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Sheffield.

Living With Dementia: How Do Literacy Practices Change Over A Lifetime?

Sharon Weatherall

A thesis submitted in partial fulfilment of the requirements for the degree of
Doctor of Education

The University of Sheffield
Faculty of Social Sciences
School of Education

Submission Date: June 2017

For:

Rose Weatherall – my mum

Annie Awcock – my gran

Robina Phillips – my aunt and godmother

Any story differs with each passing moment, new purpose and favored vantage point. Neither the whole story nor the true one ever exists, however much we may wish for it. If we could achieve the wholeness and absolute truth in our stories, we would have no more stories to tell. And tell stories we must.

(Heath, 2012, p.7)

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Acknowledgements

I would like to take this opportunity to thank my supervisor Professor Kate Pahl for her enthusiasm and inspiration throughout the entirety of the education doctorate programme and particularly for her support, suggestions and feedback while I wrote my thesis.

To my research participants, who are at the very heart of this study and so very generously shared their life stories with me.

To my work colleagues at Age UK in north London, whose immense support and knowledge of dementia helped to make a very difficult journey so much easier to cope with. I hope that I can continue to pass on your knowledge to others.

Finally, to my friends and family, who have given support and encouragement when it was most required. With very special thanks to Allan and Carolyn, who so generously gave their time to read and give feedback. To you all, I promise that I will stop complaining now!

Abstract

People who have been diagnosed with dementia typically experience a progressive deterioration in cognitive function, memory, comprehension and language abilities. There is a substantial and established field of medical research which focuses on the language disorders associated with various types of dementia (Coltheart et al., 2010; Forbes et al., 2004; Glosser et al., 2002; Lambert et al., 2007; Rousseaux et al., 2010). However, this field of research tends to focus on language and literacy loss and deficits, and give little consideration to how people with dementia socially interact and the sociocultural contexts of their lives. This research project draws on perspectives from the New Literacy Studies that literacy is socially embedded in the practices of people's everyday lives and understanding of knowledge and identity (Street, 2001), and explores how people with early stage dementia engage in everyday literacy practices (Barton & Hamilton, 1998, 2012). Using a life history approach, this study focuses on two older people in the United Kingdom who have been diagnosed with early stage dementia. Data was collected using a series of semi-structured interviews with the research participants with dementia, along with members of their families who have an integral role in their day to day lives. The interviews have produced autobiographical accounts which review engagement in a range of literacy practices throughout their lives and also explores more recent changes to engagement in literacy practices since dementia has become part of their lives. The personal narratives have also provided a way for dementia to be explored using a social lens which contextualises the lived experience of dementia for families; provides a way for self-identities to be preserved and gives a voice to people with dementia who can often feel they are "silenced" (Ward, Campbell & Keady, 2014, p.64); have an "excluded voice" (Wilkinson, 2002, p.9); or they are "invisible" (MacRae, 2011, p.446).

Keywords:

Dementia, literacy practices, communication, life history, personal narratives

Chapter 1: Introduction

This chapter provides an introduction to this thesis. I begin by considering a definition of dementia and also review the global prevalence of dementia. Next, I describe my own experiences and interest in dementia and identify the research project's objectives. I then provide a brief introduction to the research participants involved in this study and I also provide an overview of the approach I took to the research. Finally, I outline the structure of this thesis.

1.1 What is dementia?

Dementia is often described as a syndrome or is used as an umbrella term for a number of different types of diseases or dementias, with some of the most commonly diagnosed being Alzheimer's disease, vascular dementia and frontotemporal dementia (Hughes, 2011, p.23). Dementia can impact on people's memories, cognitive abilities, behaviour and mood. People's language skills can also be affected by dementia which results in difficulties with their speech and ability to communicate (Alzheimer's Society, 2016, p.1). The Alzheimer's Society (2016, p.1) identify that dementia is a progressive condition, which results in people having to live with a disease where their abilities change over time. This includes an "increasing and fluctuating impairment in the person's capacity to make decisions about life events and circumstances as well as day-to-day situations" (p.1).

The progressive nature of dementia can be viewed as three stages: early, middle and late (World Health Organisation (WHO), 2016). The early stage symptoms of dementia can include experiencing short term memory loss in terms of people, places and time. However, these symptoms can sometimes be overlooked if onset is very gradual. In the mid-stage, signs and symptoms are much more noticeable. Memory loss is more profound and people usually need help and support to complete everyday tasks, including personal care. By the late stage, people need high levels of care and support, as severe memory disturbances are experienced, and people can also experience profound physical difficulties affecting co-ordination and movement (WHO, 2016). Currently, there is no treatment available to cure dementia and there is also a lack of awareness and understanding of dementia, which can result in individuals facing

“stigmatization and barriers to diagnosis and care” (WHO, 2016). As the WHO (2016) identify, the impact of dementia can be physical, psychological, social and economic. Dementia not only impacts on the person who is diagnosed with the disease, but also on those people who have “existing relationships” with them such as family and friends (Sikes & Hall, 2016, p.3). Therefore, perhaps it is not that surprising when describing dementia, the WHO’s director-general (WHO, 2015, p.9) stated:

I can think of no other disease that has such a profound effect on loss of function, loss of independence, and the need for care. I can think of no other disease so deeply dreaded by anyone who wants to age gracefully and with dignity. I can think of no other disease that places such a heavy burden on families, communities and societies. I can think of no other disease where innovation, including breakthrough discoveries to develop a cure, is so badly needed.

1.2 The global prevalence of dementia

The WHO (2016) estimate that worldwide 47.5 million people have dementia and a further 7.7 million cases are being diagnosed every year. The WHO (2016) also estimate that 75.6 million people will have been diagnosed with dementia by 2030 and this will increase to 135.5 million by 2050. Therefore, the WHO (2016) argue that dementia is a public health priority and is also “one of major causes of disability and dependency” in older people. It is estimated that in the UK, 850,000 people have dementia and this is estimated to rise to 1 million people by 2021 (Alzheimer’s Society, 2015, p.2). Therefore, these substantial statistics show a disease that touches many individuals and families’ lives across the world. As McKillop (2002, p.113), who was diagnosed with Alzheimer’s disease in 1999 and has subsequently been involved in a number of dementia research projects states, “It is the rare person who has not been, or will not be, touched by dementia through family, friends, acquaintances and workmates”.

1.3 My own experiences of dementia

My own initial interest and understanding of dementia were through experiences in my own family. I think I first became aware of dementia in the mid-1980s. My grandmother, my mother’s mother, began to experience the symptoms of dementia following a stroke when she was about 80 years old. I was a teenager at the time, so

my memories are not recent or particularly clear. However, I do remember that my grandmother seemed to live in the past as the stories she recalled were from the 1920s and 1930s, when she was a young wife and mother, living in Islington in north London. My grandmother lived the last 10 years of her life in a care home, as she did not make a recovery from the stroke she experienced. Although I have no recollection of her ever being given a formal diagnosis of dementia, I suspect from the reading and research that I have conducted that the dementia my grandmother experienced was likely to have been vascular dementia (VaD). VaD is the second most frequently diagnosed dementia and is associated with cerebrovascular disease affecting the circulation of blood to the brain (Reilly et al., 2010, p.445). VaD is usually caused by a person experiencing a large stroke or a series of small, mini-strokes where blood supply to the brain is interrupted or restricted, and therefore causes damage to brain tissue (Hughes, 2011, p.48). Not only did my grandmother have dementia but the stroke impacted on her physical mobility, as it left her unable to walk for the final 10 years of her life.

If I then move forward in time to about 15 years ago, my aunt (my mother's sister) began to display what can be described as forgetful behaviour in relation to everyday tasks. Examples included regularly losing household items such as her door keys and handbag, and also more concerning, forgetting where one of daughters lived when attempting to visit her one day. My aunt's children were concerned, so they liaised with my aunt's general practitioner as they suspected that she might be experiencing the onset of dementia. Following tests at a memory clinic, my aunt was diagnosed with the early stages of Alzheimer's disease.

Alzheimer's disease (AD) is the most commonly diagnosed dementia (Hughes, 2011, p.28; WHO, 2016). Sabat (2001, p.7) states that AD causes damage to the "left hemisphere's temporal, parietal, and visual association areas" of the brain. Outcomes from medical research identifies that AD is caused by a combination of cerebral atrophy (shrinkage) of the medial temporal lobe, which is the area of the brain that controls episodic memory (Hughes, 2011, p.39) and the accumulation and profusion of beta-amyloid tissue (a protein) (Sabat, 2001, p.5). Amyloid plaques build up between neurons in the brain. Neurofibrillary tangles can be identified inside neurons and these

are argued to be the “major neuropathological signs of the disease” (Sabat, 2001, p.336). Medical research has shown that the plaque count of people diagnosed with AD is significantly higher than those who have not been diagnosed with AD (Sabat, 2001, p.5). The build-up of the amyloid plaques, along with the presence of neurofibrillary tangles caused by changes in Tau protein in the brain, results in the loss and degeneration of neurons and therefore, also the synaptic connections in the cerebral cortex of the brain (Kitwood, 1997, pp.22-23). This can result in people experiencing a “profound effect on information processing and behaviour” (Sabat, 2001, p.5).

Over time, my aunt’s AD progressed and impacted on her day to day life. What became particularly noticeable to me was how the AD affected her oral communication. My aunt’s speech became more verbose and she would use lots of words to describe a memory or personal experience that previously she would have described much more succinctly. Additionally, I observed that she would verbally recall a personal story and almost immediately recall a further story, barely pausing for breath between. My aunt would also recall and repeat the same story in a very short space of time and obviously had no recollection that she had told the same story only moments before. I am sure I particularly focused on my aunt’s speech and use of oral language because of my own research interests in literacy and its uses as an integral part of our everyday lives (Barton & Hamilton 1998, 2012; Heath, 1983). I am particularly interested in people’s literacy practices and take a sociocultural perspective of literacy from the work of New Literacy Studies’ researchers, where literacy is viewed not just as a neutral set of skills that are learned, but as a social practice which is always culturally and socially situated (Street, 2011, p.581; Barton & Hamilton, 1998, p.7).

I am aware from dementia research from the medical field that people diagnosed with a range of dementia types often experience a ‘breakdown’ of processes involved in oral communication and the complex associations across linguistic, pragmatic and cognitive processes (Blair et al., 2007; Noble et al., 2000; Reilly et al., 2010; Rousseaux et al., 2010). Research by Noble et al. (2000, p.51) argues that some people diagnosed with AD experience problems with oral language production. Outcomes from Bond-

Chapman et al.'s (1998, p.57) research outlines that some people with AD can experience word-finding difficulties such as anomia, where they lose the ability to name objects and also make paraphasic errors (unintended linguistic errors). However, this did not particularly appear to be the case for my aunt as she experienced the early and middle stages of dementia. However, Bond-Chapman et al.'s (1998, p.57) research suggests that circumlocutions or empty language, can be observed in some people who have been diagnosed with AD, and that they can become verbose, using more words than perhaps is necessary to express thoughts and ideas. Rousseaux et al. (2010, p.3884) concur with this view, arguing that people with AD often exhibit "sentence repetition". Therefore, Bond-Chapman et al. (1998, p.57) and Rousseaux et al.'s (2010, p.3884) observations and viewpoints seem to support my observations of my aunt's speech and oral communication skills as her AD progressed.

In 2011, my mother also started to display forgetful behaviour. Keys were lost, appointments at the dentist and opticians forgotten, and perhaps most concerning, she became lost on a bus journey which she had made numerous times in her life and was very familiar with. This resulted in a visit to my mother's general practitioner to discuss these events and she was subsequently tested for dementia at a local memory clinic. My mother was diagnosed with vascular dementia in spring of 2012. I became an integral part of her dementia journey and her main family carer. My mother's dementia journey was relatively short, as her experience of the disease was that it progressed rapidly in a time period of approximately three and a half years. My mother changed from a person who was totally independent in terms of managing her home, her financial affairs and being a very sociable person who regularly visited friends and family, to someone who lost her ability to walk, to cook and care for herself. She almost lost the ability to speak by the end of her life. In the last six months of her life, my mother required 24 hour care and she sadly died from vascular dementia in the summer of 2014.

I found that like most people who suddenly find that they are the main family carer for a relative who has been diagnosed with dementia, the journey was often emotional and the learning curve was very steep. I attempted to balance a busy home and work life, and studying for an Education doctorate with the new found care responsibilities

for my mother. Part of my personal coping mechanism was to reduce my working hours as a teacher training lecturer at the university I worked for and I took on a new, part time job role as an assistant care co-ordinator for a dementia project. The dementia project was based locally to my mother's home and was co-ordinated by a north London branch of Age UK, who are the UK's national charity for older people (Age UK, 2017).

As I became a more integral part of my mother's care, what became particularly noticeable to me were the differences I could observe between my mother and my aunt's use of speech and verbal communication skills. Where my aunt's speech was quite verbose, I observed my mother's speech and oral communication constantly declining over time. My mother had always been a strong oral communicator who had been confident to talk to people. She was the sort of person who would talk to a complete stranger in a queue. My mother now experienced anomia (word-finding difficulties). She forgot people's names and she struggled to name everyday objects which she found very frustrating. Her sentences became jumbled as she made syntactical errors, which when combined with her word finding difficulties began to make oral communication very challenging for her and those who were trying to understand her. My mother also began to speak more quietly, which could make her speech even more difficult to understand.

Reilly et al. (2010, p. 445) state that people with vascular dementia can experience problems with oral communication in terms of a decrease in phonemic fluency; the grammatical complexity of their sentence construction can be reduced and also that some people experience changes to their vocal quality such as a flattening of pitch and changes to the amplitude of their speech. I found as my mother's speech changed over time, it became essential to observe her body language carefully, plus her use of non-verbal strategies, as these were essential to being able to understand what she wanted to communicate.

I also observed that my mother's literacy practices (Barton & Hamilton, 1998, 2012) changed as her dementia progressed. My mother had always managed all the administrative tasks and the financial affairs with respect to running her home. She

had written letters to keep in touch with family and friends and had sent an abundance of birthday and Christmas cards each year. She had also written lists of things that needed to be completed in relation to her home and shopping lists were written each week. My mother had always read a lot. She had inspired me to read as a child. She read a daily newspaper and a locally published, weekly newspaper. She read a plethora of what I describe as women's magazines each week: *Woman's Weekly*, *Woman's Realm*, *My Weekly* and the *People's Friend* to name a few. My mother also read books and particularly enjoyed fiction. My mother was interested in London's history, so she read about the history of London. She had bought books on the subject over the years and had also borrowed books from the local library. My mother also completed the crossword in the daily newspaper and word puzzles published in the women's magazines.

I noticed that my mother had begun to stop writing. With hindsight, I realised that she completed fewer writing tasks long before I noticed her memory difficulties and forgetfulness in 2011. She wrote and sent fewer birthday cards and I began to help her to write the eighty plus Christmas cards that she sent each year. She no longer wrote letters. Family and friends received phone calls from her and the more formal written communications that were required, such as letters and forms by institutions such as banks or the local authority, I completed for her. Over time, my mother stopped completing word puzzles and crosswords. By 2012, when my mother was diagnosed with vascular dementia, she could no longer write a shopping list or a cheque. The last thing she was able to write was her signature and eventually she found this impossible to do. She could not remember how to form the letters, which she found very upsetting when she realised what was happening.

Similarly, my mother's reading practices changed over time. Books became "too long to read" and she focused on reading newspapers and magazines. By early 2013, she no longer wanted to read the daily newspaper. She would 'browse' through the local, weekly newspaper and magazines. She appeared to focus more on the photographs and images than the text, and would sometimes read a headline aloud, or the odd sentence or two. We would often look at the local newspaper and magazines together and I would read articles to her that she seemed interested in. My mother had an

experienced care team. They would also look at magazines and newspapers with her and read to her when they visited her at home.

During the last few weeks of my mother's life, she was too ill to have any interest in newspapers or magazines, and her speech continued to deteriorate. Her speech was limited to a very few words and this was usually in response to being asked a question. I recognise from Blair et al.'s (2007, p.238) research that my mother experienced global aphasia, where language production is so severely impacted on, the results are that people are only able to say a very few words. However, some people in the very late stages of dementia become completely mute (Blair et al., 2007, p.238; Reilly et al., 2010, p. 441).

1.4 Introducing the research project and objectives

My observations of the difference in my mother and my aunt's speech and language practices as they experienced living with dementia were my initial motivation for this research project. I began to investigate research and found that there is literature which gives advice on best practice when communicating with people who have dementia (Killick & Allan, 2001). There is also a substantial and established field of medical research which focuses on language disorders associated with various types of dementia (Bond-Chapman et al., 1998, 2002; Coltheart et al., 2010, Forbes et al., 2004, Glosser et al., 2002, Lambert et al., 2007, Perkins et al., 1998; Rousseaux et al., 2010). However, this research from the medical field tends to focus on language and literacy loss and deficits and seems to give very little consideration to how people with dementia socially interact and the sociocultural contexts of their lives (Beard, Knauss and Moyer, 2009, p.227). Therefore, I acknowledge that this research project is rooted in my own personal interests and has echoes of Sikes' (2015, p.45) experiences that it was "research which demands to be done".

I bring a sociocultural perspective of literacy to this research and wish to explore how older people with early stage dementia describe their engagement in everyday literacy practices (Barton & Hamilton, 1998, 2012) throughout their lifetimes. I am particularly interested in whether losses to people's language and literacy skills through the

progression of dementia impacts on how they engage in literacy practices and what these changes are. Therefore, my research objectives for this research project are:

1. Review how older people who have been diagnosed with early stage dementia have engaged in a range of literacy practices throughout their lifetime.
2. Explore if losses to language and literacy skills through the progression of dementia are changing how older people engage in literacy practices and what these changes are.

1.5 The research participants

The research participants who sit at the heart of this study are two older people. They both live in north London in the United Kingdom and both were diagnosed with early stage dementia during 2014. Belinda is 69 years old and was diagnosed with Alzheimer's disease, while Henry is 93 years old and was diagnosed with a combination of Alzheimer's disease and vascular dementia. I am also interested in the views of people who are integral to Belinda and Henry's day to day lives and to their care, and so two further research participants who are central to this research project are Belinda's daughter, Sandra, and Henry's daughter, Pam. Both Sandra and Pam describe themselves as their respective parents' main family carers.

1.6 The research approach

I have selected to take a life history approach (Goodson & Sikes, 2001; Goodson, 2013) to this research project as I wished to explore personal narratives and autobiographical accounts of older people who experience early stage dementia, plus the accounts of people who are close to them. I wanted to select a methodology which would allow me to review the lives of older people with dementia over a span of time, as I was interested in my research participants' literacy histories. I support Barton and Hamilton's (1998, p.3) view that "literacy is essentially social, and it is located in the interaction between people". Therefore, I wanted to use a methodology that would allow me to consider dementia as a social process and to contextualise the lived experience of dementia. I hoped that this would provide an alternative to dementia

research based on a medical model of disability, which can often seem to disregard the sociocultural contexts of people's lives. I also hoped that capturing people with dementia's autobiographical accounts and personal stories would give a voice to people who can often feel they are "invisible" (MacRae, 2011, p.446).

1.7 The structure of this thesis

In chapter 2, I engage with a range of academic texts which span different and contrasting fields of research. These include: literacy studies; medical research into dementia which focuses on language and literacy skills; research which reviews the use of neuropsychological standardised tests in clinical assessments of dementia; and finally, narrative studies and dementia.

Chapter 3 outlines the methodological approach I took in relation to this research project. I review the methods used to support using a life history approach to this research. This includes: the recruitment of research participants with early stage dementia; the development of a process consent method; ethical considerations in relation to conducting the research; and using a thematic approach (Riessman, 2008, p.74) as a way of analysing the resulting narrative and autobiographical data, which was collected through the use of semi-structured interviews with the four research participants.

Chapter 4 is the first of two chapters in which I present the outcomes and findings from completing this study. In chapter 4, I present overviews of the lives of the research participants with dementia, in sections titled: Belinda's Story and Henry's Story.

In Chapter 5, I present this study's findings as a result of having applied a thematic analysis (Riessman, 2008, p.74) of the data collected in relation to the study's main research objectives. Chapter 5 is organised into five main sections:

- i. Everyday reading practices.
- ii. Everyday writing practices.
- iii. Literacy practices and living with dementia.
- iv. Collaboration, storytelling and dementia.

- v. Performative and embodied dimensions of storytelling and dementia.

In Chapter 6, I review the overall outcomes of completing this research in relation to the study's main research objectives. I consider implications for dementia practice and identify further areas of research in relation to literacy practices and dementia. I also consider aspects of taking a life history approach to this research. Finally, I outline the contribution this research project has made to the body of knowledge in the field of literacy studies.

Chapter 2: Literature Review

Introduction

In this chapter, I engage with a range of literature which spans different and diverse fields of academic research. In the first section of the chapter, I review literature from the field of literacy studies. In particular, I draw on researchers' work from the New Literacy Studies, as I wished to explore research which views literacy from a sociocultural perspective. This body of research has pertinence to this study, as I wish to consider dementia as a social process and explore how older people with early stage dementia have engaged in everyday literacy practices throughout their lifetimes.

In the second section of this chapter, I review dementia research from the medical field to explore how dementia can impact on people's oral communication, reading and writing skills. I felt it was relevant to explore findings from this field in relation to dementia and literacy and language, as I wished to develop my understanding of dementia when viewed from a clinical perspective.

The third section of this chapter focuses on literature which critiques the use of neuropsychological standardised tests in clinical assessments of dementia. This literature presents viewpoints which question the validity of using standardised tests to assess people with dementia's language and literacy skills. I have found it relevant to consider these arguments in relation to this study, as the medical literature and research previously explored predominantly uses methodological approaches based on the use of neuropsychological standardised tests in the assessment of dementia.

The final section of this chapter reviews literature from the field of narrative studies which focuses on the personal narratives and life stories of people with dementia. I wished to explore research from this field, as having selected to take a life history approach (Goodson & Sikes, 2001; Goodson, 2013) in this study, I recognised that the recording of personal narratives and autobiographical accounts of people with dementia would be central to this research.

2.1 A sociocultural perspective of literacy

This first section of the literature review draws on a range of research from the field of literacy studies. It draws on perspectives from the New Literacy Studies, such that literacy is socially and culturally embedded in the practices of people's everyday lives and their understandings of knowledge and identity. Literacy is also viewed as being influenced by factors such as discourse, context and power (Street, 2011, p.581; Barton & Hamilton, 1998, p.7). I am particularly interested in the literacy practices (Barton & Hamilton, 1998, 2012) of older people who experience dementia. I also recognise that literacy can be considered as multiple (Gee, 2015, p.36; Street, 2011, p.581), therefore "literacies", as different types of literacy can be used in different contexts (Barton & Hamilton, 1998, p.9), and span different scripts and languages and can involve a "crossings of languages" (Pahl & Rowsell, 2010, p.3).

In this first section of the literature review, I draw on work from Street (1993, 2001, 2011), who proposes and reviews contrasting models of literacy. Next, I consider research into critical literacies by Janks (2010) and Keating (2005). I also review Barton and Hamilton's (1998, 2012) research into the concepts of literacy practices and ruling passions. Next, I consider literacy events and review research by Barton and Hamilton (1998, 2012) and Heath (1983). I found it useful to consider Brandt and Clinton's (2002) work in relation to literacy and context and particularly, the relationship between the 'local' and the 'global'. I also review Brandt's (2001) research in relation to sponsors of literacy and Gregory and Williams' (2000) work which explores mediators of literacy. Technological developments have spanned the lifetimes of the research participants involved in this study during the 20th and 21st centuries. This has resulted in people using new technologies and literacies to communicate with each other. Therefore, I also explore Davies (2012, 2014) and Kell's (2011) research into digital literacy practices. I am also aware that literacy can be viewed as multimodal (Kress, 1997) in that people draw on a wide range of artefacts and resources to communicate with each other and make meaning. Therefore, I also engage with research by Davies (2014), Jones (2014), Leander and Boldt (2013), Mackey (2016), and Pahl and Rowsell (2010) which reviews the material and embodied nature of literacy.

Models of literacy: autonomous and ideological

Street (2001, pp.6-7) developed two contrasting models of literacy: autonomous and ideological, as a result of completing anthropological fieldwork in Iran in the 1970s. Street argues that in the autonomous model, literacy can be viewed as a singular phenomenon and “simply as a technical and neutral skill” (2001, p.7) which is viewed as independent of any social context (1993, p.5). Street (2001, p.7) also argues that the model “works from the assumption that literacy in itself – autonomously – will have effects on other social and cognitive practices” and “disguises the cultural and ideological assumptions” which underpin the model, and can be “presented as though they are neutral and universal”. Street (1993, p.7) emphasises that the “neutrality” and “autonomy” of literacy in this model is in itself ideological, in that it does not account for the relationship between literacy and power structures within society.

Similarly, Ivanič et al. (2009, p.20) argue that when literacy is regarded as autonomous, it is viewed as a “value-free attribute lying within the individual – a set of singular and transferable cognitive technical skills which can be taught, measured and tested at a level of competence against pre-specified standards”. However, this perspective fails to take into account the extensive range of ways that literacy is used as an intrinsic part of people’s everyday lives. Street (2011, p.581) considers issues of power and inequality in relation to this view of literacy arguing that there is, “inequality for those who ‘lack’ it and advantages for those who gain it”. Brandt (2001, p.2) supports this view, stating that “literacy undeniably has been an instrument for more democratic access to learning, political participation, and upward mobility”, while also acknowledging that “at the same time, it has become one of the sharpest tools for stratification and denial of opportunity”. Janks (2010, p.3) recognises the historical nature of inequalities linked to literacy and outlines that it is often translated as “educated or schooled” in languages which do not have a word for literacy. Janks argues that this translation can be aligned with “notions of refined, learned, well-bred, civilised, cultivated, genteel” and cites the Oxford English Dictionary (1980) which records that as early as the year 1550, “literacy came to be seen as the mark of a ‘liberally educated or learned person’... at a time when few people had access to this technology” (p.3).

In contrast, Street (1993, p.8) argues that the ideological model of literacy is based on perspectives from contemporary anthropology, socio-linguistics and cultural studies where ideology is viewed as “the site of tension between authority and power... and resistance and creativity”. Literacy in the ideological model is always viewed as multiple or plural, so therefore, “literacies” (Street, 2011, p.581) and is viewed as a “social act” (Street 2001, p.8) embedded in “socially constructed epistemological principles” (p.7). Therefore, the “ways in which people address reading and writing are rooted in conceptions of knowledge, identity and being” (p.7). Street (1993, p.2) also argues that literacy is always ideological in character in terms of the “acquisition, use and meanings of different literacies” which is significant in terms of how authority and power are distributed within society.

A personal experience described by Susan Suchan (2016) illustrates the relationship between identities, authority, power which are integral to the ideological model of literacy (Street, 1993, 2001, 2011). Suchan (2016) diagnosed with a combination of young onset Alzheimer’s disease and frontotemporal dementia described she assigned power of attorney to close family members after her diagnoses. She recalls when a contract was signed with a film company who were documenting her experiences of living with young onset dementia:

Contracts to be signed and we’ll be able to get started... My daughter and my sister were handed very important looking paperwork. I sat waiting for mine... not anymore. For the first time since the dementia diagnosis, I was forbidden to sign a contract. Wow, I can’t even put into words how small I felt. I squabbled about my pride and asked my family to put themselves into my shoes, just for a minute. I guess I always thought I would be ‘unable’ to sign my name at some point due to the effects of dementia. Just didn’t think about actually recognizing and being physically able yet legally unable. It has taken me a minute to adjust to this prescribed reality. It has raised the question for me, should documents that so profoundly affect my ability to participate, be signed so early in one’s diagnosis? Should a person’s loved one’s be asked to make decisions when the diagnosed person still be functioning with little assistance?

Suchan (2016) asks very pertinent questions with respect to the legal authority that Power of Attorney assigns to people who have been granted it. Her experience also particularly demonstrate the imbalance in power that written mediation can bring to families and the potential this has for leaving a person with dementia questioning their

identity as a result of feeling powerless within a situation or literacy event (Barton & Hamilton, 1998, p.7; Heath, 1983, p.392) in their everyday life.

Ivanič et al. (2009, p.20) also review the ideological model of literacy and argue that it acknowledges the “many different ways of reading and writing for different purposes and with different cultural practices [and] the focus is on what is read and what is written, where, how, by whom, why and under what conditions”. Similarly, Bloome and Green (2015, p.20) argue that an ideological view of literacy sees literacy as situated, contextualised and being used by people “as they interact with each other within social institutions and social spaces in which they live their lives”. Pahl and Rowsell (2010, p.7) acknowledge that literacy is always “shaped by context, power and history” and argue for the importance of “interrogating how literacy is situated” so that issues of power and inequality can be challenged through the use of critical literacies. Therefore, it is literacy from this ideological perspective that I wish to explore within this research. I am interested in the reading and writing that the research participants with dementia have engaged in and used throughout their lives and the “where, how, by whom, why and under what conditions” (Ivanič et al., 2009, p.20). I am also interested in the social institutions and spaces that have influenced my research participants’ lives. I particularly want to gain a longitudinal view of my research participants’ literacy histories through capturing their autobiographical accounts, as I wish to explore the range of literacy practices they have engaged in throughout their lives and to discover how these practices are changing since dementia has become part of their everyday lives.

Critical literacies

The field of critical literacies is pertinent as it understands literacy as social and political, and focuses on exploring how unequal political, economic, cultural and institutional structures impact on textual and social practices (Janks, 2010). As Janks (2010, p.12-13) states, critical literacies strive “...to uncover the social interests at work... Who benefits? Who is disadvantaged?”. Janks (2010, p.13) reflects on the work of Brazilian educator and philosopher, Paulo Freire (Freire 1972, Freire & Macedo, 1987) who argues that power and language are inextricably intertwined. Freire’s work has challenged viewing literacy simply as technical skills (Freire & Macedo, 1987, p.xii)

and assumptions that literacy pedagogy is “simply teaching students the skills necessary for reading and writing” (Janks, 2010, p.13). Freire argued that literacy should be seen as a form of cultural politics which can be viewed as a set of practices and can either “empower or disempower people” (Freire & Macedo, 1987, p.xii). When literacy is viewed from this perspective, it can be analysed to ascertain whether it is being used to “reproduce existing social formation” or “serves as a set of cultural practices that promotes democratic and emancipatory change” (p.xii). Freire (1972, p.52) argues that people are able to change social situations through critical praxis stating that “Liberation is a praxis: the action and reflection of men upon their world in order to transform it”. Integral to the relationship between people’s engagement with literacy and their critical consciousness of the world in terms of “meaning making” and “mediated activity” (Berthoff, 1987, p.xix) is Freire’s (1984) view that reading and writing the *word* cannot be isolated from reading the *world*. Freire states:

The act of learning to read and write has to start from a very comprehensive understanding of the act of reading the world, something which human beings do before reading the words. Even historically, human beings first changed the world, secondly proclaimed the world and then wrote the words. These are moments of history. Human beings did not start naming A! F! N! They started by freeing the hand, grasping the world (Berthoff, 1987, p.xvii).

Keating’s (2005, p.106) ethnographic research into the literacy practices of a group of Portuguese women living in London at the beginning of the 21st century reflects Freire’s view of critical praxis (1972) and the process of reading the *word* and the *world* (Freire & Macedo, 1987). Keating’s (2005, p.106) study focused on the research participants as they negotiated the process of creating new self-identities in a changing environment from being perceived as migrants to European citizens. The study explored how the women engaged with a range of texts to develop their critical consciousness (Berthoff, 1987, p.xix) to make sense of their self-identities in various contexts present within their lives in the UK. Keating (2005, p.126) argued that for her research participant Isaura, her regular engagement with two women’s magazines helped her to make sense of experiences in her everyday life. Isaura regularly read a popular Portuguese magazine, *Maria*, along with a UK published magazine *Take a Break* (p.115). Keating argued that Isaura preferred *Take a Break* to *Maria*, as she was able to learn from it (p.126) and “*esclarece-se* (one gets information)” (p.122). Keating described how Isaura was able to negotiate meaning and gain a sense of self from her

regular interaction and reading of the magazine through synthesising the information she read with her own personal experiences and her wider knowledge of how global forces were impacting on her life (p.125). Isaura also used the magazine genre which was familiar to her to help her negotiate meaning of a less familiar discourse; the “institutional discourse” of medicine (p.126). This personal negotiation of meaning had a direct relevance to Isaura’s family, as her daughter had a medical condition and she needed to be able to understand a doctor’s description of her daughter’s illness (p.126).

Therefore, in my own research I wish to review the range of texts my research participants have engaged with throughout their lives and to capture through their recall of autobiographical memories the ways they have used these to develop their critical consciousness, negotiate meaning in their own lives, and to also make sense of situations, contexts and their own identities.

Literacy practices

Barton and Hamilton’s (1998, 2012) seminal, ethnographic study of literacy in the city of Lancaster in the north of England at the end of the 20th century identified the “local” and “everyday” situated nature of literacy (p.i). Barton and Hamilton (1998), like Keating (2005) also witnessed evidence of praxis, as they observed their research participants using literacy as an integral part of their day to day lives across a range of contexts. Barton and Hamilton (1998, p.231) describe, “literacies are used to satisfy people’s desires for information and explanation; to pursue leisure interests and enthusiasm, as a means of gaining control over their environment; and to create or maintain a sense of time and place”.

One outcome of Barton and Hamilton’s (1998, p.6) research was their presentation of “a social theory of literacy” in which they argued that “the basic unit of a social theory of literacy is that of literacy practices”. Barton and Hamilton described that, “Literacy practices are the general cultural way of utilising written language which people draw upon in their lives...[and that] literacy practices are what people do with literacy” (p.6). Barton and Hamilton also outline that literacy practices also involves people’s “values, attitudes, feelings and social relationships...[which] includes people’s awareness of

literacy, constructions and discourses of literacy, plus how people talk about and make sense of literacy” (p.6). Ivanič et al.’s (2009, p.48) research which focused on Further Education students’ literacy practices, proposed that literacy practices offer “a powerful way of conceptualising the link between the activities of reading and writing and the social structures in which they are embedded, and that they help to shape”. Ivanič et al. (2009, p.15) also argue that the study of literacy practices offers researchers an opportunity to study “the inherent creativity in the ways in which people use and do literacy [which] can be embraced as the achievements of people making meaning and communicating for themselves and others in their lives”. Ivanič et al. (2009, p.48) and Barton and Hamilton (1998, p.7) concur that literacy practices are social processes which connect people with one another and exist in the “relationship between people within groups and communities” (Barton & Hamilton, 1998, p.7). They also help to shape people’s shared understanding of social identities through “shared cognitions and artefacts represented in ideologies, rituals and identities” (Ivanič et al., 2009, p.48). Barton and Hamilton (1998, p.7) also argue that literacy practices are impacted on by power and identify that, “practices are shaped by social rules which regulate the use and distribution of texts, prescribing who may produce and have access to them” and therefore, “some literacies become more dominant, visible and influential than others”.

It is the concept of literacy practices that lie at the very heart of my research. I wish to discover how my research participants with dementia describe their engagement with literacy practices throughout their lives. I am interested in the diversity of the literacy practices the research participants have experienced; how they have used, understand and have made sense of literacy; the ways in which they use literacy to communicate with others; and to also explore the extent to which literacy has played a part in shaping their personal identities. I also wish to compare whether there are changes to the types and range of literacy practices the research participants engage in, through considering the personal experiences they can recall from before the onset of dementia, and now more recently as they live with the disease on a daily basis.

The concept of life history (Goodson & Sikes, 2001; Goodson, 2013) and how people’s literacy practices are located in their life stories is also a central part of this study, as I

wish to be able to view the research participants' experiences from their earliest memories of childhood, through adolescence and into adulthood, and to their present life stage. I recognise that literacy is "historically situated" (Barton & Hamilton, 1998, p.7) in terms of how people make sense of changes in their personal literacy histories brought about by wider changes in society. I am very aware that the research participants' lives extend across a period of history spanning the 20th and early 21st century witnessing world-wide political, economic and technological change. Brandt (2001, p.2) argues that literacy in this time period has had to respond to these changes and this has resulted in "an unprecedented pace of change in the uses, forms and standards of literacy." Brandt also asserts that this rapid period of change has resulted in "the meaning of what it is to be literate has seemed to shift with nearly every new generation" (p.2). Therefore, I am interested in the extent to which my research participants' literacy practices have had to change and diversify in response to new technological developments in the contemporary world. I am also interested in new literacy practices the research participants have engaged with to make changes to their own lives and what motivated these changes. I recognise that the incorporation of new literacy practices into a person's life can be gained through informal and formal learning experiences (Barton & Hamilton, 1998, p.12; Brandt, 2001, pp.6-7). Therefore, I am also interested in the types of learning the research participants have been involved in during their lives and what motivated them to engage in these learning experiences.

Literacy events

Barton and Hamilton (1998, p.7) acknowledge that literacy events are "observable episodes" which "arise from" and are "shaped" by literacy practices. Heath's (1983) seminal ethnographic research conducted in the late 1960s examined the literacy and language practices of three communities located in the rural Piedmont area of the Carolinas in the south-eastern United States. Heath's research (1983) showed how families from the different communities socialised their children into the literacy and language practices and events of their communities. Heath also reviewed the ways in which school teachers responded to the children's different "Way with Words" within the school environment, along with the differences in the children's home and school literacy practices.

Heath (1983, p.392) argued that in literacy events, there is a relationship between texts and 'talk' and that talk "revolves around" pieces of text as they are used in everyday life. Heath (1983, p.392) cites Anderson, Teale and Estrada (1980) who define "a literacy event as, 'any action sequence, involving one or more persons, in which the production and/or comprehension of print plays a role' ". Heath proposes that literacy events have "social interactional rules which regulate the type and amount of *talk* about what is written, and define ways in which *oral language* reinforces, denies, extends or sets aside the written material" (p.392). Heath asserts from her observations of research participants who lived in the neighbourhood of Trackton, that reading is viewed as a social activity, and often takes place within family groups or between groups of neighbours and friends (p.196). Heath observed texts such as newspapers, circulars and letters being read aloud by one family member, which then generated talk and discussion within the family group who had been listening (p.196). Heath describes, "... when something is read in Trackton, it almost always provokes narratives, jokes, sidetracking talk, and active negotiation of the meaning of written texts amongst the listeners" (p.196). Barton and Hamilton (1998, p.7) also recognise that literacy events are "observable episodes which arise from practices" noting that written text is central to literacy events and the "talk around the text".

Technological developments during the initial years of the 21st century have led to literacy events being viewed as multimodal (Kress, 1997) as people are able to draw on a wide range of different modes, including digital technologies, to develop different ways to communicate and make meaning. I find Pahl and Rowsell's (2006, p.6) definition of multimodality useful as it describes "communication in the widest sense, including gesture, oral performance, artistic, digital, electronic, graphic and artefact related". As Ivanič et al. (2009, p.21) argue, technological changes provide a "complex semiotic landscape" for researchers to explore, as "artefacts and media are taken up by people in different and diverse ways in order to take and make meaning, communicate and do things through meaningful activity" (p.15). Therefore, I am also interested in reviewing the range of modes which are used by my research participants to communicate and make meaning, and to also explore whether or not living with dementia appears to change how they communicate with others.

Literacy, context and digital communication

The context or the situated nature of literacy is fundamental to the sociocultural view of literacy (Street, 2011, p.581; Barton & Hamilton, 1998, p.7). Ivanič et al. (2009, p. 47) describe that literacy “always exists in a particular context and gets part of its meaning and value from that context”. Barton and Hamilton (1998, p.9) argue that literacy changes between contexts, so different literacies are related to different domains of people’s lives such as home, school and workplace. Related to ideas about context and literacy is the relationship between the ‘local’ and the ‘global’ (Brandt & Clinton, 2002). Brandt and Clinton (2002, p.338) argue that although literacy practices can be viewed as taking place at a local level, attention must always be paid to the global forces which mediate people’s access to texts, and therefore influence their engagement with literacy practices.

Brandt and Clinton’s (2002, p.338) view seems particularly pertinent at this particular moment in the 21st century where an unprecedented amount of virtual social interaction can be observed at a local level across many parts of the world but with the knowledge that this online and mobile communication is only made possible through engagement with global, communication systems (Pahl & Rowsell, 2006, p.5). As Brandt and Clinton (2006, p.257) state, “electronic texts now reside at specific addresses – homes we must visit in order to read them – where writers or their sponsors can keep close tabs on the readers”. Therefore, many people’s everyday literacy practices include the use of virtual and mobile technologies to create and use a wide range of digital texts to communicate with others in ways that go beyond time and geographical spaces (Davies, 2012, p.21). This ongoing development and use of digital literacy practices to enhance opportunities for people to digitally communicate and socially interact has challenged older and more traditional perceptions of the relationship between situation, context, space and literacies (Davies, 2014, p.74; Kell, 2011, p.607). As Kell, (2011, p.607) identifies, “digital technologies enable literate communication to stretch between people, across contexts and over time”. Therefore, Kell (2011, pp.606 - 607) advises that researchers need to review meaning making in, and more importantly “across”, contexts, to consider “the relation between literacy, its affordance and issues of power and scale; in the context of intensified mobility and the flows of people, objects and information”.

Therefore, I am interested in the different contexts I can identify in my research participants' lives and the range of literacies and literacy practices they engage with and that are embedded within and "across" (Kell, 2011, p.606) these contexts. I am also interested in whether changes have taken place as dementia has become part of their lived experiences. I am also interested in exploring the digital literacy practices the research participants engage in with consideration to their experiences through the possibilities offered by new technologies and digital communication. Whilst I recognise that many older people do regularly use digital technology, I also recognise there are also substantial numbers of older people who do not (Damant & Kamp, 2015, p.5). As Burnett et al. (2014, p.11) identify, "the impact of technology... clearly has uneven take up across different populations".

Recent survey data published by the Office for National Statistics (2016) relating to internet access identified that while 53% of adults in the UK aged 65 and over regularly access the internet to use email, 34% to read the news online and 31% to access services related to travel (p.6), there are also "nearly half of single pensioners who still have no internet access at all" (p.2). Age UK (2015, p.7) argues that this has particular relevance at a time when businesses, government and public services are trying to improve efficiency and to cut costs through developing online services, which has resulted in that some older people use the internet "by proxy" as family members and friends access the internet for them (Age UK, 2015, p.25). However, while some older people are content for their access to the internet to be mediated by others on their behalf, some older people describe that this leaves them feeling frustrated, lacking in independence and privacy, and it also potentially leaves them more open to risk of experiencing financial exploitation (Age UK, 2015, p.25). This links to Hamilton's (2008, p.64) acknowledgement in her review of the changing nature of older adults' literacy practices that some of the key issues in relation to the role of literacy through the "lens of aging" are:

relations of interdependency and mediation, especially the delicate balances of inter-generational support and control, negotiating the boundaries of public and private knowledge, and the importance of considering trust, fear and respect as factors in supporting literacy practices among older people that are acceptable to them.

People with dementia can experience digital exclusion and this has been acknowledged by the UK government (Department of Health, 2012) and the Alzheimer's Society (2013a). Age UK (2015, p.34) also acknowledge that further research is required into how people with dementia engage with digital technology.

Both the Alzheimer's Society (2013a) and the UK government (Department of Health, 2012) have identified the urgent need for the development of digital and assistive technology to support the lives of people experiencing dementia. There is a growing body of research evidence which proposes that people with dementia find touchscreen devices such as smartphones and computer tablets easier and more intuitive to use than conventional computers and laptops, as these require keyboard skills and the use of an electronic mouse (Astell et al., 2016, p.e1). Astell et al. (2016, pp. e1-2) state that touchscreen technology is being used with people with dementia for cognitive assessments and to provide cognitive support and/or stimulation. However, Astell et al. (2016, p.e2) also argue that there is potential to develop applications for people with dementia to be able to use and engage with independently. Astell et al. (2016, p.e2) cite earlier research conducted in the Netherlands by Groenewoud and colleagues (2012) who evaluated the use of ten touchscreen iPad applications being used by people with dementia. It was found that the most popular application was 'Sjoelen' ('Shuffleboard') which was developed to represent a popular Dutch board game. Astell et al.'s (2016, p.e2-3) research focused on people with dementia's engagement and enjoyment when playing two game applications using iPads: *Solitaire* and *Bubble Xplode*. Astell et al. (2016, p.e5) concluded that overall their research respondents (80%) enjoyed playing the touchscreen games independently, and there is potential to identify further applications which people with dementia can enjoy engaging with through the use of touchscreen, tablet devices (p.6).

Blogging about dementia

Further to the discussion of how people with dementia engage in digital literacy practices is consideration of the growing number of blogs published by people who experience dementia. Many of the blogs' authors are people who have a young onset variant of the disease having received a diagnoses when they were under 65 years of

age (Young Dementia UK, 2017). In the following section, I review excerpts from authors' blogs to explore the views they express about the value they gain from blogging and digitally engaging with others through social media sites such as *Facebook* and *Twitter*. I also review some of the authors' reflections on the reading and writing practices they participate in during their day-to-day lives and the changes they have observed to these as they live with dementia.

Ken Clasper (2014), diagnosed with young onset dementia with Lewy bodies, describes that he writes a blog as it provides him with a "memory bank" of problems that he faces in his everyday life. He also describes that writing helps him to understand some of the symptoms he experiences and to connect to other people who have dementia and organisations such as universities who are undertaking dementia research. Carol Fordyce (2017) also reflects that her blog will be her "memory book for the future". Fordyce hopes that she will be able to use it as a way to recall and revisit personal life events in the future. Fordyce also describes that sharing personal experiences with other people through her blog is important to her, so that she can raise awareness about dementia.

Researcher and dementia activist, Kate Swaffer (2017), diagnosed with young onset dementia, also describes that she writes a blog to create a personal "memory bank", and to stay connected with herself and others:

I write to stay inspired, to share my thoughts, to remind me of *who I really am*, and to keep tabs on my life, my thoughts and my philosophies so that later on, I can *remember* what it is I was thinking or doing. I am creating my own memory bank. For now, *Creating life with words* [blog] is my way of staying connected with myself and the rest of the world.

Capturing memories is also important to Wendy Mitchell (2017a), diagnosed with a young onset variant of dementia:

I started this blog to allow me, in the first instance, to write all my thoughts before they're lost ... I have calendars that take care of the future but this blog serves as a reminder of what I've done and said in the past – it now serves as my memory.

Lupe Picazo (2015), diagnosed with a combination of young onset Parkinson and Alzheimer's disease, reflects that he writes in the hope that it will offer him a way to communicate with his family in the future:

I write something each day no matter how little it is. I write letters to my kids who I hope one day will be able to read them. I write letters to my wife who will one day read them when I can no longer communicate with her. Writing is harder than it used to be. But somehow that makes me appreciate it more. I don't take it for granted. I work at it harder. I love it. It is a passion of mine. It will live on and speak for me when I cannot.

Using social networking sites to communicate with others is considered by some of the blogs' authors. Swaffer (2017) describes:

In fact social media is almost the only way to connect with others these days as few answer their mobile phones, even fewer answer their home phones if in fact they have one, and almost no-one has time for a coffee and a chat any more. It seems we are all too busy with our lives to talk to each other, and so this is my way of staying connected, even if it is just in cyberspace.

Tommy Dunne (2015b), diagnosed with early onset Alzheimer's disease, reviews why he uses *Twitter* and the benefits he gains from this:

It gives me the opportunity to communicate with my peers and carers. It gives people a chance to ask questions directly to people with dementia, so they're getting straight from the horse's mouth, so to speak... It gives my peers and myself the opportunity to say exactly how we feel and hopefully pass on some information that will help carers and my peers. Twitter allows you to use your brain 24/7 and helps keep it active which is very important for us.

Dunne (2015a) also describes what he gains from the process of writing:

Writing is therapy for me. It frees my mind. I can express my feelings in the written word without getting emotional. But the best thing about writing on Twitter is that I can take my time doing it and I can do it in 140 characters or less.

Agnes Houston (2015), diagnosed with Alzheimer's disease, reflects on what she gains from using the social networking site *Facebook*:

I can only say that I see my Facebook friends and my virtual friends as great peer support, I rely heavily on it and have a daily dose of it at least. I have a Facebook page, I use it to get information about dementia... it's a great media

to visually see what's happening with others with the diagnosis of dementia. Not terribly good with it but I do try.

Some of the blogs' authors reflect on how dementia is impacting on their verbal communication, writing and reading practices. Mitchell (2017c) describes that her dementia is impacting on her speech and her ability to talk, so she finds that writing "can be very therapeutic... it's a way to feel normal as I can type far better than I can speak". Mitchell (2017b) also describes that "typing is taking over from talking":

In that world of silent conversation, I can type my thoughts, speedily and eloquently... Sentences flow as if in normal conversation, no fragmented sentences. In this silent world of the keyboard, I can speak the thoughts in my head and at the same time convert them to the written word via the keyboard. However, open my mouth to speak and the speed is gone. There's a short circuit where the wiring in my brain has become disconnected. I type a whole sentence, but speaking the same words, without those words in front of me, often leads to the ending fading away as the words become lost.

Picazo (2015) in contrast, describes how challenging writing can be:

Writing can be hard for me at times... My brain doesn't work like it used to. Much of the time I find my mind silent or confused. Many times I don't comprehend things that are going on... Just getting my words together to make sense can be a daunting task that can sometimes take me up to four hours to write a two page blog. Many times I know what I want to say but I just don't know what the words are to say it. Sometimes I have resort to rewording my thoughts completely because I don't know how to say what I want to say.

Valerie Blumenthal (2017), diagnosed with Posterior Cortical Atrophy (PCA), describes how this has impacted on her ability to write:

When I write, it is like being incredibly dyspraxic and dyslexic – letters just leap about and go back to front. I can't touch type anymore and I struggle to find letters on the keyboard, sometimes I can sit for two minutes just looking for one letter. I can write for eight or nine hours and have only written two pages.

Blumenthal (2014) also comments on how PCA began to impact on her reading three years before she received a formal diagnosis:

... I began to read aloud. Stumbled. Stopped. Started again. The same thing happened. I could not comprehend it; I had always been such a fluent reader. I continued for a few sentences, from memory and adlibbed, but had to abandon the idea...

Mitchell (2016) also describes the difficulties she experiences with reading:

I miss reading books as I can't remember the plot from one day to the next which takes away the pleasure of reading and is simply a constant reminder of something you can no longer do.

Mitchell states that she tries to find books which contain short stories as these present less information for her to have to retain. She is also enthusiastic about the *Quick Read* range of books and has found these to be more accessible to her:

The print is slightly bigger and they have a range of length of stories within. They had [the library] 'Quick Read' books by all the most popular authors – they weren't childish in any way – simply quick reads as the title suggests. I like 'Whodunnits' and it took me about an hour to read. At the moment I could retain the information long enough to make it an enjoyable read.

The enjoyment Mitchell (2016) expresses she gains from reading has also been acknowledged in a recent study, *Read to Care*, commissioned by the Reader Organisation (2017). The study, focused on outcomes from people, who had been diagnosed with mild to moderate dementia and lived in four care homes situated in the north of England. The study followed their participation in shared reading groups where they read and reviewed selected poems (p.3). The concept of shared reading sits at the very heart of the Reader Organisation's work, as their overall aim is to connect people from a wide variety of backgrounds with literature through their participation in shared reading groups. Selected texts are read aloud at each group and the participants are encouraged to discuss the text by a group leader. Discussions encompass themes, descriptions and language used in the text, along with people's reflections and memories prompted through reading the text (p3). Participants in the *Read to Care* study reported enjoyment at being involved in groups and that the experience "helped them to remember things from the past" (p.37). Overall, the study concluded that the shared reading groups had improved the participants' quality of life and "there is at best a richly attentive presentness in the shared reading activity and a sense of activated newness or renewal in the experience (p.69).

This review of account from blogs written by people who experience young onset-dementia shows the benefits they gain from digitally engaging with online communities and the opportunities this gives them to raise awareness about

dementia. They also provide some insight into the way in which people's reading and writing practices are changing over time and the personal challenges this presents as they live with dementia.

Materiality, embodiment, artefactual literacies and ruling passions

Research relating to the material and embodied aspect of literacy practices also has resonance (Davies 2014; Jones 2014; Leander & Boldt 2013; Mackey 2016; Pahl & Rowsell 2010), as I recognise that people's communication is multimodal through drawing on a wide range of mediums (Kress, 1997). As Mackey (2016, p.166) describes, "literacy is not simply abstracted from ordinary experience. It is simultaneously rooted in material conditions" (p.166). Davies' (2014) study investigated three young women's lives and considered how the materiality of the girls' lives blends with digital spaces through their use of digital texts in a social networking site. Davies (2014, p.74) argues that "The material dimension of our experiences, including our own embodiment, are inextricably entwined with the meaning making process" (p.74). This view is shared by Leander and Boldt (2013) who considered the role of embodiment in literacy practices through their examination of a ten year old boy's interaction and reading of the English translation of two Japanese graphic novels from the *Manga* series and his subsequent play which was inspired by the novels (p.26). Leander and Boldt (2013) argue that literacy should be unbounded (p.41) and that "literacy-related activity" should not be "projected toward some textual end point but as living its life in the ongoing present, forming relations and connections across signs, objects, and bodies" (p.22).

Mackey (2016, p.166) also considers the relationship between literacy and embodiment and reviews how literacy interacts and connects with everyday objects found in the home environment. Mackey (2016, p.166) cites Kucirkova et al.'s (2015) concept of "dual representation" and reviews that household objects can be viewed at a tangible level to be "handled and incorporated into daily life", but also from a symbolic or abstract perspective, where they can be viewed as "a set of potential ideas". Mackey (2016, p.170) connects what she describes as "literate knowledge" and "manual activity" which she considers as "literacies of the hand" and recalls her own experiences:

I learned to read recipes and perform the requisite motions to assemble a tin of squares. I learned to interpret the hieroglyphics of knitting patterns and produce dolls clothes... For all of these activities, I retain substantial residues of muscle memory. I read K2P2 and do not stop to translate.

Mackey compares these personal experiences to Rosenblatt's (2005, p.73) concept of "efferent – reading to take away" which Mackey suggests is a productive form of reading in order "to make something" (p.170). Mackey argues that this allows "the environment that the information gleaned from the reading is taken away *into* becomes part of the scaffold of the literate event" (p.170).

Pahl and Rowsell's research in *Artifactual Literacies* (2010, p.1) also considers the ways in which people draw on the objects and artefacts that are present in their everyday lives, so they become embedded in the multimodal ways in which people communicate orally and through texts. Pahl and Rowsell argue that objects and artefacts can also be viewed as part of the semiotic complexities of identity, as they are an integral part of the way in which people make sense of their lives, experiences and the environments they live in (p.39). As Pahl and Rowsell state, "Artifacts never sit alone; they sit in spaces among other artefacts, people, and action" (p.38). Pahl and Rowsell also suggest that emotions and memories can be evoked by particular artefacts and objects (p.39) and propose that objects and artefacts can be viewed as "an embodiment of a lived experience" (p.1). Objects and artefacts can also be linked to cultural history and to families' histories, as objects are often handed down through generations of families (p.1). Objects and artefacts also evoke talk and stories, as people view them as integral parts of their lives and life stories (p.5). As Pahl describes from her research with migrant communities in the UK:

When people move across borders, objects come to stand for "who they are" – their identities. These objects remain powerful in their memories, which are evoked in their stories (Pahl & Rowsell, 2010, p.8).

Research completed by Jones (2014) into the everyday literacy practices of families who live on a housing estate in the Midlands in central England, also showed the integral relationship between objects, memories and identity. Jones reports that one of her research participants, Peggy, was having to move after a period of thirty three years to a new, smaller home. Jones describes that personal possessions and objects

were significant to Peggy and that they became “an important theme in Peggy’s talk” before her move, as she was having to decide which possessions she would be able to take to her new home and those that would have to be discarded (p.63). Following Peggy’s house move, Jones filmed a video tour of Peggy’s new home to “present the ways in which she was undergoing the process of constructing it” (p.64). Jones reviews that the “notion of show” of a range of objects and artefacts was a key way in which Peggy was negotiating “her new role as a single occupant of this space” (p.64). Jones describes Peggy’s collection of fridge magnets, which are a combination of presents from family and friends and ones that Peggy had purchased as mementos. Jones identifies that these can be read as “an example of a text which signifies the way she [Peggy] has written herself into her new home” (p.64). Objects and artefacts also evoke emotional bonds and the relationships people have with others. Jones describes that a small, teddy bear displayed in Peggy’s home has particular emotional importance to her, as it was the last item her late husband bought for her before he died (p.64). Jones also cites Barton and Hamilton’s (1998) concept of “ruling passions” in response to a display of Cliff Richard memorabilia, which takes “pride of place” in Peggy’s new home (p.64).

Barton and Hamilton (1998, p.18) argue that people’s ruling passions have a close relationship with the “emotional dimensions of literacy”. They state that people express strong feelings about literacy, which include “disapproval, triumph, control or mastery, stigma, fear; the subject is charged with emotion” (p.18). Barton and Hamilton define that ruling passions are the interests and pastimes that are an integral part of many people’s everyday lives and that literacy practices often sit at the very heart of people’s engagement with their ruling passions. Barton and Hamilton (1998, p.83) describe,

When we went to interview people we wanted to find out about reading, writing and literacy practices. Unfortunately, it seemed, the people we interviewed often wanted to talk about something else; each person had a ruling passion, something *they* wanted to talk about and share with us. We talked to them about literacy, it seemed, and they talked to us about their lives. Often this appeared to have no relation to reading and writing, and we were tempted to say, ‘No don’t talk about that: tell us about where you keep your books; tell us if you use the library’. In fact as the interviews continued, we found that when people told us their stories, they ended up telling us much more about literacy.

Therefore, I wish to ascertain whether the research participants in this study have ruling passions and explore how they influence their lives and the literacy practices they engage in. I also wish to explore the relationship between the materiality of the research participants' lives and their literacy practices, through exploring if particular artefacts and objects have importance to them and the personal memories and stories these may evoke. I am also interested in how the research participants respond to these artefacts and make sense of their personal experiences and the complexities of their identities.

Sponsors of Literacy

Brandt's (2015, p.330) concept of "sponsors of literacy" emerged from research (2001) she undertook, where she collected personal accounts of literacy learning from eighty people born in the United States between 1895 and 1985. Brandt explored her research participants' personal accounts of literacy learning to gain insight into the mass literacy development which took place in the United States during the 20th century, and to also consider literacy learning and development against the context of the extensive social, political and economic change experienced during this time period. Brandt (2015, p.330) reviewed that her research participants' descriptions of literacy learning were, "populated by interested others who came and went over the course of a lifetime and whose presence and power varied by socioeconomic, political and generational circumstances". Brandt (2015, p.330) also acknowledges that for younger learners in her study, their personal accounts were "often congested and even incoherent... because of the proliferation of interests that accumulated around literacy as the twentieth century unfolded". Brandt (2015, p.330) describes that the "interested others" she decided to call "sponsors of literacy", which she defines as:

...any agents, local or distant, concrete or abstract, who enable, support, teach, and model, as well as recruit, regulate, suppress or withhold literacy - and gain advantage by it in some way... they lend their resources of credibility to the sponsored but also gain benefits from their success, whether by direct payment or, indirectly by credit of association (Brandt, 2001, p.19).

Brandt (2001, p.26) argues that sponsors of literacy present "a particularly illuminating lens" to monitor the impact of large scale economic forces on literacy learning in America in the 20th century and to trace "connections between the ways that money

gets made and the way that literacy gets made". Brandt also argues that literacy is valued in the same way as a commodity or a resource, and therefore, it is a vital component in the relationships between individuals, economic and political development, organisations such as businesses and social institutions, and public infrastructure (p.5). Brandt (2001, p.5) states:

To treat literacy in this way is to understand not only why individuals labor to attain literacy but also to appreciate why, as with any other resource of value, organized economic and political interests work so persistently to conscript and ration the powers of literacy for their own competitive advantage.

Mediators of literacy

Brandt's (2015, p.330) sponsors of literacy has similarities to Gregory and Williams' (2000, p.11) concept, "mediators of literacy", proposed in their study examining the range of literacy practices younger children engaged in throughout the 20th century in two contrasting inner-city areas of London. Gregory and Williams acknowledged that although many children are "initiated" into literacy by their parents, many of their literacy practices can be viewed as a "*collaborative group activity*" involving a range people which they describe as mediators of literacy (p.11). Gregory and Williams reviewed that these mediators encompassed "out-of-school community or religious classes, clubs or drama activities, but also institutions such as libraries, which enable children to make use of their facilities" (p.11). Gregory and Williams also acknowledged Padmore's (1994) concept of "guiding lights" and argue that mediators can also be "mentors, role models, grandparents or siblings" (p.11). Therefore, Gregory and Williams' concept of mediators has some similarities to Brandt's (2001, p.19) concept of sponsors of literacy in that she noted that the "figures" who were often present in "people's memory of literacy learning" included "older relatives, teachers, religious leaders, supervisors, military officers, librarians, friends, editors, influential authors". However, Gregory and Williams' (2000, p.11) emphasis is that mediators are those that support and encourage children's participation in literacy practices and learning at a local level, where integral to Brandt's (2001, p.19) concept of sponsors is the importance of the global sense of the relationship between individuals, political and economic change, businesses, public infrastructure and the value and power of literacy.

Therefore, in this study, I am interested in whether mediators of literacy can be observed in the research participants' lives and to explore the influenced they may have had on the research participants' literacy learning and involvement in literacy practices. I am also interested to find out whether the research participants view themselves as mediators of literacy and whether they can identify specific times in their lives where they have supported and encouraged other people's engagement in literacy learning and practices.

Collaborative approaches to learning

Gregory and Williams' (2000) view that literacy practices can be viewed as "collaborative", communal or involving a range people, can be compared to Lave and Wenger's (1991) work which focused on how people can learn from each other through the "process of social participation" within communities (Wenger, 1998, p.i). Lave and Wenger (1991, p.98) proposed the concept of *communities of practice* and argued that communities are defined by skills, knowledge and shared cultural practices. They also reviewed that newcomers to a community gain knowledge and skills and learn from existing members of community, which they describe as "old timers" (p.56). Lave and Wenger suggest that over a period of time, as a newcomer learns and gains an understanding of the skills, knowledge and cultural practices of the community, they will move from "legitimate peripheral participation" (p.29) to "full participation" in the community (p.37).

Jones' (2014) research into the everyday literacy practices of families also reviews the sociocultural nature of literacy learning and focuses on the shared nature of engagement in literacy practices which can be witnessed within family groups. Jones' research reviews how family members work collaboratively to support each other and are mediators of literacy to each other, so they can achieve the literacy activities that are demanded of them as a family (p.62). Jones' research participants included a family that comprised of Colin, his 13 year old daughter Katie, and son, James. Jones reports that Colin described that he lacks confidence in his own reading and writing skills, while he views his daughter as "a prolific reader" (p.62). When Colin had to apply for a carer's allowance for his son, Katie, his daughter, supported him to complete this writing task. Colin stated, "I'll write this out but tell me if it's ok... and she'll go over it

and change things like correct my spelling mistakes and put the punctuation in” (p.62). Similarly, Katie stated, “We help each other out like that... say I’m stuck on a maths problem he’ll help me out with that and then, in return, if he’s typing a letter or something I’ll help with his spelling and stuff” (p.62). Therefore, Jones’ research acknowledges that the mediation of everyday literacy activities can be achieved through collaboration and shared participation in literacy and language practices within family groups and can be viewed as part of a family’s “negotiation of experience” of day to day life (p.62).

Research conducted by Frazer, Oyebode & Cleary (2011, p.684) focused on how older women with dementia made sense of their experiences. One of their research participants, Emily, described how her son helps her to make sense of her experiences and has become a mediator of literacy (Gregory & Williams, 2000, p.11) to her. Emily explained how her son will help her to make sense of words that are unfamiliar to her when she is reading:

... I’ve found a book, and I haven’t got very far, but I’m reading the words, it sounds a bit daft, I know the words but I’ve got to read them/and I go over the road and I say to John when he comes home, ‘What’s so and so John?’, and he’ll say, ‘Oh mother’ and then he’ll sort me out, but it’s silly things that I can’t remember...

(Frazer, Oyebode & Cleary, 2011, p.684)

Therefore, I will be interested to explore if the families who are involved in this study can describe involvement in collaborative or shared literacy practices, and whether there are particular instances that they can recall, where they have supported each other to mediate particular literacy tasks demanded by their day-to-day lives.

2.2 A medical perspective: the impact of dementia on oral communication, reading and writing skills

This second section of the literature review explores research from the medical field and considers the difficulties people can experience with oral communication, reading and writing skills in relation to a range of dementia types. A review of medical literature was pertinent to me, as I wanted to develop my understanding of how and why dementia impacts on people’s oral communication, and reading and writing skills from a clinical perspective.

The research I have drawn on was conducted by medical research teams located in Australia, Canada, Western Europe, New Zealand and the USA. I searched for this literature using the University of Sheffield's Library Catalogue and its *Star Plus* search facility. This searches all resources held by the university's library including special collections and academic journals (University of Sheffield, 2017a). The key search terms I used were *dementia*, *Alzheimer's disease*, *vascular dementia*, *frontotemporal dementia* and *semantic dementia*. I then combined these terms with terms relating to literacy and language: *literacy*, *language*, *discourse*, *narrative*, *linguistics*, *reading*, *writing*, *communication*, *communicative*, *oral communication*, *verbal communication*, *speaking* and *speech*.

In the following sections, I firstly review research from: Blair et al. (2007); Bond-Chapman et al. (1998); Martínez-Sánchez et al. (2013); Noble et al. (2000); Perkins et al. (1998); Reilly et al. (2010) and Rousseaux et al. (2010) in relation to how dementia impacts on oral communication. I then review research from: Creamer & Schmitter-Edgecombe (2010); Bayles (2003); Berthier et al. (1991); Bond-Chapman et al. (2002); Coltheart et al. (2010); Glosser et al. (2002); Levine et al. (1993) and Noble et al. (2000) with respect to how dementia impacts on reading. Finally, in relation to how dementia impacts on writing, I review research from: Forbes et al. (2004); Garrard et al. (2005); LaBarge et al. (1992); Lambert et al. (2007); Luzzatti et al. (2003); Menichelli et al. (2008) and Platel et al. (1993).

The impact of dementia on oral communication skills

When people with dementia experience oral communication difficulties, it can have a profound impact on their abilities to socially interact and to fully engage in social activities (Rousseaux et al., 2010, p.3884). Martínez-Sánchez et al.'s (2013, p.326) research focused on people who had been diagnosed with Alzheimer's Disease (AD) and they argue that oral language difficulties can be pervasive and experienced by between 8% and 10% of people in the early stages of AD. They also state that that these percentages increase as people's health deteriorates in the later stages of dementia. Rousseaux et al. (2010, p.3884) argue that people with AD often exhibit anomia (word finding difficulties), can make "literal and neologistic errors" and can also exhibit "sentence repetition". Bond-Chapman et al. (1998, p.57) identify that

some people with AD can be observed using empty language and, therefore, this can result in them being described as verbose when explaining their thoughts and ideas.

Rousseaux et al.'s (2010, p.3884) work also considered the comprehension difficulties some people with AD experience. They argue that people with AD can experience difficulties with interpreting metaphors and humour, and as people move into the middle stages of the disease, some could be observed having difficulties "untangling cause-effect relationships [and] often produced irrelevant, vague and incomplete responses" (Rousseaux et al., 2010, pp.3884 - 3885). Perkins et al. (1998, p.57) state that syntax and phonology can also be affected in people with AD, but the deterioration of these are often presented in the later stages of the illness. Bond-Chapman et al. (1998, p.57) cite Chapman & Ulatowska (1997) who propose that people with AD's simplification of the use of syntax may be a result of changes in a memory function and, therefore, this disrupts people's abilities to use complex grammatical structures.

Blair et al. (2007, p.238) review the oral language profile of people with Frontotemporal Dementia (FD). FD refers to a group of "pathologically diverse brain disorders" (Noble et al., 2000, p.51) including semantic dementia (Hughes, 2011, p.61). This affects the frontal and temporal lobes of the brain, which control behaviour, emotions and personality (Noble et al., 2000, p.51). Frontotemporal lobar degeneration can result in people experiencing a loss of insight, a decline in their social and interpersonal conduct, plus a lack of apathy and empathy, which can result in behaviour that can be viewed as socially inappropriate, and/or obsessive and aggressive (Hughes, 2011, p.63). Similarly, Blair et al. (2007, p.238) review that people with FD can experience "disinhibition, impulsivity, indifference, loss of insight and stereotypic behaviours". Family members of people with FD can often find the changes to their relative's social conduct to be deeply concerning and can put a strain on existing relationships (Hughes, 2011, p.62). Blair et al. (2007, p.238) report that people with FD can experience decreased speech output and a reduction in conversation initiation, but often there is an increase in their use of stereotyped utterances and repetitive responses. The behavioural changes experienced by people with FD can also result in changes to pragmatic aspects of conversations and it can be observed that

they often interrupt others and redirect the conversation to their own agenda (Blair et al., 2007, p.238).

Reilly et al. (2010, p.442) argue that people with semantic dementia (SD) have damage to the anterior, lateral and ventral temporal lobe in the left hemisphere of their brains but that there is also “a growing body of literature”, which suggests the right anterior temporal lobe can also be affected. Noble et al. (2000, p.50) review that people with SD can have a progressive fluent aphasia in that they can experience severe anomia and a “profound and pervasive semantic deterioration”, which includes “an overwhelming and progressive loss of expressive and receptive vocabulary in the face of fluent, prosodic speech”. Similarly, Reilly et al. (2010, p.442) argue that SD patients often “produce fluent but empty speech that is rife with deictic expressions (e.g. I don’t know....It’s that thing) and semantic paraphasias (e.g. ‘cat’ when the target word is Chihuahua)”. Noble et al. (2000, p.50) note as the disease progresses, people’s speech can be “highly stereotyped” and Reilly et al. (2010, p.442) also describe that SD patients will often say “overlearned phrases effortlessly”, which can make it initially appear in conversations that there is not “any hint of impairment”. Reilly et al. (2010, p.443) also state that as people move into the later stages of the disease, they can show a loss of empathy and sympathy with others, their oral interaction will lessen and they are less likely to engage in conversation with others.

The impact of dementia on reading skills

Creamer & Schmitter–Edgecombe (2010, p.279) argue that people with dementia can experience difficulties with reading as their dementia progresses over time in terms of comprehension and in relation to oral reading fluency. Therefore, this can result in people experiencing difficulties in reading practices such as reading instructions, following healthcare information and also reading for pleasure (Creamer & Schmitter–Edgecombe, 2010, p.279). In the following sections, I review medical literature in relation to how dementia impacts on people’s reading comprehension and oral reading fluency.

Reading comprehension

Noble et al. (2000, p.61) and Coltheart et al. (2010, p.256) argue that reading for meaning or reading comprehension is compromised for people who have a range of dementia types. Glosser et al. (2002, p.902) cites Hodges et al. (1992) and Martin (1992), arguing that reading comprehension for people with AD can be attributed to a "semantic processing disorder". Creamer & Schmitter-Edgecombe (2010, p.279) concur that semantic knowledge is required for effective reading but also consider that reading is a multifaceted process "consisting of grammatical relations, semantic/world knowledge elements, and cognitive components such as attention and working memory". Bayles' (2003, p.209) study focused on people with early stage and moderate AD. She carried out a series of tests that required participants to read individual words and sentences. Bayles found that reading performance was good for people with early stage and moderate AD when reading individual words but people with moderate AD found reading sentences much more demanding (p.212). Bayles concluded that "understanding the words did not seem to be the problem but rather the number of words to be processed" (p.212) and attributed these difficulties to "problems with storing, retrieving, and manipulating linguistic information" (p.214).

Research by Bond-Chapman et al. (2002) used narratives to assess levels of comprehension in people with the early stages of AD and also people with a mild cognitive impairment (MCI). MCI is often used to describe a "pre-dementia state", where a person is experiencing problems with memory, but "it is not felt that this amounts to dementia" (Hughes, 2011, p.33). Bond-Chapman et al.'s (2002) research focused on larger pieces of text, as they felt that the texts represented the type of reading that many people engage in during their everyday lives. They reviewed levels of comprehension relating to the gist in the text as well as detailed information. Bond-Chapman et al. (2002, p.183) found that both people with AD and MCI had difficulties processing the gist and detailed information in comparison to a non-dementia control group. However, the MCI group gained better scores for gist than detailed information, so Bond-Chapman et al. (2002, p.183) concluded that although further research was required, it appears that, "...in prodromal stages of AD (i.e., MCI), memory for details may precede gist-level deficits".

Creamer & Schmitter-Edgecombe's (2010, p.279) research focused on the roles that inference and memory play in narrative comprehension. They found that AD research participants in comparison to a 'non-dementia' control group found it more problematic to provide explanations of events in stories and were also less skilled at using prior text information to predict and explain story outcomes (p.288). They also found that the AD group tended to rely more on their semantic or world knowledge, made more inferences which were superficial and also made more overall non-inferential statements than the non-dementia control group (pp.288 – 289). Creamer & Schmitter-Edgecombe (2010, p.289) concluded that these difficulties "affected the AD group's ability to create a global coherence to support comprehension" and that memory difficulties seemed to be an important cognitive factor which impacted on the ability of people with AD to use inferences to integrate stories' events.

Oral reading fluency

Dementia also impacts on oral reading fluency skills (Coltheart et al., 2010; Glosser et al., 2002). Coltheart et al. (2010, p.257) argued that difficulties are associated with mid-stage of SD, while research by Fromm et al. (1991) and Storandt et al. (1995) identified that some patients in the very early stages of AD develop oral reading difficulties. A range of research explores different explanations of how dementia impacts on oral reading fluency. Glosser et al. (2002, p.902) cite Patterson et al. (1985) and explores the possibility that problems in a person's orthographic lexicon can result in oral reading difficulties. The orthographic lexicon holds mental representations of previously encountered letter patterns in each written word, including the order in which they are presented (Noble et al. 2000, p.49). Glosser et al. (2002, p.902) identify that some people with AD, when assessed using standardised tests, have difficulties reading "exception" words. Exception words are words that are not phonically regular as they have an "unusual or unique correspondence between their spelling and pronunciation (e.g. *pint*), as compared to words with "regular" spelling-to-sound correspondence (e.g. *pine*)" (Glosser et al., 2002, p.902). Some people with AD have been observed to make "regularization errors", where they pronounce exception words with "common, but incorrect, spelling to sound correspondences (e.g. pronouncing *pint* to rhyme with *mint*.)" (Glosser et al., 2002, pp.902-903). However, research by Noble et al. (2000, p.62) noted that not all AD patients had increased

difficulties reading exception words and cite research by Behrmann et al. (1992), who identified that the frequency of word use appears to impact on regularization errors, with very low frequency words causing more difficulties in comparison to higher frequency words. Coltheart et al. (2010, p.257) also argued that people in the mid stages of SD demonstrated difficulties with reading low frequency, exception words.

An alternate explanation for oral reading difficulties is that problems associated with the semantic lexicon can result in processing difficulties in the orthographic and/or the phonological lexicon (Noble et al., 2000, p.49). Noble et al. (2000, p.49) cite a range of studies carried out by Patterson, Hodges and colleagues in the 1990's who proposed that "representations in the orthographic and phonological lexicons operate at the sub-word level of the word fragment". Noble et al. (2000, p.49) argued that semantics, the meaning, is important for binding these sub-word elements together into whole word units. Therefore, if the semantics system is viewed as "the 'glue' that binds the phonological and orthographic elements of the word together", and dementia causes the functioning of a person's semantic lexicon to deteriorate, then this deterioration could account for the increase in the number of errors made during oral reading (p.49). Noble et al. (2000, p.49) suggest that if semantic processing is impaired, then oral reading has to be achieved through the "segmental translation from orthography to phonology". Potentially, this would result in the oral reading of regular words not being affected, as pronunciation of individual phonemes lead to the same 'translation' as the whole word. However, for exception words that do not have a spelling to sound correspondence, oral reading errors may occur. Noble et al. (2000, p.50) use the example of the word *gone*. They describe that if *gone* is read using an individual segment approach, this could "lead the reader to pronounce the letter string to rhyme with *cone*, thereby producing a regularization errors". Noble et al. (2000, p.50) conclude that Patterson, Hodges and colleagues predict that semantic processing difficulties will result in a person with dementia being more likely to make errors when reading exception words than with regular words, and errors in exception word reading are likely to be regularization errors.

Research by Levine et al. (1993, p.305) argue that the experience of AD for some people is one that is dominated by visual disturbances because of damage to the

posterior cerebral hemispheres in the brain. This results in people's vision deteriorating over time as they experience visual difficulties such as loss of vision, deterioration in hand-eye co-ordination and difficulties in recognising visual objects, particularly when light conditions are poor. Glosser et al. (2002, p.903) argue that a further explanation for oral reading in people with AD may be accounted for by visual processing dysfunctions resulting in impaired visual analysis and perception of written letters and words. Glosser et al. (2002, p.903) suggest that some people with AD's reading difficulties could result from the "disturbed processing of visual inputs or access to linguistic orthographic representations by visual stimuli". Berthier et al. (1991, p.1110) argue that some people with later stage AD can be observed reading "letter by letter" and this type of reading can also be observed in the clinical syndrome of alexia without agraphia. Alexia without agraphia is associated with a loss of ability to process the visual forms of letters and words, and includes "the inability to process letter arrays in a simultaneous or parallel fashion, or a disconnection between visual letter analyzers and lexical orthographic representations leads to a reading through a serial letter-by-letter procedure in such patients" (Glosser et al., 2002, p.903).

The impact of dementia on writing skills

Research from the medical field identifies that people with dementia can experience the progressive loss of their ability to write, in the same way that they can experience difficulties with reading and oral communication (Forbes et al., 2004; Garrard et al., 2005). Lambert et al. (2007, p.935) state that the writing difficulties people with dementia can experience, in comparison to oral communication difficulties, were largely under-researched until the 1970s. They argue that this was because writing as a mode of communication was viewed as of "secondary importance compared with oral language". However, Lambert et al. acknowledge that this lack of interest into writing deficits in the early to mid-20th century was surprising, as some of the very earliest research into dementia identified that writing production could be affected by the disease (p.935). Lambert et al. cite Alöis Alzheimer's (1907) research, where he observed that his patient, Frau Auguste Deter, "In writing, she repeats separate syllables many times, omits others and quickly breaks down completely" (p.935). In the following sections, I review a range of research which explores the range of difficulties people with dementia can experience with central and peripheral levels of writing.

Impact of dementia on the central levels of writing

Forbes et al. (2004, p.19) argue that people with AD experience damage to the central system of writing and these arise from “a linguistic problem impacting on the phonological or semantic spelling system”. Forbes et al.’s (2004, p.21) research used a methodological approach where their research participants were asked to describe in writing everything they could observe in two visual images; one image being described as simple and the other as complex. Forbes et al.’s (2004, p.19) analysis of their research participants’ writing identified impairment to the lexico-semantic level in the written narratives that were produced, as sentences were shorter and grammatically less complex than those produced by control research participants (who did not have a diagnosis of AD). Forbes et al. (2004, p.19) also report that they observed that the people with AD’s written narrative contained, “empty phrases and indefinite terms, poor narrative organisation, semantic and graphemic substitution errors, word omissions and intrusions, and a reduction in the number of pictorial themes described”.

Forbes et al. (2004, p.19) and Luzzatti et al. (2003, p.760) argue that people with AD can also display surface dysgraphia. Forbes et al. (2004, p.19) report that people with AD experience significant difficulties writing phonically irregular words such as *yacht* in comparison to writing phonically regular words. However, they also reported that the majority of writing errors made were plausible such as, *yot* for *yacht*, which they argue demonstrates people with AD are being over-reliant on their phonological knowledge. Lambert et al. (2007, p.947) and Luzzatti et al. (2003, p.769) concur this view and concluded in their respective studies that people with AD had more difficulties spelling phonically irregular words than regular words. Similarly, Reilly et al. (2010, p.443) reported that people experiencing SD also have an over reliance on using a direct grapheme-to-phoneme conversion process which causes “regularization errors” for phonologically irregular words such as *yacht* and will produce plausible alternative such as *yot*.

However, Harnish and Neils-Stunjas (2008, p.56) argue that impairment to writing skills, and particularly, declines in written narration can be “difficult to assess” as there are variations in writing performance as people adopt their own style particularly in

relation to “written paragraph descriptions”. They also suggest that it is often difficult to collect samples of people’s writing that have been produced prior to diagnoses of dementia for comparison to writing produced post-diagnoses (p.56). However, research by Garrard et al. (2005) focused on an analysis of written narratives produced by the same writer over a time period of forty years, spanning before and during the onset of AD. Garrard et al. (2005) reviewed and analysed three novels of the renowned, post-war author Iris Murdoch. They compared *Under the Net* (1954), *The Sea, The Sea* (1978) and *Jackson’s Dilemma*, published in 1995 when Murdoch was experiencing the early stages of AD. Garrard et al. (2005, p.258) found that the syntactic structure was similar across the three novels, but the vocabulary was more restricted in *Jackson’s Dilemma* with a greater use and repetition of a smaller set of higher frequency words in comparison with the two, earlier novels.

Impact of dementia on the peripheral levels of writing

People who experience dementia can also experience disturbances to the peripheral levels of writing, which can be described as damage to the allographic or grapho-motor level (Forbes et al., 2004, p.19) and can impact on how people’s writing is spatially organised on the page, the style of handwriting and the choice of letter case used (Forbes et al., 2004, p.19). A study by LaBarge et al. (1992, p.1154) focused on research participants who had a diagnosis of mild to moderate AD. They found that the writing of the people with moderate AD contained a higher number of illegible words and also that there were more frequent instances of poor spacing between words in a sentence than those research participants with a diagnoses of mild AD.

Outcomes from a study by Platel et al. (1993) also observed people who had a diagnoses of mild to moderate AD and seems to concur with LaBarge et al.’s. (1992) findings. Platel et al. (1993) conducted a nine month to one year follow up on their research participants and their results appear to indicate that writing seems to decline over time, as grapho-motor errors increased from 16% to 33% in a period from first testing to second testing (p.1152). Platel et al. (1993, p.1156) also reported from the second test results that those AD patients demonstrating grapho-motor difficulties relied more on capital letters and the presentation of these were often “separated and shaky letters”.

Forbes et al. (2004, p.21) used a modified version of the *Mechanics of Writing Scale* from the *Boston Diagnostic Aphasia Examination* to assess grapho-motor errors made by people with a diagnosis of mild and moderate AD. Forbes et al. (2004, pp.21-22) argued that people with a diagnosis of moderate AD had significantly more difficulties with letter formation and demonstrated more stroke errors than those people with a diagnosis of mild or early stage dementia. Writing style also seemed to be impacted on by the degree of AD experienced by people. Forbes et al. report that 53% of people with a moderate AD diagnosis used a cursive style of writing and 47% used a print style, in comparison to those with diagnosis of mild dementia, where 90% of people used a cursive style and 10% printed (p.22). Menichelli et al.'s (2008, p.866) research focused on a patient with early stages of FD. They found that she could not write upper case printed letters, but could more easily write lower case letters using a cursive style.

This review of literature from the medical field has shown that people diagnosed with a variety of dementia types can experience a wide range of difficulties impacting on their oral communication, reading and writing skills and these difficulties are likely to progress and worsen as their dementia advances over time. The review has also revealed that a positivist approach underpins the medical research reviewed, in that methodologically, it relies on the use and outcomes of neuropsychological standardised tests administered within clinical settings by the research teams or medical professionals such as psychologists and neurologists. Therefore, people's literacy and language seems to be viewed through an autonomous lens, where literacy is seen as a "technical and neutral skill" (Street, 2001, p.7) which can be assessed against "pre-specified standards (Ivanič et al., 2009, p.20). The research seems to give little attention to a social practice view of literacy (Barton & Hamilton, 1998, 2012), as it does not consider how people with dementia engage in literacy practices within the contexts of their everyday lives. Therefore, in the following section, I have found it useful to review research by Dijkstra et al. (2004); Hamilton (1994); Jones (2015); Kemper et al. (1995); Moss et al. (2002); Perkins et al. (1998) and Sabat (2001), who consider the validity of the use of neuropsychological standardised tests in the assessment of dementia and question whether outcomes from these types of tests provide a reliable indication of how dementia impacts on people within the contexts of their day-to-day lives.

2.3 Critiquing the use of neuropsychological standardised tests in clinical assessments of dementia.

Hughes (2011, pp.85-89) states that clinical processes used to diagnosed dementia include the administration of a range of neuropsychological, standardised tests and they are used to judge cognitive and behavioural function, such as sensory and motor function, memory, attention, information processing, and language and linguistic skills. Garrard et al. (2005, p.250) question the reliability of the use of standardised tests with people who have dementia and states that they “lack ‘real-world’ validity”. Similarly, Jones (2015, p.556) argues that dementia assessments in relation to language and literacy skills rely on tests such as naming objects in images, the use of topic directed interviews to generate conversations and auditory comprehension tests present “artificial discourse situations”. Jones (2015, p.556) goes on to cite Nebes (1985), who argues that poor results gained from tests carried in clinical settings “reflect the demands on the person with dementia in these situations”. Jones (2015, p.556) also argues that it is “difficult to extrapolate from research in such artificial situations to the difficulties that a person with Alzheimer’s may experience in their natural everyday interactions”.

Sabat (2001, p.viii) also argues that there are limitations to using standardised tests with people who have dementia. He states that the outcomes from testing focuses on how the disease impacts on a series of an individual’s cognitive functions, but questions whether this provides a “valid reflection” of people’s cognitive abilities in their day to day social world (p.viii). Sabat argues that the use of standardised tests only then provides a “snapshot” view of the person with dementia, which tends to highlight the deficits dementia brings to a person, whilst paying little regard to what the people can do in their everyday lives (p.viii). Sabat (2001, p.165) cites cultural psychologists Shweder and Sullivan’s (1989) concept of “psychometric persons”. Shweder and Sullivan argued that rather than understanding people as individuals, people’s cognitive lives can come to be understood based on their performance during psychometric tests, the resulting statistical scores and the calculation of these scores into statistical aggregates and averages (Sabat, 2001, p.165). Therefore, people can potentially be viewed or represented by statistics that have been generated by the sampling and assessment of what might be a limited range of their abilities, and this

can be compounded in that testing has taken place in an environment which is artificial in comparison to the contexts present in people's everyday lives. Sabat (2001, pp. viii-ix) calls for research which extends beyond assessing a range of limited cognitive processes in a 'controlled' environment and proposes instead that the understanding of a person with dementia should be built upon observation and interaction in social settings in which people's day-to-day lives take place. In this way, people would be observed as they "navigate through the social world to the best of his or her ability and take note of the successful attempts, and the circumstances in which they occur, as well as those in which failure seems to occur" (Sabat, 2001, p.ix).

Familiar conversation partners

Perkins et al.'s (1998, p.35) work considers the role of other participants in conversations and verbal exchanges with people who have dementia. Perkins et al. (1998, p.35) outline that when people with dementia are asked to complete assessment tasks such as "describe a picture, tell a story or engage in a topic directed interview", this is usually with an assessor who is unfamiliar to them and not a familiar conversational partner such as a spouse would be. Perkins et al. (1998, p.35) argue that oral discourse abilities should not only be viewed in terms of deficit and the breakdown of communication processes, but also "in terms of the interactions in which they are displayed". Perkins et al. (1998, p.35) found in their research that a familiar conversation partner could positively influence the communication ability of the person with dementia, and oral communication difficulties were less pronounced with a familiar conversation partner when contrasted with an unfamiliar one. Hamilton (1994, p.3) concurs with this view that conversations always "take place between *at least two* people" and that "far too many studies of language disability focus, however, on only one of the interlocutors, namely the individual with the disability, ignoring the language used by the "normal" conversational partner and its potential influence on the interaction" (p.5).

Dijkstra et al. (2004, p.268) agree that an effective conversation partner can help to reduce the demands on the person with dementia's memory, as an effective conversation partner will use strategies such as repeating questions, repeating and paraphrasing information, providing verbal cues and prompts, and using memory aids

such as objects and artefacts to provide visual prompts to help to improve the coherence and cohesion of conversations and to avoid conversation 'breakdowns'. This view is also shared by Kemper et al. (1995), whose research focused on people with AD telling aspects of their life stories with the support of their spouses. Kemper et al. (1995, p.214) describe that when spouses helped and supported their partners with dementia to recall personal stories, they were "significantly longer and more elaborated personal narratives". Kemper et al. (1995, p.215) concluded that people with AD are able to communicate more effectively when they received support from their spouses, as they can provide "contextual cues for the participants, settings, and significant events in the lives of the patients with AD".

Therefore, as Perkins et al. (1998, p.35) argue, the outcomes from the analysis of samples of discourse collected during standardised tests are "unlikely to reflect what happens between people with dementia and their caregivers on a daily basis". The outcomes from these assessments can be viewed as "highly subjective and speculative" as the person may demonstrate their use of language in test situation very differently when compared to their usual social contexts (p.35). This view appears to be supported by outcomes from Moss et al.'s (2002) research. It focused on how people with AD communicated during reminiscence group activities and compared this to individual's outcomes during diagnostic assessment. Moss et al. (2002, p.40) reported that conversations seemed more cohesive during group activities in comparison to outcomes from diagnostic language sessions and identified that "the sequencing and expression of ideas and sentence structure were often more complete [and] patients maintained appropriate topics of conversation and used appropriate social exchanges".

The review of this literature into the use of neuropsychological standardised tests as part of the clinical/medical assessment of dementia has highlighted the potential limitations of using standardised tests in terms of their 'real world' validity (Garrard et al., 2005, p.250), particularly as assessments tend to be conducted away from the 'usual' contexts of people's everyday lives (Jones, 2015, p.556). Additionally, outcomes tend to focus on loss and deficits. Therefore, language and literacy are being viewed from an autonomous perspective, as there appears to be limited acknowledgment of a

social practice view of literacy and little consideration to how people with dementia socially interact with others, and engage in reading and writing practices within the reality of their day to day lives. Additionally, research by Dijkstra et al. (2004, p.268); Kemper et al. (1995, p.215) and Perkins et al. (1998, p.35) identifies the importance of familiar conversation partners to people with dementia and the extent to which they can have a positive influence on people with dementia's verbal communication abilities. Therefore, I hope that this research project underpinned by an ideological, sociocultural perspective of literacy and using a life history methodology will provide a contrasting view to the outcomes summarised in the previous section in relation to the medical research undertaken.

2.4 Personal narratives, life stories and dementia

Having selected to take a life history approach to this research, I recognised that this study would focus on the autobiographical accounts of people with dementia.

Therefore, I was interested in exploring literature and research in relation to the use of personal narrative in disability studies, and in particular, dementia studies. Moreover, literature critiquing the use of neuropsychological standardised tests in medical assessments of dementia had also highlighted the impact of familiar conversation partners and the benefits of collaboration during verbal communication for people who experience dementia. Consequently, I was also interested in reviewing literature which explored the use of co-constructed approaches to narrative and personal storytelling for people with dementia.

Therefore, in this fourth section of the literature review, I explore research which focuses on the use of individuals' narratives and autobiographical stories to explore people's experiences of living with dementia and their perceptions of personal identity. I firstly review work by Goodley (2011) and Smith and Sparkes (2008) to consider the use of personal narratives in disability studies and the use of life story work in dementia care practice (Cooney et al., 2014; Kindell et al., 2014; McKeown et al., 2010a). I will then focus on dementia research and review the work of Hydén and colleagues (2009, 2010, 2011, 2013); Baldwin (2005, 2006); Angus and Bowen-Osborne (2011, 2014) and McRae (2010, 2011) to explore the use of personal stories and

collaborative narrative approaches in dementia research, and to also consider the performative and embodied nature of personal storytelling.

Storytelling and personal narratives

Storytelling and the communication of personal narratives can be viewed as a central part of the range of the day to day activities in which people engage and provides an important way for people to share experiences and communicate with each other (Bruner, 2010, p.45). Connelly and Clandinin (1990, p.2) suggest that “humans are storytelling organisms who, individually and socially, lead storied lives”. While Langellier and Peterson (2004, p.1) state that storytelling is “an integral and consequential part of daily life”. People also use stories and personal narratives to interpret and make sense of their personal experiences (Fernyhough, 2013, p.9). As Finnegan (2015, p.35) argues, “personal narratives can be regarded not as simple reflections of life but rather as a way of constructing it”. Similarly, Bruner (2010, p.45) states that personal storytelling gives “form to what we imagine [and] to our sense of what is possible” and to make connections between past and present (Hydén & Örvulv, 2009, p.206). Mace (1995, p.99) also concurs arguing that, “our perception of our present circumstances colour and shape that of our past experience”. Narratives also provide a way for people to tell others “who we are – and of who we want to be” (Hydén & Örvulv, 2010, p.149), so provide ways to maintain a sense of self and help to define personal identity (Baldwin, 2015, p.184; Angus & Bowen-Osborne, 2014, p.148). This view is supported by Hydén & Örvulv (2009, p.206) who identify that, “Through the creation, elaboration and revision of narratives of our own lives we come to develop and possess an identity and a sense of ourselves as persons – a sense of self.” However, central to the concept of ‘self’ is also the relationship with others and the stories “that others tell about us” (Angus & Bowen-Osborne, 2014, p.148).

Hydén & Örvulv (2009, p.205) argue that from the perspective of the listener, autobiographical stories and personal narratives provide an opportunity “to make inferences about who and, more often, what kind of person the teller is” and for the complexities of the social world to be viewed through their experiences. Hydén & Antelius (2010, p.588) state that, “Stories ... are important tools for inviting into and establishing, confirming and negotiating common shared worlds”. Personal narratives

also provide a way for moral, social and political contexts to be viewed. Smith & Sparkes (2008, p.18) argue that narratives are “social creations”, which expose socio-cultural life and cite Riessman (1993) who argues that “society and culture ‘speak themselves’ through an individual’s story”. Finnegan (2015, p.30) concurs with this view, arguing that personal stories and narratives have “... emerged as a powerful tool for the analysis of cultural products and processes”. While Bruner (2010, p.45) argues that the conventions of narratives help cultures:

to maintain their coherence and to shape their members to their requirements. Indeed, commonplace stories and narrative genres provide a powerful means whereby cultures pass on their norms to successive generations.

Goodley et al. (2004, ix-x) concur stating that “Narratives are always politicised, structured, culturised and socialised [but they] may be our best hope of capturing structures that continue to shape, divide and separate human beings”.

A social construction of disability

Finnegan (2015, p.35) states that, “An interest in the life stories of ‘ordinary’ people has for long been one strand in the social sciences” and is “currently the focus of extensive interdisciplinary collaboration, involving amongst others, anthropologists, psychologists, folklorists, historians, therapists and literacy scholars as well as sociologists”. Smith and Sparkes’ (2008, p.17) work focuses on disability studies and also acknowledges an increased visibility in the use of personal narratives within this field of research. This has given a voice to people who experience disabilities, so they are able to talk about their personal experiences in the context of their everyday lives (Smith & Sparkes, 2008, p.17). Goodley (2011, p.1) argues that disability studies have emerged over the last 40 years encapsulating a broad area of theory, research and practice with disability being viewed through a lens as a “social, cultural and political phenomena”. Goodley (2011, p.xi) also argues that disability studies reject the view that “disability equates with personal tragedy” and that while recognising that people can experience cognitive, physical, sensory and/or mental health impairments, disability studies support the social model of disability and “place the problems of disability in society” and not with the individual. Goodley and Tregaskis (2006, p.631) further this argument by stating that the social and physical disadvantages and barriers which disabled people face should not be viewed as a “natural and inevitable

consequence of their impairments [as] a wheelchair user might never be able to negotiate a flight of steps, but an architect could be trained to design more accessible buildings". Angus and Bowen-Osborne (2014, p.149) concur with the view that disability is socially constructed and argue that the use of personal narratives in disability research "speaks to the links and contradictions between body, self and modern society which often exclude disabled people from full participation in social life". Similarly, Smith and Sparkes (2008, pp.18-19) propose that people's autobiographical accounts of their experiences and insights of living with a particular disability "locate impairments in and as personal and social narratives", which contest a medical model of disability by offering "counter narratives" of disability "that refuse and displace the tragedy story, that challenge and resist social oppression and that allow different body-self relationships to emerge".

Therefore, storytelling and the collection and review of individuals' personal stories provide a way to consider and explore people's life experiences using a social process lens. It is from this perspective that I wish to view the lives of the research participants in this study. I am very conscious that dementia research can often be based on a medical model of disability and central to this study is being able to view the sociocultural contexts of the research participants' lives. I am aware that over the last 20 years in dementia care and research there has been an on-going challenge to viewing dementia through only a medical lens. This challenge can be traced back to Kitwood's (1997) seminal work. This posed a significant challenge to medical and care professionals' perceptions of dementia, where the focus was on the diagnoses of the disease and the subsequent positioning and labelling of people as deficient, which Kitwood (1997, p.46) described as a "malignant social psychology". Kitwood's work did much to raise awareness of dementia from a social rather than medical perspective, and it also significantly helped "to stimulate an agenda for change" (Clarke & Keady, 2002, p.30). Kitwood argued that dementia should be viewed where the person and not the dementia comes first, and that approaches to care should be person-centred and "look far more to human than medical solutions" (p.2). Kitwood suggested that person-centred care environments should enable people with dementia to be "acknowledged as a person ... in his or her uniqueness" (p.90) and the care environment should support people with dementia to be able to maintain

relationships with others; to express their feelings and preferences; and to also make choices and have control over their care (pp.90 - 91). Kitwood argued that if this wider approach to dementia care is not applied, then an individual's very personhood becomes threatened (p.8).

Kitwood (1997, p.8) defines personhood as "...a 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". Therefore the preservation of a person's self and his or her identity is central to this concept, along with the view that "the nature of self is social in that its existence hinges on social interaction" (Kontos, 2005, p. 554). Moreover, an understanding and knowledge of a person's biography is essential, if a person's identity and selfhood is to be sustained, particularly as an individual's personal memories begin to fade (Kitwood, 1997, p.56).

Kitwood's recognition of the importance of reminiscence builds on psychiatrist, Robert Butler's (1963), work on "life review". Butler challenged the dominant view of the time that the process of reminiscence in older people was an outcome of psychosocial dysfunction where people wanted to escape the realities of the present and "live in the past" (Moos & Björn, 2006, p.433). Butler argued that recalling life events provided opportunities for older people to review both positive and negative past events and allowed for a process of personal adjustment and change to take place towards the end of life (Swann, 2013, p.614). Kitwood's (1997, p.56) recognition of the value of personal reminiscence for people with dementia also acknowledged the benefits of using these activities to have the potential to go beyond just revisiting a person's past. Kitwood proposed that "memories provide metaphorical resources for people to talk about their present situation in a way they can handle" (p.56).

Life story work

Kitwood's (1997) work has significantly influenced dementia research and care practices over the last two decades. During this time period, life story work has become established practice in dementia care (Williams & Keady, 2006, p.163). Its use, offers a way of permanently capturing people's personal stories, interests and wishes, with the aim of using this information to make their care more personalised (Brooks,

Savitch & Gridley, 2017, p.2; Kindell et al., 2014, p.151). Encouraging people with dementia to recall personal experiences can give a voice to people who often feel they have been silenced (McKeown et al., 2010a, p.156) and it can help to affirm self-identity (Kindell et al., 2014, pp.151-152). A permanent record of a person's life story is produced in resources such as life story books or storyboards, where autobiographical text can be combined with artefacts such as photographs (Dementia UK, 2011, p.2; Kindell et al., 2014, p.152). A life story or memory box (Dementia UK, 2011, p.2) is a further resource which can be used to store personal artefacts such as images, photographs, texts and personal documents. Multimedia resources can also be used to collect and store digital recording of a person's stories and memories, along with music and voices which have personal significance to them (McKeown et al., 2010a, p.148). These resources provide "a tangible product" which can be referred to and revisited. They can also be shared with other people (Brooks, Savitch & Gridley, 2017, p.2) and where relevant, can help to support a person's transition to a different care setting (Gridley et al., 2016, p.1).

Completing life story work can help to build relationships between people with dementia and care staff (Ward, Campbell & Keady, 2014, p.66) by supporting care staff to gain an awareness of people's "present day actions, belief and values" (Kindell et al., 2014, p.151) and "to see the person beyond dementia" (Cooney et al., 2014, p.3570). Family members of a person with dementia can also benefit from life story work, as it can lessen the "burden of 'preserving' the personhood of the person with dementia" (Cooney et al., 2014, p.3571). Research studies also report positive outcomes for family members who have involvement in recording their relatives' memories:

I got something out of it in that I spent quality time with her [mother]. When I visit her at home, I'm perhaps doing other things, like the washing or housework, so it's not necessarily quality time with her, so that was good (Melunsky et al., 2015, p.849).

I thought we had nothing in common these days but doing the life story made me realise that we had a lifetime of experience and joy. My husband loves looking at the photos of us all (Thompson, 2010, p.4).

Therefore, the use of life story work can help a person with dementia to have a voice to tell personal stories and to be understood within the context of their past life and its

orientation to the future. It can support care staff to view people with dementia as individuals and provide care which is personalised to an individual's needs. It can also provide a resource to support family members in upholding their relative with dementia's personhood (Gridley et al., 2016, p.1).

Having reviewed how personal narrative accounts can be used as a way of viewing disability as a social process (Goodley, 2011; Smith & Sparkes, 2008); the significance of Kitwood's (1997) work with regard to perceptions of dementia and dementia care practice; and how life story work can be used in dementia care settings (Brooks, Savitch & Gridley, 2017, p.2); in the following section I explore the use of personal narrative and collaborative approaches to narrative in dementia research. I focus on the research of Hydén and colleagues (2009, 2010, 2011, 2013), Baldwin (2005, 2006) and Angus and Bowen-Osborne (2011, 2014).

Personal narratives and storytelling

Beard, Knauss & Moyer (2009, p.227) state that narratives told by people with dementia provide accounts of the "lived experiences of individuals" and help to support the analysis of dementia as a "social process". They argue this can provide an alternative to the medical model of dementia, which gives "prominence to biological and neuropsychiatric markers of decline" and can result in a prominent "discourse of loss" (Beard, Knauss & Moyer, 2009, p.227). Wilkinson (2002) concurs with this viewpoint, arguing that the placing of dementia as a "disease category" (p.10) impacts on the way in which society views people with dementia where they can often be perceived as "diseased brains rather than individual people" (p.11). Angus and Bowen-Osborne (2014, p.149) also argue that the capturing of personal narratives can "expose attitudes and practices imposed upon a person" and also provides opportunities to review "individual subjectivity in how disability and chronic illness is perceived, enacted and responded to, by self and others".

However, storytelling and the recalling of personal experiences is a complex social, cognitive and linguistic activity, which can prove problematic for people with dementia experiencing, short term memory loss and deteriorating cognitive and linguistic skills, which in turn can result in difficulties with oral communication (Hydén, 2013, p.359;

Baldwin, 2006, p.103). Therefore, people with dementia can sometimes find it difficult to engage and interact with others through personal narratives, which then impacts on their ability to use personal storytelling to show and talk about their identities (Baldwin, 2006, p.103; Hydén & Örvulv, 2009, p.205). People with dementia may appear to others to be “less competent storytellers than they actually are” (Hydén & Antelius, 2010, p.589), as they can experience difficulties remembering words, phrases, contexts and characters; some events may be repeated on multiple occasions during the telling of a story, where other life events which can be viewed as pertinent to a story, might be omitted. Therefore, stories can be viewed as fragmented (Baldwin, 2006, p.106; Moore & Davis, 2002, p.263) and lacking in coherence, when events are presented out of temporal order and sequenced in a way which can be viewed as not following the ‘expected’ structural conformity of autobiographical stories (Angus & Bowen-Osborne, 2014, p.149; Baldwin, 2006, p.103; Hydén & Antelius, 2010, p.592; Hydén & Örvulv, 2009, p.205).

Hydén (2011, p.340) postulates that these anticipated narrative norms at a macro-linguistic level can be linked to a ‘traditional’ view of the oral, personal experience narratives associated with the seminal work of Labov (Labov & Waletzky, 1967; Labov, 2007). Labov and Waletzky (1967, p.20) defined narratives as “a method for recapitulating past experiences by matching a verbal sequence of clauses to the sequence of events which actually occurred” and proposed that the construction of a prototypical narrative: “beginning with an abstract, orientation, an evaluation section embedded in the complicating action, a resolution and a coda ... narrative construction follows the order of events in time” (Labov, 2007, p.47). Therefore, if such a view is taken with respect to the constructions of personal narratives (with a focus on the temporal and referential aspects), then stories told by people with dementia may be viewed as “failed stories” (Hydén & Antelius, 2010, p.589) or deviant stories (Hydén, 2011, p.340), which could result in them being not included in analysis and discussions, and the storytellers being viewed as incompetent storytellers of their own autobiographies (Hydén, 2011, p.340). This also infers that people with dementia cannot use autobiographical narrative as a way of sustaining their identity and selfhood (Hydén & Örvulv, 2009, p.206) and this loss of narrative agency (Baldwin, 2005, p.206) results in them having to redefine their “relations with others, becoming

someone standing on the side, not being able to participate anymore” (Hydén, 2011, p.346).

Baldwin (2006, p.103) argues that people with dementia can find that they become “narratively constrained”, resulting in more limited opportunities to express themselves, because they are increasingly defined by others as lacking capacity to be able to communicate and make decisions for themselves. This can result in decisions being made for them and also their stories are told for them by others, which leads to a reduction in opportunities for social interaction and the telling of personal narratives. In addition, Baldwin (2006, p.103) also argues that the mental space in which narratives can be told become restricted as the “meta-narrative of dementia” is mobilised by others which “defines the person in terms of decline, loss and fragmented cognitive functioning”. This results in people with dementia being viewed as less able to present a recognisable narrative. Baldwin (2005) argues therefore, that people with dementia can become narratively dispossessed in that people’s narratives are not just heard, but “*they cannot be told*” (p.1023).

MacRae’s (2010, 2011) research into people’s experiences of living with AD considers identity and concepts of self. MacRae (2011, p.445) argues that people with dementia can be viewed in terms of “loss of self” and “decline” and that there is a socially constructed view of AD, “that ‘robs’ persons of their minds” (MacRae, 2010, p.293) where the “self is steadily eroded and ultimately lost as cognitive impairment increases and abilities diminish” (MacRae, 2010, p.293). MacRae (2010, p.294) supports a social constructionist theory of the nature of the self and cites Sabat and Harré (1992, p.444) who propose that even in the later stages of AD “there is a self that remains intact despite the debilitating effects of the disorder”. However, MacRae (2010) acknowledges that maintaining the self is particularly difficult when “others impose an illness identity on the person” (p.293) and “position the person with dementia as “demented” (p.294). Sabat (2001, p.107) recalls that, a Mrs R, who when attending a day care centre was a “consummately social person who enjoyed warm interaction with others” but following her diagnoses of AD, became “an outcast among members of her own family”. Similarly, MacRae (2011) reports that people with AD can feel that they are “discounted and ignored or, treated as if they are invisible” (p.446). MacRae

(2011, p.446) cites research by Katsuno (2005, p.206) who described that one of her research participants with AD experienced a combination of being ignored and narrative dispossession:

[When] they know you have Alzheimer's, they will just kind of ignore you... They leave you alone because they figure you don't know what you're talking about, you don't know what is going on...

Similarly, Batsch and Mittelman (2012) reporting on outcomes from an international survey on dementia and stigma give examples from the survey's respondents who also describe their experiences of narrative dispossession. A respondent from Canada describes:

Upon diagnoses [people] think that you have lost your intelligence and you no longer have any of the knowledge you have attained over the years. [People] no longer ask your advice on anything. [They] talk to the person you are with and not you (p.25).

While a respondent from New Zealand explains, "They think I'm stupid and can't talk properly" (p.28) and a further respondent from the United States describes that:

My cognitive abilities are still fairly high. However, when I have difficulties remembering words or am slow in my responses, I sometimes encounter impatience, people trying to find words for me, exasperation and so forth (p.28).

Therefore, these examples give weight to MacRae's (2010, p.303) view that "Whether a positive sense of self is retained or prematurely lost, as Kitwood (1997) forewarns, is dependent not on the impact of the disease itself so much as the response of others".

Co-constructing autobiographical stories

The possibilities that the personal recall of autobiographical events and storytelling offers as a way of helping people with dementia to preserve their self-identities, and to provide a platform from which their voices and stories can be heard, is particularly pertinent to me. However, I also recognise the impact dementia can have on people's oral communication skills from the previously reviewed medical research, and therefore, some people can find talking and the recall of personal stories particularly challenging. Therefore, I find it useful in this section to review Hydén (2011) and Baldwin's (2006) work into the co-construction of autobiographical stories, Baldwin

(2006), Bamberg (2004, 2006) and Georgakopoulou's (2007) research on small stories, Moore and Davis' (2002) work on narrative quilting and Hydén's (2011) research on the use of narrative scaffolds to support personal storytelling for people with dementia.

Hydén (2011) and Baldwin (2006) propose that one way of overcoming narrative dispossession and "reconfiguring narrative agency" (Baldwin, 2006, p.105) is through collaboration and co-authorship of narratives, where the narrative process is shared between the person living with dementia and those who are close to them (family, friends and/or carers). Baldwin (2006, p.106) describes that the co-construction of a narrative becomes a very "deliberately and consciously negotiated product between those people living with dementia and others". Baldwin (2006, p.107) also states that for a person with dementia, maintaining "a narrative trajectory ... over a reasonably lengthy period of time" is often unrealistic. He draws on Bamberg's (2004) work to advocate that one way of overcoming these narrative difficulties is through the collection of a person with dementia's "small stories" by a person without dementia (P.107).

Bamberg (2004, 2006) and Georgakopoulou's (2007) research focused on the construction of narratives as a social practice and the storied identity of people through their telling of "small stories". They contrast small stories to the more traditional analysis in narrative research of what they described as "big stories" (Bamberg, 2006, p.43) and argue that small stories are always told as part of the performance of identity in everyday interaction between people (Georgakopoulou, 2007, p.18). Bamberg (2004, p.367) states that small stories are "the ones we tell in passing, in our everyday encounters with each other", are the '*real*' stories of our *lived* lives", while Georgakopoulou (2007, p.148) suggests that small stories can cover "a whole range of under-represented narrative activities ranging from literally small and fragmented tellings to refusals to tell and deferrals of telling". Baldwin (2005, p.1024 & 2006, p.107) argues that for people with dementia, the recall of "small stories can be important in the maintenance of Self" (Baldwin, 2005, p.1024). Similarly, Hydén and Orulv (2010, p.149) suggest that for a person with dementia, the "repetition of stories

or fragments of stories may capture something important in the way the person makes sense of his or her life”.

Baldwin (2006, p.106) also draws on Moore and Davis’ (2002) work, who propose the use of a collaborative and co-constructed approach to storytelling for people with dementia, which they describe as narrative quilting (Moore & Davis, 2002, p.263). Narrative quilting requires a person without dementia to remember the fragments of stories or small stories that they have previously been told by the person with dementia. In subsequent conversations, it is the person without dementia’s role to remind and re-tell these to the person with dementia, with the view that these verbal prompts and cues will help the story fragments to be built into a whole story (Moore & Davis, 2002, p.263). Baldwin (2006, p.106) suggests that using this “quilting” approach offers a “meaningful whole” to be achieved through the “assemblages of fragments related by meaning”.

Hydén (2011, p.346) also proposes a co-constructed and collaborative approach to storytelling for people with dementia, where people such as family members and the person with dementia jointly telling “a story about the shared past”. Hydén (2011, p.339) argues from a viewpoint that storytelling is always impacted on by the social context in which it takes place and is never an individual act but a collaborative activity. Hydén (2011, p.340) proposes that storytelling involves:

several tellers, be highly integrated into ongoing conversations, and hence be less easy to spot and delineate from an analytical perspective, and show considerable fluidity concerning both the order of events referred to in the story and the moral evaluations of those events.

Therefore, Hydén (2011, p.340) argues that it is not surprising to find that oral stories lack the structural narrative norms of being “discernible discursive units of talk” and that for people with dementia, this can only be compounded by the cognitive and linguistic difficulties they face. Hydén (2011, p.340) proposes that people with dementia are much more successful story tellers when a collaborative or co-constructed approach is used and they are supported by other people, particularly those who are familiar to them such as family members and friends.

Hydén (2011, p.340) states that the audience's role in storytelling is that of an active participant as they will "follow and anticipate" the teller's story. The teller and audience respond to each other and mutual understanding is often checked. A shared commitment to the conversation can often be observed, along with displays of mutual engagement, an understanding of what they are doing together and a commitment to accomplishing the conversation by finishing it (p.340). Hydén (2011, p.341) also argues that the concepts of conversational 'turns' and 'repairs' are particularly significant for productive interaction and collaboration in storytelling to take place.

Hydén (2011, p.341) suggests that there needs to be co-ordination between the teller(s) and audience during storytelling, so that all the participants are able to listen to and understand the same story. The content of stories is negotiated through the contributions of the tellers and responses to these contributions from the audience. Contributions by tellers can be explained in terms of the use of 'turns'. These turns can be observed to be accepted by the audience using verbal acknowledgements such as 'mmm', 'oh yes', 'really?' or repeating a small part of the utterance made by the teller, and also by non-verbal methods such as nodding. These positive responses from the audience demonstrate to the teller that the story is being accepted and the teller will continue to tell the story. Hydén (2011, p.341) also identifies that 'repairs' may be required during collaborative storytelling, if problems or a 'break-down' in the storytelling takes place. This can refer to situations when the audience might not be able to hear what the teller is saying; they may not understand what has been said or the information being conveyed is intelligible. Therefore, a 'repair' to the conversation is required, such as repetition and rephrasing of information, elaboration, or further explanation by the teller, so shared understanding is re-established and the story can continue.

Hydén (2011, p.341) suggests the use of "narrative scaffolding" to overcome conversational difficulties, where the person or people without dementia will take more responsibility during storytelling and "be more engaged in quite extensive repair work in order for the participant with dementia to continue to be an active conversational participant". Hydén (2011, p.341) compares this approach to Bruner's (1976) concept of scaffolding, where an adult is viewed as the expert helping a child to

accomplish an unfamiliar task through providing a 'scaffold' of breaking the task into smaller steps and providing appropriate feedback and support, so that the child is able to complete the task. Therefore, Hydén observes that as dementia progresses, and a person's storytelling skills diminish, the person without dementia can act as the 'expert' in storytelling and "construct a scaffold that can be used by the person with AD in order to understand and be understood"(p.346). Scaffolding strategies can include: the interpretation of meanings of contributions; the use of closed (yes/no) questions to encourage the person with dementia to respond; prompting the person with dementia with particular vocabulary or phrases they wish to use but cannot remember; and to also provide references for people or past events (pp.341-342). Hydén suggests that the use of scaffolding techniques can help support the person with dementia to continue to be an active storyteller and the narrative scaffolding "becomes an integrated part of the ongoing collaboration as a means for joint meaning making" (p.342).

This review of literature recognises the importance of the recall of small stories for people with dementia (Baldwin 2006; Bamberg 2004, 2006; Georgakopoulou 2007; Moore and Davis 2002) and the use of collaborative approaches in personal storytelling (Hydén 2011). I recognise that Hydén's (2011, p.339) recommendations for the co-construction of autobiographical stories through using a narrative scaffolding approach has similarities to the recognition given to the communication support a familiar conversation partner can give to a person with dementia. Therefore, it would be pertinent for me to consider in this study how opportunities for collaborative storytelling can be supported within the data collection process. I am also aware from Moore and Davis' (2002) work that I may need to remind the research participants with dementia across interviews about fragments of stories they recalled at previous interviews, as this may support them to recall further personal memories and to remember a more 'complete' story over time.

Performative and embodied dimensions of storytelling

Research by Hydén and colleagues (Hydén 2013; Hydén & Örvulv 2009; Hydén & Antelius 2010) also reinforces the importance of performative and embodied dimensions of storytelling for people with dementia and their work offers a further

alternative to analysing personal narratives using a lens which only focuses on textual coherence (Hydén & Örvulv, 2009, p.213; Hydén 2013, p.365). Hydén (2013, p.360) argues that when people take part in storytelling they are “physically present to each other”, so “they use their bodies as communicative resources”. Hydén and colleagues draw on the work of Kontos (2005, p.556), who argues for the “notion of embodied selfhood which captures the idea that fundamental aspects of selfhood are manifested in the way the body moves and behaves”. Hydén and colleagues review storytelling in terms of an act of performance and embodiment where people engage with each other verbally and non-verbally in order to tell a story (Hydén & Örvulv, 2009, p.213; Hydén 2013, p.360). Hydén (2013, p.365) argues that storytelling is “multimodal” and non-verbal aspects of the stories should also be analysed, as stories are performed and embodied through use of “non-vocal semiotic resources” such as the use of paralinguistic means including gestures and eye movement. People also refer to physical artefacts that may be present to them, such as letters or photographs, to support their story (Hydén & Antelius, 2010, p.590; Hydén & Örvulv, 2009, p.213).

Hydén (2013, p.361) also suggests that when people with AD encounter a problem with spoken language during storytelling, they will often use non-vocal semiotic resources and these can often take a “lead role”. For example, a person may forget a word or a phrase and instead replace these with the use of gestures. Therefore, Hydén and Antelius (2010, p.599) argue that if the use of non-verbal strategies by people with AD are not considered by researchers, then this impacts on the “understanding of the organisation of illness narratives”. Hydén (2013, p.365) also reviews the importance of the relationship between participants during collaborative storytelling. He observes that people with AD will use an embodied storytelling approaches to mimic, dramatize or direct their listeners’ attention to events in a particular story. They will also let the combination of words and the “embodied semiotic means be part of comments or evaluations of the story ... thus aiming at effecting the relation between the participants” and so the relationship between the participants is as valid as the story being told (p.365).

Therefore, Hydén and colleagues’ (Hydén 2013; Hydén & Örvulv 2009; Hydén & Antelius 2010) work shows the multimodal aspects of storytelling in relation to people with

dementia. This has led me to recognise that I need to consider how to record not only the oral telling of autobiographical stories in this study, but that I also need to capture when non-verbal strategies are used by the research participants with dementia, so performative and embodied aspects of their personal narratives are also captured.

Conclusion

In this chapter, I have surveyed literature from diverse fields of academic research. Viewing literacy from a sociocultural perspective sits at the very centre of this study, so I found giving consideration to Street's (1993, 2001, 2011) models of literacy was a useful way to begin considering literacy from a social practice perspective. Barton and Hamilton's (1998, 2012) concept of literacy practices provides a way to explore how people with dementia have engaged with literacy throughout their lives. Therefore, I will specifically draw on Barton and Hamilton's work in my analysis. Janks' (2010) work highlighted the importance of critical literacies and made me consider how political, economic, cultural and institutional structures impact on textual and social practices (Janks, 2010). In particular, I will draw on Freire's view of critical praxis and the process of reading the word and the world (Freire & Macedo, 1987), as I wish to explore the extent to which the research participants with dementia have used literacy to make sense of the different contexts they have experienced in their lives. How people are using technology and digital literacy practices to create new digital spaces to communicate across contexts (Davies, 2012, p.21; Kell, 2011, p.607) also interests me. I found the perspectives expressed by people who have been diagnosed with young onset dementia and regularly use social media sites and online blogs to write about their experiences of living with dementia (Blumenthal, 2017; Mitchell, 2016, 2017; Picazo, 2015; Swaffer, 2017) particularly pertinent. However, I also recognise that engagement with new technologies is irregular across diverse groups of people (Burnett et al., 2014, p.11) and that many older people experience digital exclusion (Department of Health, 2012; Alzheimer's Society, 2013a). Therefore, I wish to draw on these ideas to review the research participants' engagement in digital literacy practices.

Research relating to the material, artefactual and embodied nature of literacy (Davies 2014; Leander & Boldt 2013; Mackey 2016; Pahl & Rowsell 2010) also interests me,

and particularly Jones' (2014) research which explored the connection between people's ruling passions (Barton & Hamilton, 1998, p.18) and displays of objects in the home. I wish to consider whether the research participants in this study can be viewed as having ruling passions and examine how these have influenced their lives and the literacy practices they have engaged. Jones' (2014) research also reviewed the shared nature of literacy practices within family groups, which has similarities with Gregory and Williams' (2000, p.11) work on mediators of literacy. Therefore, I wish to draw on these ideas in my analysis to consider whether some of the literacy practices the research participants engage in can be viewed as being shared or collaborative practices.

Reviewing literature from the medical field developed my knowledge of how people with a range of dementia types can experience a number of difficulties in relation to their oral communication, reading and writing skills. I recognised that this medical literature methodological relies on outcomes generated by the use of neuropsychological standardised tests and literacy is viewed from an autonomous rather than a social practice perspective. Therefore, I also found it useful to review research which examines the validity of the use of neuropsychological standardised tests in the assessment of dementia (Dijkstra et al., 2004; Jones, 2015; Kemper et al., 1995; Perkins et al., 1998; Sabat, 2001) and also research that explores collaborative approaches to oral communication with a focus on familiar conversation partners for people with dementia (Dijkstra et al., 2004, p.268; Kemper et al., 1995, p.215; Perkins et al., 1998, p.35). The importance of collaborative approaches and the multimodal nature of storytelling for people with dementia was also the emphasis in research from the narrative field (Baldwin 2006; Hydén 2011; Hydén 2013; Hydén & Örvulv 2009; Hydén & Antelius 2010). Therefore, I will find it useful to draw on these fields of research, as I review and analyse the research participants in this study's personal stories and autobiographical memories.

In the following chapter, I explore the methods and approaches used to conduct the research for this study through taking a life history approach.

Chapter 3: Methodology

In this chapter, I give an overview of the methods used to take a life history approach to undertaking this research to investigate the range of literacy practices older people with early stage dementia have engaged in throughout their lives. This includes: selecting a methodology; ethical considerations relating to conducting the research for this study; the methods used to collect data; and taking a thematic approach (Riessman, 2008, p.74) to analyse the data collected.

3.1 Selecting a methodology

I wanted to select a methodological approach which would enable me to investigate the range of literacy practices older people with early stage dementia had engaged in throughout their lives, including more recent times where they have had to live with dementia on a daily basis. I also wanted to use a methodological approach which would allow me to capture the voices of people with dementia through their recall of memories and experiences, as I recognise that they can often feel they are “silenced” (Ward, Campbell & Keady, 2014, p.64). I also wished to explore the experiences and observations of individuals that are close to people with dementia, such as family members, as I hoped that their personal accounts would provide an additional way of capturing viewpoints and observations of the person with dementia’s literacy practices before dementia became part of their lives and as they experience living with the illness.

I considered taking an ethnographic approach to this study, as ethnographies focus on “real-world settings” and “people’s real lives” (Barton & Hamilton, 1998, p.57) and are concerned with “the quality and integrity of human life” (Heath and Street, 2008, p.30). Therefore, I recognised that if an ethnographic approach was taken, it would provide a social lens through which I could observe and analyse people’s lived experiences of dementia. However, I was also conscious of Heath and Street’s caution that, “To undertake ethnography is to enter willingly into a messy set of tasks that will continue over a considerable period of time” (p.29). I was completing this study as part of an Education doctorate programme which was time bound and I also recognised that I had a busy work and home life to consider. Therefore, I was concerned that I

may not have the “considerable period of time” which would be required to effectively use this approach. I also reviewed that the “messy set of tasks” refers to multiple research methods that ethnographers use including interviews, the analysis of documents and artefacts (Barton & Hamilton, 1998, p.58) and that participant observation is a “key means of collecting data” (Heath & Street, 2008, p.31). I acknowledged that the use of interviews would provide a way for the research participants to be able to describe and recall their autobiographical memories. I also recognised that the research participants may describe and make reference to artefacts and documents which they viewed as important and integral to their lives, so these could also become part of the data generated during research interviews. However, I questioned how ethically appropriate the use of observations with research participants with dementia might be. The observations would potentially need to span a prolonged period of time so participation in a range of literacy practices could be observed. It was also likely that they would encompass a range of locations including the research participants’ homes, settings where interaction with family members and friends could be observed, plus settings relating to dementia care and support. Heath and Street (2008, p.31) view that, “Ethnography forces us to think consciously about ways to enter into the life of the individual, group or institutional life” resonated with me, as I concluded that the observing the research participants with dementia would potentially be too intrusive to their everyday lives and would require more time than I could make available for this particular study.

I also considered taking a case study approach to this research and recognised from Yin’s (2014, p.4) work that case study research contributes to knowledge about individuals, groups and organisations and is used across an extensive range of research fields. I was also aware that case studies often arise “out of the desire to understand complex social phenomena” in real-world contexts and are particularly appropriate for research where the main objectives are to investigate the “why” and the “how” of a particular phenomenon (i.e. the case) (Yin, 2014, p.4). Therefore, taking this approach could be appropriate for this study in that living with dementia can be viewed as a complex social phenomenon and the study’s research objectives focus on ‘how’ questions in terms of investigating how older people with early stage dementia had engaged in literacy practices throughout their lifetimes. However, I was also aware

that case studies need to be 'bound', so the unit being analysed is clearly defined and there are clear parameters in terms of what factors will and will not be included relating to, for example, people, context and time (Yin, 2014, pp.33-34). As the aim for my study was to review older people with dementia's lives with particular consideration to their literacy histories, I was unsure of the actual time periods their personal accounts might span and also anticipated that they had the potential to encompass a very wide range of people and contexts. Therefore, as I planned the study, I was uncertain to whether I would be able to define the study's boundaries in a way that would be appropriate for taking a case study approach.

Ultimately, I decided to take a life history approach, as I recognised that this approach offers a way of exploring the "personal and subjective perceptions and experiences of individual people" (Sikes, 2006, p.2) and to get close to "individual men and women, accurately picking up the way they express their understanding of the world around them, and ... providing an analysis of such expressions" (Plummer, 1990, p.1). I also drew on the work of the American sociologist, Wright Mills (1959) and his concept of "sociological imagination". Wright Mills (1959, p.8) argues that connections need to be made between an individual's story and history to make sense of the relations between the individual and society, and therefore, that "personal troubles" can be considered in relation to public issues and concerns. As Goodson (2013, p.6) argues, life history "asks whether private issues are also public matters". Similarly, Goodson and Sikes (2001, p.16) state that life history grounds people's personal experiences into the wider social, cultural and historical contexts they inhabit, with consideration to social relations of power. Silverman (1998, p.111) also argues that personal stories can illustrate wider processes of social change and observes, "as sociologists we all have stories ... what matters is to understand how and where the stories are produced, which sort of stories they are, and how we can put them to intelligent use in theorizing about social life". These views seem particularly relevant to people with dementia because I recognise that many feel powerless, as they often inhabit "a society where ageism and stigma against mental health issues reflect deep power inequalities in the relationships between individuals and wider society" (Wilkinson 2002, p.9). I also recognise that people with dementia can often feel as though they are "discounted and ignored" (MacRae, 2011, p.446), which can result in people's personal stories and

experiences being left 'unheard' and not necessarily being recognised or understood within society.

Therefore, I hoped that using a life history approach would allow me to work collaboratively with research participants and it would give them a 'voice' through eliciting and capturing the "thick description" (Geertz, 1973) of their detailed personal accounts, so I could explore how they "construct their identities" (Chase, 2011, p.422) and contextualise their lived experiences of dementia. As Hodkinson and Hodkinson (2001, p.3) argue, individual cases, "retain more of the 'noise' of real life than many other types of research". Considering dementia from a sociocultural perspective also provides an alternative to the often more prominent care narratives based on a medical model of disability which describe dementia through identifying "biological and neuropsychiatric markers of decline" (Beard, Knauss & Moyer, 2009, p.227), and focus on deficits, loss and impairments (Baldwin, 2015, p.184). As Witherall and Noddings (1991, p.280) argue, personal stories provide, "a picture of real people in real situations, struggling with real problems. They banish the indifference often generated by samples, treatments, and faceless subjects".

The recall of autobiographical memories

I am aware that using a life history approach can be critiqued for the potentially subjective nature of the findings presented and a lack of representation through the use of small samples (Munro, 1998, p.8). However, Sikes and Hall (2016, p.5) argue that the aim of life history work is "not to generalise but rather gain a sense of how people with different biographies go through similar social and cultural experiences". Goodson and Sikes (2001, p.45) acknowledge the importance of effective collaboration and communication between researcher and research participants as this can impact on the nature and content of the life stories which emerge. They also argue that research participants will have 'notions' of what it means to be involved in a research project, and therefore, this can "influence what they tell and how they tell it and the information they make available to the researcher" (p.45). As Bruner (1993, p.39) states, "there is no such thing as a 'uniquely' true, correct or even faithful autobiography" and Riessman (2008, p.29) argues that all stories are "selective and perspectival, reflecting the power of memory to remember, forget, neglect, and

amplify moments in the stream of experience". Similarly, Sikes and Gale's (2006, p.30) argue that a life story can only be an interpretation or representation of a person's life, as people will tell their personal stories in different ways and this is influenced by their understanding of the different situations they are in as they tell their story. I am also aware that research participants are influenced by the identity they wish to present and how they perceive listeners will respond to their story (Sikes and Gale, 2006, p.31). As Goodson & Sikes (2001, p.41) state, the concept of self is always "contested and controversial".

I also acknowledge a growing body of research from the field of cognitive science in relation to how humans retrieve autobiographical memories and communicate these to others. I have found it useful to consider the work of psychologist, Charles Fernyhough (2013). Fernyhough (2013, p.6) argues that cognitive scientists' investigations of memory from a neural perspective have explored the interaction between cognitive systems such as thoughts, emotions, beliefs and perceptions which underpin people's ability to be able to recall and remember autobiographical events. Fernyhough suggests that memories are "mental constructions" which are reconstructed by individuals as they are recalled, and these are created and formed in a way that is integrated and applicable to the demands of the 'present' (p.6). It is in this relation between past and present that "errors and distortions can creep in" during the recall of a particular memory and "a coherent story of the past can sometimes only be won at the expense of the memory's correspondence to reality" (Fernyhough, 2013, p.7). Fernyhough (2013, p.8) cites Schacter (2003) who concurs with this view describing:

We extract key elements from our experiences and store them. We then recreate or reconstruct our experiences rather than retrieve copies of them. Sometimes, in the process of reconstructing we add on feelings, beliefs, or even knowledge obtained after the experience. In other words, we bias our memories of the past by attributing to them emotions or knowledge we acquired after the event.

Therefore, as Fernyhough (2013, p.13) summarises, "Memories are changed by the very process of reconstructing them".

I am mindful of the pertinence of this research from the field of cognitive science in relation to my own research, as my study centres on the memories and personal experiences of people with dementia for whom memory loss and the deterioration of cognitive and linguistic skills are a daily reality (Alzheimer's Society, 2016). I have, therefore, also found it useful to consider the work of Wilkinson (Wilkinson 2002; McKillop & Wilkinson, 2004) and the perspectives she brings to involving people with dementia in research.

Involving people with dementia in research

McKillop and Wilkinson (2004, p.117) suggest that the belief that people with dementia are not able to describe personal experiences or express opinions "has been increasingly rejected over recent years". Wilkinson (2002, p.10) argues that if people with dementia are not given opportunities to express and share their personal views and participate in research, this then reinforces "negative stereotypes of incapacity" linked to "traditional stereotypes of senile old people who have 'lost their mind'". Therefore, Wilkinson (2002, p.10) argues that taking a stance of this kind reinforces a medicalised view of dementia placing it purely in a "disease category" which can further reinforce the marginalisation of people with dementia. Wilkinson (2002, p.11) states that a social model of disability approach to dementia is essential, arguing that including people with dementia in research offers a way to understand "what it means to be a person with dementia living in a society" and allows for barriers of attitude, policy and environment to be explored. Wilkinson also purports that including people with dementia in research allows personal perspectives to be captured (p.13); provides a way to "shift the power inequalities" in relationships (p.14); reduces and challenges "stigmatised and stereotypical" views (p.14) and offers a way for people with dementia to inform dementia policy and practice through "hearing and privileging their voices"(p.14).

However, perhaps most pertinent to the discussion of whether it is valid for people with dementia to be involved in dementia research is to give consideration to the views and experiences of people who live with dementia and have had involvement in dementia research. McKillop (McKillop & Wilkinson, 2004, p.124) was diagnosed with dementia in 1999 and has been involved in a number of dementia research projects

(McKillop 2002, 2003). McKillop (2002) reflects on the question 'Did research alter anything?' and describes the importance of being involved in dementia research and identifies the new understanding this brings about the disease to a potentially wider audience. McKillop (2002, p.113) states:

Did research alter anything? Remember when I met Rebekah [researcher], it was fait accompli as I had finally been told of my diagnoses, so was research too late for me? I think not! My experiences (and those of others) will surely shape the future and others will benefit. I also met kindred spirits, gained confidence to face the public and speak out (how can I ever thank Rebekah and Heather?) [researchers] and you – the reader – have been given the chance to reflect. It is the rare person who has not been, or will not be, touched by dementia through family, friends, acquaintances and workmates. You are better prepared now. Many people want to help but are unclear how. Hopefully some will now be motivated into action to do 'something'. There is a lot to be done and people's individual talents could culminate in awesome pressure groups.

Similarly, Robinson (2002), diagnosed with Alzheimer's disease in 1999 reflects on her experiences of being involved in dementia research. She describes the personal value she associates with these experiences and the benefits that she believes are to be gained from recording personal accounts of the illness from people who experience dementia. Robinson (2002, p.104) states:

I really think that people like myself should be encouraged to take part in any research and made to feel their contribution, no matter how small, would be greatly valued. After all, who else would know what it's like to have the disease? No doctor, no matter how eminent, could ever truly appreciate how we perceive the horrors, which lie in wait at times in our often fuzzy and confused world, unless he or she suffers from it too ... What a wealth of hidden personal experience the skilful researcher can tap into. I also think that we should be encouraged to involve ourselves in research as often as possible, as long as we find it comfortable to do so, during our journey. If I am able to put my thoughts down on paper or to speak about my feelings and opinions – why shouldn't I be included? ... What a hugely missed opportunity it would be if people with Alzheimer's were excluded from the very thing that could be used to gain a fuller understanding of their disease. It would be simply denying us the chance to fill in the gaps that no one else can.

These personal accounts from individuals with dementia provide insightful arguments to the benefits of engaging people who experience dementia to become involved in research projects. Sabat (2003, p.5) concurs and identifies that encouraging people

with dementia to become partners in dementia research allows for a better understanding of their:

hopes, dreams, fears, what they need, what they don't like, what provides them with purpose, meaning, pride, peace, enjoyment and how they go about navigating the social world in which they live each day.

Therefore, I hope that my research through taking a life history approach to capture the autobiographical accounts of people who live with dementia will enable me to explore the objectives of this study. Firstly, to review the range of literacy practices the research participants have engaged in throughout their lifetimes; secondly, to explore if and how dementia is changing how they engage in literacy practices; and finally, what these changes are.

3.2 Ethics – Gaining approval

My research received clearance from the University of Sheffield, School of Education's Ethics Committee in December 2015. This involved the submission of a written application which was reviewed by three academics who were unconnected to this research. Research participants were then recruited during the period from December 2015 to January 2016 and interviews took place between January and March 2016. In the following sections, I outline the actions taken to recruit research participants with early stage dementia and people that are close to them such as family members. I also review the consideration that was given to gaining informed consent from research participants through the development and use of a process consent method. In addition, I also review issues relating to the confidentiality and anonymity of the research participants, plus particular ethical considerations which were pertinent to this study. These included the use of the word dementia in the research participants with dementia's information sheet; the time that was required for research participants to be involved in the study; issues relating to the interpretation of data collected and the potential for evoking upsetting memories for research participants through the recall of autobiographical stories.

3.3 Recruiting research participants

I planned to recruit research participants through my work with the UK's charity for older people, Age UK. I have worked and also volunteered for Age UK since June 2013

in north London, Hertfordshire, and more recently, Essex. My work with the charity has enabled me to be involved with dementia projects which support people with dementia and their families. Therefore, I recognised that the ultimate sample of research participants I recruited can be described as a convenience sample as I had relatively “easy access” to these families through my work (Goodson & Sikes, 2001, p.24). I also recognised in my position as a researcher working with research participants who engaged in these Age UK dementia project, I can be viewed as an ‘insider’ researcher (Coffey, 1999, p.21), which as Goodson and Sikes (2001, p.25) describe is “doing research ‘in your own back yard’ ”.

Age UK in north London organises regular support meetings for people with dementia and their families and carers. I gained agreement from the charity’s dementia services manager to attend one of these support meetings. This gave me the opportunity to talk about my proposed research and to explain to people how they could become involved (see appendix 1 for information included in this presentation). I was also able to answer members of the audience’s questions during the presentation and I also ensured that I was available at the end of the meeting to give people an opportunity to ask any further questions that they had about the research. I then hoped that following this initial presentation, potential research participants/families would make contact with me to express an interest in being involved in the research.

3.4 Informed consent

Fundamental to this research was the active participation of older people with early stage dementia. However, I recognise that people with dementia are viewed as vulnerable adults (University of Sheffield, 2017b; Alzheimer’s Society, 2016) and that they have often been excluded from research. McKeown et al. (2010b, p.1936) acknowledge this is because of ethical fears that informed consent cannot be gained, while Wilkinson (2002, p.15) argues that this exclusion is due to a “limited and fragmented understanding and experience of methods that are known to enable the voice of the person to be safely and effectively encouraged, heard and understood”. The field of dementia research underpinned by a social model of disability has grown over the last 20 years and it provides a lens for dementia to be viewed from the personal perspectives of people as they live with and experience the disease (Clarke &

Keady, 2002, p.31; Wilkinson, 2002, p.13). Dewing (2008, p.59) acknowledges this drive to include people with dementia as active participants in research and also argues that “capacity legislation” has strengthened “the case for ensuring that persons with dementia are actively enabled to make their own decisions for as long as possible”.

Therefore, I wished to use an informed consent process which was inclusive and meaningful to everyone involved in this study and so developed a *process method of informed consent* (Bartlett & Martin, 2002, p.51; Dewing, 2007, 2008). This led to informed consent being checked and gained throughout the process of research, rather than only being checked at one point in time. In order to develop a process method of informed consent for my research, I drew on Dewing’s (2007, 2008) work on using a process consent method for dementia research.

A process consent method

Dewing’s (2008, p.61) overall aim was to develop a consent process which ensured the person with dementia was fully involved in the consent process, and that the process of consent runs throughout the entirety of research projects. Underpinning Dewing’s process consent method is her view that “ethical decisions and actions are context-specific, and centred on interdependence with a caring relationship [and] allows for a particular rather than a universal approach to consent” (p.61). Dewing’s (2008, p.62) process consent method comprises of five elements:

1. Background and Preparation
2. Establishing the basis for capacity
3. Initial consent
4. On-going consent
5. Feedback and support

Therefore, as I developed an adapted informed consent process, I considered Dewing’s (2007, 2008) process consent method and its five key elements (2008, p.62). The model I developed and used had six key elements:

1. Background, preparation and the basis for consent
2. Initial contact
3. Initial family meeting

4. Initial consent
5. Adapted informed consent
6. On-going consent monitoring, feedback and support

Background, preparation and the basis for consent

The aim of using an initial presentation (see appendix 1) was to provide an overview of the research to families who might like to become involved.

Initial contact

Following the presentation, I hoped that families would make contact with me and express an interest in being involved in the research. During this initial contact, I proposed to mirror an approach used in dementia research carried out by McKeown et al. (2013, p.5) which was also informed by Dewing's process consent method. McKeown et al. (2013, p.5) used some initial questions to assess people with dementia's suitability to be involved in research. The three questions I proposed to ask were:

1. Has *(use the person's name) been someone who likes to talk about his/her life to others?
2. Have there been any past indications of distressing or unpleasant memories that *(use the person's name) may prefer not to discuss?
3. Is *(use the person's name) happy to share his/her views and opinions with others when the opportunity arises?

I hoped that the responses generated from these questions would help families to decide if their relative was likely to feel comfortable and want to participate in the research, and would also help them to assess whether their relative enjoys discussing elements of his/her memories and life story. I also hoped that these questions would provide me with some initial biographical background information which Dewing (2008, p.61) identifies as an important element of the process consent method.

Initial family meeting

I then planned to hold an initial meeting with each family, as this would be an opportunity to discuss the research project in a little more depth. I also hoped it would

give family members the opportunity to clarify their own and their relative's involvement in the research and to be able to ask any questions they had about the research. I suspected that some families might prefer to meet with me first and then have a second meeting that included their family member with dementia. I also felt that some families would prefer that their family member with dementia was involved from the start and just one meeting would take place. I was happy to respect each family's preferences. I also wished to discuss with the families where they would like the research interviews to take place. I was aware that people with dementia often feel most confident and comfortable in surroundings that are most familiar to them such as their own homes (Cotrell & Schulz, 1993, p.209; McKillop & Wilkinson, 2004, p.120). However, if a family felt it would be more appropriate for the research interviews to be held at an alternative location, then I would respect their wishes and agree a suitable venue with them.

I also hoped that the initial meeting would give me an opportunity to discuss the consent process with the families in terms of explaining the process and the written information they would receive, such as research information sheets and consent forms. I also wished to highlight to families that the study had been approved by the University of Sheffield's ethics committee. Drawing on Dewing's (2008, p.62) work, I was also aware at this stage of the process consent method that it was important to establish with families if they felt their relative with dementia had the capacity to decide whether he/she wished to be involved in the research. I hoped that these explanations would help to inform the families' decisions to whether they wish to be involved in the research or not.

Initial consent

I planned to meet with all family members to gain initial consent. I believed that while some families would be willing to give consent at the initial meeting, I recognised that some families might like to meet with me on a second occasion following the initial meeting, so they could have time to consider their involvement in the study.

Adapted informed consent

I prepared an information sheet for family members (*Appendix 4 – Research project information sheet for family member*) which outlined information about the research and the proposed involvement of their family member with dementia. A second information sheet was also prepared for the person with dementia (*Appendix 2 – Research project information sheet for research participant with dementia*). I adapted the written information in this information sheet so it was moderately simplified and focused on the key aspects of their involvement in the research. My aim was to provide relevant information which was accessible, as I did not wish the person with dementia to feel overwhelmed by too great a volume of written information. However, I also did not wish to make anyone feel patronised by providing too simplistic information. I also proposed to verbally explain all of the information included in the research project information sheets and to ensure that I answered any questions that arose from this. If the person with dementia and their family were in agreement to being involved in the research, I would then gain written consent from the person with dementia and their family member by asking them to both sign the written consent form (*Appendix 3 – Consent form for research participant with dementia*) and I would also sign this.

I then prepared a second research information sheet and consent form (*Appendix 5 – Research project information sheet for research participants & Appendix 6 – Consent Form*) for family members who would like to be involved in my research. Again, I planned to explain the information included, answer any questions they may have and gain written consent through the signing of the consent form. I then proposed to agree suitable interview times with the families.

On-going consent monitoring, feedback and support

I recognise that research participants with dementia may forget about their involvement in research because of the short term memory difficulties they can experience (Bartlett & Martin, 2002, p.51). Therefore, I planned that at the start of each interview, I would remind research participants who I was, why we were meeting and explain about the research project using the initial information sheet that was reviewed when initial consent was given. I also planned to check that they were still

willing to be involved in the research. I am aware that people with dementia can have 'good' and 'bad' days, so may decide to 'opt in and out' of research depending on how they are feeling. McKeown et al. (2010b, p.1940) cite Hubbard et al. (2002) who describe that some of their research participants opted in and out of research on the same day and in the same encounter. Therefore, I recognised the need for flexibility in terms of timings of interviews and that I would need to work closely with the person with dementia and their families to ensure that they were still giving their on-going consent to be involved in the study. I also recognised that on-going consent may not be achieved and new research participants may need to be found, if people decided that they no longer wished to be involved in the research.

3.5 The research participants

Ultimately, two families became involved in my research. Henry and his daughter Pam being one family, and Belinda, and her daughter Sandra, the second family. Neither of the families attended the meeting where I presented an overview of the research that was held at Age UK. Both Henry and Pam, and Belinda and Sandra heard about my research from colleagues that I worked with at Age UK and contacted me. Pam contacted me by phone and Sandra spoke to me when she was visiting Age UK's north London dementia day centre. I followed up these initial contact conversations by visiting both families at their respective homes for initial meetings. Both Pam and Sandra wanted their respective parents, Henry and Belinda, to be involved in these initial meetings. The initial meetings gave an opportunity for the research to be discussed and I was able to answer questions the families had about being involved in the research. This included explaining the informed consent process to each family and giving them opportunity to look at and read the research participant information sheets and consent forms. I also explained how I would continue to gain on-going consent as the interviews progressed overtime. We also discussed the structure, timing and suitable locations for the interviews to be held and what would be most suitable to all of the research participants.

Both families agreed to be involved in the research project at these initial meetings and we also agreed the dates, times and locations of the first interviews for each research participant. Both families wished for the interviews to be held at their homes

rather than at an alternate location. All four research participants also gave written consent at these meetings. At subsequent interviews, I found it useful to refer back to the research participant information sheet and signed consent forms with Henry and Belinda, as it provided a visual prompt to them as I checked that they still gave consent and still wished to be involved in the research. On each occasion that I met with the research participants, their ongoing consent was gained and I did not have to recruit any further research participants to this study.

3.6 Confidentiality and anonymity

In the research participant information sheets (see appendices 2, 4 & 5), I included information in relation to the confidentiality of research participants and I then discussed this with each family at the initial meeting. Each research participant chose a pseudonym and we also agreed pseudonyms where other family members, friends or carers were referred to during interviews to protect people's identities. Following the first interviews with each research participant and their subsequent transcription, it became apparent how many geographical locations such as towns and cities were being referred to and also the names of companies in relation to where the research participants with dementia had worked. At the second interviews, I discussed this with each of the research participants with the aim of agreeing pseudonyms that they wished me to use instead of the names of the actual towns and workplaces. However, both families decided that they would like the majority of the original place and companies' names to be included. As Henry described, "If you change them [the names], it wouldn't really be my story anymore!" (Interview note, 28/01/2016). However, the current towns in which the research participants live have not been included in this research report with the aim of protecting the research participants' identities.

3.7 Ethical considerations

There were some particular ethical considerations in relation to this research. Firstly, there was a consideration in relation to the inclusion of the word dementia in the research participants' information. Furthermore, there were also considerations in respect to the potential harm the research might have on research participants in relation to the amount of time required to be involved in the research, the potential to

be incorrectly interpreted in the research and that the recall of personal experiences and autobiographical memories may evoke upsetting memories for research participants.

Not including “Dementia”

The first consideration related to how I wished to present my research project to my research participants with dementia and particularly, whether I included the word dementia in the research participant information sheet (*Appendix 2 – Research project information sheet for research participant with dementia*). The information sheet gave an overview of the research and the research participant’s role within it and I did not include the word ‘dementia’. My reasoning for not including it was from my own observations of how families interact during my work at Age UK. I was aware that many families do not express to their relation that they have dementia, but often use terminology such as ‘memory difficulties’ or ‘problems with your memory’. Family members at Age UK had explained that they do not wish to keep reminding their family member that they have dementia, as they feel the word dementia is a ‘label’ which has negative associations and they want to avoid upsetting their relative.

I am aware that the use of the word dementia is a dilemma that has been given consideration previously in dementia research. Reid, Ryan and Enderby (2001, p.383) concluded that it is important to meet research participants on their own terms, while McKeown et al. (2010, p.1937) report that Helstrom et al. (2007) decided not to use the word dementia in their research unless it was introduced by the person with dementia or his/her family members. Pratt (2002, p.174) warns that “There is always the possibility that people are not informed about their diagnosis or, if they have been informed, may have forgotten”. Similarly Bartlett and Martin (2002, p.52) consider the potential deception of not using the term dementia, but question whether it is a researcher’s role to cause harm and distress to a research participant by discussing a diagnoses that they may be unaware of.

I was aware that both families I ultimately worked with did not use the word dementia from the initial contact I had with Sandra (Initial contact notes, 17/12/2015) and Pam (Initial contact notes, 21/12/2015). I observed that Sandra and Pam used terminology

and phrases such as “a bit forgetful” and “perhaps not always remembering” (Initial meeting notes, 22/12/2015 & 5/1/2016). As Pam, Henry’s daughter stated, “If anyone said to Henry that he had dementia, he would tell them he did not and that he was fine!” (Interview notes, 14/01/2016). Therefore, I did not include the word dementia in the research participant information for the research participants with dementia, as I wished to respect the wishes of the families that I was going to be working with and I did not at any time during the interviews use the word or mention dementia with the research participants with dementia.

Potential harm to research participants: Time

I estimated how much time I believed each research participant would need to be involved in the research and included this detail in the participant information that I prepared for the research participants (see appendices 2 & 5). I discussed time commitments with the research participants in the initial meeting I had with each family. I estimated that I would need to meet with the research participant with dementia on two to three occasions and the meetings would last for approximately 30 – 45 minutes. However, I recognised the need for flexibility, as I am aware that people with dementia have good and bad days and can experience changes over time (Pratt, 2002, p.176). I also recognised that the time of day can be important to people with dementia and they can feel more able to talk at particular times of the day (McKillop & Wilkinson, 2004, p.120).

Therefore, I agreed interview times with my research participants that best suited them. I recognised that the interviews might need to be broken into small time periods with breaks in between as a way of avoiding my research participants with dementia becoming too tired or overwhelmed by being involved in the research (McKillop & Wilkinson, 2004, p.119). Therefore, I also recognised that additional interviews might be necessary and the data gathered over a longer period of time. I was also aware that I was a ‘new’ person or stranger to my research participants with dementia, so it might take a while for them to feel confident to talk about their lives (Pratt, 2002, p.176). Therefore, I also discussed at the initial meetings whether Henry and Belinda would prefer to have their respective daughter, Pam and Sandra, present when they were being interviewed. Neither Henry nor Belinda expressed that this was particularly

important to them. Sandra was at home when Belinda was interviewed but was not particularly present in the room where Belinda's interviews took place. Pam was present at Henry's home when he was interviewed and became involved in parts of Henry's interviews. In terms of my own interest in Hydén (2011) and Baldwin's (2006) work into the co-construction of autobiographical stories in families, I found that the parts of Henry's interviews where Pam was present gave me opportunities to observe the extent to which storytelling can become a collaborative process.

I met with both research participants with dementia (Belinda and Henry) on two occasions to interview them. As the interviews proceeded, I checked with Belinda and Henry when they needed to take a break during the interviews, so they did not become too tired or feel overwhelmed by being involved in the interviews. I also reminded Belinda and Henry that they could terminate the interviews at any time.

I had estimated I would meet with Pam and Sandra (Henry and Belinda's respective daughters) on one occasion each to collect interview data for approximately thirty minutes. Ultimately, I met with both daughters twice, as following transcription of their first interviews, I found there were additional themes that I wished to explore further.

Potential harm to research participants: Being interpreted correctly

I recognise that collaboration and communication between researcher and research participants sits at the very heart of the life history methodology and is a way of ensuring that research participants are correctly interpreted in final research reports. As Atkinson (1998, p.9) identifies, researcher and research participant are "collaborators, composing, constructing a story the teller can be pleased with". However, I am also very conscious of Denzin's (1997, pp.4-5) view of the researcher's position in relation to the presentation of the life history data. Denzin (1997, pp. 4-5) states:

The text presumes that there is a world out there (the real) that can be captured by a 'knowing' author through the careful transcription (and analysis) of field materials (interview, notes, etc.). The author becomes the mirror to the world under analysis. This reflected world then represents the subject's experiences through a complex textual apparatus. The subject is a textual

construction because the real flesh and blood person is always translated into either an analytic subject as a social type or a textual subject who speaks through the author's pages.

Similarly, Goodson and Sikes (2001, p.49) also acknowledge that it is impossible to offer a definitive version of reality as, "social positioning and life experience militate against the possibility of there being a single, literal writing or reading of any text".

As a way of ensuring there were opportunities for collaboration between the research participants and myself, so I could gauge their reactions to the data collected and for them to be able to make revisions, I asked each research participant at their second interview to review a transcription of their first interview. I hoped this would help to ensure that their personal accounts had been captured accurately. Again, after each research participants' second interview, the same process of review was followed again, where each research participant checked the transcription of their interview, and where necessary, amendments were made.

There was then further collaboration between Sandra, Pam and I after I analysed the data (please see section 3.11) and I had formulated a draft of what ultimately became *Chapter 4: Belinda and Henry's Stories*. I sent a copy of *Belinda's story* (see section 4.2) to Sandra and a copy of *Henry's story* (see section 4.3) to Pam and asked if they could review these for accuracy and to make any amendments they felt were necessary. Both were positive about the accounts of their parent's life histories and felt they were accurate. I would have liked to have involved Belinda and Henry in this process of co-construction. However, I was aware that with the ethical consideration in this study of not referring to dementia (see section 3.7), I could not share these texts with Belinda and Henry, as they make references to their lives as they live with dementia.

I then planned to work collaboratively with Sandra and Pam again once I had a complete draft of the analysis which ultimately became *Chapter 5: Analysis & Findings*. However, on contacting them to try to arrange these meetings, both expressed that they did not have time to be involved further in the study owing to their family and work commitments. I recognise from Goodson and Sikes' (2001, p.36) work that issues relating to gaining research participants' validation of the analysis of life histories is not

uncommon owing to time pressures in people's lives. If I was to undertake further research using a life history approach, I would try to ensure that the time required for co-constructing the final analysis was better planned for in the original research design.

Potential harm to research participants: Evoking upsetting memories

I was aware that using a life history approach with people with dementia has the potential to evoke upsetting memories and strong emotions as autobiographical memories are recalled (Clarke et al., 2003, p.699; Killick & Allan, 2001, p.305; Swann, 2013, p.616). From my previous experiences of working at Age UK, I have witnessed that people with dementia do become upset for a variety of reasons and offering them support and the opportunity to talk about what is upsetting them at that moment in time can often be a useful way for them to release their emotions in a safe environment where they feel supported. This is a view shared by Killick and Allan (2001) whose work focuses on communication with people who experience dementia. Killick and Allan (2001, p.175) suggest that emotional releases can be a "relief" to people as it gives an opportunity for feelings to be expressed and that when people are recalling difficult memories "telling the individual not to be upset or cry, and making attempts to steer the person onto less painful subjects would seem demeaning". Similarly, Clarke et al. (2003, p.699) cite Bornat (1998) and Parr (1998) who argue that if, "the older person is prepared to talk about a difficult or painful issue, at the very least, they should be listened to". I am also aware of Pratt's (2002, p.172) advice that "the 'right' strategy is one that responds to the needs of the person during the interview". Pratt (2002, p.172) recalls when interviewing one of her research participants with dementia that she felt, "...it was important to listen to Peter for as long as he wanted to talk and to provide the opportunity for him to express his feelings". Pratt describes that she offered to stop the interview with her research participant when he was upset, but it was only terminated when "he was ready" (p.172). Pratt also describes that she ensured that her research participant received further support from those she describes as "gatekeepers" who had arranged for her research participant to be involved in the research, which she hoped would further help to contribute to her research participant's "safety as an interviewee" (p.172). Pratt suggests that "gatekeepers" to people with dementia can be professionals such

as “doctors, community psychiatric nurses and support agencies” (p.167) and that their gatekeeping “reflects the need for a vulnerable group of people to be cared for and protected” and are important to researchers as they offer a way to gain access to people with dementia (p.167).

Family carers can also be viewed as gatekeepers. Therefore, during the initial conversations I had with Sandra (Initial contact notes, 17/12/2015) and Pam (Initial contact notes, 21/12/2015), I asked if they could identify past events which they believed might be distressing or cause the recall of unpleasant memories for their respective parents. Pam requested that I did not ask Henry any questions which related to the time period of the Second World War, while Sandra explained that Belinda would not talk about her ex-husband (Sandra’s father) and therefore, I should not ask Belinda any questions about him. Therefore, I ensured that I did not specially asked about this topic and person during interviews with Henry and Belinda respectively, while recognising that Sandra and Pam in their role as gatekeepers had partly influenced the structure of the interviews for this study through prohibiting these topics. I also contacted Sandra and Pam soon after each of the interviews with their respective parents (during the evening of the same day or the following day) to check that Henry and Belinda had not become upset or distressed in anyway which appeared to be related to participating in the research interviews. I hoped that working with the families in this way would help to ensure the safety of the research participants with dementia.

Through using the process of on-going consent that I had developed, I also ensured that I checked at each interview that each research participant wished to continue with being part of the research. During each interview, I checked how the person was feeling as the interview progressed and checked if they were willing to continue. I recognise that recalling personal events and memories, and the retelling of these can be very tiring for people with dementia. On a couple of occasions, I recognised that Belinda stopped and paused and considered how she was going to tell certain aspects of her life story. This was particularly apparent as Belinda recounted her memories of attending a secondary school in Birmingham.

When I went to school in Jamaica, it was a mixed school and this school I went to in Birmingham was a girls' school. And I thought You know You don't think It was intimidating When they say you going to a school that is all girls when you are used to going to one that is mixed But it was lovely.
(Belinda, interview 6/1/2016)

This supports Goodson and Sikes' (2001, p.25) view that research participants can be "cautious about what they reveal" and that life story accounts are "inevitably partial and selective" (Hodkinson, 2005, p.3). Additionally, as Riessman (2008, p.31) argues, "The audience... exerts a crucial influence on what can and cannot be said, how things should be expressed, what can be taken for granted, what needs explaining, and so on".

3.8 Interview design

Goodson and Sikes (2001, p.27) state that a "one to one interview-conservation between informant and researcher is perhaps the most commonly used strategy for collecting life history data" (p.27). Social anthropologist, Pink (2012, p.40) supports the use of interviews as a way of collecting data with research participants, as she acknowledges that interviews provide researchers with "a valuable route to knowledge about how people describe their activities and values". Pink (2012, p.41) also argues that interviews provide researchers with a way of "understanding the representational layers of everyday life", as they give research participants an opportunity to "represent verbally and classify their sensory experiences of specific environments, localities, performances and practices" (p.41). I found it useful to consider Goodson and Sikes' (2001, p.28) advice when planning the design of the interviews for this study. They assert that life history interviews should be "relatively unstructured, informal conversation-type encounters" (Goodson & Sikes, 2001, p.28). I recognised that the overarching question that I wished to explore with the research participants with dementia for this study was: *How have you used reading, writing, speaking and listening throughout your everyday life?* However, this is a very wide question to consider in terms of timespan and content, and therefore, could be overwhelming for research participants to begin to know how to answer. Riessman (2008, p.25) cites Elliott (2005, p.31) who states that, "Respondents are likely to find it easier to talk

about specific times and places rather than being asked about a very wide time frame”.

Therefore, as a way of offering some structure to the interviews, I considered literacy practices in relation to the contexts or domains (Street, 2011, p.581; Barton & Hamilton, 1998, p.7; Ivanič et al., 2009, p.47) which are present in many people’s lives and suggested to the research participants that the initial interview be structured around the following contexts of home, school, work and family. I formulated these contexts into prompts in the research participant information sheet (*see appendix 2 – Research project information sheet for research participant with dementia*):

- Memories of how reading, writing, speaking and listening were used by you and your family and friends when you were a child.
- Memories of literacy during your school days.
- Memories of how you have used reading, writing, speaking and listening during your adult life up until the present time. This might include reading and writing skills that were required for job roles, reading for pleasure, writing letters or helping your younger family members with their school work.

I then used these prompts verbally during the initial interviews to offer some structure to the interviews with the hope that this would support the research participants with dementia to not feel too overwhelmed by being interviewed and having to recall personal memories and experiences.

The second interview I conducted with each of the research participants with dementia built on the first interview and also followed (in time span) the interview I had with each of the research participants with dementia’s daughters. I used the second interview to ask further questions in response to what I had learnt from the first interview and to also follow up on information that Belinda and Henry’s respective daughters had provided when interviewed. For example, when I interviewed Belinda on the first occasion (6/1/2016), she did not mention that she had been a childminder or studied for a NVQ qualification in Childcare. I learnt about this from Sandra at her first interview (22/1/2016). Therefore, when I interviewed Belinda on the second

occasion (2/3/2016), this was a topic that when prompted, Belinda then talked about and it highlighted literacy practices she had used for this job role and as an adult student. Similarly, at Pam's first interview (14/1/2016), she spoke extensively about the positive impact of carers visiting Henry. However, Henry made no mention of the carers at his first interview, so again this was something I ask Henry about when I interviewed him for a second time (28/1/2016). Therefore, these experiences reflected Goodson and Sikes' (2001, p.34) view that because life history interview- conversations are "not tightly structured... researchers will take opportunities to check out ideas, themes and thoughts as they proceed".

When I interviewed the family members, Sandra and Pam, I included a suggested structure for their initial interviews in the research participant information sheets (*Appendix 5 – Research project information sheet for research participants*):

- I am interested in your thoughts and observations of how *(insert relation's name or relationship name e.g. father) uses reading, writing, speaking and listening now and also from your memories prior to *him/her being diagnosed with dementia.
- I am also interested in your thoughts on any changes that you have observed.

I wanted to offer some structure to their interviews, but at the same time wanted to give Sandra and Pam opportunities to share their memories of how their respective parent had used reading, writing, speaking and listening throughout their lives and to gain their perspectives on any changes they could identify since their parents had experienced the onset of dementia.

3.9 Transcribing the interviews

All of the interviews were recorded using a digital recorder and I transcribed each of these as I was aware that this would enable me to become familiar with the data (Goodson & Sikes, 2001, p.33). I also kept written notes or field notes of all phone conversations, meetings and interviews I had with the research participants in relation to my own observations of things that seemed pertinent or I felt needed to be followed up at a further interview and had not been captured by the digital recorder. This included the research participants' body language and also any movement that

took place during the interviews. I then incorporated this into the transcription of the interviews. I recognised from research completed by Hydén and colleagues (Hydén 2013; Hydén & Örvulv 2009; Hydén & Antelius 2010), and also Davies (2014), Jones (2014), Leander & Boldt (2013), Mackey (2016) and Pahl & Rowsell (2010) that oral communication and storytelling can be performative and embodied. Therefore, I wished to try to capture the non-verbal and multimodal strategies used by the research participants as they recalled their memories and autobiographical stories. However, I also recognise Finnegan's (2015, p.3) view that the "richness and subtlety" of the telling of personal narratives are often lost when transcribed into written texts and she argues that this is because:

"the reality lay in the performance" and written transcriptions miss "the subtle characterization, the drama, the way the tellers used volume, pitch, tempo, repetition, emphasis, dynamics, timbre, onomatopoeia, and a whole plethora of non-verbal indications to convey humour, pathos, irony, atmosphere".

Therefore, I am not sure that Henry's twinkling eyes and dry sense of humour is that present in the transcriptions I present, nor the great love and enthusiasm he showed when he reminisced about his Lagonda car; or the regret that he is not able to drive it anymore. I noted in the transcriptions when Belinda laughed and when she made me laugh as she recalled her memories. However, I am not sure that Belinda's warmth, laughter and humour is as strongly present in the written transcriptions as it is in real life. Belinda's accent and dialect fascinated me and again this is somehow lost in the written transcriptions I present. It feels pertinent to note that Belinda's accent and dialect seems to be a reflection of the geographical locations in which she has lived throughout her life. Belinda speaks with a Birmingham accent, while her dialect seems to combine and embrace her early life in Jamaica, her teenage years living in Birmingham and the last forty plus years of living in north London. However, these experiences give particular resonance to Riessman's view (2008, p.29) that transcribing a taped conversation constructs a written account which "straddles a border between speech and writing" and it can only be "a representation ... on a two dimensional page of what had been said ... Much is lost, and key features slip away".

3.10 Narrative analysis - using a thematic approach

Drawing on Riessman's (2008, p.74) work, I took a thematic analysis approach to interrogating the research participants' life stories, as I recognise that this approach is suited to biographical and life story data and has an "established tradition with a long history in qualitative inquiry". Riessman argues that a fundamental part of narrative analysis is that it "case centred" and the story is kept intact to "preserve the sequence and the wealth of detail contained in long sequences" (p.74). When taking a thematic analysis approach to narrative and life story data, the focus is on the content of the stories told by research participants during interviews. As Riessman describes, the "primary attention is on "what" is said", "rather than "how", "to whom" or "for what purposes" (pp.53-54). As the interview data is then analysed, "thematic elements" that are "common" across the research participants being studied need to be identified, which Riessman argues are based on a combination of known "prior theory" and "novel theoretical insights" which become apparent as the data is interrogated (p.74).

3.11 Analysing the data

I transcribed each research participant's interview soon after the interview had taken place, so the interview was 'recent' in my mind. I then re-read the written observation/field notes that I had taken and added information I had noted to the interview transcriptions.

I began thematic analysis of the transcripts of the interviews once all interviews were completed. I had established an initial list of themes that I thought might be present in the data. I then began to read and re-read the transcripts on numerous occasions, firstly applying this initial list of themes and then identifying new themes which the interview data presented. Therefore, this process seemed to reflect Riessman's (2008, p.74) view that in thematic analysis, the researcher's interrogation of data is based on knowledge of "prior theory" and also "novel theoretical insights" which become apparent as the data is interrogated. As I completed this analysis, I could also compare my experiences with Barton and Hamilton's (1998, p.69) descriptions of "cycling back and forth between theory and data in order to identify patterns and regularities", and also that "sorting" (p.69) the data was necessary, so comparisons were made between the data collected from each research participant to look for similarities and

differences. When I identified a specific theme in one person's interview transcription, I then checked to see if I could identify the same theme in the other research participants' transcriptions. Barton and Hamilton (1998, p.69) describe this process as "linking", where connections are made "between different parts of the data". I present the findings from completing this analysis in the next two chapters.

In chapter 4, I present Belinda and Henry's stories, which are overviews of the research participants with dementia lives. In chapter 5, I present the findings of having applied a thematic analysis to the data collected.

Chapter 4: Belinda & Henry's Stories

4.1 Introduction – Presenting the data

This chapter is the first of two in which I present the outcomes and findings from completing this study. I chose to take a thematic approach (Riessman, 2008, p.74) to analysing the research data generated from taking a life history approach to capture the research participants' personal accounts and autobiographical memories. I explored these personal narratives for themes while also considering their overall life stories as a whole (Sikes & Hall, 2016, p.5). Riessman (2008, p.74) argues that during thematic analysis, research participants' life stories should be kept as complete as possible. However, I am also very conscious that the purpose of taking a life history approach is to “move from the collection of individual life stories towards a method that investigates the social and historical context in which these stories are enmeshed” (Goodson, 2013, p.31). Therefore, I recognised the need to try to balance capturing my research participants' voices and retain the richness of their descriptions contained within their autobiographical accounts, while also identifying and analysing the themes which became apparent through interrogating the data generated through completing this research.

Additionally, I had been conscious from the outset of this research that I also wanted this study to be an opportunity to be able to give a voice to older people with early stage dementia and validate their personal experiences, as I recognise that so often they can feel as though their voices are not heard or excluded (Wilkinson, 2002, p.9). Therefore, I found that the consideration Luttrell (2000, p.499) gives to the representation of ethnographic research data closely describes the difficulties I experienced as I considered how to best present the findings from this study. Luttrell (2000, p.499) describes that researchers:

who use narrative are caught between the proverbial rock and a hard place. On the one hand, we strive to listen and represent those that we study, and in their terms. On the other hand, we recognise that our role in shaping the ethnographic encounter is huge; consciously or not, we listen and make sense of what we hear according to particular theoretical, ontological, personal and cultural frameworks in the context of unequal power relations. The worry

always exists that the voices and perspectives will be lost or subsumed to our own views and interests.

Therefore, I hope the findings I present provide a balance between preserving the 'voices and perspectives' of my research participants and a thematic analysis of the data collected.

In this chapter, *Belinda's Story* (section 4.2) and *Henry's Story* (section 4.3), I present outlines of Belinda and Henry's respective lives. My aim for these outlines of the research participants' lives is to present an overview of their personal characteristics, values and beliefs, while also incorporating key life memories from their early childhoods and schooldays, working lives, and their home and family lives. Included in these outlines are personal accounts from Sandra and Pam (Belinda and Henry's daughters), who provided their own descriptions of their respective parents, and also evaluate the ways in which they believe dementia is impacting on their parents' lives.

In the following chapter (Chapter 5), I present the findings of this study as a result of having applied a thematic analysis of the data collected through interrogating the personal accounts of the four research participants involved in this study: Belinda, Henry, Sandra and Pam.

4.2 Belinda's Story

Belinda currently lives in north London with her youngest daughter, Sandra, and her grandson, Levi, who is twelve years old. Belinda's older daughter and granddaughter live nearby, while Belinda's son lives in the west of England. Sandra described that Belinda has a great love for her family and that they are very important to her. Sandra also described that Belinda had to work very hard to financially support her children and this sometimes had resulted in Belinda working for two different employers at the same time.

Before I was born, my mum worked two jobs in Birmingham. In the morning she'd drop my brother and sister off at school and go to work. Come back, pick them up and drop them at my grandparents. Go back out to work, come back in the evening, pick them up and take them home. By the time the weekend comes, it's cleaning and cooking and shopping and the week starts again ... Mum never really had much of a social life. She was just committed to her kids

and work. She never really went out ... Other than at one stage, she started to do a bit of water aerobics And then she learnt to swim. But other than that; that was it really.

(Sandra, interview 22/1/2016)

Sandra also described that Belinda has always had a good sense of humour, is a good listener and that she is a “talker”.

My mum is the type of person who would be at the bus stop and she'd strike up a conversation with someone. Or she'd be on the bus and she'd just get talking!
[Laughs].

(Sandra, interview 22/1/2016)

How dementia has impacted on Belinda

Belinda was diagnosed with the early stages of Alzheimer's disease in October 2014. Sandra is Belinda's main carer and takes responsibility for all of Belinda's care and support needs. This has involved liaising with local authority social services teams and care agencies to try to ensure that Belinda has an appropriate level of support to meet her needs. Sandra also manages all of Belinda's financial affairs and deals with all of Belinda's day to day written correspondence such as letters, emails and the completion of forms.

Sandra identified some of the changes she has noticed in Belinda since the onset of her dementia and also contrasts aspects of Belinda's life before and after her diagnosis of Alzheimer's disease.

It's Alzheimer's ... It's early stages. It's her short term memory. She can ask you something and then ten minutes later, she can ask you the same thing again. Medication ... she does not remember to take medication. She has no motivation to cook anymore. That's just sort of ... and my mum used to cook all the time. Every day, without fail. She'd cook all the time. She'd bake. She doesn't have the oomph to do it anymore. If she's hungry, she'll pick. She'll search the cupboards. She'll pick. Anything she can literally find, she'll just pick up ... like biscuits. All of a sudden she just wants biscuits all the time. Constantly ... She's just got into a bit of a habit where every time she comes into the kitchen, she going to get biscuits or get a slice of bread. That's her sort of thing now. But anything that requires preparing, even a sandwich, she won't. She'd rather ... I've seen her pick up a slice of bread, pick up a piece of ham and stuff it ... Kind of stuff it and fold it once and that's it. She won't prepare it properly. And she used to cook every day without fail at home. One hundred percent! She cooked ... Even when we'd all left home and she was living on her own. She would cook and she'd freeze meals as well, because she never could quite cook for one! [Laughing] So she'd freeze meals and then reheat them later. But now ... On a Sunday morning breakfast, she used to cook sausages, bacon, beans,

eggs; she'd make dumplings from scratch. Now – nothing!

(Sandra, interview 22/1/2016)

Belinda's childhood

Belinda was born in Jamaica in 1947. In the early years of her life, she lived with her parents, brother and sister. Belinda described that she lived in a small town in Jamaica and that as a child she spent quite a lot of time playing outside with her friends and siblings.

I lived inland but not far from the coast. It was quite easy to get to the sea but a lot of the time... we had rivers that we could go and swim and things like that. But at the end of the day, we preferred to go the beach. [Laughs]

(Belinda, interview 6/1/2016)

When Belinda was six years old, her parents travelled to England from Jamaica. They were part of a movement of Commonwealth citizens who were encouraged to emigrate to the UK from the Caribbean in the post-war years through the introduction of the British Nationality Act (1948), which gave all Commonwealth citizens free entry into Britain (National Archives, 2016). Belinda's parents made their new home in the city of Birmingham in the West Midlands. Belinda, along with her brother and sister, remained in Jamaica; each living with a different family member. Belinda lived with an aunt and described how she moved with her aunt to Birmingham some years later.

I was in Jamaica until I was twelve and then I came here [Birmingham]. My auntie didn't have any children, but she has a partner and they broke up, so she decided to come and she told my mum she wouldn't leave me behind!

[Laughing]

(Belinda, interview 6/1/2016)

Belinda attended schools in Jamaica and in Birmingham. She described and contrasts the schools, and also described her feelings about the schools.

I can remember going to school. It was all right. It was a lot different to what it was when I came here [Birmingham]. In Jamaica you had like one big school ... Right ... it wasn't different classrooms. It was different sections for different ages but you were all in one big room. There were a lot of children, yes a lot, but it worked for them because the kids knew they had to behave themselves, so it worked. Each group had their own teacher and like if you changed, it's like here [England] ... Different lessons, different teacher and that, but you were in the same place ... just the teacher would change over. But it ... But it was all right. We didn't know any different so we made it work ... I sometimes wonder, oh my god, how did we get on ... But we did.

(Belinda, interview 6/1/2016)

When I went to school in Jamaica, it was a mixed school and this school I went to in Birmingham was a girls' school. And I thought You know You don't think It was intimidating When they say you going to a school that is all girls when you are used to going to one that is mixed But it was lovely. And the teachers were nice. The school that I went to, there were only three of us that were black girls at the girls' school. Afterwards, two, three years later, a lot more came, but when we went there, there was only three of us. It felt ... At first you don't know what to think, you know, but the pupils were friendly so we got on. So after a few days it didn't really matter. We were just students [laughs].

(Belinda, interview 6/1/2016)

Starting work

Belinda described that she developed a love of sewing as a young child.

When I was growing up, I had an auntie who sewed and I was forever sitting under her machine [lots of laughing] watching her! And then when I could, I bought myself a sewing machine ... Brand new! I was about eighteen.

(Belinda, interview 6/1/2016)

Belinda's sewing skills went on to determine that much of her early working life was as a seamstress working for clothing manufacturers. Belinda speaks with great pride that she has worked for most of her life and she describes with lots of laughter and pride that she left school a week early to start work as a seamstress for a company in Birmingham.

When I left school I was 15 and ... [laughs]. It was so funny because then they had the Christmas leavers and I started working one week before they break up for Christmas [laughs]. So I finished school early [laughs] to work! [Laughing]

(Belinda, interview 6/1/2016)

The first job I had, they made coats and that firm did a lot of exporting to Russia so we made coats, dresses, suits and it ... And you wouldn't believe the different length in the clothes for the Russian women to us ... Cos the Russian women were very tall. The clothes had to be much longer [Belinda indicates a length with her hands and then points to her ankle]. And sometimes you would take it up [the hem of the garment] and I would say, "My god, that would be touching the floor if we was wearing it", but that's how they were. We did a lot of those.

(Belinda, interview 6/1/2016)

Belinda then described further companies she worked for in Birmingham.

Then I worked for a company that made a lot of erm ... A lot of suits and then I went for another one [job] and I went in one day and somebody must have got up his [the boss'] nose and he came and he started shouting at me for no

reason at all and I took my bag and I said "Bye" [laughs] and I walked down the road and I got another job!

(Belinda, interview 6/1/2016)

When I left that one I went and worked for another one [company] that did clothes... all sorts of clothes - trousers, dressers, skirts, blouses ... that sort of thing ... but I've always worked in dressmaking. I like making adults' clothes. Children's clothes are nice and all that but I like to look at them, I don't like to sew them! [Laughs]. A lot of the time you have to do so much intricate things because they are so small. You have to ... err ... no! [Laughs] ... No, no, no! [Laughing]

(Belinda, interview 6/1/2016)

Moving to London

Belinda married and had her first two children while she lived in Birmingham, and she continued to work as her children started to grow up and attend school. However, Belinda described how a visit to her brother and his girlfriend instigated a move to London.

*When my brother came to London, he met this girl and they got on well and things like that and I used to come and visit them. But what she used to do was because she had children, she worked at home. And I thought, oh my god, she's looking after her children and she's still working. And I thought my goodness ... If I could ... We don't have that sort of facilities in Birmingham. So she said to me, she kept saying, "Come ... Come to London. You could sew and I'll see what ..." So I come to London ... And in days, I got a job working at home. I used to work for one of those companies in Finsbury Park. And he [the boss] used to bring the work to me. When I finished, I'd call him and he'd know when to come and collect. And I did it that way and I was still earning money and I was looking after my children. And I didn't come out of the house until my youngest daughter went to senior school. And then I thought **freedom!** [Shouting] [Laughs]*

(Belinda, interview 6/1/2016)

However, the "freedom" Belinda describes was not quite realised as, at this time, Belinda made a career change and trained to be childminder. This meant that Belinda continued to work at home for a further eight years. Belinda described,

I'd look after the younger children all day ... and then the older ones ... I'd take and collect them from school. I enjoyed that.

(Belinda, interview 2/3/2016)

Being an adult student

Part of Belinda's training to be a childminder included her studying to gain a National Vocational Qualification in Childcare, which meant that Belinda returned to studying for the first time since leaving school.

They [the tutors] had to make sure you were capable of looking after the children. So they had a few different classes you had to go to ... Near to where we lived. They had to make sure you knew what you could do and what you couldn't do when you were looking after the children. They had to make sure you knew what you were doing. They showed you what you are meant to do, rather than what you might want to do. [Laughs]. It [the course] was very practical. Occasionally you had to write. To describe what you would do. But it was mainly practical.

(Belinda, interview 2/3/2016)

Moving to Bedfordshire

Belinda decided to relocate from north London to Bedfordshire when all of her children had left home. This move also brought a further career change for Belinda. She secured a job as an escort on the buses used by older people attending a luncheon club and also for children with special needs to travel to and from school. Sandra described that it was during the time Belinda lived in Bedfordshire, the family began to notice changes in Belinda's behaviour and they became concerned about her welfare. Sandra described,

I wasn't driving at the time and Levi was younger. Mum was working Monday to Friday. Every Friday without fail, she would get the coach down to London to stay with me and then get the coach back on a Sunday and go back home. I just thought everything was ok. Then ... We went to my mum's [home] and it was a mess. It was a mess and that's not my mum. It was a mess. It was dirty, it needed cleaning. So things started to trigger at that point. We did a massive clean-up.

(Sandra, interview 22/1/2016)

Sandra also described that up until this time, Belinda had always managed the medication that was prescribed to her by her general practitioner. However, health care professionals who regularly saw Belinda also raised concerns about her at this time. Sandra described,

Mum had taken them [the pills] out [of the packet] and put them down and they'd got left and forgotten about. So we realised that we needed to do something. We got in touch with the doctor and social services. Mum's diabetic nurses also got in contact with social services because they were concerned that

mum wasn't going to her diabetic check-ups where she had always gone before, but she wasn't remembering to go.

(Sandra, interview 22/1/2016)

Sandra described that the family were very concerned about their mum and although she had been diagnosed as having the early stages of Alzheimer's disease, they struggled to get appropriate care support so Belinda could continue to live independently in her own home. Sandra described,

It was like... this is getting too much now. We can't continue like this anymore. She can't live like this anymore. The carers in Bedfordshire were not supporting her in the way they should be for her to be able to stay in her own home, so we've got to nip this in the bud now. So mum moved in with us.

(Sandra, interview 22/1/2016)

Belinda has now been living with Sandra and Levi for two years.

In summary, Belinda is an outgoing, friendly person who enjoys talking to people. She loves her family and has worked very hard throughout her life to care for and support her family. Belinda's early life was spent in Jamaica, her teenage years in Birmingham in the UK, and she then moved to London as she was a young mum in the early 1970s. Belinda has always loved to cook and sew and it was her love of sewing that influenced her career choice of becoming a seamstress when she left school. Belinda was diagnosed with Alzheimer's disease in 2014 and is supported by her daughter Sandra. She also attends a local dementia day centre and a specialist dementia carer also visits Belinda at home each week.

4.3 Henry's Story

Henry lives independently, in his own home in north London, England. He was born in 1923 and grew up in north London with his parents and younger brother. Henry has lived in his current home for over eighty years, as he moved to the house with his parents when he was about 10 years old. Henry has a daughter, Pam, who lives about eight miles away from Henry, and she has two daughters. Pam describes that Henry has always been fairly quiet and not particularly sociable, but that he is quite witty.

Henry has a 7 year old Labrador dog called Lala, who originally belonged to Pam. Pam described that when she increased her working hours about six years ago, she realised

that Lala and Henry would be great company for each other, so Lala now spends the majority of the time living at Henry's home. Pam described,

Lala will follow Henry round the house. If Henry is in the kitchen, Lala is in the kitchen. But, she's not stupid, she knows if Henry is preparing lunch, she's likely to get a snack or two. But Henry talks to her all the time. However, he will say to me and laughs as he is saying it, "I talk to the dog, but she doesn't talk back!" Henry also walks Lala in the local park when he remembers ... So that gets him out of the house and they are good company for each other.

(Pam, interview, 14/1/2016)

Henry was diagnosed with a combination of Alzheimer's disease and vascular dementia in November 2014. Pam is Henry's main carer and visits him several times each week. She has taken on the responsibility of ensuring that Henry has suitable care so he is able to continue to live independently in his own home. Pam also manages the maintenance of Henry's home and garden, along with all of Henry's day to day written correspondence such as letter and emails that have to be sent, along with Henry's financial affairs.

Henry's schooldays

Some of Henry earliest memories are of attending a local elementary school which is close to where he lives. The elementary school was attended by both primary and secondary aged children. Henry talks with regret that he failed the 11-plus examination. The result of this was that Henry was not able to attend the local grammar school when he was eleven years old, where he would have had the opportunity to study for the Ordinary National Certificate. Instead, Henry had to stay at elementary school until he reached schooling leaving age. Henry described,

When I left school ... that was it. You left at fourteen and you started work at fourteen! You see in those days you sat the 11-plus [examination] and if you didn't pass, then you just carried on. If you passed that, you went to secondary [grammar] school and erm ... That was obviously better. But if you didn't pass, then you just sat where you were and carried on until you left [school] at fourteen.

(Henry, interview 14/1/2016)

Henry's working life

Henry described that he has always had a love of art and drawing, and this influenced his choice of career as he began his working life.

I'd always liked drawing so that's why I ended up being a draughtsman. My first job ... There used to be a little factory called Nelson's Art Signs and that made posters and that sort of thing. I was always interested in art and that was the nearest I could get to doing it within walking distance [of home]. I used to do printing. And that was where I started and it was only a five minutes round the corner and I was there two or three years.

(Henry, interview 14/1/2016)

Henry described further companies he worked for.

I worked for BERCO ... They did mechanical assembly ... and bits and pieces. Mainly small resisters and transformers.

(Henry, interview 14/1/2016)

I went to Sangamos, but whether that was next or not I can't remember. I was on the drawing board most of the time. I'd always liked drawing.

(Henry, interview 14/1/2016)

Henry also described how an increase in salary inspired him to move companies.

In those days, if you could get a pound a week more, you left, and went there. So I also went to Standard Telephones over at Southgate. I was there for a few years and then a pound a week more attracted me to Borehamwood ... Elliott Brothers at Borehamwood ... It became Marconi later on.

(Henry, interview 14/1/2016)

Pam confirms that Henry was a draughtsman at Marconi for many years of his working life. She described,

Henry kept that job all the way through. I think he was quite reasonably high up in his office. They did the design for projects like the TSR-2 [a reconnaissance aircraft] that got scrapped.

(Pam, interview 14/1/2016)

Attending evening classes

Henry also described that he attended evening classes at a local college during the early days of his working life, as he realised that the education he received at his elementary school was insufficient to support his career path to becoming a qualified draughtsman. Henry described,

They [employers] didn't really train you then. They took advantage of you! [Laughs]. You had to do it yourself. Firms didn't train you then! You went in as a junior and learnt as you went. I liked drawing anyway, whereas some people were doing it and hated it. I always did evening classes because I only went to

elementary school so I ... My maths wasn't up to much so I did evening classes for maths. I had to start doing evening classes myself because it isn't enough to leave at fourteen from elementary [school]. It's not enough to get on.

(Henry, interview 14/1/2016)

My brother did secondary grammar and I realised how much I was missing, so I thought I better go and do evening classes. I did evening classes to catch up a bit. I learnt most at evening classes. I got my Ordinary National Certificate and I got a City and Guilds [certificate] ... Drawing and some mechanical bits and pieces. After that ... That was enough for me. You could have gone and done a Higher National Certificate but I wouldn't have used it, I don't think. The Ordinary National was enough for me! [Laughs].

(Henry, interview 28/1/2016)

How dementia and hearing loss have impacted on Henry

Pam described that Henry's memory difficulties first became apparent about three years ago. She described that the dementia has particularly impacted on Henry's short-term memory and he forgets things that he needs to remember on a daily basis such as taking prescribed medication.

It started off because Henry wasn't taking his medication. He's got morning and evening medication. Even though I wrote it in his diary 'Take your pills' and I'd put them out, he didn't remember to take them. I would come over, say four times a week, and he might have missed two days' worth, so I needed to get someone in to ensure that Henry was taking his medication. He takes tablets for his dementia and blood pressure tablets.

(Pam, interview, 14/1/2016)

Pam described that at this time she arranged for carers to regularly visit Henry to help support him to take his medication correctly. She described how the carers' work has now extended to a far wider remit than she had first anticipated when organising the initial care visits.

We have sorted out a rota. Henry has somebody in the morning and somebody in the evening. So he has either the carers, or I always visit on Thursday and at the weekends. It has worked out that they are absolutely wonderful. It has worked out far better than I imagined because they do talk to him ... And Mark [one of the carers], takes Henry out. Mark is going to take Henry to the opera in a few weeks' time. He has a two hour visit with Henry one of the days each week and we are happy to pay extra if there is something like this going on. Mark does marvellous things and things I don't always have time to do at the moment. He's is good at taking Henry out and talking to him. Henry doesn't remember it, but at the time he enjoys it. They go into the local town for coffee, or the pub, and have a drink. They go for dog walks. At Christmas time, Mark

took Henry to a carol concert – so that type of thing.

(Pam, interview, 14/1/2016)

Rosa, the other carer, does housework, which is unbelievable. Because I was doing all the gardening, the housework, all the correspondence and I wasn't coping, so to have someone to do all the hovering and the dusting ... So it's really, really helpful to me and it's really nice for Henry. I see Mark's role as taking Henry out and talking to him, that really is his forte. He will do some housework, like washing up, but mainly it's about talking to Henry. Henry doesn't remember Rosa too much. I think, because she is newer. It's a shame because she is so kind. She's even bought presents for the dog! Whereas Mark has been visiting for quite a while now and they been out a lot. I'm sure in the end Henry will remember Rosa, but not at the moment.

(Pam, interview, 14/1/2016)

Pam's assessment that Henry does not particularly remember the carers' visits beyond the time they spend with him seems to be confirmed by Henry's quite limited description of the carers, which are in stark contrast to Pam's enthusiastic descriptions of the benefits of the carers' visits.

Rosa ... I'm not sure

Oh Mark ... yeah, we have a chat. We go down the town for a coffee. I can't remember these things now. He [Mark] looks in now and again.

(Henry, interview 28/1/2016)

Pam also described that Henry has also experienced hearing loss in recent years and he now has to wear a hearing aid in his right ear. Pam feels that the combination of Henry's dementia and hearing loss is having an impact on his memory of people and also to an extent how he is able to communicate with other people. Pam described,

Henry does repeat things over and over again and forgets who people are. Unfortunately, Henry has very, very bad hearing. He is profoundly deaf affecting both ears. He wears a hearing aid in his right ear. And that actually has affected him more than the dementia I would say. But what has deteriorated is that he doesn't want to communicate so much but that is because he cannot hear. But when he does say something, he is quite good at making jokes and is quick thinking. He's got good language and is eloquent when he does speak. When I get him on a conversation and also with Mark, he will talk and he will get photos out and he will talk about them and he just about remembers who people are. He did actually say a few weeks ago "Have I got a brother?" So that was a bit scary and that makes you think ... So he is forgetting who family members are and he does get muddled up between myself and his

grandchildren. Sometimes he calls my daughter my name. So his memory for names is going and his memory for people is going but his conversational skills haven't deteriorated that much. He can still crack a joke!

(Pam, interview, 14/1/2016)

Henry also described how his hearing loss impacts on his communication with other people.

I'm all right here [at home] but sometimes on the phone I can't hear at all and I have to say, "You'll have to excuse me, I can't hear." Whether it's their voices or not. I have to take this out [Pointing to his right ear and hearing aid] or I can't hear on the phone. I think hearing loss creeps up on you so suddenly. It's so gradual you don't notice it. A couple of years later you are speaking to someone and you can't hear what they are saying. So it makes things difficult for you.

(Henry, interview 28/1/2016)

In summary, Henry is a fairly quiet, witty man who has lived in the same home for the majority of his life. Henry has a close relationship with his daughter Pam and loves his dog Lala. Henry has a love of art and drawing and this influenced his career choice of becoming of a draughtsman, which was a career he pursued for most of his working life. Henry was diagnosed with a combination of dementias, Alzheimer's disease and vascular dementia in 2014, and Henry also experiences hearing loss difficulties. Henry is supported and cared for by his daughter, Pam, and a small team of carers who visit him at home each week.

Chapter 5: Analysis and Findings

Introduction

In this chapter, I present the findings from this study as a result of having applied a thematic analysis of the data collected through using a series of semi-structured interviews with the research participants. My overall aim for this research was to be able to review the range of literacy practices the research participants, Belinda and Henry, had engaged in throughout their lives, and this included more recent times as dementia has become part of their day-to-day lives.

This chapter is organised into the following five main sections:

- i. Everyday reading practices
- ii. Everyday writing practices
- iii. Literacy practices and living with dementia
- iv. Collaboration, storytelling and dementia
- v. Performative and embodied dimensions of storytelling and dementia

5.1 Everyday reading practices

This section focuses on, and reviews, the everyday reading practices which Belinda and Henry have memories of engaging in throughout their lives, and also includes Sandra and Pam's perspectives on their respective parent's reading practices.

When asked about reading, Belinda described,

I have always read the newspaper.

(Belinda, interview 6/1/2016)

Sandra, Belinda's daughter, also confirmed,

My mum always reads the newspaper and she always has. It's her thing to read.

(Sandra, interview 22/1/2016)

When Henry was asked about reading, he described,

I've always done a fair amount of reading.

(Henry, interview 14/1/2016)

Pam, Henry's daughter, also confirmed,

Henry reads an awful lot and he always has done. Mainly non-fiction and some fiction, but I would say through choice, it's non-fiction.

(Pam, interview, 14/1/2016)

These statements from Belinda, Sandra, Henry and Pam indicate that Belinda and Henry view themselves as people that have always read regularly and their respective daughters, Sandra and Pam, also view them in this way. Barton and Hamilton (1998, p.158) identify that people perceive themselves and others as “being readers or not being readers”. Therefore, it seemed that Belinda and Henry view themselves as part of their individual self-identities as being ‘readers’. This view is also shared by their respective daughters, which is important with consideration to the concept of “personhood” (Kitwood, 1997, p.8) and the role other people have in preserving and maintaining the personhood and identity of people with dementia.

Henry and Belinda’s early memories of reading

I asked both Henry and Belinda about their earliest memories of reading. Some of Henry’s earliest memories were from reading at home when he was a young child. Henry could recall reading comics and children’s magazines.

I’ve always read quite a bit, but I don’t think parents read to children much in them days. I had the usual kids’ magazines Hotspur and Rover and that. That was after we finished with comics. We started off with the old comics. They don’t exist now – do they? Oh dear me – what are they? I can only remember the colour of them. There was a green one and a pink one... I can’t remember the name of them. They don’t exist now anyway. But Hotspur Adventures and Rover. They were sort of boys’ books about daring deeds. And then there was a more adult one Triumph ...Triumph. But none of those exist now. I don’t know what kids read now!

(Henry, interview 14/1/2016)

Henry’s memories of reading comics and children’s magazines has similarities to one of Gregory and Williams’ (2000, p.105) research participants, Robert, who participated in their research into reading and learning to read in two contrasting inner London areas. Gregory and Williams describe that, “Robert recalls ‘graduating’ from favourites such as *The Beano* and *The Dandy* at age 8, to *The Wizard*, *The Champion* and *The Hotspur*, later still going on to more grown-up publications such as *Film Fun* and *Radio Fun*” (p.105). A further research participant of Gregory and Williams, Stanley, remembers being read to by teachers at his inner London school in the 1920s. He describes:

...on Friday afternoons after play at 3 o'clock, till we went in for the last hymn at quarter to 4, they were allowed to pick up a book and read to us, the teachers, so we had King Solomon's Mines and all these good ones and we always used to look forward to those (Gregory and Williams, 2000, p.96).

During a similar time period in the 1920s, in a school situated on the edges of north London, Henry, when he was about four or five years old could also recall being read to by his teacher.

We sat and listened to the teacher reading at school.

(Henry, interview 14/1/2016)

Henry also remembers when he was about seven or eight years old, his teachers would sometimes use a 'round robin' technique where each child in the class had to read a paragraph in turn from a book.

Now and again... They [the teacher(s)] went all round the class ... and you get up and read your paragraph ... and you sat down again. And it would come to reading again and you'd forgot, because you weren't following in the book [laughs]. But that's how we did it ... A paragraph at a time.

(Henry, interview 14/1/2016)

Henry also described how he used to enjoy browsing in a local bookshop for books when he was a teenager.

There used to be a bookshop on the corner called the Town Bookshop. I used to browse there quite a bit when I had time. I had time in those days. I used to walk round bookshops browsing. Every time I went down the town ... there was a bookshop right on the corner there. It doesn't exist now ... The Town Bookshop ... So I'd walk round there and have a look at what was going on. I used to like that, but course, it's all gone now. I miss that, you know. There are bookshops now but you have to go right inside [the shopping centre].

(Henry, interview 14/1/2016)

Belinda, in contrast to Henry, had very little recall of reading at school. However, Belinda could recall attending a nursery or "pre-school" when she was about four years old. Belinda described,

Before I started going to the older school, I went to the pre-school and this was a lady teaching us privately like the ABC and stuff like that, so that when we go to school we don't have to struggle sort of thing ... So ... and I remember that ... but it was all right.

(Belinda, interview 6/1/2016)

However, in contrast to Belinda's quite limited memories of reading at school, Belinda has very clear and strong memories of reading the newspaper when she was a young child in Jamaica.

Belinda: Reading the newspaper

Belinda recalled reading the newspaper at home with her siblings as part of a regular, family literacy event (Heath, 1983, p.392; Barton & Hamilton, 1998, p.7). Barton and Hamilton (1998, p.29) describe that newspapers feature prominently in people's homes and the sharing of newspapers is a regular practice in many families (p.155). Brandt (2001, p.31) also states that her research participant, Martha, recalls her father, who she describes as "smart and a good scholar and a most interested man in politics and everything that was going on", also read the newspaper each day as soon as he came home from working on the family's farm. Similarly, Belinda clearly remembers her father reading the newspaper each day when she was a young child and she also recalls that she and her siblings would read the newspaper when they returned home from school. Belinda described:

My dad is someone who gets the paper every day. So we don't get to read it in the morning because we go to school, but when we come home at night, we'd always read the newspaper. So we ... So we got our reading ... Really just from that. You know, it's like sometimes you go to school and you'd struggle with words ... We never did, because we always had the paper and if we didn't know something, we'd ask Dad. We always had the newspaper.

(Belinda, interview 6/1/2016)

Belinda's account also highlights her belief that this home reading practice of regularly reading the daily newspaper also helped her with reading, which was required of her and her siblings at school.

Belinda's memories of her father as a role model for reading the newspaper can be compared Gregory and Williams' (2000.p.11) concept of mediators of literacy, as Belinda's father inspired and motivated Belinda and her siblings to read the daily newspaper each day as young children. This particular literacy practice has continued throughout Belinda's life, as she described,

I still read the paper every day.

(Belinda, interview 6/1/2016)

Belinda also described how she encouraged her own children to read the daily newspaper, as she felt it would help them to develop their reading skills and their understanding of world events.

And my kids ... I thought reading the newspaper is a good way to get them to know all the different words and things that can happen in the world. So we did that.

(Belinda, interview 6/1/2016)

Therefore, it started to become apparent as Belinda recalled her memories of reading, that in her role as a parent, she became a mediator of literacy (Gregory & Williams, 2000, p.11) to her own children through encouraging them to read the newspaper regularly. However, as Belinda and her daughter, Sandra, recalled their memories of engaging in literacy practices over time, it also became apparent that collaborating in literacy practices and events, literacy learning and the concept of being mediators of literacy to each other was an integral part of their everyday lives across multiple generations of their family.

Belinda: Shared literacy practices between generations of a family

Belinda described that after she moved to Birmingham when she was twelve years old and was reunited with her parents, she began to help her mother with the day to day literacy tasks which needed to be achieved for the family.

My mum wasn't very good with reading and writing so I used to do most of that for her ... Forms and stuff like that. My mum was lovely.

(Belinda, interview 2/3/2016)

Sandra also described how Belinda helped and supported her grandmother with the everyday literacy tasks that were required by family life, and Sandra also explained that Belinda had helped her grandmother to learn to read and write.

My grandma was illiterate. My grandma couldn't read or write, so when my mum was of an age where she could read and write, my mum started to help my grandma to get enough [literacy] to get by ... To be able to fill out basic forms and have certain conversations that needed to be had, and to be able to read the forms and fill them in correctly. I think eventually my grandma knew enough to do the basics and my mum had taught my grandma to do that.

(Sandra, interview 22/1/2016)

Therefore, not only can Belinda be identified as a mediator of literacy for her own children, but as a child and teenager, she was also a mediator of literacy to her own mother, as she supported her to complete the literacy tasks which their family life demanded.

Sandra described how she and Belinda continue this collaborative family approach to support each other with the reading and writing practices which are required in everyday life. Sandra described that when she moved away from the family home to her own home for the first time that:

If my mum ever had any paperwork come through that she wasn't too sure of, she would hold it off for me to read to make sure it was all right.

(Sandra, interview 22/1/2016)

Therefore, on occasions, Sandra became a mediator of literacy to Belinda. However, Belinda continued to be a mediator of literacy to younger members of the family, as Sandra can recall saying to her son, Levi:

"Read to your grandma!"

(Sandra, interview 22/1/2016)

Belinda also recalls helping Levi with reading and homework from school. She described,

When he [Levi] was younger ... It was mostly with ... Like with Maths and ... Sometimes there was a big word that he can't get through. He'd say it, but it's not the way it should be said and then you would sort him out with things like that. And he is quite good at remembering cos, once you have told him ... He knows. [Laughs].

(Belinda, interview 6/1/2016)

Therefore, the shared nature of literacy practices within Belinda and Sandra's family not only demonstrates how being mediators of literacy to each other is an integral part of their everyday lives, which can be traced across multiple generations of their family, but their experiences also show how they work collaboratively to make sense of, and achieve, the literacy tasks that are regularly demanded of them as a family by day to day life. These experiences support findings from Jones' (2014, p.62) research, where she identified that an essential part of everyday family life was "the centrality of

shared practices around language and literacy in the negotiation of experience”.

Belinda and Sandra’s observations of how they have engaged in literacy practices across the generations of their family also reflects Barton and Hamilton’s (2012, p.xxix) view that literacy practices are always “embedded in collective action and the creation of everyday worlds”.

Belinda and Henry: Reading the word and the world

Belinda’s experiences of reading a daily newspaper throughout her lifetime can also be linked to Freire and Macedo’s (1987) concept of reading the *word* and the *world*.

Belinda identified that her preference was to read a daily newspaper about ‘real life’ stories rather than fictional stories, as she felt it helped her to keep informed about current affairs and world events:

To me, you get more information from the newspaper than reading a book, cos that’s everyday life. A lot of the books are fiction anyway but most of the stuff, not all, most of the stuff you read in the newspaper are life things that happens ... I like to know what is going on! [Laughs]

(Belinda, interview 6/1/2016)

A lot of the time, people can tell you things that are not true. A lot of the time you can read things in the paper that are not true. But if you are reading it every day, you tend to get an idea of what could be true and what could not be true.

(Belinda, interview 6/1/2016)

Therefore, through reading the newspaper, Belinda expresses that she is able to *read the world* to develop her critical consciousness (Berthoff, 1987, p.xix) and formulate her own opinions about world affairs, which have the potential to impact on Belinda’s day-to-day life. Belinda descriptions of encouraging her children to read the newspaper also reflects the relationship between reading the *word* and *world*, as she believed this practice would also help her children to develop their knowledge of current affairs, while also developing their reading skills.

And my kids ... I thought reading the newspaper is a good way to get them to know all the different words and things that can happen in the world. So we did that.

(Belinda, interview 6/1/2016)

The significance of newspapers was also expressed by one of Brandt's (2001, p.192) research participants, Ellen. Ellen's family were Jews who had fled from persecution in Poland at the beginning of the 20th century (p.192). Ellen described that newspapers were important in her family and she could recall "receiving a persistent message" that "it was important to read the newspapers and keep up with things" (p.192). Ellen also noted that for her grandparents, "the newspaper symbolized literacy" and "if you could read the newspaper, you could know" (p.192).

Henry also described a preference for reading about "the real world", as he explained that he preferred to read non-fiction to fiction. Henry seems to view non-fiction as 'real' and described fiction as "made up stuff" and that the 'real' has more value.

I like to read non-fiction. I used to read fiction, but not a lot now. There is so much that is real to read, rather than made up stuff. I used to like fiction at one time, but then you get interested in other things and you drop fiction... Because that's all made up stuff. Later on you read the real world.

(Henry, interview 14/1/2016)

Similarly, Barton and Hamilton (1998, p.90) reported that their research participant, Harry, also expressed a preference for "authentic, real-life stories" and seemed to hold the view that factual books were educational, while fictional stories were a "waste of time".

Henry: Materiality, Artefactual Literacies and Ruling Passions

Henry's enjoyment of reading and some of the texts that he likes to read were evident from the first moment that I entered his main living room. On a side table, next to the armchair where Henry usually sits, there was a large pile of magazines and newspapers, which was propped against the wooden surround of the fireplace to ensure it did not fall over (see Figure 1), (Interview notes, 14/1/2016).

I also observed a number of wooden items displayed on a sideboard and a shelving unit in Henry's living room, along with watercolour paintings and photographs of family members displayed on the walls of the living room and on the mantelpiece. I commented to Henry about the wood carving of a Labrador dog displayed on a shelf behind the pile of books (see figure 1) and Henry responded:

Oh, I made that. [Henry gets up from his armchair and shows me a wooden fruit bowl displayed on the sideboard.] *I've got a lathe down the shed. I think that is probably the one and only thing I made on it!* [Laughs]. [Henry then opened a cupboard in the alcove next to the fireplace and showed a wooden stand holding about a dozen different screwdrivers.] *Then you get more into the utilitarian things you see.* [Laughing].

(Henry, interview 14/1/2016)



Figure 1: Magazines, newspapers and woodcarvings in Henry's living room

I also commented on the wooden carving of the Rolls Royce logo (see figure 1) which is displayed with the Labrador dog carving. This instigated Henry to tell me about a vintage car that he owns, and Pam, Henry's daughter also participated in this part of the interview with Henry.

Sharon (Researcher): *I noticed the Rolls Royce carving too. Are you interested in cars as well?*

Henry: *I've got an old car. It's in your garage isn't it?* [Checking with Pam].

Pam: [She confirms that the car is in her garage with a nod]. *It's in bits.*

Henry: *Is it?*

Pam: *Yes, you took the battery off ages ago and something else, but I'm not sure what.*

Henry: *I'll have to have a look when I come over next. Anyway, it's a Lagonda. I've got a picture of it. It's 1935.*

[Henry looked in a drawer of a unit, found a photograph of his car and showed it.]

I used to use it every day. I used to go to work in it every day. It's an open car you see. [Pointing to the car in the photograph].

(Henry & Pam, interview 14/1/2016)

When I commented on the watercolour paintings that are displayed on the walls of Henry living room, Henry described that he has always had a love of art.

I've always liked art. I used to do a bit but I don't do much now ... Watercolours ... [Henry showed a watercolour painting displayed on the living room wall.] *That's one of mine.* [Laughs]. *I've got more in the other room. Do you want to see?* [Henry showed me into his second living room and there was a large pile of watercolour paintings stored on a table in the window.] *These are work in progress!* [Laughing]. *I did a little bit of oil. I did a fire screen once, but not much. I did ... I did evening classes in art of some sort, but I can't remember much about that.*

(Henry, interview 14/1/2016)

When I asked Henry about the pile of magazines and newspapers in his main living room, he explained:

I like to read about what I am interested in. Things you do with your hands. [Henry then stands up and starts to show some of the magazines and newspapers in the pile.] *Woodwork, carving, wood turning, furniture and that's only about the top five here!* [Laughs]. *I'll get rid of that pile one day when I can get through it.*

(Henry, interview 14/1/2016)

Pam also described that Henry's choice of reading material has always been linked to his hobbies and interests, his work as a draughtsman, and that Henry also used to read a weekly newspaper. It also became apparent from Pam's explanations that Henry not only likes to keep magazines and newspapers in his living room, but that he also likes to keep some of the articles from the magazines and newspapers that he has bought over the years and these are stored in one of Henry's spare bedrooms.

What Henry reads ... It's to do with his interests. For example, his job. For example, he was very interested in maths, science and engineering, so he would read things to do with scientists and maths. As a draftsman, he needed to have an understanding of metalwork and engineering. And that's what he read about. He was interested in design. He would read design magazines. He would read engineering magazines ... He has always had lots of magazines to do with

engineering, design, art, construction and even things like Ideal Home. And he would always be collecting manuals for paintbrushes and price lists for things. Henry used to get a weekly newspaper. He would buy a newspaper every week and a magazine each week. Henry would also subscribe to magazines and they would be delivered. And then they would pile up and he would not throw them out and he'd ring things he would want to read and cut out articles that he wanted to read. And they would pile up and up and up. And upstairs, there are still newspapers from the 1960s ... They are still there and when I go and say, "You don't want these anymore. And he'll say, "No, I'm still going to read them!" So, he is a bit obsessive about articles. He still does that...he still rings things.

(Pam, interview 14/1/2016)

Barton and Hamilton's (1998, p.18) concept of "ruling passions", which they argue are the interests and pastimes which are an integral part of people's everyday lives and offer a way in which people "talk about literacy", seems particularly applicable to Henry's personal accounts of his passion for art and painting, woodwork and woodcarving, and his love for his vintage Lagonda car. It also resonates with Mackey's (2016, p.166) work on *Literacy as Material Engagement* and her view that household objects which make "literacy possible are part of the jumble of daily life". As Henry and Pam talked about Henry's hobbies and the reading material he has selected to read throughout his life, it became apparent that there was a clear link between the two. Henry's reading supported his hobbies and the production of objects and artefacts through his interest in art and painting, woodwork and woodcarving. Therefore, Henry's experiences reflect Mackey's (2016, p.170) concept of "literacies of the hand" and has similarities to Rosenblatt's (2005, p.73) concept of "efferent", which Mackey argues is a productive form of reading in order "to make something" (p.170).

Pahl and Rowsell's (2010) research also resonated as Henry showed and talked about the various objects and artefacts that are on display in his living rooms. Strong parts of Henry's identity are that he is a designer through his work as a draughtsman; a craftsman using the medium of wood; and also as an artist who expresses himself through producing watercolour paintings. Therefore, the objects and artefacts that were on display in Henry's living room are integral to Henry's self-identity and can be viewed as an "embodiment" of Henry's lived experiences (Pahl & Rowsell, 2010, p.1). Henry spoke with equal passion and love for his vintage car. However, as this is stored in a garage at his daughter's home, he could not show this to me in the same way that

he had referred to the wooden items and paintings that he had made and were on display in his home. Instead, Henry referred to a photograph of the car and, for those moments, the photograph became the artefact; a replacement for the actual car that became an integral part of Henry's descriptions of owning and driving the vintage car. This highlights the multimodal nature of photographs, in that they can be viewed in the same way as people view artefacts and objects, which as Pahl and Rowsell (2010, p.1) identify, "objects are special, and they tell stories".

Summary of everyday reading practices

Belinda and Henry's autobiographical memories of their reading practices were detailed and extensive, and both viewed themselves to be 'readers'. They could both recall reading from a young age, and spoke with enthusiasm about reading regularly and the integral part it had played in their respective lives. Both identified a preference for reading which they felt was based in 'real life'. Belinda has read a daily newspaper regularly throughout her life as a way of keeping up to date with current world events. Therefore, Belinda and Henry's reading practices build on Freire and Macedo's (1987) view that people develop their critical consciousness and praxis through reading the *world* and the *word*.

Henry's reading practices have strong links to his ruling passions (Barton & Hamilton, 1998, p.18) of art, woodcarving, woodwork and also owning a vintage car. Mackey's (2016) and Pahl and Rowsell's (2010) research, which considers materiality and artefacts in relation to literacy practices also has resonance with Henry's experiences, as there is a connection between the texts Henry has chosen to read throughout his life, his interests and the resulting items he has made, which seem integral to Henry's perceptions of his self-identity.

5.2 Everyday writing practices

This section focuses on, and reviews, the everyday writing practices that Belinda and Henry have memories of engaging in throughout their lives. It also includes Sandra and Pam's memories of their respective parent's writing practices.

Belinda: Writing to stay in touch

In comparison to the enthusiasm with which Belinda talked about her reading practices, her memories of the writing practices she had engaged in seemed to be less extensive, and Belinda did not display the same enthusiasm when she spoke about writing:

I will do the correspondence, but I'm not one of those people that I've got to do it every day ... sort of thing! [Laughs]. But I will do it ... Bills, somebody write to you, you sit down and you think about what you are going to say and you write it and stuff like that ... I'd either write or if it is something important, I'll give them a call. But we keep in touch. I used to write letters more. I'm long winded, I just write [Belinda gestures with her hands to illustrate a long letter/piece of text] and they write back and it's [Belinda gestures with her hands to illustrate a short letter/piece of text] [Laughs]. The family I grew up with are not there anymore; they are all over the place. Some of them have died and stuff like that ... But we still keep in touch. We phone.

(Belinda, interview 6/1/2016)

Therefore, for Belinda, it seemed that writing was way of maintaining communication with distant family members, although she described how she also kept in contact by telephone. Sandra also recalled that when she was a child, Belinda kept in touch with relatives by telephoning them.

Mum would be on the phone to relatives, probably, like most evenings ... She'd be talking to someone on the phone for a little while, having a catch up ... My grandparents in Jamaica, my aunt in Florida, my other aunt when she lived in Germany ... Like once a week or once a fortnight, she would speak to them. And other relatives, she would talk to.

(Sandra, interview 22/1/2016)

Belinda: Childminding and written records

Belinda described that her job role as a childminder demanded that she kept written records for each child in her care. Belinda also explained that these were checked by Ofsted (Office for Standards in Education) inspectors when they visited her home.

I had to keep a record of each child. I had to keep a note of the date and the time they came in and the time they left. Like a register.

(Belinda, interview 2/3/2016)

Ofsted used to come down once a year. They used to make sure the house was safe and the kids were playing naturally and they'd look at the records. It wasn't anything too much.

(Belinda, interview 2/3/2016)

Henry: Labelling drawings and writing letters

Pam described that Henry has always had, and still has what she described as “*beautiful, neat handwriting*” (Interview notes, 14/1/2016). She explains that Henry had always had a tendency to print, rather than to use a cursive style, as printing was required in his job role as a draughtsman where he had to label the drawings he produced. Pam described that Henry has always dealt with his own correspondence and any paperwork linked to managing his own home, owning a car and his financial affairs. Pam’s descriptions also made it apparent that Henry’s ‘ruling passions’ could also be seen to influence his writing practices as he would write letters when he required materials or equipment to support his hobbies of art and woodworking. Pam described,

Henry would quite often write to companies to ask, “Can I have a sample of this or your catalogue for that?” There are numerous letters upstairs where he has written to companies asking for them to send him the latest catalogue on this and that.

(Pam, interview 14/1/2016)

Pam also described that Henry would also write notes and plans for building projects he was completing at home.

For example, if he was building a garden shed, he would write notes to himself as he research things and he would write down all the dimensions and what he needed to do.

(Pam, interview 14/1/2016)

When writing practices were discussed with Henry, in contrast to his clear recall of the reading practices he has engaged in throughout his life, he did not seem to have any particular memories of writing. When asked about letter writing, Henry’s response was:

I dunno Whoever needed a letter! [Laughs]. I can’t remember. I didn’t write many letters. I didn’t do much writing.

(Henry, interview 28/1/2016)

However, as Henry talked a little more about owing a vintage car, he described a motoring holiday where he had driven the Lagonda through Europe to Switzerland in the 1960s. Henry clearly recalled and with some annoyance,

And I had to get the papers from the AA ... Insurance, I think ... And they didn’t post them [the papers] to me. It was almost the day of the holiday and they hadn’t arrived. I had to ring them up [the AA] and go and collect them from

Stanmore. It was a terrible, terrible system ... No, it wasn't a useful system at all.
(Henry, interview 28/1/2016)

Therefore, Henry's recall of engaging with the bureaucratic literacy of insurance documents which were required to travel to Europe by car in the 1960s, can again be linked to one of Henry's ruling passions; the ownership of a vintage car.

Summary of everyday writing practices

Belinda and Henry's writing practices and their purposes for writing builds on Barton and Hamilton's (1998, p.150) view that writing in the home aligns with three general areas: "writing to maintain the household, writing to maintain communication and personal writing". Overall, Belinda and Henry's recall and memories of writing practices appear quite limited and fairly unenthusiastic when contrasted to the reading practices they described. However, this seems to draw some parallels with Brandt's (2001, p.160) observations that people's experiences of reading are often linked to more pleasurable activities such as learning and relaxing, where writing is associated with more bureaucratic tasks, "associated with earning money, paying bills, and maintaining communication with distant family relations". Therefore, this might explain why Belinda and Henry do not describe their writing practices in such a favourable way as their reading practices.

5.3 Literacy practices and living with dementia

In this section, I review the range of literacy practices Belinda and Henry have engaged in since dementia became an integral part of their lives and I also aim to explore if and how these practices have changed since the onset of dementia.

Belinda: Reading practices and dementia

Sandra described that Belinda continues to enjoy reading the newspaper each day but she believes the short-term memory difficulties which Belinda now experiences as result of Alzheimer's disease has impacted on how Belinda reads. Sandra described that she had observed that Belinda will re-read the same newspaper several times during a day. Sandra believes that Belinda will do this, as she does not have any recollection that she has already read the newspaper earlier in the day and also that she does not remember any of the details of the articles that she has previously read.

I buy mum a newspaper and she reads it. Where before she'd read it once and that will be it. Now, I'll buy her a newspaper in the morning and by the evening she will have read the newspaper four or five times because she'll go back to it ... Like it's a fresh newspaper again. And I've noticed with catalogues as well. When we go out, she might pick up like an Argos catalogue and the other day we were in Robert Dyas and she picked up their catalogue. And probably every day, two or three times a day she will look at the same catalogue, looking at bits and bobs ... And then she'll put it down and then pick it up again, and go through it again.

(Sandra, interview 22/1/2016)

Sandra described that Belinda also likes to browse for books when they go shopping in town and seems to have a real desire to read, but it really is only the newspaper that Belinda engages with on a regular basis at home.

Mum's got the motivation to read. She's got it in her head that she wants to read more and that she wants to read books [novels]. And every time we are out, she will want to buy a book. And we've bought quite a few books [novels], but she ... There is something, she doesn't have the trigger to actually pick the book up and read it. The want to read is there. She'll see a book and "Oh, I'd like to read that", but when they [the books] are actually there, the actual motivation to pick it up and start reading, it's just not there. She'll pick up cook books. She'll flick through cook books but I don't think she is actually reading anything. I think she is looking at the pictures.

(Sandra, interview 22/1/2016)

Sandra also described that Belinda's regular attendance at a dementia day centre twice a week also supports Belinda's love of reading the newspaper.

*There are always newspapers at the day centre. The centre have them delivered every day. However, if the delivery is late, apparently my mum will chase up the manager and ask where **her** newspaper is! [Laughing]. My mum starts the morning off at the day centre with a cup of coffee and the newspaper.*

(Sandra, interview 22/1/2016)

Belinda is enthusiastic about activities she gets involved in at the day centre. It became apparent that not only does she read the newspaper, but she regularly participates in a range of other literacy practices including word based puzzles and quizzes, along with reading and sharing magazines with other people who attend the day centre.

They do quizzes and like ... We all go through the newspaper in the morning together and things like that. And we do floor games and stuff like that. It's lovely. There's always something to do and if they are doing something you don't like, you can go and sit quiet and do stuff on paper or whatever you want to do. They don't sort of say you've got to do this or you've got to do that. I like that they have story books and like the magazines and stuff like that. I do quite

a lot. You go in, in the morning and they'll have two or three different magazines and you read it and you pass it on to somebody else or they'll read it and pass it on to you. It's good.

(Belinda, interview 6/1/2016)

Belinda's description shows the enjoyment she gains from engaging with a range of texts at the day centre and it also seems that the opportunities given for the reading and sharing of magazines are also important to Belinda.

Belinda is also very enthusiastic when she describes that she is visited by Denise, a specialist dementia care worker, who visits her at home each week.

Belinda: *Oh Denise is lovely. We go gallivanting! [Laughing]. We go... bingo and then we go in the shopping centre. And sometimes we go to the market, and we've been to ... oh god ... what is that place? ... I can't even remember ... I'll remember in a minute ... You know, we just spend the day together!*

Sharon (Researcher): *So what is like when you go to the bingo?*

Belinda: *Sometimes it is quite busy, but it's mostly women [laughs]. But sometimes there are only a few ... You know, depending on the weather and blah blah. They have the monitor and then when they call the number, you do the number on the monitor. And then when you win, you go "HOUSE" [Shouting] [Bursts out laughing]. But I've never said it yet! [Continues laughing].*

Sharon: *You have never won? [Laughing]*

Belinda: *Never! [Laughs] We've never won anything! [Laughing]. Nothing! [Laughing].*

(Belinda, interview 2/3/2016)

Belinda's descriptions of the visits from her specialist carer shows that she regularly participates in the literacy event (Barton & Hamilton, 1998, p.7; Heath, 1983, p.392) of playing bingo at a local bingo hall each week. This requires Belinda to engage in the reading and numeracy practices that are required to play bingo, along with the use of digital literacy practices, as Belinda uses a touchscreen computer to play bingo. Belinda's interaction with other people is also central to these visits. Belinda attends the bingo hall with her carer, but she also has to listen to the bingo caller during each game. Belinda also makes reference to the other people who attend the bingo hall, when she describes, "it's mostly women".

Sandra also described the importance of Belinda playing bingo each week and the opportunity this gives Belinda to be able to talk and socialise with a range of people.

It gives mum the opportunity to go out and do something with someone, opposed to always going out with me. More or less, to go out with me and do things I need to do on a day to day basis - shopping, going to appointments. Mum and Denise get time to do things that they both mutually enjoy. So what they have been doing for over a year now. They go to bingo each Thursday and that's the thing they do together. Denise comes and picks mum up and they go to bingo. Mum has her lunch too; fish and chips. They haven't won yet [laughing] but, hey, you know ... But, it's a nice time for them. And mum gets to socialise with people of a similar age because of the time of day they go to bingo [lunchtime/early afternoon]. Most people who go there are retired. So it's another opportunity for mum to socialise with other people, apart from the family and the people she sees at the day centre. I think it is something nice for my mum to do and to have something of her own to do on a weekly basis. It gets her out of the house, as opposed to being at home or going to the day centre.

(Sandra, interview 2/3/2016)

Therefore, Belinda's experiences support Heath's (1983, p.392) view that literacy events "define ways in which *oral language* reinforces, denies, extends, or sets aside the written material". Additionally, Belinda's engagement with the digital literacy practices required to play bingo effectively at her local bingo hall each week reflects Astell et al.'s (2016, pp. e1-2) view, that people with dementia are able to use and enjoy touchscreen technology independently.

Henry: Reading practices and dementia

Pam described that Henry continues to enjoy reading magazines since he was diagnosed with dementia and notes that this is important as he finds it difficult to engage with the television or radio owing to his hearing loss.

And I would say he actually reads more because he can't listen to the television and he can't listen to the radio. So at least he sits with a magazine in front of his nose.

(Pam, interview 14/1/2016)

Henry described that he likes to regularly browse and buy magazines when he goes to the local shopping centre.

I buy one when I'm down there [the shopping centre] and it catches my eye. There's no regularity. It happens when I see them. I think I fancy that and I buy it, but I don't have them regularly. I'll never get that pile down, I just add to it [laughs].

(Henry, interview 14/1/2016)

Pam confirms Henry's enjoyment of browsing for new magazines and describes that his wish to do this acts as a motivator for Henry to go out of the house independently.

Henry still goes out and that is the one thing that will make him go out actually. It's to go and buy a magazine. And quite often when I go out and I'll say, "Do you want some shopping?" And we'll go and look in the fridge and he'll say, "Can you get me a magazine?" So it is top most on his mind.

(Pam, interview 14/1/2016)

However, Pam questions whether Henry is able to remember and process all of the information that he reads, since the onset of dementia.

It is so difficult to assess. He does sit and read all the time because he doesn't listen to the television now because of his hearing. He reads more I'd say. But is he actually reading it? Or is he just looking at it and ... is it going in? Whether or not it is going in or he is reading the same paragraph over and over again, I don't know. That, I'm not sure about.

(Pam, interview 14/1/2016)

Summary: Changes to reading practices since the onset of dementia

Sandra and Pam described that both their parents continue to enjoy reading. Belinda, reads the newspaper each day, while Henry continues to enjoy reading magazines linked to his hobbies and interests. However, both Pam and Sandra describe that they believe that the dementia their parents experience impacts on their reading practices, in terms of the number of times the same piece of text is engaged with, as the same text can be re-read on multiple occasions. This suggests that Belinda and Henry's short term memory difficulties results in neither of them being able to recall that they have previously read and engaged with pieces of text.

This can be compared to Mitchell's (2016) experiences, where she describes that her dementia leaves her not being able to remember the plot of a fictional story "from one day to the next" and she now prefers to read purposely written, shortened books that she can read within an hour, as this is long enough for her to retain the information she is reading. Mitchell's experiences may help to explain that while Belinda enjoys browsing for new books, she then loses the motivation to read the book after it has been purchased. Belinda may have found that each time she returns to a book that she cannot remember what she has previously read.

Belinda described her enjoyment at being able to read magazines when she attends a dementia day centre. Sandra also described that Belinda likes to look through catalogues and cookery books and particularly seems to find the images engaging. These descriptions made me consider whether Belinda enjoys reading these type of texts, as they are visually appealing through generally having a greater proportion of images to the amount of text presented.

Shared literacy practices and people's interest in similar texts are important to Belinda. Belinda's descriptions of her attendance at a local bingo hall indicate that she enjoys the social interaction with other people and using a touchscreen computer to play bingo. Belinda also described her enjoyment of being able to read and share magazines with others when she attends the dementia day centre. Therefore, it seems for Belinda she views reading with others as a social activity (Heath, 1983, p.196) and the shared participation in literacy practices are important to her. These experiences in Belinda's current life link to her earliest memories of reading the daily newspaper as a family in Jamaica, as well as the shared family literacy practices which Belinda and Sandra described, where across the generations of their family they have supported each other with the literacy tasks family life has demanded.

Opportunities to browse for new reading material are important to Henry. Pam described that Henry's desire to buy a new magazine presents a substantial motivator for him to visit local shops. Henry's reading continues to be inspired by his ruling passions of art, woodwork and woodcarving. Overall, although it seems dementia is impacting on Belinda and Henry in terms of their recall of texts; their interest and enjoyment in reading continues and is a regular practice in both of their lives.

Henry: Writing practices and dementia

Pam described that although Henry had always dealt with his personal correspondence, correspondence linked to running his own home, owning a car and his financial affairs, since the onset of Henry's dementia, she has taken over the management of all Henry's written correspondence and financial affairs (Interview notes, 14/1/2016).

Henry also describes,

*I don't write now ... There's no one to write to! I pick the telephone up now ...
... There's only you [said to Pam].*

(Henry, interview 28/1/2016)

Pam described that although Henry is able to write, she feels that writing is losing its meaning for him. Pam also identified that Henry's short term memory difficulties means that he is unable to remember whether correspondence has been completed or not. Pam describes,

Henry can still write but he is muddled about what has been done and hasn't been done and is totally muddled about everything like that. He will write the same list out three times. I find them in the kitchen. He still writes beautifully, but it's the fact that it's his memory. He can't remember what he's written. For example, I'll bring in milk and I'll say "I've bought that and it's here" and he's say "Oh right." And then five minutes later, he'll write down 'milk' on the list again. So it's not the ability to write, it's just the fact that it doesn't mean anything anymore. I bought a diary for Henry for all the appointments but I write these in. Henry has a dog walker, two different carers and a neighbour comes in, and they all write in the diary. But Henry doesn't write in the diary because he doesn't know what day it is.

(Pam, interview 14/1/2016)

Belinda: Writing practices and dementia

Sandra identifies that although Belinda can still write, she does not write anymore and she is not able to manage her day-to-day written correspondence. Therefore, Sandra manages all of Belinda's written correspondence and financial affairs.

Mum doesn't do any writing now! Even to the extent where at birthdays ... She'd buy me a card and say "Write it up". And I'd be like, "Mum, I'm not writing my own birthday card!" She'll sign forms ... Like your forms [research participant consent form] and when the social worker visits and documents like care plans have to be signed, but nothing else I can think of really.

(Sandra, interview 22/1/2016)

Sandra described that as a family, it was when they noticed that Belinda was not managing her financial affairs, was becoming confused about the payment of household bills and matters relating to her bank account, that it made them start to suspect that something might be wrong. The behaviour they were witnessing was very out of character for Belinda. Sandra described,

My mum had always managed all of her bills. She was that type of person. She was quite methodical. In those days, the bills would be paid at the bank or the post office. Then when direct debits came about, everything was more or less set up by direct debit so it was taken care of. But suddenly, my mum had signed up for some things from people on the doorstep ... Not really knowing about it and then got tied into something. Also, she ended up going into her bank one day. And she had a credit card that she managed perfectly well. But then, she was offered a balance transfer and she ended up with two credit cards and the original card wasn't cancelled. I don't know if mum had forgotten, but a direct debit hadn't been set up for the new credit card to make the payments. So each month, she wasn't paying and then getting letters and she couldn't understand why. So I had to go and sort all of that out for her and make sure the direct debit was set up properly and make sure the credit cards were paid up and cancel one of them. I'm not sure if the bank had explained the credit card to my mum in a way she didn't understand or if she had forgotten. But she didn't understand and she didn't understand why these letters were being sent.

(Sandra, interview 22/1/2016)

Digital literacy practices and dementia

Both Sandra and Pam identified that neither of their parents own or use computers at home, and both daughters describe sending emails on their parents' behalf as part of the day to day management of their parents' written correspondence.

Pam described,

I email the care companies. It's a really easy way to keep in touch and they email me Henry's care visit rotas and the bills!

(Pam, interview 14/1/2016)

Similarly, Sandra described,

I email mum's social worker, the day centre and the manager that organises the care visits at home. I prefer email, as there is a record of what has been said. Information can sometimes get lost over the phone.

(Sandra, interview 22/1/2016)

Therefore, Pam and Sandra's descriptions of sending emails on behalf of their parents in relation to their care needs seems to support Age UK's (2015, p.25) findings that some older people use computers "by proxy" through family members and friends. Henry appears to have no personal engagement with digital literacy practices, which contrasts with Belinda, who engages in some digital literacy practices. Sandra explained that she has recently bought Belinda a new mobile phone.

It supposed to be dementia friendly. I researched it online. It's got a simple keypad, bigger buttons and a green button to call ... Yeah, mum's ok with it.
(Sandra, interview 22/1/2016)

Belinda also describes her new mobile phone and explains that she uses it to keep in contact with family and friends.

I had one [a mobile telephone] before ... But this one is more modern ... Cos like ... But I'm getting on all right with it. I'm not finding any problems! [Laughs]. I call my daughter, I call my cousin. And a few friends.
(Belinda, interview 6/1/2016)

However, Sandra highlights that a lack of telephone battery charge can hinder Belinda's communication with family members.

Mum uses her mobile phone to call family. My sister, my niece and her cousin in Birmingham. She forgets to charge it though. We have to remember to remind her. My sister phones her and can't get her because the phone has run out of charge!

(Sandra, interview 22/1/2016)

Therefore, it would seem that Belinda's use of a mobile telephone is fairly successful as long as she is regularly reminded by her family that it needs to be charged.

Summary: Changes to writing practices since the onset of dementia

For both Belinda and Henry, there are significant differences in the ways in which they engage in writing practices since they have lived with dementia. Previously, both had used writing practices for written correspondence and financial literacy practices to manage their respective financial affairs. However, now, both Belinda and Henry rely on their respective daughters to complete their writing practices for them and to manage their financial affairs. This includes some digital literacy practices, as both Sandra and Pam report sending emails on behalf of their respective parents.

Therefore, Sandra and Pam's relationships with their respective parents seems to have moved beyond that of mediators of literacy (Gregory & Williams, 2000, p.11), as both daughters have taken on the full responsibility of their parents' writing practices. I recognise that there are potentially implications in terms of power (Street, 2011, p.581) in the relationships between Belinda and Henry and their respective daughters with regard to these writing practices. Neither Belinda nor Henry expressed any particular regrets when being interviewed or showed any recognition that these

writing practices are carried out for them. However, I recognise from Suchan's (2016) work that Belinda and Henry's acceptance of their writing practices being mediated by family members is not necessarily a view commonly shared by all people with dementia owing to the resulting feelings of powerlessness this can lead to.

5.4 Collaborative storytelling and dementia

In this section, I review aspects of the co-constructed nature of storytelling for families who have a family member with dementia. Hydén (2011) and Baldwin's (2006, p.105) research outlines that stories and personal narratives can be told and constructed through collaboration, co-authorship and the use of "narrative scaffolding" (Hydén, 2011, p.341) between a person living with dementia and people that are close to them, such as family members. Parallels can also be drawn to Dijkstra et al. (2004, p.268), Kemper et al. (1995, pp.214 - 215) and Perkins et al.'s (1998, p.35) work which reviewed the benefits of familiar conversation partners. Therefore, I was interested in exploring whether Pam and Sandra could be viewed as conversation partners and co-constructors of autobiographical stories with their respective parents. To do this, I firstly review a story that Henry told in collaboration with Pam, about his vintage car. Secondly, I explore Sandra's role in supporting Belinda to recall a story about a job role.

Henry: The Vintage Car

For Henry, his passion and love of owning a vintage car became quickly apparent as he spoke about the vintage Lagonda car that he owns. I also recognised that Pam's contributions were also integral to Henry's recall of this particular story.

Line 1 **Sharon** (Researcher): *I noticed the Rolls Royce carving too. Are you interested in cars as well?*

Line 2 **Henry**: *I've got an old car. It's in your garage isn't it?* [Checking with Pam].

Line 3 **Pam**: [She confirms that the car is in her garage with a nod]. *It's in bits.*

Line 4 **Henry**: *Is it?*

Line 5 **Pam**: *Yes, you took the battery off ages ago and something else, but I'm not sure what.*

Line 6 **Henry**: *I'll have to have a look when I come over next. Anyway, it's a Lagonda. I've got a picture of it. It's 1935.*

[Henry looks in a drawer of a unit, finds a photograph of his car and shows it.]

Line 7 **Henry**: *I used to use it every day. I used to go to work in it every day. It's an open car you see.* [Pointing to the car in the photograph].

Line 8 **Henry:** *It had a canvas top, so I couldn't leave it in the road all day. It had to go in the garage. I used to come out from work after it had been raining and there would be about five gallons of water in it and I used to have to [Henry mimes bailing the water out of the car.] [Laughing].*

Line 9 **Pam:** *I remember meeting you at the end of the road when I was a little girl when you were coming home from work.*

Line 10 **Henry:** *Oh yeah.*

Line 11 **Pam:** *And I used to jump on this bit. [Showing Henry the photograph of the car and pointing to it]. This part.*

Line 12 **Henry:** *Oh, the running board.*

Line 13 **Pam:** *And you used to give me a lift down the road! [Laughing].*

Line 14 **Henry:** *If you did that now, you might break it! [Laughing].*

Line 15 **Pam:** [Laughing]

Line 16 **Henry:** *I miss going out in that [the car]. Not in this weather of course! [Henry looks at the window at an overcast day.] Them were the days ...*

(Henry & Pam, interview 14/1/2016)

In line 2, Henry begins by responding to my question and tells me that he owns “an old car”. He then includes Pam in the conversation by checking where the car is being stored. In line 3, Pam confirms Henry’s understanding but then reminds Henry that the car is “in bits”. Henry’s use of “Is it?” in line 4, is said with complete surprise. It seems Henry has no recollection of this, and so when Pam responds in line 5, she reminds Henry that he had removed the battery and “something else” from the car. In line 6, Henry responds to Pam and then turns his attention back to me and my original question and tells me the make of the car and its year of manufacture. Henry also refers to a photograph of the car. In lines 7 and 8, Henry provides more information about the car and recalls how he used to drive to work in the Lagonda. At line 9, Pam re-joins the storytelling and within lines 9 and 15, Pam recalls her own memories of the car and “a lift down the road” and Henry responds to what she is saying. This aligns to Hydén’s (2011, p.341) view of ‘turns’ in the process of collaborative storytelling and can be clearly observed in this part of the interaction between Henry and Pam. In line 16, Henry compares the past to the present and expresses, with some sadness, that he does not drive his vintage car anymore.

The story of the vintage car can be viewed as being co-constructed between Henry and Pam. They are collectively recalling their “previous experiences” and “common history” (Hydén, 2011, p.339). The information that Pam provides in line 5 is quite pertinent, as Henry seems to have forgotten that he had been working on the car.

Pam's reference to a past event is a strategy that Hydén (2011, pp. 341-342) outlines as relevant when a narrative scaffold is being provided, as it acts as a prompt for information they may have been forgotten. Further evidence of the use of narrative scaffolding can be seen in lines 9, 11 and 13, as Pam recalls a particular memory of the car. In line 9 she sets the scene and Henry responds in line 10, with "Oh yeah" which seems to indicate that this has helped to remind him of this particular event. In line 11, Pam continues the story and uses a photograph of the car to clarify a particular part of the car she is referring to. This action aligns to Dijkstra et al.'s (2004, p.268) view that effective conversation partners will often refer to visual prompts and artefacts to improve the coherence and cohesion of conversations. Henry responds to Pam in line 12 and tells her that she is referring to the running board of the car. In line 13, Pam concludes her part of the story and in line 14, Henry responds and his dry sense of humour is very apparent in his response to Pam. Therefore, this co-construction of the vintage car story by Henry and Pam aligns with Hydén's (2011, p.340) view that collaborative storytelling involves the participants responding to each other, understanding is checked and displays of mutual engagement can be witnessed.

Belinda: Not remembering and a verbal cue

As Belinda described the various jobs she has had over the years, she recalled the time in her life when she moved to Bedfordshire. However, initially in the interview, she was unable to remember the job she had at this time, although she could remember that she had worked.

Belinda: *I used to ... oh gosh ... What was I doing? I was working for a place ... What did they do? ... I can't think ... but I work there for about 7 years. I can't remember what I was doing!*

Sharon: *Perhaps we can ask Sandra a bit later on?*

Belinda: *Oh yes, yes... but I've always worked.*

(Belinda, interview 2/3/2016)

However, when Sandra was asked about Belinda's work in Bedfordshire, the verbal cue of, "Oh, you worked for the bus company" was all Belinda needed as a prompt for her to remember the details of the job.

Sharon: *Your mum was thinking about the job she had in Bedfordshire but couldn't remember the company she worked for.*

Sandra: *Oh, you worked for the bus company.*

Belinda: *Oh yes ... Yes ... When you worked for them, they see the way you work and if the clients like you, when they've got a vacancy they put you onto the permanent. When you work with them, you work with the children and the older people. You do the children in the morning and then you do the older people. And then in the afternoon you take the older people home and then you take the children home so you were working with both.*

(Sandra & Belinda, interview 2/3/2016)

This use by Sandra of a verbal cue that related to this past event reflects Hyden's (2011, p.342) view that narrative scaffolding strategies can include references to people or past events. Sandra can also be viewed as a familiar and effective conversation partner (Dijkstra et al., 2004, p.268; Kemper et al., 1995, p.215; Perkins et al., 1998, p.35), as she was able to positively influence Belinda to recall this particular event in her life. Belinda was then able to describe detailed information about her job role, the contract under which she was employed and what the job role entailed each day. This example supports Kemper et al.'s (1995, p.215) view that effective conversation partners can help people with dementia to tell personal stories that are "significantly longer and more elaborated".

5.5 Performative and embodied dimensions of storytelling and dementia

In the final section of this chapter, I consider research by Hydén and colleagues (Hydén 2013; Hydén & Antelius 2010; Hydén & Örvulv 2009) which identifies the multimodal strategies people with dementia can be observed using to support their oral recall of autobiographical stories. I wanted to explore Belinda and Henry's accounts of their personal memories to consider whether they drew on embodied semiotic resources as they recalled their personal stories and autobiographical memories.

Hydén and colleagues (Hydén & Antelius, 2010, p.590; Hydén & Örvulv, 2009, p.213) argue that people with dementia will often refer to physical artefacts that are available to them at the time of telling a story, to support their descriptions and explanations. Pam described that Henry will sometimes use photographs to support his recall of stories.

When I get him on a conversation and also with Mark, he will talk and he will get photos out and he will talk about them and he just about remembers who people are.

(Pam, interview 14/1/2016)

When Henry was describing his vintage car, he showed a photograph which helped to support his description of car and the stories he was telling about it.

Anyway, it's a Lagonda. I've got a picture of it. It's 1935. [Henry looked in a drawer of a unit, found a photograph of his car and showed it.] I used to use it every day. I used to go to work in it every day. It's an open car you see. [Pointing to the car in the photograph].

(Henry, interview 14/1/2016)

Similarly, as Henry was talking about his passion for art and woodwork, he referred to watercolour paintings he had painted and two wooden items he had made:

I've always liked art. I used to do a bit but I don't do much now ... Watercolours ... [Henry showed a watercolour painting displayed on the living room wall.] That's one of mine. [Laughs]. I've got more in the other room. Do you want to see? [Henry showed me into his second living room and there was a large pile of watercolour paintings stored on a table in the window.] These are work in progress! [Laughing].

(Henry, interview 14/1/2016)

Oh, I made that. [Henry gets up from his armchair and shows me a wooden fruit bowl displayed on the sideboard.] I've got a lathe down the shed. I think that is probably the one and only thing I made on it! [Laughs]. [Henry then opened a cupboard in the alcove next to the fireplace and showed a wooden stand holding about a dozen different screwdrivers.] Then you get more into the utilitarian things you see. [Laughing].

(Henry, interview 14/1/2016)

Hydén (2013, p.365) also argues that people with dementia's stories can be embodied through the use of paralinguistic features. I observed that both Belinda and Henry used gestures to demonstrate pertinent aspects of particular stories. As Belinda described her first job, she recalled that she was asked to make women's clothes for Russian customers and the skirts of the dresses had to be much longer than she was used to making. When describing the length of the skirts, she demonstrated with her hands to show the longer length and then pointed to her ankle to show that if she had been wearing the skirt, it would be touching her ankle.

The first job I had, they made coats and that firm did a lot of exporting to Russia so we made coats, dresses, suits and it ... And you wouldn't believe the different length in the clothes for the Russian women to us ... Cos the Russian women were very tall. The clothes had to be much longer [Belinda indicates a length with her hands and then points to her ankle]. And sometimes you would take it up [the hem of the garment] and I would say, "My god, that would be touching the floor if we was wearing it", but that's how they were. We did a lot of those.

(Belinda, interview 6/1/2016)

Similarly, when Henry was describing his first job at a signage company, he used gestures to support his descriptions of the different processes that were used to print the signs.

I used to do printing with a ... You had a sort of a framework [Henry indicated the size of the frame he was describing by making a rectangle with his hands] with a mesh on... Sort of stocking mesh on it and stencils and a roller. And you put the paper underneath and you put the lid down [Henry demonstrates with his hands to show placing a piece of paper on a surface and then shutting a lid down] and you rolled the stamps out [Henry demonstrates a rolling action]. That was one way. And the other way was you put the lid down, a big blob of paint and then used the squeezy across it [Henry demonstrates a rolling action] and you lifted it up [Henry demonstrates lifting a lid up].

(Henry, interview 14/1/2016)

Henry also used gestures to mime the action of hoisting his vintage car onto the docks at Harwich, as he recalled a motoring holiday he took in the 1960s.

I took it [the car] abroad once. I went to Switzerland in it. I used to enjoy that. I see it hoisted up to get off the docks at Harwich. [Demonstrating the action of hoisting]. I said, "I hope you don't drop it!" I would have preferred to drive on [to the ferry] but they hoisted it.

(Henry, interview 14/1/2016)

Hydén (2013, p.361) argues that non-vocal resources can sometimes take a "lead role" in storytelling and he observed in his research that people with dementia sometimes use gestures to replace words and phrases. Hydén (2013, p.361) suggests that the substitution of gestures for words can sometimes be used as a strategy by the person with dementia when they are unable to remember a word or a phrase they wish to use when recalling a personal story. I observed that when Belinda described writing letters to her family members in Jamaica, she demonstrated the lengths of the letters she wrote and received, rather than using verbal description:

I used to write letters more. I'm long winded, I just write [Belinda gestures with her hands to illustrate a long letter/piece of text] and they write back and it's [Belinda gestures with her hands to illustrate a short letter/piece of text] [Laughs].

(Belinda, interview 6/1/2016)

Similarly, when Belinda described the day centre that she attends each week, she gestured a long pointy nose to show that she thought some of the other clients who attend are a little standoffish.

It's lovely ... Like the centre that we go to, everybody get on. I mean, you know, some of them ... they're [Belinda gestures a long pointy nose indicating she thinks some people can be a little standoffish and she then bursts out laughing]. But our centre, everybody gets on!

(Belinda, interview 6/1/2016)

Henry also used a mime when he described owning a vintage car. Henry explained that his car would leak on rainy day and he mimed the action of bailing rainwater out of the car before driving home from work.

It had a canvas top, so I couldn't leave it in the road all day. It had to go in the garage. I used to come out from work after it had been raining and there would be about five gallons of water in it and I used to have to [Henry mimes bailing the water out of the car.] [Laughing].

(Henry, interview 14/1/2016)

Hydén (2013, p.365) also suggests that during storytelling, participants will dramatize or mimic to direct their listeners' attention to particular aspects of the story. Belinda used the volume of her voice to make two of her stories more dramatic. Firstly, as Belinda came to the end of her story about working at home as a seamstress, she shouted the word 'freedom' for dramatic effect.

*And I didn't come out of the house until my youngest daughter went to senior school. And then I thought **freedom!** [Shouting] [Laughs]*

(Belinda, interview 6/1/2016)

Secondly, when Belinda described her visits to the local bingo hall, she shouts 'house' in the story, as she would, if she were to win when playing a game of bingo.

Belinda: *Sometimes it is quite busy, but it's mostly women [laughs]. But sometimes there are only a few ... You know, depending on the weather and blah blah. They have the monitor and then when they call the number, you do the number on the monitor. And then when you win, you go "**HOUSE**" [Shouting] [Bursts out laughing]. But I've never said it yet! [Continues laughing].*

(Belinda, interview 2/3/2016)

Additionally, when Belinda recalled her experiences of working for the bus company in Bedfordshire, she described that she preferred taking the children to and from school, rather than taking the older people to a luncheon club. When asked why, Belinda refers to the older people's 'moaning' and mimics what some of the older people would say to her.

Line 1: *A lot of the older people were more trouble than they were worth!*
[Laughs]. *Oh god, there isn't anything they wouldn't moan about!*
Line 2: *"Oh, she won't move over."* [Belinda mimics]
Line 3: *"Oh, I want to sit there!"* [Belinda mimics]
Line 4: *They are all the same seats.*
Line 5: *What is the matter with you!*
Line 6: *"No, I want to sit there!"* [Belinda mimics]
Line 7: *Well you can't sit there because somebody else is already sitting there.*
[Laughs].

(Belinda, interview 2/3/2016)

Belinda mimics what the older people said to her in lines 2, 3 and 6, while in lines 4 and 7, Belinda recalls her responses. Line 5 is less clear who it is directed at. However, it is possible that this is one of Belinda's thoughts in response to what is being said to her by the older people. The mimicking Belinda uses dramatises and brings humour to the story. I observed that Belinda's eyes 'twinkled' and 'danced', as she recalled this particular story and I started to laugh in reaction to the humour of the story (Interview notes, 2/3/2016). Therefore, this example seems to align with Hydén's (2013, p.365) view that the use of embodied semiotic resources by storytellers with dementia can be an integral part of storytelling, which affects the relationship between the participants involved in a storytelling event, and that the relationship between the participants is as valid as the story being told.

Summary

Within this chapter, I have critically reviewed and analysed the everyday reading and writing practices that the research participants with dementia, Belinda and Henry, have engaged in throughout their lives, through their recall of autobiographical memories and from personal accounts given by their respective daughters. Included in this analysis, was consideration of the co-constructed approaches to storytelling, along with an evaluation of the performative and embodied dimensions of these personal accounts.

In the next chapter, I review the overall outcomes of completing this research, consider implications for dementia practice and identify further areas of research in relation to literacy practices and dementia. I also consider aspects of taking a life

history approach to this study. Finally, I discuss the contribution this study has made to the body of knowledge in the field of literacy studies.

Chapter 6: Conclusion

My overall aim for this study was to use a life history approach to explore how older people with early stage dementia have engaged in everyday literacy practices throughout their lifetimes. I also wished to identify if losses to older people's language and literacy skills through the progression of dementia impacts on how people engage in literacy practices and what the resulting changes are.

This study has centred on the lives of two research participants: Belinda and Henry. Both were diagnosed with early stage dementia in 2014 and it is their life and literacy histories which were the focus of this research. Belinda and Henry's respective daughters, Sandra and Pam, were also integral to this research. They also provided personal accounts and observations of their parents' lives and literacy practices before and as they live with dementia in their day-to-day lives.

Literature was reviewed which spanned four contrasting fields of academic research. Investigating research which explores literacy from a sociocultural perspective was an important way of developing my own knowledge and understanding of this field, and it was also essential to considering older people with dementia's literacy practices. The literature reviewed from the medical field investigated the impact of dementia on people's oral communication, reading and writing skills. This literature enabled me to develop my knowledge of dementia from a clinical perspective. It also highlighted that the research relied on outcomes generated from the use of neuropsychological standardised tests. This led to me to explore further literature which critiques the validity of using standardised tests in dementia assessments and also questions the reliability of outcomes gained when considered in relation to the social context of people's lives. Finally, research from the narrative field developed my understanding of how people's personal stories and autobiographical memories can be used as a way of exploring experiences of living with a range of disabilities, including dementia.

In this final chapter, I review the overall outcomes of completing this research and consider these in relation to the study's research objectives. I also consider the implications of these findings in relation to dementia policy and practice and suggest

further areas of research which could be completed in relation to dementia and literacy practices. I then reflect on aspects of taking a life history approach to this research. Finally, I consider the contribution this research project has made to the body of knowledge in the field of literacy studies.

With consideration to the first research objective:

1. Review how older people who have been diagnosed with early stage dementia have engaged in a range of literacy practices throughout their lifetime.

The following section summarises the literacy practices the research participants, Belinda and Henry, have had involvement in throughout their lives.

6.1 Everyday reading and writing practices

Belinda and Henry's memories and personal accounts of their reading practices were detailed and extensive. Reading is an integral part of both of their lives and both view themselves as being a reader. Importantly, in terms of their personhood, they are also viewed as 'readers' by their respective daughters. Both Belinda and Henry described a preference for reading about 'real life'. Belinda values being able to read a newspaper each day as a way of keeping up to date with world events, whilst Henry enjoys reading magazines and which focus on his interests of art, woodwork and owning a vintage car.

Freire and Macedo's (1987) ideas in relation to how people develop their critical consciousness of the world to make meaning (Berthoff, 1987, p.xix) and reading the *word* to be able to read the *world* were particularly useful, as these reflected views Belinda and Henry both expressed in relation to using reading as a way of developing their knowledge of the wider world. Barton and Hamilton's (1998, p.18) concept of ruling passions, and Mackey (2016) and Pahl and Rowsell's (2010) research relating to literacy practices, materiality and artefacts also had relevance to Henry's reading practices. These can be viewed as productive (Mackey, 2016, p.170), as there is a strong connection between the texts Henry reads and the items he has made, which seems an integral part of Henry's self-identity.

When Belinda and Henry described their personal writing practices, both were fairly unenthusiastic and Henry, in particular, had very little recall of writing practices he had previously used. Belinda recalled writing letters to family members, and both Henry and Belinda had completed specific writing practices as part of job roles. Pam and Sandra also described that both of their parents had always dealt with personal written correspondence, financial affairs and the correspondence linked to managing their own homes. Therefore, Belinda and Henry's writing practices seem to reflect Brandt's (2001, p.160) view that people's writing practices are very often connected to personal bureaucratic responsibilities.

6.2 Literacy practices and dementia

With consideration to the second research objective:

2. Explore if losses to language and literacy skills through the progression of dementia are changing how older people engage in literacy practices and what these changes are.

The following section reviews the range of literacy practices Belinda and Henry have engaged in since dementia has become part of their lives. Consideration is also given to the implications of these findings in relation to dementia practice and I suggest further areas of research which could be completed in relation to dementia and literacy practices.

Everyday reading practices and dementia

Belinda and Henry continue to read regularly since they have begun to live with dementia. However, short-term memory difficulties influences how often the same piece of text is read and engaged with, although this does appear to affect their enjoyment of reading. Belinda engages with a wide range of texts including the daily newspaper, magazines, cookery books and catalogues and she likes to browse for new reading material when she goes shopping. Belinda also particularly enjoys being able to read and exchange magazines with other people when she attends a dementia day centre. It seems that Belinda views reading as shared, social activity and this includes her regular visits to a local bingo hall. This builds on experiences in her family life of reading and sharing the daily newspaper and the use of collaborative approaches to achieve bureaucratic literacy tasks demanded by day-to-day life. Belinda's enthusiasm

and positivity about these shared activities seem far removed from the isolation and loneliness that many people with dementia describe (Alzheimer's Society, 2013b, p.25). Henry continues to enjoy reading magazines linked to his ruling passions of art, woodwork, and owning a vintage car; and the desire to buy new magazines are a motivating force for him to leave his home to visit local shops.

Engagement with magazines seems important to both Belinda and Henry. I question whether this is because the texts are image-rich in relation to the amount of text presented. Potentially, the visual appeal of texts could be particularly relevant for older people with dementia and could be a motivating factor in their decision making processes about which texts they prefer to engage with. It appears that this is an area which would benefit from further research.

Being able to browse and buy a range of texts is also important to both Belinda and Henry. With the knowledge that many people with dementia can feel "afraid of the outside world" (Alzheimer's Society, 2013b, p.46), it would be relevant for dementia research and care practice to consider how older people with dementia can be supported to access and browse texts at external locations such as retail spaces and public libraries. Additionally, dementia care facilities also need to consider how a diverse range of reading materials can be made available to clients who access their services, if people's reading practices are to be supported and encouraged. Findings from this study have also shown the relevance of making texts available which reflect people's personal interests, hobbies and ruling passions. Although neither Belinda nor Henry expressed any particular interest in reading fiction, consideration could also be given to making this genre available. With the knowledge that short term memory loss results in the same text being re-read on multiple occasions; and Mitchell's (2016) description that her dementia does not allow her to remember the plot of a story over a 24 hour period; making 'shortened' texts such as the *Quick Reads* (The Reading Agency, 2017) publications available would be particularly appropriate, along with short story publications.

Findings relating to the enjoyment Belinda gains from being involved in share literacy practices, plus consideration to outcomes from the Reader Organisation's (2017, p.37)

study that highlighted the enjoyment older people with dementia experienced from being involved in shared reading groups; and with the knowledge of the benefits gained from reminiscence activities and the use of life story work in dementia practice (Brooks, Savitch & Gridley, 2017); it appears there is much potential for research and the development of practice which combines and supports opportunities for shared reading and reminiscence for older people with dementia. It is also particularly pertinent with the knowledge that Reader Organisation's (2017, p.68) study concluded that being involved in shared reading seemed to bring some of the older people with dementia "back to life for the moment", as it appears that engagement with literature triggered "significant emotional areas" and supported a "personal reawakening".

Everyday writing practices and dementia

Findings in relation to writing practices showed that neither Belinda nor Henry particularly engage in writing practices now that they live with dementia and their respective daughters mediate all of the writing practices that are required to support their day-to-day lives. This also includes digital literacy practices relating to the sending of emails, as Henry does not engage in any digital literacy practices; and Belinda while regularly uses a touchscreen computer to play bingo; she does not use a computer at home.

These outcomes contrast to the experiences of a growing number of people who have been diagnosed with young onset variants of dementia and regularly write blogs and also use social networking sites to promote awareness about dementia. Some of the writers describe that they find the process of writing more difficult now that they live with dementia (Picazo, 2015; Blumenthal, 2017); although Mitchell (2017b) describes that she finds it easier to type about her thoughts and experiences than speak about them. Therefore, it would be pertinent for further research to be undertaken which explores the range of writing and digital literacy practices that people with dementia engage in, and to also investigate what motivates them to use these practices in their everyday lives.

Additionally, the mediation of writing by others for people with dementia also deserves further consideration. Although neither Henry nor Belinda expressed any

particular concerns that their daughters take responsibility for their writing practices; this contrasts to the feelings of powerlessness expressed by Suchan (2016) when her close family members signed a contract with a film company on her behalf. Suchan's experience shows that there is a need in families for careful negotiation relating to decision making and written mediation because of the imbalance of power this can present in relationships for people who live with dementia. In addition, recognition that not everyone who has dementia are positioned to have family members to support them with the bureaucratic literacies that are demanded by everyday life would also be relevant to consider, if further research into this area was undertaken.

6.3 Methodological reflections

Fundamental to undertaking this research was the selection of a methodology which would effectively support a sociocultural investigation into older people with early stage dementia's engagement in literacy practices. I particularly wanted to select a methodology which would allow me to capture the personal perspectives and the voices of the research participants with dementia. Using a life history approach to this study has allowed me to achieve this aim. However, including people with dementia in research did raise ethical concerns in relation to ensuring that informed consent was gained from all of the research participants involved. I recognised that the short-term memory difficulties that many people with dementia face could result in them not being able to recall decisions they had made to be involved in the research and additionally, they may not recall participating in research interviews over the span of time that data collection would take place. Therefore, a consent process needed to be used which would enable the research participants' consent to be checked throughout the data collection period. Developing and using a process consent method allowed me to do this, as I was able to ensure that all the research participants were able to make an informed decision about whether they wished to be initially involved in the research, and to then ensure that they were giving their ongoing consent to be involved in the research throughout the entirety of the study.

Deciding to involve people that are close to the research participants with dementia was also beneficial to this study. I found that Sandra and Pam's observations and personal accounts have added to the detail and volume of the data collected.

Information I learnt during interviews with Sandra and Pam helped to shape subsequent interviews with Belinda and Henry, as they described memories and experiences that their parents had not recalled when being interviewed. I was then able to follow up on this information when I next interviewed their respective parent. Sandra and Pam's involvement in aspects of their parents' interviews resulted in that some of the autobiographical stories that were recalled were co-constructed. The resulting stories that were told were more elaborate in detail, as Sandra and Pam provided verbal cues to support Belinda and Henry's recall of their memories. Without these prompts, some of Belinda and Henry's autobiographical memories may have remained forgotten and, therefore, untold.

Conducting life history research also has the potential to evoke upsetting memories for research participants. Sandra and Pam are gatekeepers to their parents and I regularly contacted them to ensure that being involved in the research was not impacting negatively on either Belinda or Henry. Specific topics were identified by Sandra and Pam which they believed may cause Belinda and Henry distress. Therefore, I ensured that these were not discussed during interviews. Therefore, in their role as gatekeepers, Sandra and Pam partly shaped the structure of the research interviews. I also recognise that because neither Belinda or Henry could be shown outcomes from this study which acknowledged their individual diagnoses of dementia, this substantially influenced the extent to which Belinda and Henry could be involved in the process of data analysis and construction of their life histories which are presented in chapters 4 and 5 of this thesis.

6.4 The contribution this research project has made to the body of knowledge

This study explored how older people with early stage dementia have engaged in everyday literacy practices throughout their lifetimes. It has reviewed whether living with dementia changes their literacy practices and what these changes are. Outcomes and findings from this study identified that people's literacy practices do undergo changes as dementia becomes part of their everyday lived experience.

Findings in relation to reading practices identified that older people with early stage dementia can repeatedly re-engage with a piece of text, but this does not seem to impact on the enjoyment of reading. Reading practices established over lifetimes

continue and a range of texts are regularly read and engaged with. Engagement with magazines seems to have pertinence, as they can be selected to support personal interests and hobbies and because of their visual appeal. Browsing for new reading material is also enjoyed and can be a motivating force for people to want to go out to purchase new texts. This has pertinence, particularly with the knowledge that many older people with dementia can become afraid to leave familiar environments such as their own homes (Alzheimer's Society, 2013b, p.46). Engagement in activities which incorporate shared literacy practices are also pertinent, as these offer opportunities for interaction and communication with other people.

Therefore, in relation to dementia practice, care providers should ensure that people with dementia are able to have access to a variety of texts and reading material within the contexts of their everyday lives. Consideration should be given to prioritising visually appealing texts and a range of genres should be selected and made available to support people's individual interests and hobbies. Consideration also needs to be given to identify ways to support people with dementia to browse and select texts, as this provides a way to not only encourage people's enjoyment and engagement with reading, but also supports personal independence, choice and engagement in a wider community.

Consideration to engaging people in social activities which support shared literacy practices is also pertinent and offers not only opportunities for engaging in reading, writing and digital literacy practices, but also has the potential to offer people opportunities to socially engage and communicate with others; to participate in storytelling and reminiscence activities; and to engage in activities within the wider community. This could help to alleviate some of the isolation and loneliness that many older people with dementia experience (Alzheimer's Society, 2013b, p.36).

Finally, consideration needs to be given to explore the ways in which people with dementia engage with digital technology, and to also investigate the ways in which this can be developed further, as this offers opportunities for people to communicate with others across contexts (Kell, 2011, p.607; Dunne, 2017b; Swaffer, 2017); to use online applications which can be enjoyable and stimulating (Astell, 2016, p.6); and presents

opportunities to engage with alternative support mechanisms through using assistive technology (Alzheimer's Society, 2013a).

Findings from this study suggests that older people with dementia's writing practices are more severely impacted by the onset of dementia than reading practices, which results in writing practices being mediated by close family members. This is an area that requires further investigation as I recognise that written mediation by others can leave people with dementia feeling powerless in decision making relating to their day-to-day lives. Moreover, outcomes ascertained from people who have young onset variants of dementia shows that although there is acknowledgment that the process of writing can become more problematic in relation to the progression of dementia; they continue to write and publish blogs as a way of retaining personal memories and raising awareness about the disease.

In conclusion, this study's findings have provided a contrasting view of dementia and literacy to outcomes gained from the established field of medical research, where literacy is viewed from an autonomous perspective and findings tend to focus on loss and deficits to literacy skills associated with language disorders. Taking this stance, results in literacy being viewed in isolation, and little consideration is given to how it is used by people with dementia within the social contexts of their everyday lives. In contrast, this study, through taking a life history approach has resulted in findings which identify that older people's literacy practices do undergo changes as dementia becomes part of their everyday lived experiences. The changes identified in relation to writing practices can be viewed in terms of loss, as neither of the research participants in this study particularly write anymore. However, outcomes in relation to reading practices have shown that these continue to be an integral and important part of the research participants with dementia's lives and are described with enthusiasm and enjoyment. Additionally, and perhaps most importantly in terms of self-identity and personhood, both research participants with dementia view reading as an integral part of their individual identities and they also continue to be viewed in the same way by others that are close to them. Overall, this study adds to the body of knowledge in relation to furthering understandings of literacy and dementia as a social process through exploring older people with early stage dementia's autobiographical

memories and their recall of personal events. This study has also provided a platform for people with dementia's voices to be heard, which adds to the body of knowledge with respect to the contextualised, lived experience of dementia.

Appendices

Appendix 1: Information included in research presentation at Age UK

Appendix 2: Research project information sheet for research participant with dementia

Appendix 3: Consent form for research participant with dementia

Appendix 4: Research project information sheet for family member

Appendix 5: Research project information sheet for research participant

Appendix 6: Consent form

Appendix 1:

Information included in research presentation at Age UK

My position: I am a research student at the University of Sheffield working towards gaining a Doctorate in Education.

My research interest: How people use literacy on a day to day basis in their everyday lives across their lifetime and changes that take place over time. Explain the research project has been reviewed and approved by the School of Education's Research Ethics Committee.

Background to the research: Outline that there is an established field of clinical/biomedical research that identifies that many people with a range of dementia types experience a progressive loss of oral communication and literacy skills.

Explain that I would like to case study two to three people who have been diagnosed to be in the early stages of dementia. Explain that I would like to investigate the range of literacy practices (reading, writing, speaking and listening) these people have engaged in throughout their everyday lives. I would then like to explore if a progressive loss of language and literacy skills changes how people engage in literacy practices and what these changes are.

Outline the research method: Explain that I intend to interview people so they can describe their experiences and memories. Explain that I would like to digitally record the interviews so that I can listen again to what is said and include people's experiences in my research project. Explain that I intend to interview people in their own homes, but if they preferred, a room at the day centre could be booked for interviews.

Confidentiality: Explain that all the information that I collect during the research will be kept strictly confidential. Assure people that no one other than me will have access to the digital recordings I make and these will be deleted at the end of the research project. Assure people that they will not be able to be identified in the research project. Explain how pseudonyms will be used.

Positives and negatives of being involved in research: Outline that being involved in research can be a positive experience as people have an opportunity to share their personal experiences and express their viewpoints. Assure people that I would like to meet with everyone involved in the research after I have written up the information gathered at the interviews, so I can show them what I have written so they can check my account for accuracy. Outline that being involved in research can also be time consuming and it can sometimes evoke difficulties or painful memories. Therefore, potential participants need to also consider these aspects of being involved in research. Explain that people would be able to withdraw from the research at any time and they would not have to give a reason for this decision.

The next steps if they would like to be involved: Explain how people can contact me if they think they would like to be involved in the research project. Explain that we would then meet we can to discuss the research project in more depth and they could ask any questions they have about the research. Explain if they decide that they would like to be involved in the research, I would ultimately need to gain their written consent and they would have to sign a written consent form.

Appendix 2:

Research Project Participant Information Sheet

Research Project Title:

How do literacy practices change over a lifetime?

I am a student at the University of Sheffield and I am working on a research project for an Education Doctorate. The University of Sheffield's ethics committee have approved my research.

I would like to invite you to take part in my research project.

I would like to talk to you about how you have used reading, writing, speaking and listening in your everyday life up until the present time.

I would like to interview you and ask you some questions about:

- Your memories of how reading, writing, speaking and listening were used by you and your family and friends when you were a child.
- Your memories of literacy during your school days.
- Your memories of how you have used reading, writing, speaking and listening during your adult life up until the present time. This might include reading and writing skills that were required for job roles, reading for pleasure, writing letters or helping your younger family members with their school work.

I would like to record the interviews using a digital recorder, so I can listen to what you said after the interview. I would then like to use some of the information in my project and in research papers that I hope to have published after my doctorate course has finished.

I would also like to be able to meet with you again, when I have written up your information, so you can check that I have written an accurate account of what you said to me.

Your information will remain confidential at all times. The digital recordings that are made will be deleted at the end of the research project. No one will be able to identify you, as I will not use your real name.

It is up to you to decide whether or not you wish to take part in the research. Please ask me any questions that you may have. If you do decide to take part, you will be given a copy of this information sheet to keep and asked to sign a consent form.

If you decide later on that you do not wish to be involved in this research, you can leave at any time. You would not have to explain why.

Thank you for taking the time to read this.

Sharon Weatherall - University of Sheffield

Date: TBC

Appendix 3:

SCHOOL OF EDUCATION UNIVERSITY OF SHEFFIELD
PARTICIPANT CONSENT FORM

TITLE OF PROJECT:

RESEARCH PROJECT TITLE:

How do literacy practices change over a lifetime?

Name of Researcher:

Sharon Weatherall

Please initial box

1. I confirm that I have read and understand the information sheet dated:
[????????] for the above project and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I agree to take part in the above project.

Name of Participant

Date

Signature

Name of Family Member

Date

Signature

Name of Researcher

Date

Signature

Appendix 4:

Research Project Information Sheet

Researcher's name: Sharon Weatherall

University: University of Sheffield, School of Education

Research Project Title:

How do literacy practices change over a lifetime?

I am a student at the University of Sheffield and I am working on a research project for an Education doctorate. My research project has been approved by the School of Education's research ethics committee at the university.

I am inviting your *(relation & relation's name, e.g. father, Louis) to take part in my research project. However, before you both decide, it is important for you to understand why the research is being done and what it will involve.

I am interested in how people use literacy (reading, writing, speaking and listening) on a day to day basis in their everyday lives. I am particularly interested in whether there are changes to how people use literacy when they have been diagnosed with dementia.

I am planning to interview some older adults (approximately 2 – 3 people) who have been diagnosed with early stage dementia to explore how they have used reading, writing, speaking and listening in their day to day lives up until the present time.

I would like to interview *(insert relation's name) on approximately two occasions for about 30 - 45 minutes and ask questions about the following:

- Memories of how reading, writing, speaking and listening were used by *him/her and *his/her family and friends when *he/she was a child.
- Memories of literacy during *his/her school days.
- Memories of how *he/she has used reading, writing, speaking and listening during *his/her adult life up until the present time. This might include reading and writing skills that were required for job roles, reading for pleasure, writing letters or helping younger family members with their school work.

I would like to record these interviews using a digital recorder, so I can listen to what *(insert relation's name) said after the interview. I would then like to use some of the

information in my project and in research papers that I hope to have published after my doctorate course has finished.

I would also like to be able to meet with *(insert relation's name) later on in the research to check I have an accurate account of what he/she described to me.

All the information that I collect during the research will remain confidential. The digital recordings I make will be deleted at the end of the research project. No-one will not be able to identify *(insert relation's name) in the research project or research papers.

It is up to *(insert relation's name) and you to decide whether he/she wish to take part in my research. Please do not hesitate in asking me any questions that you may have.

If *(insert relation's name) does decide to take part, he/she will be given an information sheet to keep and you will both be asked to sign a consent form. However, being involved in research can sometimes become too time consuming or it can evoke difficulties memories. Therefore, if at any time *(insert relation's name) decides that he/she does not wish any further involvement in this research, he/she can leave at any time and a reason does not have to be given.

If at any time you felt that a complaint needed to be made about the research, you can contact the University of Sheffield's Registrar and Secretary.

Thank you for taking the time to read this.

Sharon Weatherall - University of Sheffield

Date: TBC

Appendix 5:

Research Project Participant Information Sheet

Research Project Title:

How do literacy practices change over a lifetime?

I am a student at the University of Sheffield and I am working on a research project for an Education doctorate. My research project has been approved by the School of Education's research ethics committee at the university.

I am inviting you to take part in my research project. However, before you decide, it is important for you to understand why the research is being done and what it will involve.

I am interested in how people use literacy (reading, writing, speaking and listening) on a day to day basis in their everyday lives. I am particularly interested in whether there are changes to how people use literacy when they have been diagnosed with dementia.

I am planning to interview some older adults (approximately 2 – 3 people) who have been diagnosed with early stage dementia to explore how they have used reading, writing, speaking and listening in their day to day lives up until the present time.

Your *(insert relationship and person's name – e.g. father, Louis) has agreed to be involved in this research. I am planning to interview *him/her (on approximately two occasions) for about 30 - 45 minutes and ask questions about the following:

- Memories of how reading, writing, speaking and listening were used by *him/her and *his/her family and friends when *he/she was a child.
- Memories of literacy during *his/her school days.
- Memories of how *he/she has used reading, writing, speaking and listening during *his/her adult life up until the present time. This might include reading and writing skills that were required for job roles, reading for pleasure, writing letters or helping younger family members with their school work.

I would also like you to be involved in my research and would like to interview you. I am interested in your thoughts and observations of how *(insert relation's name or relationship name e.g. father) uses reading, writing, speaking and listening now and also from your memories prior to *him/her being diagnosed with dementia. I am also

interested in your thoughts on any changes that you have observed. I estimate that this interview will take approximately 30 minutes.

I would like to record this interview using a digital recorder, so I can listen to what you said after the interview. I would then like to use some of the information in my research project and in research papers that I hope to have published after my doctorate course has finished.

I would also like to be able to meet with you when I have written up the information, so you can check that I have an accurate account of what you described to me.

All the information that I collect during the research will remain confidential. The digital recordings I make will be deleted at the end of the research project. No-one will be able to identify you in the research project or research papers.

It is up to you to decide whether or not you wish to take part in the research. Please do not hesitate in asking me any questions that you may have.

If you do decide to take part, you will be given a copy of this information sheet to keep and also asked to sign a consent form. However, being involved in research can sometimes become too time consuming or it can evoke difficult memories. Therefore, if at any time you decide that you do not wish to be involved in this research, you can leave at any time and you do not have to give a reason.

If at any time you felt you needed to make a complaint about the research, you can contact the University of Sheffield's Registrar and Secretary.

Thank you for taking the time to read this.

Sharon Weatherall - University of Sheffield

Date: TBC

Appendix 6:

SCHOOL OF EDUCATION UNIVERSITY OF SHEFFIELD
PARTICIPANT CONSENT FORM

TITLE OF PROJECT:

RESEARCH PROJECT TITLE:

How do literacy practices change over a lifetime?

Name of Researcher:

Sharon Weatherall

Please initial box

1. I confirm that I have read and understand the information sheet dated:
[????????] for the above project and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I agree to take part in the above project.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

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