyms used, etc.).	activist will also be given a number, because extracts from their blog entries will be used in the thesis, and their blogs are publicly available online, full anonymity cannot be achieved. A specific box on the consent form will be provided to demonstrate that they understand and consent to this. Any other personally identifying data e.g. home city, names of family etc will not be included in the write-up.	
4.3	How will you ensure participant details will be kept confidential?	Consent forms and demographic characteristics will be scanned and stored on a password protected folder on the UEL One Drive to ensure separation from the anonymised data.	
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	Blog entries will be copied and pasted into a word document and stored on the researcher's UEL One Drive. Interview recordings will be transferred from Teams/Dictaphone to the researcher's One Drive. They will then be deleted from the Dictaphone & MS Teams.	
4.5	Who will have access to the data and in what form? (e.g., raw data, anonymised data)	All data will be obtained and stored by me. Access to anonymised transcripts will be accessible to the supervisor and examiners but only I will have access to the original audio files. Access to consent forms will be granted only if necessary and with participant consent.	
4.6	Which data are of long-term value and will be retained? (e.g., anonymised interview transcripts, anonymised databases)	Raw blog entries, anonymised transcripts of group and follow-up interviews.	
4.7	What is the long-term retention plan for this data?	Interview recordings and blog entries will be kept in their sources until the thesis has been examined and passed. After, they will be erased from UEL servers. Transcriptions will be stored by my supervisor on their UEL One drive for up to 3 years for dissemination purposes.	
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?	Participants, particularly people with dementia may become distressed during the group or individual interviews. I have experience of working with people with dementia professionally and I will have met each participant before-hand to get to know them gather information about how I would know if they were becoming distressed. If they show any of these signs I will re-check their consent in a way that makes it easy for them to say that they do not want to continue. The pace of the interviews will be slow, there will be a break in the middle, and more breaks can be provided if necessary. Relatives and loved ones can be present for the interviews if they wish to be. The practice will be set up clearly and sensitively and people will be told to be non-judgemental and sensitive to how their comments may be received. Interview questions will be simple and easy to understand. Time will be taken at the beginning of the group interviews to introduce each other and make people feel more comfortable. The group interview will be allowed to take whatever direction the participants choose to avoid interrupting people's thoughts. Participants will be advised to raise their hand when they want to speak. The information sheets and consent forms will contain information about where participants can seek support from should be feel distressed during or after the interviews.	
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?	Please detail the potential risks and include measures you will take to minimise these for yourself as the researcher	
5.3	If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General	YES ☒	

	Risk Assessment (GRA) form (signed by your supervisor). Please confirm that 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?	Participants will be in their own home, and I will be in my own home. The research will take place online via MS Teams.		
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:	001581910201. The DBS is subscribed to the update service and therefore will continue to be updated automatically.	
	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.	Please provide details of organisation	
	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)	Hannah Muir
8.3	Student's number:	U2075219
8.4	Date:	Click or tap to enter a date

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

Student checklist for appendices – *for student use only*

Documents attached to ethics application	YES	N/A
Study advertisement	☒	☐
Participant Information Sheet (PIS)	☒	☐
Consent Form	☒	☐
Participant Debrief Sheet	☒	☐
Risk Assessment Form	☒	☐
Country-Specific Risk Assessment Form	☐	☒
Permission(s) from an external organisation(s)	☐	☒
Pre-existing questionnaires that will be administered	☐	☒
Researcher developed questionnaires/questions that will be administered	☐	☒
Pre-existing tests that will be administered	☐	☒
Researcher developed tests that will be administered	☐	☒
Interview guide for qualitative studies	☒	☐
Any other visual material(s) that will be administered	☐	☒
All suggested text in RED has been removed from the appendices	☐	☐
All guidance boxes have been removed from the appendices	☐	☐

Appendix K: Ethical Approval

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:	Sonja Falck
Supervisor:	Maria Castro
Student:	Hannah Muir
Course:	Prof Doc Clinical Psychology
Title of proposed study:	Please type title of proposed study

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	☐	☐	☐
Detailed account of recruitment strategy	☐	☐	☐
Concerns regarding recruitment strategy	☐	☐	☐
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	☐	☐	☐
Clear and detailed outline of data collection	☐	☐	☐
Data collection appropriate for target sample	☐	☐	☐
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	☐	☐	☐
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	☐	☐	☐
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 <u>BEFORE</u> THE RESEARCH COMMENCES	In this circumstance, the student must confirm with their supervisor that all minor amendments have been made <u>before</u> 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 <u>must</u> be submitted and approved <u>before</u> 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)	Sonja Falck
Date:	14/07/2022

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	

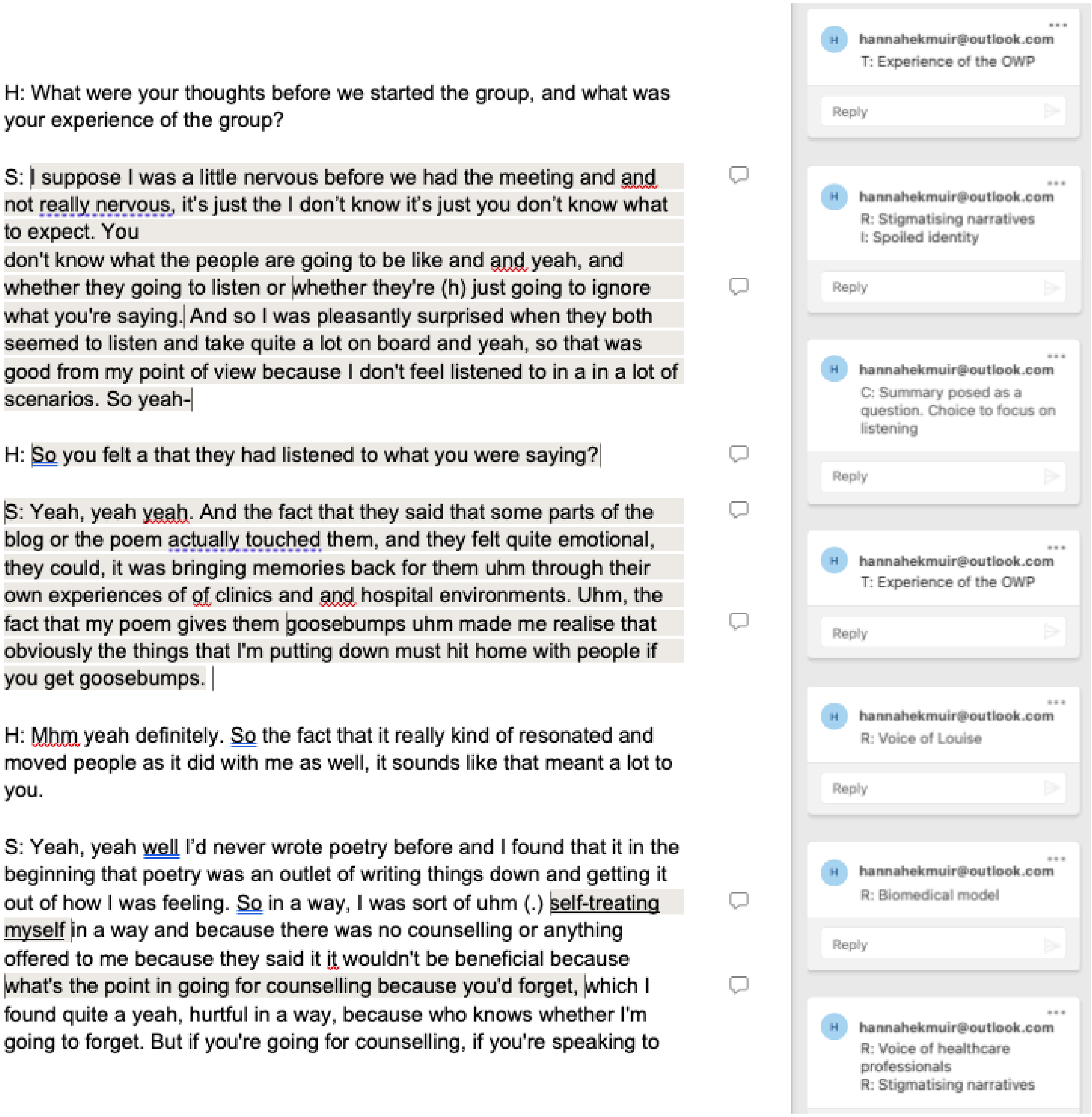
Appendix L: Transcription Symbols

Symbols are adapted from Frosch and Emerson (2005)

[Word]	Overlapping speech
<u>Word</u>	Emphasis or rise in volume
£Word£	Smiley voice or supressed laughter
Word-	Cut off speech
(.)	Micropause
(0.7)	Timed pause, long enough to indicate a time
(h)	Laughter in the conversation
Word	Reading of blog material
(^)	Nodding

Appendix M: Example of an Annotated Transcript

Key: T = Theme, R = Narrative resource, I = Identity, F = Function, C = Narrative Context



H: What were your thoughts before we started the group, and what was your experience of the group?

S: I suppose I was a little nervous before we had the meeting and and not really nervous, it's just the I don't know it's just you don't know what to expect. You
don't know what the people are going to be like and and yeah, and whether they going to listen or whether they're (h) just going to ignore what you're saying. And so I was pleasantly surprised when they both seemed to listen and take quite a lot on board and yeah, so that was good from my point of view because I don't feel listened to in a in a lot of scenarios. So yeah-

H: So you felt a that they had listened to what you were saying?

S: Yeah, yeah yeah. And the fact that they said that some parts of the blog or the poem actually touched them, and they felt quite emotional, they could, it was bringing memories back for them uhm through their own experiences of of clinics and and hospital environments. Uhm, the fact that my poem gives them goosebumps uhm made me realise that obviously the things that I'm putting down must hit home with people if you get goosebumps.

H: Mhm yeah definitely. So the fact that it really kind of resonated and moved people as it did with me as well, it sounds like that meant a lot to you.

S: Yeah, yeah well I'd never wrote poetry before and I found that it in the beginning that poetry was an outlet of writing things down and getting it out of how I was feeling. So in a way, I was sort of uhm (.) self-treating myself in a way and because there was no counselling or anything offered to me because they said it it wouldn't be beneficial because what's the point in going for counselling because you'd forget, which I found quite a yeah, hurtful in a way, because who knows whether I'm going to forget. But if you're going for counselling, if you're speaking to

hannahekmuir@outlook.com
T: Experience of the OWP

hannahekmuir@outlook.com
R: Stigmatising narratives
I: Spoiled identity

hannahekmuir@outlook.com
C: Summary posed as a question. Choice to focus on listening

hannahekmuir@outlook.com
T: Experience of the OWP

hannahekmuir@outlook.com
R: Voice of Louise

hannahekmuir@outlook.com
R: Biomedical model

hannahekmuir@outlook.com
R: Voice of healthcare professionals
R: Stigmatising narratives

Appendix N: Analysis Memo Generated After Each Reading of Sue's Narrative During the Outsider Witnessing Practice

Reflexivity:

I felt that I developed a good relationship with Sue easily and quickly. Our identities were similar in various aspects, for example we were both white women and our sameness as women meant that I resonated with her when she spoke about her roles in life. We differed in terms of age; however, it was striking that Sue was a similar age to my mum which brought a sense of reality about what my mum's life and my life could have been like should she have been in Sue's position. The difference in terms of age meant that I saw Sue as someone to look up to and to learn from. I wondered if she had a sense that because I was much younger than her, I would not be able to understand her experiences of living with dementia, though she still appeared to talk openly and honestly during her outsider witnessing practice and individual interview.

It was striking that she spoke negatively of her experiences of healthcare and of healthcare professionals, and that I was part of this system. This felt uncomfortable at times because I had to face that I was part of the problem that she was describing, and I wondered whether Sue would have felt able to be more honest about her experience if I had not been a healthcare professional.

1st Reading Memo: Identifying the Thematic Content

Themes (4)

- Experience of diagnosis
- Experience of stigma
- Interactions with others (including loved ones and professionals)
- Revising identity
- Living well with dementia

2nd Reading Memo: Asking Resource Questions

Individual voices: Dr undertaking the assessment, support worker, husband

Master narratives: Living well with dementia, tragedy/death, dementia and ageing, loss of self, personhood/person-centred care, stigma

Communities: Dementia advocacy, biomedical, media, healthcare professionals, the world

General reflections on resource questions:

- Narrative begins by drawing on typical master narratives of dementia (tragedy, loss of self, death) but as it unfolds, Sue begins to resist these narratives and tells us in essence about how she has learned to “live well” with dementia.
- Strong presence of husband – reassuring and containing which contrasts with the voice of the doctor and healthcare professionals – medical, matter of fact, cold.
- The ways in which the voices of healthcare professionals brought in was funny. This made me smile when reading the transcript. It seemed almost sarcastic and mocking, and I was aware that I have done the things in my own practice which she said she had found unhelpful.
- Moves between speaking for herself and speaking on behalf of “we” and “our” – dementia community. Much of the narrative seemed to be comprised of their voices.
- Contrast between use of the biomedical community in the first blog entry and total absence of it in the second.

3rd Reading Memo: Asking Identity and Function Questions

Identities:

- Living well
- Spoilt identity (stigma)
- Constructions of other’s identities e.g. doctor, husband
- Activist/advocate – both accepts and rejects this identity
- Authentic, accepting, determined, strong, positive, fun, “normal”
- Supervisor/manager

- Mum, daughter, wife, grandma, friend
- “Human”

General reflections on identity questions:

- Contrast between identity loss and creating a new identity. After first blog entry is read there is an absence of talk about dementia, and more talk about other identities.
- Emotional when considering how other people have rejected Sue’s identity as a person with dementia, but at how she is still so accepting of them and feels lucky to have had those friendships.
- Explicitly reiterates identity throughout the narrative “I am still a person.”
- Moves between how she sees herself and how she is seen by others.

Possible functions of the narrative:

- To teach and provide insight into perspectives
- To uphold her own identity for herself and for others
- To generate social change
- To remember

<u>4th Reading Memo: Selecting Key Stories for Further Analysis</u>

Reflections when making this decision

- Difficult decision around which material to choose for the analysis. I wanted to capture narratives of loss because this was a big part of Sue’s experience, but a larger part of Sue’s experience was about what she had gained. Needed to strike a balance between the two.
- Made decisions based on my commitment to generating less problem-saturated narratives of dementia.
- Aware of being very critical of medical communities, need to hold in mind that this way of understanding dementia is helpful to many.

Appendix O: Study Journal

Participant

Sue

Recruitment

The research consultant emailed me to tell me that he had spoken with Sue, and that Sue had agreed for him to pass her contact details to me. Her contact details were included in this email. The coresearcher also stated that Sue had told him that she would like to take part if she has time but that she was trying to keep her tasks to a minimum. I emailed Sue with a copy of the information sheets and consent form, and we agreed a date/time to meet.

Initial Meeting on Microsoft Teams on [date] to Discuss Consent

After agreeing to meet Sue, I looked online at some of her blog entries to get a sense of who she was and how I could build a relationship with her. I also considered how I could present the information about the study in a way that was simple and easy to understand, for example by using words such as “group interview” rather than “outsider witnessing practice.” I was also aware that Sue did not want to take on too much, so I wanted to be clear in outlining the time commitments involved in her participation.

We discussed what was involved in participation, and why I thought the study was important. She appeared to be very excited about the project and keen to take part, explaining that she felt that this sort of research was very much needed. Sue confirmed that the time commitment would be manageable for her, and I told her that she could withdraw at any time should her circumstances change.

We had a frank conversation about the risk that the other participants in the outsider witnessing practice could say or do something that would be distressing for Sue. I explained that I would take care to set up the outsider witnessing practice in a way that facilitated her sense of safety. We discussed how I would know whether she was distressed during the outsider witnessing practice, and she told me that she would appear quiet and withdrawn. She said that she would feel able to say if this were the case, but we also agreed that if she felt uncomfortable and unable to say this, she would hold up a pen in front of her face, and this would signal to me that I should stop the meeting. Sue gave verbal consent to take part, and she agreed to send the written consent forms back to me via email.

Consent form signed and date agreed with Sue and the other participants for the group interview.

I emailed Sue ahead of the interview to share the link. I asked her if she still wanted to take part and whether she wanted to talk again before the group interview. She said that she felt a little nervous but was happy to go ahead, and she didn't want to talk again ahead of the interview.

Group Outsider Witnessing Practice on Microsoft Teams

All participants consented to the outsider witnessing practice being audio and video recorded. Sue presented as an engaging, open, bright, and humorous interviewee. She was wearing a red, flowery top, the brightness of which seemed significant to me given the overall hope and positivity portrayed throughout her narrative. Sue read her blog entries slowly and carefully, and her tone of voice and facial expressions mirrored words that she was reading which created an emotional intensity within the outsider witnessing practice. At times she accompanied her dialogue with direct appeals to Louise, Mandy, and me, by looking directly into her camera.

I felt moved when Sue was reading her entries, as if experiencing the highs and lows of her story alongside her. I was relieved that Mandy and Louise seemed to respond in a very thoughtful way to Sue's stories, however I worried that the content of Sue's first blog entry which was about her experiences in healthcare services could have been difficult for Louise and Mandy to hear, as healthcare professionals. I was concerned that they might have felt blamed for Sue's unhelpful experiences and I, as a healthcare professional myself felt guilt and anger about the ways she had been treated within healthcare services.

Sustaining a balance between being a researcher and clinician was challenging. There were times that I wanted to validate participants' perspectives, however I refrained because this would have positioned me within more of a therapist role. It was also much easier to summarise what participants had said, rather than to ask more questions which inevitably would have interjected more of my beliefs and assumptions into the narratives that were produced.

The time ran out quickly and I was aware that we could have continued for longer however I felt it was important to keep to the time of the interview.

Feedback

I emailed Sue with the debrief sheet and invited any feedback so that I could change my approach if needed before undertaking the second outsider witnessing practice.

Member Checking

In April 2023 I emailed Sue asking her to review my analysis of her blog entries and I invited her to make any comments regarding aspects that I had “misunderstood,” “missed” or anything that she did not “feel happy with.” She responded almost immediately to let me know that she thought my analysis “looked great” and that she did not wish to make any amendments.