

Experiences of Early and Late-Onset Alzheimer's Disease: Perceptions of Stigma and Future Outlook.

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Declaration

I declare that the thesis has been composed by myself and that it embodies the results of my own research.

Rosalie Marie Ashworth, October 2015.

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Abstract

Diagnosis of Alzheimer's disease is encouraged as a first step towards people planning for their future with the condition. Despite the proposed benefits of diagnosis, it is also widely recognised that Alzheimer's disease can expose people to stigma. Therefore, this thesis explores the relationship between stigma and future outlook, from the perspective of people affected by early and late-onset Alzheimer's disease. In order to recognise the physicality of the condition and how psychological and social factors influence experiences, a biopsychosocial perspective is employed throughout.

People with Alzheimer's disease (n=15 people with late-onset, 7 people with early-onset) and their supporters (n=22) completed questionnaires about perceived stigma. This was followed by 14 interviews with a subsample of participants, which explored stigma and future outlook in more depth. Perceived stigma reporting across participants was low in the questionnaires; whereas interviews revealed higher levels of stigma with people discussing mixed, unpredictable reactions from a range of sources. Participants expressed awareness of the unpredictable nature of their futures with the condition. The subsequent lack of control was managed through focusing on 'one day at a time' and avoiding looking too far ahead.

Across reflections on stigma and future outlook there was a deliberate focus on positive experiences for people affected by early and late-onset Alzheimer's disease. The similar management of experiences across participants minimised possible age-based differences. These findings are supported by socioemotional selectivity theory, which suggests people are motivated to maintain positive emotional states when facing 'time-limiting' conditions irrespective of age. The research suggests people's experiences of stigma and future outlook interact, with stigma-driven assumptions about the future affecting how people manage their daily lives. The avoidance of looking ahead suggests that policy which encourages future planning should consider its utility and explore ways of helping people to manage both exposure to stigma, and planning for the future, whilst focusing on daily living.

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Chapter 1- Introduction

Introduction

The diagnosis of Alzheimer's disease has both positive and negative implications for people with the condition and their supporters. This thesis seeks to explore how the consequences of diagnosis interact with each other, namely considering the relationship between exposure to stigma and future outlook. The subjective experiences of people affected by Alzheimer's disease are considered from a biopsychosocial perspective, viewed as a non-linear 'journey'. The perspective aims to reflect how biomedical and psychosocial understandings of Alzheimer's disease complement each other, and allow for a more holistic understanding of experiences.

The thesis offers several new insights into the lives of people affected by Alzheimer's disease; firstly understandings of stigma are built on by considering individual perceptions of stigma as opposed to public understanding of the condition. Prior to this research there has been limited focus on individuals' perceptions in this area, which in part reflects an assumed lack of awareness. The thesis explores how people manage stigma and subsequently envisage their futures with Alzheimer's disease, given that many of the stigma-driven assumptions suggest limited, negative futures.

Across experiences, possible age-based similarities and differences are explored. The majority of previous research into experiences of Alzheimer's disease considers people with early and late-onset Alzheimer's disease separately. Although such separation provides important understandings of how the condition may impact people at different stages of their life course, it does not always give room for shared experiences to emerge or differences to be seen within the same study.

The discussion throughout the thesis recognises the physicality of the condition whilst reflecting how a wide range of psychological and societal factors impact on overall experiences. The following chapter provides the background and context to this thesis, beginning with the collaborative partnership between the Scottish Dementia Clinical Research Network and the University of Stirling, which led to this PhD. Following on from this is discussion of the importance of learning from people with dementia and

listening to their experiences, before outlining how a biopsychosocial perspective facilitates such focus. Throughout the introduction there will be reference to relevant statistics which reflect the importance of increasing research and knowledge in the field of dementia. It is important to note that these numbers reflect people and that for each person a wider web of people may be affected by the condition in various ways. The background context for researching experiences of stigma and future outlook is introduced, before a more in-depth discussion of the literature available in these areas within chapters 2 and 3. The terminology used throughout is outlined and explained. This is particularly necessary as the thesis brings together research from biology, psychology, and sociology, in order to better understand the experiences of people living with Alzheimer's disease. The different disciplines often use alternative terms synonymously, therefore clarification of terms is provided. The core aims of the research are outlined, including the research questions formulated to address these aims. Finally, an overview of the thesis structure with a summary of the content of each chapter is given.

Collaborative PhD

This PhD originates from collaboration between the University of Stirling and the Scottish Dementia Clinical Research Network (SDCRN). The Scottish Dementia Clinical Research Network (SDCRN) began in 2008, promoting dementia research across Scotland (SDCRN, 2010). The aims of the network are supported by Scotland's National Dementia Strategy, with commitment to research opportunities for people with dementia following diagnosis (Scottish Government, 2010; 2013). The strategy highlights the overlap between interest in diagnosis rates and research by referring to research opportunities within the government's commitment to meet HEAT targets and increase rates of diagnosis (Scottish Government, 2013). This overlap may reflect how a biomedical focus towards dementia can influence care policy and practice (Innes and Manthorpe, 2012).

The role of the network has evolved with the increasing amount of dementia research being undertaken in Scotland, and in 2015 the SDCRN joined with Join Dementia Research to form a UK wide register for people interested in research participation

(SDCRN, 2015a). Research registers such as this, aim to bridge the gap between people affected by dementia and research studies (Avent et al., 2013).

Part of the PhD collaboration included working as a Clinical Studies Officer within the SDCRN for one day a week. This job role enabled regular contact with people with dementia and their families, as well as a range of health care professionals. This helped to focus the research topics, and keep the needs of those affected by the condition at the forefront of the research process. Through working across disciplines, the scope for applicability and dissemination of findings increased. Additionally, the complementary nature of seemingly separate disciplines such as psychiatry and sociology emerged, and shaped the overall thesis and research.

Moving towards a biopsychosocial model of Alzheimer's disease

Internationally there is an increasing awareness of Alzheimer's disease and other types of dementia (Matthews et al., 2013). Alzheimer's disease has been identified as a neurodegenerative disease, with significant pathological changes which separate the condition from the norms of an ageing body (Braak et al., 1996). As such it is often considered within a biomedical perspective as an illness that can be diagnosed, and potentially treated (Bond, 1992). There is currently no cure for the condition, which adds to the motivation to focus efforts on helping people manage their daily lives (O'Sullivan et al., 2014).

According to the figures published in 2014, around 500,000 people in the UK are living with Alzheimer's disease (Alzheimer's Research UK, 2014). It is the most common type of dementia, and is associated with a range of symptoms including memory loss and communication difficulties (Alzheimer's Research UK, 2014). In Scotland, statistics estimate around 67,000 people have a diagnosis of dementia (Prince et al., 2014) with around 50% diagnosed with Alzheimer's disease (Alzheimer's Scotland, 2013). Importantly, these statistics reflect the estimated prevalence of the condition, but they do not capture the complexity of experiences each individual within these statistics faces. The statistics may inadvertently lead to an 'us' and 'them' view of Alzheimer's disease. However, as Benbow and Jolley (2012) reiterate, dementia is non-

discriminatory and is likely to affect many of us over the coming years. Further the condition is not experienced in isolation, but can be seen to impact the individual (Caddell and Clare, 2011), friends and family (Brodaty and Donkin, 2009), and society more widely (Wimo et al., 2013).

National policy such as Scotland's Dementia Strategy (Scottish Government, 2010) reflects the increasing incidence of Alzheimer's disease, and the wide range of consequences the condition can have for both the individual and society (Pimouguet et al., 2015). However, the voices of people affected by the condition remain underrepresented in research (McKeown et al., 2010; Batsch and Mittleman, 2012). Pervasive negative beliefs are suggested to underlie the dearth of research which prioritises dementia, or engages people affected by the condition (Benbow and Jolley, 2012). Therefore, this research seeks to provide people affected by Alzheimer's disease the opportunity to have their experiences heard.

The biomedical model considers the person by observing the physical and psychological changes associated with the condition (Wade and Halligan, 2004). The journey of Alzheimer's disease is seen to be marked by progressive neurological changes from mild to severe, with increasing 'care' needs (Cuijpers and van Lente, 2015). This perspective of Alzheimer's disease is limited by its lack of consideration for how the condition is experienced, taking into account social meanings of health and illness (Innes, 2009; Olafsdottir, 2013). Further, the cultural notion of "a pill for every ill" (Conrad and Barker, 2010:75) focuses efforts on cures rather than on long term needs of people affected by the condition. This may fuel therapeutic nihilism and loss of hope (Chaufan et al. 2012). This view is supported by O'Sullivan et al. (2014) who argue that there is still too heavy an emphasis on medical science and dementia. They propose that this leads to a narrowed vision of the future, which does not recognise or facilitate ways of living positively.

The evolution of the biomedical model to incorporate psychosocial components was proposed by Engel (1977). The rationale for this progression was to better link medicine and science, moving away from linear causality (Smith, 2002). The biopsychosocial model looks at the philosophy of illness from a molecular to a societal level, whilst practically exploring people's experiences of illness (Borrell-Carrio et al., 2004). The model is based on a General Systems Theory (Engel, 1980) which theoretically

suggests the levels of biological, psychological and social processes should not be given functional priority and are all integral to the experience of health and illness (Alvarez et al., 2012). Since its conception, the biopsychosocial perspective has been widely accepted within health psychology and medical science (Hatala, 2012). However, there remain concerns that the model cannot be applied easily to practice, and consequently Alvarez et al., (2012) suggest that it should be used as a perspective rather than as an empirical theory.

The holistic perspective of the biopsychosocial model allows for a journey of Alzheimer's disease which is continually being modified and adjusted, rather than viewed as a fixed linear process. The biopsychosocial model has been discussed by several researchers in relation to experiences of dementia (Boustani et al., 2007; Clare et al., 2011; Downs et al., 2008; Spector and Orrell, 2010). In particular, the framework is discussed as being an important move forward in our understanding of dementia; since a consistent relationship between biological markers of Alzheimer's disease and the symptoms experienced is yet to be established (Downs et al., 2008), so a biopsychosocial perspective is helpful since it incorporates psychological and social aspects of the condition that affect how it is experienced.

It is important to recognise that moving towards a biopsychosocial model should not discount the benefits of the biomedical perspective (Innes and Manthorpe, 2012). For instance, considering ways of alleviating symptoms of the condition, and possible factors which may exacerbate or contribute to the physiological experiences. Rather, it looks to consider how psychosocial factors can shape people's experiences. Given the increasing prevalence of people developing and living with Alzheimer's disease (Hebert et al., 2003), there is an ever present pressure to understand how best to support people in managing their experiences. Specifically, this research focuses on stigma and future outlook.

Background context: Stigma and Future Outlook

Coinciding with the increasing incidence and awareness of Alzheimer's disease is a drive towards early diagnosis within UK policy and practice (Department of Health,

2013). This is encouraged in allowing people to plan for their future (Luengo-Fernandez et al., 2010). Due to the advances in biomedical research, there are a growing number of techniques in place which aim to support diagnosis (Dubois et al., 2014; Nordberg, 2015; Viola et al., 2015). However, this perspective favours a biomedical approach, with a deterministic linear progression from diagnosis to end of life based on worsening symptoms (Bond and Corner, 2001). This thesis aligns with an alternative stance, depicting a non-linear journey of illness experiences based on the influence of psychosocial factors (Engel, 1977). The conceptualisation of Alzheimer's disease as a 'journey' is being increasingly used within research literature such as Chrisp et al. (2012), and policy such as Scotland's Dementia Strategy (Scottish Government, 2013), suggesting a positive move forward towards engaging in the complex nature of experiences.

Given the increased drive towards early diagnosis of Alzheimer's disease, it is important to recognise the associated strengths and limitations (Alzheimer's Association, 2011), as discussed in the following section. Importantly, diagnosis of Alzheimer's disease exposes people to negative attitudes and beliefs (Garand et al., 2009). This is known as stigma (Goffman, 1963) and relates to both the diagnostic label and assumptions about how a person will be affected by the condition (Aminzadeh et al., 2007; Langdon et al., 2007). Such exposure can lead to a variety of negative consequences for people with the condition and those close to them (Garand et al., 2009). These will be discussed in greater depth within chapter 2.

One of the driving forces behind encouraging early diagnosis for people affected by the condition is in providing the opportunity to plan for the future (Bamford et al., 2004). However, there has been limited research which considers whether this is happening in practice. Undeniably people with Alzheimer's disease are likely to experience decline over time, where additional support is needed (O'Sullivan et al., 2014). However, the 'end point' focus has led to less emphasis on facilitating people to live with the condition (O'Sullivan et al., 2014). Therefore, although this thesis is contextualised by early diagnosis and the biomedical focus on care, it does not aim to focus on the debates surrounding whether to diagnose the condition (Brunet et al., 2012; Pimouguet et al., 2015), or the use of advance care planning (Robinson et al., 2012). Rather, it focuses on how people plan for a future with a stigmatised condition.

Explanation of terminology

Throughout the thesis, a range of specific terminology will be used. The following section clarifies the use of these terms. The term ‘person with Alzheimer’s disease’ has been used throughout this thesis to refer to people with the condition. This is a deliberate move away from biomedical literature which uses ‘patient’ more frequently, similarly ‘condition’ is used over ‘illness’ where appropriate. Further, previous literature highlights how the terms ‘Alzheimer’s disease’ and ‘dementia’ are often used synonymously (Langdon et al., 2007). For example, ‘people with Alzheimer’s disease’ has been used to describe study participants when further detail highlights that the participant group included people with different diagnoses such as, mild cognitive impairment (Beard and Fox, 2008), or mixed dementia (Burgener and Berger, 2008). Different types of dementia are associated with different symptoms (Knopman et al., 2003; Gure et al., 2010; Chiu et al., 2006). This could impact on experiences of stigma and consequently future outlook (O’Sullivan et al., 2014). Within this thesis only people with Alzheimer’s disease have been included. Further, ‘people with dementia’ is only used when referring to people with different types of dementia together, or when the type of dementia has not been noted in the research being discussed.

As well as moving away from terms such as ‘patient’, it is important to consider how those who help support people with Alzheimer’s disease conceptualise their role. Common terms used throughout dementia research and health and illness literature include ‘carer’ or ‘caregiver’ (Molyneaux et al., 2011). However, interviews conducted by O’Connor (2007) highlighted that people did not see themselves as a ‘carer’, with additional literature suggesting that the dislike for the term was widespread and that it should therefore be avoided (Molyneaux et al., 2011). This thesis uses the term ‘supporter’ as an alternative. This term has been suggested as more reflective of their role in the person with Alzheimer’s disease’s life (Carers and Confidentiality, 2013). Further, it reinforces the move away from the focus on ‘care’, which is often focused on in ‘living with dementia’ literature (O’Sullivan et al., 2014), and is potentially associated with dependency (Guberman et al., 2003). Many supporters may see their role as an extension of their previous relationship (O’Connor, 2007). However, it is important to recognise that taking on such a role can have a range of positive and

negative effects (Shim et al., 2012). Therefore, supporters' experiences will be considered separately as well as together with the person they support.

Alzheimer's disease affects both older and younger people (Alzheimer's Research UK, 2014). Throughout this thesis, early-onset Alzheimer's disease refers to people who are diagnosed before 65 years old, and late-onset refers to people diagnosed after 65 years old. The age range is arbitrary (Woods and Clare, 2015), but mirrors the age categories used within clinical settings (Koedam et al., 2010). Previous research tends either to separate people with Alzheimer's disease into the two age categories in different research studies, or to include both age categories within the same study without recognition that age may be influential. For instance, research such as Caddell and Clare (2013) and Keady et al. (2009) included participants with early and late-onset dementia without discussion over whether age influenced experiences. Different experiences have been reported between the two age groups (Tolhurst et al., 2014). Therefore, this research sought to consider the experiences of people with early and late-onset Alzheimer's disease in the same study, whilst considering whether age is a causal factor in the study outcomes.

Finally, literature related to terminal illnesses has been included within the thesis. The literature has been used to consider how people manage conditions which limit their sense of time left in life. Alzheimer's disease is defined as a terminal illness, although this characterisation is still fairly under-recognised (Davies et al., 2014; Thune-Boyle et al., 2010). Literature which considers the most appropriate terminology in this area is limited, and various terms have been used (Nicholl, 2007). A commonly used term within this literature is 'life limiting' conditions. However, this may suggest that people are no longer as capable or able to continue 'normally'. For the purpose of this thesis, 'time-limiting' condition has been used as an appropriate alternative when needed. This has been chosen due to the main theoretical framework considering perceptions of time (Lockenhoff and Carstensen, 2004). Additionally, the focus on time sought to move away from unintended associations with capabilities and quality of life associated with the term 'life limiting' (Entwistle and Watt, 2013).

Research Aims

The aim of this research is to explore people's experiences of living with Alzheimer's disease, focusing on perceptions of stigma and future outlook, and whether age may influence these experiences. The design and study protocol sought to be as inclusive as possible, and encourage the indirect benefits of being involved in non-therapeutic research (Higgins, 2013). Based on an extensive review of the literature, novel areas of research were highlighted and developed into research questions which formed the basis of this study. The application of the findings to current policy and practice emphasise how stigma and looking to the future are worth considering together. This is shown by the current drive for diagnosis of Alzheimer's disease to enable people to plan for the future, despite the subsequent exposure to stigma. The thesis explored four key research questions which sought to add to what is already known in the literature, and provide new insights for future research.

1. Do people with Alzheimer's disease and their supporters experience stigma?
2. How do people with Alzheimer's disease and their supporters view and plan for the future?
3. Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters?
4. Are there differences in experiences, in terms of both stigma and future outlook, for people experiencing early-onset Alzheimer's disease and late-onset Alzheimer's disease?

Thesis Overview

This thesis initially reviews the background research literature which has influenced this study. The background context is provided across two literature review chapters, which identify areas of research to be explored in the subsequent study. This is followed by chapters 4 and 5 on research methodology, including reflections on method in practice. The heart of the thesis is in the research findings, which are presented across three chapters (6, 7, and 8) reflecting three of the four research questions. The

fourth research question has been addressed throughout the three chapters, considering age as a variable across the findings. Finally, in chapter 9 the research findings are brought together with the previous literature to consider how the research contributes to current understanding and directions for the future.

Chapter 1: Introduction

The introduction chapter presents the background context for the PhD, and for researching the subjective experiences of people affected by Alzheimer's disease. Relevant statistics and policy are drawn upon to highlight the importance of adding to this field. The terminology to be used throughout the thesis is explained and justified, particularly in cases where multiple terms could be used synonymously. Finally, the aims of the thesis are presented before the structural overview.

Chapter 2: Developing Alzheimer's disease: Exposure to stigma

This chapter is the first of two literature review chapters. The methods behind the review are outlined, including specific search strategies used to collect literature for synthesis. The chapter moves on to focus on how the diagnosis of Alzheimer's disease may expose people to stigma. The process of stigmatisation is discussed, before highlighting the consequences of this for how people experience their condition and their prospective futures.

Chapter 3: Living with Alzheimer's disease: Managing stigma and future outlook

The second literature review chapter focuses on how people affected by Alzheimer's disease manage the negative consequences associated with stigma. Namely, how people remain positive in the face of adversity, and manage their futures following diagnosis. Socioemotional selectivity theory (Carstensen, 1991) is discussed as the overarching theoretical framework for this thesis. Further, a range of biopsychosocial literature has been synthesised to consider future outlook and how it may be influenced when facing conditions such as Alzheimer's disease.

Chapter 4: Methodology

The methodology chapter considers the epistemological positioning of this research. It focuses on how a mixed method design, made up of questionnaires and semi-structured interviews, is most suitable for answering the proposed research questions. This is

followed by considering the use of research registers, and sampling of participants. The inclusion and exclusion criteria are outlined, and discussed with reference to possible ethical and practical concerns. Finally, reflections on the sampling and recruitment process are provided.

Chapter 5: Methods

The methods chapter expands on the discussions of chapter 4, discussing how the study design was utilised. The specific research measures are explained, with reference to appropriate literature. Further, a detailed protocol is provided, which seeks to make the research process transparent. Reflections on data collection are discussed, before outlining the data analysis process.

Chapter 6: Do people with Alzheimer's disease and their supporters experience stigma?

The first of three findings chapters considers the data collected from questionnaires and interviews, relating to participants' experiences of stigma. Reporting of stigma is compared between people with Alzheimer's disease and their supporters, as well as across age groups. There was a clear discrepancy between the degree of stigma reported in questionnaires and interviews, which has been discussed with reference to methodological and theoretical considerations. The findings reflect that people affected by Alzheimer's disease are exposed to stigma from a range of sources. People with Alzheimer's disease reported higher stigma than their supporters, in keeping with previous research in this area. Age-based differences emerged for the different types of stigma reported, although age itself was not statistically significant.

Chapter 7: How do people with Alzheimer's disease and their supporters view and plan for the future?

This chapter focuses on the second research question. The findings emerging from thematic analysis of the interview data are discussed across the journey of Alzheimer's disease, from initial adjustment through to considering one's future with the condition. In general people felt unable to look too far ahead, due to the emotional strain this could cause. As an alternative, people chose to focus on one day at a time and accepted that the future was outwith their control. The experiences shared across interviews suggested

minimal age-related differences in future outlook and subsequent strategies for managing the unpredictable nature of Alzheimer's disease.

Chapter 8: Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters

The final findings chapter focuses on the association between stigma and future outlook. The findings presented in chapter 6 and 7 are brought together with previous literature, to highlight how people affected by early and late-onset Alzheimer's disease manage exposure to stigma and its impact on future outlook. The interviews highlight a focus on being 'the lucky one' and seeing one's situation as unique and unpredictable, to facilitate separation from the group-stigma attached to 'people with Alzheimer's disease' and the corresponding feared futures.

Chapter 9: Discussion and Conclusions

The concluding chapter brings together research presented across the thesis, summarising the key findings and how they contribute to the wider field of dementia. People affected by early and late-onset Alzheimer's disease report a range of negative experiences in relation to stigma. As such, people separate themselves from the group-identity and the negative responses of others, and focused on remaining positive as much as possible. People avoided situations which involved confronting their fears of the future, instead focusing on one day at a time. Future directions of research arising from the study findings are presented including, exploring ways of helping people to manage both exposure to stigma and planning for the future, whilst focusing on daily living. Finally, the experiences of people affected by Alzheimer's disease and how best to support the needs highlighted from this research are discussed, namely maintaining positive emotional states.

Chapters 2: Developing Alzheimer's disease: Exposure to stigma

The following two chapters present the literature reviews which have informed this study, from initial conception through to data analysis and discussion. The first chapter focuses on how diagnosis of the condition can expose people to stigma, and the possible consequences of this. This is contextualised within a biopsychosocial perspective, moving beyond the biomedical model to consider how social constructions of health and illness can influence experiences. Literature which demonstrates how Alzheimer's disease is currently understood is synthesised, with theoretical and research-based examples. The chapter goes on to acknowledge areas which have informed the subsequent research questions. Firstly, that people with Alzheimer's disease and their supporters may be exposed to and perceive stigma. Secondly, age may influence experiences of stigma, although the direction of this influence is unclear.

The second literature review (chapter 3) considers how people manage the consequences associated with stigma outlined in chapter 2. Literature related to managing stigma and future outlook is explored with a particular focus on socioemotional selectivity theory (Carstensen, 1991). This provides an overarching framework to understand people's experiences of early and late-onset Alzheimer's disease. The theories discussed help to inform investigation of responses to stigma and looking to the future, by focusing on the preservation of positive emotional states. Areas to explore outlined from the literature in chapter 3 include a possible association between stigma and future planning, as well as potential age-based similarities in managing experiences. The literature review concludes with the research aims and questions for this study.

Search strategy

The origins of this thesis began with the question “How do people with dementia and their carers look to their futures.” With this question as a baseline, mind maps were generated which considered the wealth of topic areas which could be explored. Dementia was conceptualised as a journey from pre-diagnosis, through to diagnosis, learning to live with the condition, and end of life care. The experiences of the person with dementia and their supporter were viewed as separate but shared. The complex journey was narrowed following synthesis of the literature and presentation of ideas to academic audiences, as well as people affected by dementia. The conceptualisation of this has been presented in Figure 1. Two core topics central to this thesis are stigma and future outlook. Possible age-based similarities and differences in experiences relating to these topics were also explored.

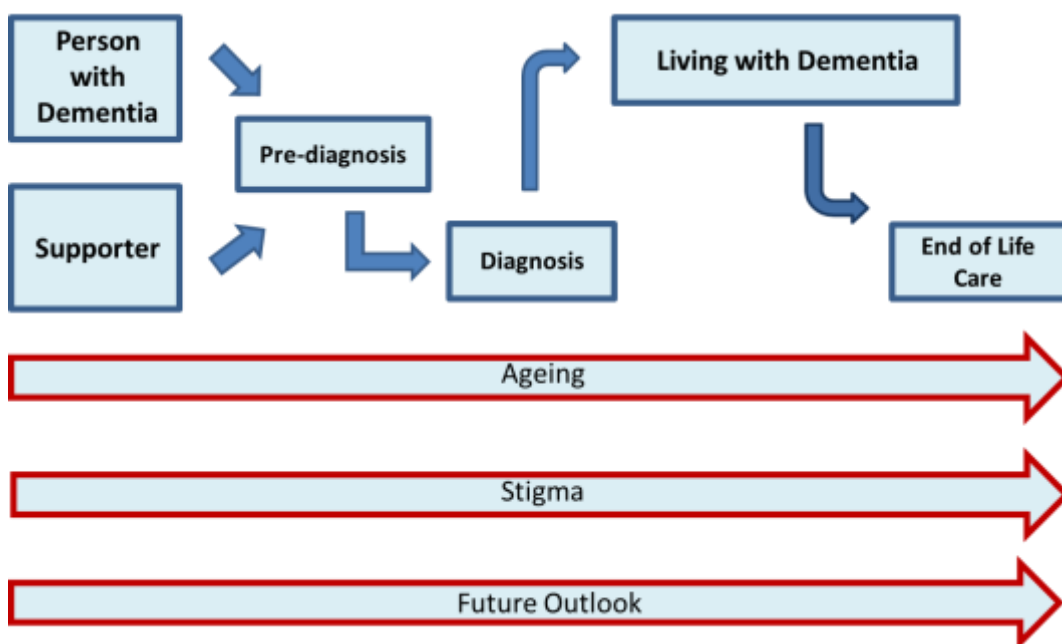


Figure 1. Visual conceptualisation of the journey of dementia for both the person with the condition and their supporter.

The following literature review chapters have synthesised the literature in relation to the aforementioned topic areas. These topics individually are broad and complex; therefore it was important to narrow down the literature for review. A narrative review was

chosen over a systematic review in keeping with the exploratory nature of the research and the need for broader literature (Bryman, 2012). The primary purpose of the literature review is to provide a comprehensive background on the topics this thesis aims to explore, identifying gaps in knowledge and determining research questions (Cronin et al., 2008). Although the search prioritised peer-reviewed journal articles, a range of sources has been accessed due to the overall need to gain a thorough overview of the topic. One of the main limitations of a narrative review, in comparison to a systematic review, is the reduced clarity of process (Cronin et al., 2008) and increased possibility of researcher bias (Cipriani and Geddes, 2003). The following sections seek to demonstrate clarity of process. The majority of literature fits within the psychological discipline, with biological and sociological literature being introduced to complement the main discussion, and reflect the biopsychosocial perspective introduced in the previous chapter.

The literature search used a variety of databases, as well as snowball strategies, where literature cited in a relevant article was sourced and read. The combination of 'protocol defined' searches and 'snowballing techniques' can be a more effective method of searching than relying on search terms alone (Greenhalgh and Peacock, 2005). This process allowed for a wide range of literature to be sought, as well as permitting literature which might not have fitted with the original search terms. For example, 'future planning and dementia' searches often produced more policy and economic-focused literature, rather than psychosocial experiences. Whereas, citations obtained from papers which were relevant revealed more appropriate search terms for this topic including, 'imagined futures'. This increased the scope of applicable literature in this area.

As the field of dementia research spans many different disciplines, it was important to be aware that different terms are often used when referring to the same underlying idea. For instance, 'mental time travel' is more reflective of neurobiological literature for future outlook, with 'imagined futures' used more in psychosocial contexts. In addition, using a combination of search techniques is particularly useful when the amount of literature relating to the topic is small (Horsley et al., 2011). Where the gaps in the literature were broad, literature from similar fields was introduced as a source of comparison. For example, literature on social constructions of health or illness, and experiences of mental health and 'life-limiting' conditions was included.

Initial literature searches were carried out between October 2012 and June 2013, during the development of the research topic and possible research questions. Further literature searches were undertaken the following year in July 2014 alongside the data collection. These reviews sought to update the previous review with a more specific focus on future outlook emerging from the study visits and interviews. A third round of literature searches took place between January and April 2015, bringing together the literature reviews previously written with up to date literature relevant to the emerging thesis findings to develop the final literature review chapters. Overall, literature searches were carried out throughout the development of the study from considering research questions, through to understanding the data produced from the research and considering the application of findings to policy and practice. Searches ranged from general to more specific terms. Table 1 on page 26 provides primary and secondary search terms used during the literature searches and subsequent review process.

A variety of search engines were used including: Google Scholar, Stirgate (University of Stirling resource platform including: Cochrane Database of Systematic Reviews, PsychiatryOnline, ScienceDirect, and Social Sciences Citation Index), Dementia Catalogue (Alzheimer's Society library database), and PsychInfo. A range of literature was included for review, such as research-led articles, discussion papers, literature reviews, and reflective pieces relating to working with people with dementia. The relevance of papers to ageing, stigma, and future outlook was assessed by the researcher through critical reading (Saunders and Rojon, 2011) of the broader literature on experiences of dementia, social constructions of health and illness, and attitudes towards mental health. Bryman (2012) suggests there is always an element of judging research based on what the researcher finds relevant and interesting. In addition, policy literature such as the national dementia strategies was included to provide additional context to people's circumstances.

Abstracts were read with articles that contained information relevant to ageing, stigma, and future outlook being read in more detail. Although the study was focusing on Alzheimer's disease, dementia was included as a search term due to the synonymous use of the term in previous literature (Langdon et al., 2007). Further, articles which related to one of the three topics, but looking at a different type of dementia, were considered in more detail as a source of comparison. The primary focus of this thesis is how the individual experiences stigma and future outlook. Alternative perspectives

have been noted for their relevance, but not focused on in detail. For instance, there is general consensus that people with dementia are affected by stigma (Batsch and Mittleman, 2012). Therefore, the thesis is not looking to establish whether it is a stigmatised condition, but whether the stigma is perceived by those affected by Alzheimer's disease. Similarly, research that explores healthcare professionals' attitudes towards stigma and public attitudes was noted in terms of contextualising attitudes, but was not the main research focus as by its nature this type of research tends to miss the voices of people with dementia, and this thesis sought to keep people with Alzheimer's disease at the centre of the work. In addition, research which focused on residential settings, and areas such as minority groups, were used in the context of reading for background knowledge but not looked at in as much detail due to the nature of the participant sample (see chapter 4) and the type of research being carried out. Instead, the research aimed to understand the experiences of people living with Alzheimer's disease in the community in Scotland, in terms of stigma and future outlook. Therefore, literature which focused on these areas was prioritised.

Table 1 illustrates some of the search terms used relating to dementia, stigma, future outlook, and ageing. Search terms were added across the research process based on emerging themes from the data collection and analysis. This was particularly the case for papers which relate to 'future outlook' as there was limited literature available on this topic when starting the study. Similarly, the theories which have been discussed in the subsequent review emerged from common themes in the interviews, and through exploring the possible reasons behind people's responses.

	Example Search Terms	
Topic Area	Primary	Secondary
Ageing and Dementia	‘Older Adult’ ‘Young Onset’ ‘Early Onset’ ‘Late Onset’	‘Age associated’
Stigma and Dementia	‘Stigma’ ‘Stereotypes’ ‘Discrimination’ ‘Attitudes’	‘Courtesy Stigma’ ‘Family Stigma’ ‘Self-Stigmatisation’
Future Outlook and Dementia	‘Future Planning’ ‘Future Outlook’ ‘Advance Care Planning’ ‘End of Life Care’	‘Anticipated Future’ ‘Mental time-travel’ ‘Future time orientation’
Experiences of Dementia	‘Experiences of dementia’ ‘Living with dementia’	‘psychosocial factors’
Surrounding Literature	‘Stigma and mental illness/health’ ‘Experiences of mental illness/health’	‘Social constructions of health/illness/dementia’

Table 1. Examples of search terms used for synthesising literature relating to experiences of Alzheimer’s disease

The field of dementia research is growing rapidly, with national policy focused on increasing the numbers of people with dementia involved in research (Department of Health, 2012). As a result, the literature review sought to present the latest knowledge available relating to stigma, future outlook, and ageing, for people affected by Alzheimer’s disease. Initial searches were not limited by date, although Alzheimer’s disease was not recognised as an illness until the 1970’s (Fox, 1989), which would affect the research available prior to this. As literature was synthesised the latest research on each topic was sought to look for possible changes over time. Restrictions of 10 years, to 5 years were then included, depending on the scope and specificity of the

search. Overall, the literature searches produced a wide range of research papers which have been synthesised across the following two chapters.

Finally, as discussed in the previous chapter, this thesis has adopted a biopsychosocial perspective. This is not without critiques, with some suggesting that the model does not give clear guidelines about the relative emphasis on the biological, psychological, and sociological domains, with relevant implications for literature reviewed, and methodology chosen (Benning, 2015; Ghaemi, 2009). It should be noted that this is not an issue exclusive to the biopsychosocial model. Lilienfield et al. (2015) argue that the term biomedical model often faces similar ambiguity. The lack of clear guidelines to the integration for the different domains is discussed as being a result of the biopsychosocial model being developed as a solution to the biomedical model, rather than being based on theoretical understandings (Benning, 2015). Despite the lack of clarity between the emphases of each domain, the benefit of this freedom is in allowing researchers to focus on their particular areas of interest and expertise. My emphasis throughout the literature review has been a greater focus on the psychological literature, due to interest in how psychological frameworks explain the individual's experience of stigma (Modified Labelling Theory: Link, 1987) and future outlook (Socioemotional Selectivity Theory: Carstensen et al., 1999), contextualised with biological and sociological literature where appropriate.

Developing Alzheimer's disease: Exposure to stigma

The remainder of this chapter explores the literature currently available around how developing Alzheimer's disease can expose people to stigma. This process begins as people start to develop the condition, and recognise that symptoms may be impacting on their everyday life. This recognition of symptoms and subsequent help seeking is complex. It can be initiated by the person developing the condition, or from the awareness of those around them. This review has not focused on why people seek help; rather it acknowledges that one of the barriers to help seeking and diagnosis can be fear of stigma (Clement et al., 2015; Mackenzie, 2006). In order to understand how a diagnosis of a condition such as Alzheimer's disease can lead to negative attitudes of others, a biopsychosocial perspective has been adopted. This recognises that diagnosing conditions such as Alzheimer's disease is more than acknowledging a set of symptoms.

The experience of these symptoms and the way people respond to the condition are socially constructed.

Diagnosis of Alzheimer's disease

Diagnosis rates for dementia have increased over time and have been seen to correlate with the introduction of national dementia strategies which promote early diagnosis (Mukadam et al., 2014). According to Pratt and Wilkinson (2003) the diagnosis process is one of the most fundamental components in people's experience of dementia. It can be seen as the point in which someone adopts the identity of 'person with Alzheimer's disease' (Manthorpe et al., 2010) or 'supporter' (Ducharme et al., 2011). Literature which considers people's experiences of diagnosis will be synthesised before focusing on the two core topics this thesis explores: perceptions of stigma and future outlook. Although much of the discussion will focus on people's journey following a diagnosis, it is important to note how people experience their diagnosis and the potential consequences this may have on learning to live with Alzheimer's disease. This is particularly important when applying findings back to policy and practice, as much of the discussion surrounding stigma and future outlook is embedded within 'positives and negatives of early diagnosis' debates (Fox et al., 2013).

A range of emotions and experiences have been reported in the diagnosis of Alzheimer's disease literature, although the area is still discussed as under-researched given the importance of understanding people's experiences (Lee et al., 2014). A systematic review by Bamford et al. (2004) summarises commonly cited reasons for and against diagnosis including: facilitating planning and maximising opportunities for intervention, as well as risk of distress and stigma.

Stigma is a commonly cited reason for avoiding diagnosis and taking on the identity of a 'person with Alzheimer's disease' (Bunn et al., 2012), therefore suggesting caution regarding the drive for early diagnosis. Conversely, a proposed strength of diagnosis is the opportunity to plan for the future (Derksen et al., 2006). As noted previously the thesis does not aim to look at these two aspects distinctly, but to consider how they influence each other. For instance, much of current 'future planning' research focuses

on ‘care needs’, or considers the end points of the journey of Alzheimer’s disease, without the much needed recognition of the on-going journey following diagnosis.

Diagnosis may be where people take on the label of ‘Alzheimer’s disease’ (Manthorpe et al., 2010). However, their journey with the condition begins prior to this (Chrisp et al., 2012). A number of processes can be worked through by the person with dementia and their supporter, separately and together, before seeking a diagnosis (Keady and Nolan, 2003). Examples include, people covering up for minor ‘slips’ in memory, and normalising experiences until a point where the frequency and amount of change becomes harder to trivialise. The hurdles people experience prior to diagnosis highlight how pre-diagnosis can be associated with fear of being diagnosed with a condition like Alzheimer’s disease (de Vugt and Verhey, 2013).

Reactions to diagnosis can understandably be negative with experiences of shock, grief, distress, and denial reported in the literature (Bamford et al., 2004). Research which explores these experiences over time has suggested that these feelings can fluctuate and reduce (Vernooij-Dassen et al., 2006) as people adapt to both the label of the condition (Beard and Fox, 2008) and living with the symptoms (MacRae, 2008). Further, although a diagnosis can reduce uncertainty relating to symptoms experienced, the future is viewed as unpredictable and can be a threatening prospect for the person with Alzheimer’s disease and for their families (de Vugt and Verhey, 2013). The perspectives discussed are influenced by both biomedical understandings and societal assumptions about the condition, and may reproduce the stigma surrounding the condition by focusing on care needs.

A review of diagnostic-disclosure literature highlights that despite the negative experiences, the majority of people wish to know their diagnosis (Robinson et al., 2011). The preference for diagnosis can be contextualised by the work of Keady et al. (2009), who discuss how seeking and receiving a diagnosis can enable people to find ‘balance’. As such, they are able to move forward with the journey of Alzheimer’s disease, striving to keep balance as part of a dynamic process of decision making (Keady et al., 2009).

In light of this, understanding more about how people live with their condition post-diagnosis may help to influence the type of support provided to people with Alzheimer’s disease. In particular, how people manage the potential exposure to stigma

following diagnosis of Alzheimer's, and whether this influences future outlook and their engagement with future planning. The following chapter will focus on exposure to stigma, before considering the consequences of stigma and how people learn to manage their experiences. The following section synthesises literature relating to the process of stigmatisation, to illustrate how Alzheimer's disease and stigma have been connected.

Process of stigmatisation

There is general agreement relating to the meaning of stigma, however there are various definitions depending on the perspective being taken (Benbow and Jolley, 2012). For the purpose of this thesis, the definition given by Goffman (1963) has been used as a starting point. He defines stigma as "an attribute that is deeply discrediting" (p.13). This is based on prevailing social norms (Olafsdottir, 2013). A distinction is made between "discredited and discreditable" attributes (Goffman, 1963:14), which refers to whether the mark by which the person is stigmatised is immediately obvious to those around them (discredited), or is concealable or not recognised as quickly (discreditable). This level of visibility is suggested to impact on how intrusive a condition is on a person's everyday life, and their ability to manage (Kelly and Field, 1996). For example, Kelly and Field (1996) suggest that people with discredited attributes will experience greater challenges to their social identity, than people with discreditable attributes. The literature remains unclear regarding how people who experience symptoms which fluctuate in their level of intrusiveness manage their everyday lives. Specifically, the discredited/discreditable distinction does not consider experiences of stigma for people with Alzheimer's disease, where symptoms can be unpredictable in terms of their visibility (Phillips et al., 2012; Hellstrom and Torres, 2013).

The different elements of stigma and lack of agreement on an operational definition, make it a challenging concept to understand and research (Benbow and Jolley, 2012), despite general agreement towards its meaning. There are various models which seek to explain the complex process of stigmatization, particularly in the field of mental health (Olafsdottir, 2013). For example, Modified Label Theory (Link, 1987) was proposed to address the increasing need to acknowledge both the physiology of mental illness, and the social construction of labelling. The theory focuses on the behaviour of others in

labelling mental illness, whilst also acknowledging that stigma is made up of an individual's perception of others stigmatising them (Link and Phelan, 2012). The consequences are discussed based on how able a person is to continue 'normally' in society (Link and Phelan, 2012). The inherent involvement of people in the environment giving negative responses, as well as how the individual perceives and manages this, moves away from earlier models of stigma, which viewed labelling as a direct result of mental illness (Link and Phelan, 2012).

When considering differences in people's experiences of stigma, three different types of stigma are noted by Earnshaw and Chaudoir (2009): anticipated, enacted, and internalised. These will be discussed in more detail to highlight the different aspects of stigma, and how they may differentially influence future outlook. Within these three types, a distinction between prejudice and discrimination is noted. Prejudice refers to a group or its members being evaluated negatively, without considering who they are as individuals (Taylor et al., 2006). Discrimination is the behavioural consequence of prejudice, where the person or group is then treated adversely (Benbow and Jolley, 2012). Anticipated stigma defines people's expectations of experiencing prejudice and discrimination. This may be particularly prevalent within the earlier stages of people's journey with Alzheimer's disease. Recognition of symptoms and deciding whether to act on this is tied in with fears about what the diagnosis may mean, and the anticipated stigma attached (Vernooij-Dassen et al., 2005; Aminzadeh et al., 2007; Garand et al., 2009). Further, the presence of anticipated stigma highlights how future outlook is also relevant prior to diagnosis.

Enacted stigma refers to whether people believe others have been prejudiced and discriminatory towards them (Earnshaw and Chaudoir, 2009). This may be more relevant following diagnosis, where people are learning to live with Alzheimer's disease, and managing how people may react. Thirdly, internalised stigma focuses on whether a person endorses the negative feelings and beliefs associated with the stigmatised attribute towards themselves (Earnshaw and Chaudoir, 2009). This is also referred to as self-stigmatisation (Byrne, 2000). Importantly, the internalisation of stigma-driven assumptions such as 'no future' following diagnosis (Devlin et al., 2007) could influence a person's future outlook.

For people with Alzheimer's disease, internalised stigma includes a person's previous understanding of the condition as well as awareness of the changes they have experienced. For example, O'Sullivan et al. (2014) noted how participants who previously held prejudiced beliefs about people with dementia, had since found it harder to disclose their own diagnosis. Importantly, one of the myths of dementia is that people with the condition do not have awareness of their situation (Mendez and Cumming, 2003; Baste and Ghate, 2015). However, there is increasing literature highlighting that this is not the case, and that 'awareness' fluctuates along a continuum influenced by biopsychosocial factors (Clare et al., 2012). Despite this increasing knowledge of 'awareness', there remains a disproportionately small amount of literature which considers stigma from the perspective of those affected, with the majority of research focusing on how others view people with Alzheimer's disease (Burgener and Berger, 2008).

The approaches described thus far encompass a socio-cognitive approach to stigma (Corrigan, 2000). Alternative approaches which could be applied to people's experiences of Alzheimer's disease include sociocultural frameworks, where stigma develops through social injustice (Corrigan, 2000). Sociocultural models provide greater detail about the social and environmental elements of stigma than is possible when a socio-cognitive approach is taken, and offer an approach for understanding additional coping strategies to cognitive reactions (Yang et al., 2007). The work previously outlined by Link and Phelan (2001) has made important contributions in the shift towards sociocultural aspects of stigma by including a structural component to their model of stigma, whilst still maintaining an individual focus (Kleinmen and Hall-Clifford, 2009). Although a sociocultural approach provides useful insights for policy and practice, particularly in challenging public attitudes, Corrigan (2000) notes that socio-cognitive approaches are a promising alternative framework within psychology and mental health, and are particularly appropriate for exploring the individual's perceptions of stigma, as focused on within this thesis.

The majority of the research discussed so far has focused on either public understanding of Alzheimer's disease, or the person with the condition. However, it is important to recognise that close family and friends can also be exposed to stigma relating to their

association with Alzheimer's disease. Goffman (1963) termed the spreading of stigma from the stigmatised individual to their close connections as 'courtesy stigma'. Alternative terminology, such as 'family stigma' has also been used (Larson and Corrigan, 2008). Supporters have been documented as experiencing stigma based on their association with the person with dementia (Phelan, 2005), as well as stigma attached to their role (Werner et al., 2010). The extent of this stigma is unclear; Werner and Heinik (2008) reported that courtesy stigma has been largely unexplored in relation to supporters of people with Alzheimer's disease. There is some research which suggests courtesy stigma may be explained through assumptions about the origins of the stigmatised attribute. For example, Phelan (2005) found that people were more likely to stigmatise the sibling of a person with a stigmatised condition, if they believed it was genetic in origin. Similarly, Burgener and Berger (2008) discussed how the perceived genetic causes of dementia led to greater stigmatisation of people with dementia. Notably, this may suggest differences in stigma applying to people with early and late-onset Alzheimer's disease, as early-onset Alzheimer's disease is hypothesised by some to have a greater genetic influence than late-onset (Alzheimer's Association, 2004).

This discussion reiterates that Alzheimer's disease is not experienced in isolation, with stigma felt by the person with the condition and those close to them. It is important to consider how people's experiences interact, as the reactions of close family and friends to the diagnosis of Alzheimer's disease are seen to be much more important to people living with the condition, than the reaction of others (Benbow and Jolley, 2012). Therefore, when researching stigma it is important to explore both the person with Alzheimer's disease and their supporters' perspective of stigma.

The research literature presented considers people with Alzheimer's disease and their supporters as a fairly homogenous group. However, as Link and Phelan (2012) highlight, people's perception of stigma is made up of both individual and societal attitudes. The literature discussed highlights that the process of stigmatisation involves both the individual with the stigmatising attribute, and people within their social environment responding to this (Link and Phelan, 2012). This suggests that how people manage their experiences can shape their perceptions of stigma and vice versa. When exploring how people with Alzheimer's disease perceive stigma, the underlying assumption is that they are identifying themselves as somebody affected by the

condition. However, taking on such an identity involves exposure to the stigma attached to the group as discussed within the following section.

Research grounded in social psychology suggests that when diagnosed with a stigmatising attribute, people may separate themselves from the stigma through seeing others with the condition as worse off than themselves. This phenomenon is known as personal/group discrimination discrepancy (Taylor et al., 1990). By individuals framing their situation as better than others, they may also be able to disassociate themselves from the group norm, thereby protecting themselves from the negative consequences of stigma, which will be discussed in more detail later in the chapter.

Personal/group discrimination discrepancy (Taylor et al., 1990) was developed to explain the emergent finding that people perceived a higher level of discrimination towards their group (such as people with Alzheimer's disease) compared to themselves as an individual within the group (Taylor et al. 1990). Early research by Taylor et al. (1990) suggests several reasons for personal/group discrimination discrepancy, including attempting to minimise personal discrimination, an exaggeration of the amount of stigma directed at the overall group, and cognitive information-processing mechanisms. These findings are important to recognise when exploring how people with Alzheimer's disease and their supporters experience stigma. The theory suggests that if Alzheimer's disease is viewed as a stigmatised condition, individuals will report personal stigma as lower, than if they are discussing experiences of other people in the same group. Therefore, when measuring or exploring stigma, it is important to note that the nature of reporting may be influenced by how much people engage with the group identity. The following section will draw attention to some of the stigma attached to the group, to illustrate why people may find it beneficial to separate themselves from the group identity.

Components of stigma and Alzheimer's disease

A range of stigma in the form of negative attitudes and inaccurate beliefs has been reported in the literature towards people affected by Alzheimer's disease. Mendez and Cummings (2003) describe several myths including, Alzheimer's disease is

synonymous with dementia; dementia is an inevitable part of ageing; and that people with dementia cannot have insight into their condition. These myths have been seen within the general public, as well as amongst healthcare professionals (Baste and Ghate, 2015). Similar attitudes can be seen from public survey data in Ireland with responses including, once someone has dementia the person you knew will eventually disappear; and that people with dementia are like children and should be cared for as such (McParland et al., 2012). Similar examples appeared in focus groups in Scotland, with people with dementia viewed as having little awareness and whose ‘life is nil’ (Devlin et al., 2007:52). In addition, people noted that the public assumed the condition would be obvious or visible (Devlin et al., 2007). The myths highlight that the stigma is not just attached to the diagnostic label, but to the assumed experiences people will have post-diagnosis. They present an image of dementia as being something that cannot be lived with, which potentially leads to the skewed focus on end of life. Further, they fuel the catastrophizing discourse of dementia as a ‘living death’ (Sweeting and Gilhooly, 1997; Peel, 2014). As Behuniak (2011) argues, the stigma attached to Alzheimer’s disease is dehumanising and based on fear, describing how the socially constructed image of the condition has alarming parallels to that of zombies (Behuniak, 2011). The stigma-driven assumptions therefore do not recognise the continuing futures of people living with Alzheimer’s disease which this thesis will explore.

As noted within the introduction, the thesis explores people’s experiences of Alzheimer’s disease over other types of dementia. As well as the challenge of synonymous use of the terms ‘Alzheimer’s disease’ and ‘dementia’, there is debate among researchers as to whether the terms used influenced the extent of stigma. For example, Aminzadeh et al. (2007) found that people expressed greater distress about a diagnosis of Alzheimer’s disease, compared to vascular dementia. This is despite a similar illness trajectory (Kalaria and Ballard, 1999). Similarly, Robinson et al. (2011) suggests that ‘Alzheimer’s disease’ holds more negative connotations than ‘dementia’, which may in turn affect adjustment to diagnosis. Conversely, Langdon et al. (2007) found that both ‘Alzheimer’s disease’ and ‘dementia’ produced negative reactions, but particularly ‘dementia’ in its association to the word ‘demented’. This association is mirrored by Gilmour and Brannelly (2010) who used examples from fictional literature to reflect the underlying meaning, such as the ‘Dementors’ from J.K.Rowling’s Harry Potter novels. These are negative, soulless characters, which make a person ‘demented’.

This is described as ‘a fate worse than death’; a description also discussed in dementia literature (Innes, 2002). The literature presented does not lead to clear conclusions related to which terms will be viewed more negatively, adding to the complexity of exploring stigma and Alzheimer’s disease.

Understanding the stigma attached to the label of dementia or Alzheimer’s disease poses a challenge for health care professionals, among others. For instance, Moore and Cahill (2013) found that general practitioners (GPs) were avoidant of these terms, preferring to use ‘memory problems’. Part of this avoidance was explained as concern over scaring the person with the condition, reflecting fear. However, although avoidance of the word dementia may be them trying to protect people, arguably it continues to fuel the stigma (Milne, 2010). Further, the use of ‘memory problems’ as a synonym for Alzheimer’s disease may add to the confusion around what to expect, and how it differs from the ‘norm’. This may be particularly true for older people, given the uncertainty between what constitutes age-related memory loss or dementia (Leung et al., 2011). Additionally, previous research indicated that reducing dementia to memory problems can make it harder for people to manage. For example, Ikels (1998) found evidence of supporters blaming the person with dementia for behaviours that they had not understood were symptoms of the condition. Similarly, Stokes et al. (2014) reported that supporters found it harder to adjust to the full impact of dementia when symptoms other than memory loss were present. This was explained through being inconsistent with previous expectations about dementia equating to memory loss.

Alternatively, there may be people with Alzheimer’s disease who benefit from using the term ‘memory problems’ when defining their condition. Garand et al. (2009) discuss how people may adjust better to their diagnosis if they see it as ‘an expected part of ageing’, thereby not differing from the norm. As such, age-based differences may be expected for people with Alzheimer’s disease based on whether memory loss is normalised. Disentangling understandings relating to ‘normal ageing’ and Alzheimer’s disease has significant implications for older people with and without the condition, as well as younger people with Alzheimer’s disease. Therefore, ageing, stigma, and Alzheimer’s disease will be discussed in the following section.

Age-associated influences on stigma and Alzheimer's disease

Understanding what is perceived to be 'normal' influences whether people are likely to seek help or advice (Feldman et al., 2015; Werner et al., 2014; Mukadam et al., 2013). Neuro-degeneration is an expected part of ageing; but this in itself does not result in Alzheimer's disease. In previous research, such as Sonnen et al. (2011), significant beta-amyloid build up was seen in 25%-50% of cognitively 'normal' brains, despite the fact beta-amyloid is associated with Alzheimer's disease (Stern, 2002). The findings of Sonnen et al. (2011) emphasise the separation between age, neuro-degeneration and the development of dementia. Despite the neurological distinctions set out by Sonnen et al. (2011), the boundary between physiological ageing and early stages of dementia remains unclear (Derouesne, 2002).

The lack of clear boundary is further complicated by the presence of early-onset Alzheimer's disease. There is evidence to suggest younger people may take longer to diagnose as the condition is considered less likely (Van Vliet et al., 2013). However, older people may also face time delays based on the lack of clarity in age-related memory loss for healthcare providers trying to diagnose symptoms (Derouesne, 2002). Further, therapeutic nihilism whereby GPs and healthcare professionals may be more reluctant to diagnose an 'untreatable condition' may also differ by age group of the person seeking diagnosis (Rossor et al., 2010; Pinner and Bouman, 2003; Bradford et al., 2009). The complexity of the relationship between disclosure and age has been explored by Heal and Husband (2010), who found that age was a significant factor in disclosure. Younger people were more likely to be told their diagnosis (Heal and Husband, 2010). However, this could be linked to the diagnostician and type of dementia over age itself (Van Vliet et al., 2013). These findings suggest a need to explore in more depth whether age is a causal factor, or whether the expected differences by age are caused by other variables.

The differences in hypothesised age-based experiences discussed are embedded within societal attitudes towards ageing. From a biological perspective, ageing is a progressive build-up of changes to the body over time, which increases a person's probability of disease, and death (Vina et al., 2007). This perspective emphasises the inevitability of ageing, based on its universal, intrinsic, progressive, and deleterious nature (Strehler,

1977). The biological postulates suggest that ageing should not be a distinguishing feature between people, as it is a process that is continuous and happens to everyone across the life course. This would suggest that ageing, removed from its social context, would not be a cause of stigmatisation. However, focusing on the biological perspective alone does not give a comprehensive picture of how people experience their ageing and therefore how age may influence stigma.

Based on a synthesis of age-related literature, several possible directions of effects have been noted in relation to stigma. People with late-onset Alzheimer's disease may experience greater amounts of stigma than people with early-onset Alzheimer's disease. Alternatively, people with early-onset Alzheimer's disease may experience greater amounts of stigma than people with late-onset Alzheimer's disease. A final consideration is that the age of onset of Alzheimer's disease will not significantly influence the amount of stigma people experience. The literature supporting these three possibilities is discussed across the following section.

Firstly, people with late-onset Alzheimer's disease have been suggested to experience greater amounts of stigma due to the 'double stigma' of being an older adult and having Alzheimer's disease (Nolan et al., 2006). There is a wealth of research evidence to illustrate discrimination of people based on their age, with particularly acute stigma attached to older people (Richeson and Shelton, 2006). Thornton (2002) considered the myths of ageing, and how they contributed to ageism. Older adults have been stereotyped as being frail, ill, and dependent (Thornton, 2002). More recently, Erber and Szuchman (2015) revisited the myths of ageing and illustrated how there is minimal change over time to those highlighted by Thornton (2002), stressing how ingrained such views are in western society. Myths such as older people are poor drivers, and fully reliant on others (Erber and Szuchman, 2015) emphasise that older people are seen as an inferior group within society, who lose skills and abilities. This discussion is not intended to go through these myths and critique them; rather, the focus is how such assumptions impact on society and the person, particularly when these stereotypes can then accumulate with the stereotypes of Alzheimer's disease (Jolley and Moniz-Cook, 2009). As such, Scodellaro and Pin (2013) proposed that people affected by early-onset Alzheimer's disease experience less stigma than people affected by late-onset

Alzheimer's disease, as they do not have the additional stigma of being an older adult such as that described by Thornton (2002).

Alternatively, Chaston (2010) argued that people with early-onset Alzheimer's disease may experience more stigma than people with late-onset Alzheimer's disease. This is suggested to result from having a condition which is associated with older adults (Van der Flier and Sscheltens, 2005), leading to 'inverse ageism' (Chaston, 2010). This hypothesis is supported by theories such as Neugarten (1976), which consider how age-based norms influence experiences (Ferraro, 2013), and suggests that people will experience more adverse reactions to situations which take place 'off time' to their age-expected trajectory (Heckhausen et al., 1989). Therefore, the theory suggests people with early-onset Alzheimer's disease will be more affected by their diagnosis than older adults due to the 'untimely' nature of the condition.

Similarly, biographical disruption (Bury, 1982) research may suggest a difference in age groups based on experiences contrasting with the common cultural paradigms of conditions like Alzheimer's disease. Bury's (1982) work with people with rheumatoid arthritis highlighted slower diagnosis, increased uncertainty and feelings of premature ageing in younger participants. Experiences may resemble those of living with Alzheimer's disease, particularly with the awareness that there is limited medical knowledge, and no cure for the condition. However, the literature search did not find papers which have explored people with early and late-onset Alzheimer's disease in relation to biographical disruption, although researchers have suggested its applicability to experiences of dementia (Tolhurst and Kingston, 2013). A more recent paper by Boerner and Wang (2010) provides additional support for the expectation that younger people will be more affected by changes in health, by looking at vision loss among older and younger adults. The study highlighted that vision loss had more negative consequences for younger adults than older adults, and this was explained through the 'untimely' nature of the condition for the younger population (Boerner and Wang, 2010). It should also be noted that the concept of biographical disruption has been criticised for too strong a focus on biographical identity with insufficient attention to the biological and physical aspects of living with a chronic illness (Kelly and Field, 1998; Williams, 2000).

Although much of the biographical disruption literature suggests younger people may be more affected by onset of a chronic illness than older people (Pound et al., 1998; Sanders et al., 2002), conflicting research is also available to suggest older people may be more affected by change even if the disruption is expected (Larsson and Jeppsson-Grassman, 2012). The somewhat conflicting nature of the discussions of age and chronic illness within the biographical disruption literature further supports the inclusion of both younger and older people within research into conditions such as Alzheimer's disease, as this will allow for more direct age-based comparisons of the same condition. A socio-cognitive framework could therefore extend what is known about stigma across age groups to explore how people with dementia and their supporters describe, experience and manage stigma at different ages.

Interestingly, Boener and Wang (2010) highlighted that, although there were age-differences in the impact of vision loss for older and younger adults, this was not evident across all aspects of functioning. This finding suggests that age-based differences may not affect all aspects of people's experiences of adjusting to 'age-associated conditions'. For example, health psychology literature has highlighted how age-based differences may be minimised when people face a 'life-limiting' condition (Carstensen and Fredrickson, 1998; Sullivan-Singh et al., 2015). This lack of difference has been explained through people employing similar methods for managing experiences irrespective of age; thereby suggesting that age is not the causal factor (Fung and Carstensen, 2004; Lockenhoff and Carstensen, 2004). These findings will be explored in more detail in chapter 3 in relation to Socioemotional Selectivity Theory (Carstensen, 1991) and managing exposure to stigma and future outlook. Collectively, the research evidence depicts a complex relationship between Alzheimer's disease, ageing, and experiences of stigma. The relationship will be explored further by considering experiences of people affected by early- and late-onset Alzheimer's disease within the same study.

Consequences of stigma for people with Alzheimer's disease and their supporters

Although there is a wealth of literature relating to stigma, there are several gaps which are yet to be addressed. The rationale for understanding more about stigma can be seen

through the possible consequences people who are stigmatised may be exposed to. These consequences can impact on both the person with Alzheimer's disease, and their supporter in both everyday experiences and looking to the future. The second literature review (chapter 3) will consider whether exposure to stigma and its consequences can be managed effectively, thereby outweighing some of the potential risks of diagnosis and offering an opportunity for supporting people to look to the future.

A meta-analysis of studies which looked at discrimination effects on health concluded that perceived discrimination negatively impacted on a person's mental and physical well-being (Pascoe and Richman, 2009). Stigma has been seen to decrease well-being of people with dementia (Milne, 2010), including loss of confidence and subsequent withdrawal from activities (O'Sullivan et al., 2014). Further, people affected by dementia have discussed fears of disclosing their condition due to fear of stigma (Reed and Bluethmann, 2008). Fear of disclosure could increase the social isolation of people affected with dementia (Nolan et al., 2006). Importantly, stigma relating to Alzheimer's disease and other dementias can increase the symptoms and negative outcomes of the condition for people affected (Bamford et al., 2014).

Supporters of people with Alzheimer's disease have also been reported to experience various consequences of stigma including anticipatory grief defined as "the process of experiencing normal phases of bereavement in advance of the loss of a significant person" (Garand et al. 2012:159), based on the belief that the person with Alzheimer's disease will be lost (Garand et al., 2012). Anticipatory grief has been seen in supporters of people with dementia at a range of time points, due to the recognition of loss and expected losses. The literature surrounding the consequences of anticipatory grief is conflicting. For example, Garand et al. (2012) discuss how, although anticipatory grief can have negative effects on supporters' psychological and physical health, it has also been noted that expression of anticipatory grief can reduce 'caregiver burden'.

Whereas, researchers such as Holley and Mast (2009) report that anticipatory grief is significantly associated with 'caregiver burden'. This finding is more reflective of literature from other health conditions, such as Cora et al. (2012) who found that anticipatory grief led to worsened supporter stress for people living with terminal cancer. Feelings of loss and anticipatory grief have also been shown in studies surrounding insight, affecting all family members, not just the primary supporter (Allen et al., 2009). The highest levels of anticipatory grief were seen in the early stages of

Alzheimer's disease in the Garand et al. (2012) study; this could be due to facing the unknown, and predicting the future based on stereotypical knowledge, further highlighting the possible link with stigma and societal understandings of Alzheimer's disease. Anticipatory grief may decrease over time due to adaptation to everyday living with the disease and discovering how best to manage, however, this was not explicitly researched in the study.

Additional consequences of stigma for supporters include, experiences of shame and guilt (Werner et al., 2010), highlighting the similarities in consequences for the person with Alzheimer's disease and their supporter. Additionally, feelings of shame and embarrassment have been reported by older people with forgetfulness due to fear of dementia (Ballard, 2010). Taken together, the findings highlight the breadth of people the stigma attached to dementia, and its consequences, impacts upon.

An additional consequence of stigma is suggested to be reduced rates of diagnosis (O'Sullivan et al., 2014). As the previous discussions highlight, this resistance to diagnosis may be from the person with condition themselves, their families, or healthcare professionals. However, Benbow and Jolley (2012) propose that non-disclosure is denying people the opportunity to plan for their future, even if well-intentioned. These findings reiterate the overlapping relationships between stigma and future planning, following the diagnosis of Alzheimer's disease. There is also a need to consider how stigma may influence future outlook more generally, moving beyond a focus on planning. Frazier et al. (2003) found that a diagnosis of Alzheimer's disease and the attached stigma can create a feared future-self. These fears included loss of independence and becoming dependent on others. This suggests that internalisation of stigma-driven assumptions of Alzheimer's disease may affect how people adjust to living with the condition and imagine themselves in the future.

These conclusions are supported by recent research of Kristiansen et al. (2015) who considered how people with Alzheimer's disease view the future. Two very different case studies are reported. The participant in the first case study focused on the present, and deliberately avoided thinking about the future. This was suggested to positively influence their quality of life. The other participant focused on their fears relating to the future, which led to increased feelings of despair (Kristiansen et al., 2015). The findings suggest that when stigma-driven fears are highly salient, people will find looking to the

future very distressing (Kristiansen et al., 2015). Further, they suggest that diagnosis of Alzheimer's disease may not necessarily lead to people planning for the future. This will be considered in more detail in chapter 3. The difference in experiences between the two case studies emphasises the need to recognise that people with Alzheimer's disease do not represent a homogenous group, and that subjective experiences are made up of a complex interplay between biological and psychosocial factors. In addition, understanding more about how people can positively manage their experiences may provide insight for helping others who express greater fear of the future.

Conclusions and key gaps in the research literature

Overall, this chapter has outlined that there are many myths and negative beliefs relating to Alzheimer's disease. The process of stigmatisation is complex; across the research literature it is evident that there is no inherent attribute which leads to stigma (Olafsdottir, 2013). Various predictors relating to the extent to which people will be stigmatised against have been suggested. These include the origin of the condition, the visibility or intrusiveness of symptoms, and accumulation of multiple or conflicting stereotypes such as age-based expectations. Within this study, several stigma-based assumptions about Alzheimer's disease have been challenged to get a sense of how people experience the condition. This includes listening to the voices of those affected by Alzheimer's disease, and acknowledging that their future is not solely 'care' focused.

Current literature generally separates the experiences of people with early and late-onset Alzheimer's disease, with conflicting hypotheses relating to the challenges they may face. However, minimal research has been done which explicitly considers the two age groups within the same study, particularly from a biopsychosocial perspective. Therefore, it is unclear whether the findings reported about the two age groups are reflective of age, or other possible variables. This supports the inclusion of both age groups within one study for this research.

Chapter 3- Living with Alzheimer's disease: Managing stigma and looking to the future

Within the UK there is a strong drive to increase the rates of early diagnosis of dementia, as demonstrated by Alzheimer's Society (2015c) 'Right to Know' campaign. As outlined in chapter one, part of this drive is to encourage early interventions and future planning for people affected by the condition (Luengo-Fernandez et al., 2010). However, one of the consequences of diagnosis, as discussed in chapter 2, is exposure to stigma (Milne, 2010). The reasons behind the stigmatisation of Alzheimer's disease have not been linked to any one particular attribute (Olafsdottir, 2013); rather there are a range of complex processes which appear to underpin people's experiences. Given the complexities discussed, several similarities and differences in experiences of stigma have been hypothesised based on possible subcategories within the group, such as age of onset. Importantly, a range of negative consequences have been associated with exposure to stigma for people with Alzheimer's disease and their supporters.

This chapter reviews how people affected by Alzheimer's disease manage the consequences of stigma, with a particular focus on how it may influence their future outlook. Firstly, the key theoretical framework for the research, socioemotional selectivity theory (Carstensen, 1991), is introduced before applying the findings to managing stigma and the resultant fears about the future. There is minimal research which has used this theory in the field of Alzheimer's disease, however, there is literature across disciplines suggesting the theory may facilitate understanding of how people manage negative experiences and look to the future as a person with a 'time-limiting' condition. This therefore involves a novel approach to how people with Alzheimer's disease manage their condition.

The limited theoretical frameworks available for understanding future outlook and Alzheimer's disease are likely to reflect how current literature focuses more on end of life care (Denning et al., 2011; Robinson et al., 2010; Dickinson et al., 2013). Further, it is suggested that the increased presence of advance care planning literature compared to everyday future planning may inadvertently fuel the stigma, by suggesting that a diagnosis of the condition is equivalent to a lost future (de Medeiros, 2010; O'Sullivan et al., 2014). This thesis has adopted an alternative perspective to future outlook, in

which ‘care’ is one of many parts of a complex set of experiences across the journey of Alzheimer’s disease. Finally, research will be synthesised to consider whether people with Alzheimer’s disease are planning for the future, as recommended by the drive for early diagnosis.

Socioemotional selectivity theory: Stigma and Future Outlook

Given the negative beliefs attached to Alzheimer’s disease highlighted in chapter 2, it is important to consider how people may learn to manage their exposure to stigma.

Synthesis of research literature has led to a focus on how particular cognitive processes may shape the way people manage the physiology of their condition, as well as how society responds to them. Socioemotional selectivity theory (Carstensen, 1991) is one of several ‘social-cognitive approaches’ towards ageing (Christopher, 2014), and has been chosen as the theoretical framework for much of this research due to its understandings of health and ageing, as well as its applicability within a biopsychosocial perspective. One of the underlying assumptions of the theory is that human behaviour is guided by pursuit of goals (Carstensen et al., 1999). ‘Knowledge seeking’ goals refer to engaging in social interactions for the primary purpose of acquiring information. Conversely, ‘emotion seeking’ goals refer to pursuing interactions to regulate emotional states. When people are motivated by their ‘emotion seeking’ goals they are more likely to avoid negativity and focus on positive interaction (Carstensen et al., 1999). These two goal states are not mutually exclusive, but hold different consequences in time. ‘Knowledge focused’ goals are underpinned by a focus on future pursuits, acquiring information to affect future outcomes. Whereas, ‘emotion focused’ goals are about emotion regulation in the present, in keeping with a ‘day at a time perspective’.

Changing perspectives of time, from expansive to restricted, leads to greater numbers of ‘emotion focused’ goals (Carstensen et al., 1999). This has been suggested to occur for older people and people with ‘time-limiting’ conditions (Carstensen et al., 1999).

Traditional developmental theories have a tendency to separate people into age categories, which make it difficult to consider the possible overlap in experiences across groups. Socioemotional selectivity theory provides an alternative view, where

age-based differences in people's everyday experiences are a result of different motivational goals, rather than age being a causal factor (Lockenhoff and Carstensen, 2004). The use of this theory was considered important for recognising that both older and younger people can develop Alzheimer's disease (Alzheimer's Scotland, 2011). According to the theory, both older people and people who are experiencing 'time-limiting' conditions will have similar responses to stigma and views of the future. This is due to a restricted sense of time and pursuit of 'emotion focused' goals. In comparison, younger people without health conditions are seen to view time as expansive, and therefore are more orientated towards 'knowledge focused' goals (Carstensen et al., 1999).

The theory suggests that people with a 'time-limiting' condition, in this case Alzheimer's disease, are more likely to prioritise positive emotional states. This phenomenon led to literature which questions how people can maintain a positive emotional state whilst faced with negative circumstances (Sharot, 2011). For example, how people manage negative attitudes and beliefs towards Alzheimer's disease, and look to a future which is stigmatised as solely 'care'. Socioemotional selectivity theory suggests that in order to remain positive, the smaller things in life become appreciated (Hicks et al., 2012). Most importantly the relationships with those around us are prioritised, due to the pursuit of emotionally engaging experiences (Carstensen, 1991). This may explain findings of Benbow and Jolley (2012) noted in chapter 2, where family and friends' reactions to Alzheimer's disease had a greater impact on how people adjusted to their diagnosis. Emotion-focused goals lead to social networks getting smaller; this is viewed as an active, deliberate process (Carstensen et al., 1999). Further, Steeman et al. (2013) found a shift in values for people with early-stage dementia from 'being valued for what you do' to 'being valued for who you are', which mirrors the knowledge to emotion-focused trajectory suggested by socioemotional selectivity theory.

Expanding on this, one of the explanations for how people maintain positivity in the face of adversity is through a positivity bias in processing (Walker et al., 2003). Exploration of the positivity bias stems from the 'paradox of ageing' that while physical health declines as a person ages, their psychological health and well-being is often maintained or improved (Diener and Suh, 1998). The presence of a positivity bias,

whereby people are more likely to process and remember positive over negative information, can be seen as a universal bias in human cognition (Mezulis et al., 2004).

Research suggests that as people get older, they show a preference for processing positive memories, and show better recall of positive stimuli, relative to their younger counterparts (Mather and Carstensen, 2005). Similarly, Berntsen et al. (2011) found that positive events were seen as more central to older people's life story and identity. The centrality of the positive event increased over time, whereas for negative events this decreased (Berntsen et al., 2011). Negative events have also been seen to fade faster from a person's memory than positive events (Walker et al., 2003). Exploration of autobiographic memories across age groups has suggested that older adults are more likely to focus on positive memories of events, as well as use positive reappraisal of negative encounters (Mather and Carstensen, 2005; Folkman et al., 1987). The findings discussed highlight how the neurological mechanisms of memory are malleable to psychosocial factors, and importantly can be self-protective (Green et al., 2005). Within psychology literature, this self-protective quality of memory is described as 'mnemonic neglect' (Sedikides and Gregg, 2003). This term describes how people are less likely to recall information which is negative towards them (Green and Sedikides, 2004). This supports previous research which highlights a shift towards positive memory recall as people age, or face 'time-limiting' conditions. Further, Green et al. (2005) suggest that this self-protective forgetting is more likely when the negative information refers to something that a person is unable to change about themselves. This could suggest that people with Alzheimer's disease and their supporters are more likely to experience mnemonic neglect as the condition cannot be cured.

Together, these findings have important implications for how people may report the positive and negative experiences associated with Alzheimer's disease. For instance, taken alone these results may also suggest age-based differences in experiences for people with Alzheimer's disease, with older people reporting more positive experiences. However, if considered alongside socioemotional selectivity theory, similar reporting may be the case, due to the similarity in viewed time for people with 'time-limiting' conditions.

Although these findings may suggest people are able to manage their experiences of stigma through changing what they attend to, such findings have not been directly

explored in the experiences of people with Alzheimer's disease. The increased interest in whether the self-protective mechanisms of memory are applicable to people with memory difficulties has been highlighted by on-going research looking specifically at mnemonic neglect in people with Alzheimer's disease and dementia (UK Clinical Research Network, 2015). The current gap in applying findings to this population is largely due to the mechanisms such as the positivity bias being an active process which requires cognitive resources (Reed and Carstensen, 2012). Therefore it is unclear whether people with Alzheimer's disease are able to apply the bias. The available evidence surrounding this is inconclusive, with evidence to both support and refute the positivity bias in people with Alzheimer's disease (Mark, 2012).

Several hypotheses can be suggested based on whether people are able to make use of the positivity bias, and shift their motivational goals as set out by socioemotional selectivity theory. If Alzheimer's disease stops people being able to use the positivity bias, experiences of younger and older people with the condition would be expected to be similar, such as both groups reporting high levels of stigma. If the positivity bias is not influenced by Alzheimer's disease, older adults are likely to report less stigma than younger adults. Alternatively, both older and younger people could be influenced by the positivity bias, due to increased motivation to focus on positive events while facing a 'time-limiting' condition. This would result in similar experiences, but with lower reporting of negative events such as stigma. The presence or absence of the positivity bias to manage stigma also results in different hypotheses for supporters' experiences. If the bias is seen to affect people with Alzheimer's disease and older people, differences between younger and older supporters may be seen. However, this difference would rely on the assumption that younger supporters continued to see time as expansive. Alternatively, the complex relationship between people with Alzheimer's disease and their supporters may result in a shared perception of time, leading to both being influenced by the positivity bias.

The research presented thus far highlights the possible applicability of socioemotional selectivity theory to people's experiences of Alzheimer's disease in terms of perceptions of stigma. It also draws attention to the change in people's motivational goals which not only impact on interpretation of events, but also affect how people manage their future. When time is seen as restricted, people are more likely to focus on each day at a time, optimising resources to focus on meaningful experiences over

gathering knowledge for the future (Lockenhoff and Carstensen, 2004). Therefore, the theory would suggest that people affected by Alzheimer's disease are likely to avoid looking to the future. This raises important questions for the debate surrounding diagnosis and opportunity to plan ahead. However, several challenges to the applicability of the theory should be noted. For example, socioemotional selectivity theory is based on the assumption that a person feels that their time is restricted, whether that be by age or health condition. However, people with Alzheimer's disease experience differences in levels of awareness about their condition (Clare, 2004). This is further complicated by the fact that this awareness is not stationary, but continually fluctuating along a continuum with marked individual as well as group differences (Phinney, 2002). Such difficulties make it a very difficult area to research as it is unclear how time will be viewed; however, the available literature supports further research in this area.

Biopsychosocial perspective on looking to the future

In order to understand more about whether people with Alzheimer's disease are able to look ahead and plan for the future, the process of looking to the future will be discussed. These findings will then be applied to what is currently known about Alzheimer's disease. The physical process of looking to the future has been most widely considered within neurobiological literature. The phrase 'mental time travel' has been used to explain the experience of thinking of oneself across time (Tulving, 2005). Importantly for considering the experiences of people with Alzheimer's disease, the neural mechanisms behind remembering the past have been linked to imagining future events (Addis et al., 2007). This is indicative of a specific core brain system (Buckner and Carroll, 2007) which influences ability to 'mentally time travel'. This is particularly true for episodic memory (Abram et al., 2014), the type of memory focused on events, rather than facts which is referred to as semantic memory (Squire et al., 1993).

The simulation of future events requires a system which can flexibly bring together details of past events (Schacter et al., 2007). As this requires a piecing together of information, rather than a replay of the past, studies have shown that people find it easier to imagine a future where simulated events have familiarity (De Vito et al.,

2012). As such, it may be more difficult for people with Alzheimer's disease to look ahead if they have not had previous experience of the condition, or if their current experiences are very different to past circumstances. The research on the neurological mechanisms of memory suggests that there is significant overlap between how people remember the past and how they imagine the future (Addis et al., 2007). This has recently been looked at more specifically in research including older adults, and people with Alzheimer's disease. Schacter et al. (2013) reviewed studies which looked at older adults' memory capacities, and found that the ability to imagine future events is correlated with memory deficits. They reported that increasing memory deficits were associated with greater difficulties with such imagination. This can be explained through the additional complexity of recombining stored information, which needs to be easy to retrieve (Schacter and Addis, 2007).

Similarly, people with Alzheimer's disease have been shown to have marked impairments in simulating future events (Addis et al. 2009). This is unsurprising given the importance of core networks in facilitating this, as well as the increased cognitive load associated with such activity (Schacter et al., 2013). The reviewed evidence appears to suggest that people affected by Alzheimer's disease are not able to imagine the future. However, it is unclear whether the ability to 'mentally time travel' influences people's ability to plan ahead. This would pose a significant challenge to earlier discussions on diagnosis and future planning.

More recently, there has been increasing insight into the psychosocial experience of imagining the future (Schacter et al., 2012). This has the potential to increase our overall understanding of people's experiences, when combined with the neurobiological perspective. A study conducted by Szpunar and Schacter (2013) found that if people repeatedly simulated a personal event in their future, it increased the subjective plausibility of that event taking place. For instance, if a person repeatedly imagined a job promotion in their future, it led to them believing this was more likely to happen. This was found for both negative and positive events. Similar responses can be seen in terms of discussions around topics such as death, where there is often a fear that discussion will make death more imminent (Kirshbaum et al., 2011). These findings could have a significant impact on those affected by Alzheimer's disease. Imagining a future which is stereotypically very negative, and involves an increasing need for care (Chenoweth et al., 2009) may make this possible future feel more likely. This could

have a significant emotional impact (Kristiansen et al., 2015). Overall, these findings suggest that even if people affected by Alzheimer's disease are cognitively able to look to the future, they may deliberately avoid it, therefore not utilising the future planning focus promoted through diagnosis. The following section will consider the factors associated with future outlook in more depth to understand the processes involved and possible influences of Alzheimer's disease.

Are people affected by Alzheimer's disease looking to the future?

The search strategy presented in chapter 2 highlighted that there are many terms used when referring to future outlook. These terms are often used interchangeably (Aspinwall, 2005), but do not all cover the same aspects of future outlook. For example, central to economic theories of decision-making is the notion of a plan (Hey, 2005). Research in this field has explored whether and how far people plan ahead, to understand decision-making processes in more detail (Hey and Knoll, 2007). Similarly, future planning or 'future-orientated thinking' has been extensively explored in psychological literature, focusing on achievement-orientated behaviour (Aspinwall, 2005). Planning is proposed to be a central skill within human behaviour (Friedman and Scholnick, 1997). It has been suggested that planning for the future in relation to an event such as an exam, may differ from planning for future care needs (Aspinwall, 2005). Further, as well as types of planning there are individual differences in whether people choose to plan ahead (Hey and Knoll, 2007). The way people look ahead is also likely to be influenced by social structures (Settersen, 1999) and expectations about how people should approach their futures (Trommsdorff, 1983). In the context of people living with Alzheimer's disease, this includes policy focus such as Scotland's Dementia Strategy's (Scottish Government, 2013) commitment to supporting people to plan for future needs.

It has been suggested that people will not plan if they believe the outcome is not amenable to personal control (Skinner, 1997); however this relationship is complex. Making the decision to plan involves recognising the need for a plan, and believing that making a plan will be advantageous (Skinner, 1997). In essence, the majority of research has focused on how people view the future when seeking to achieve particular

goals or outcomes. Looking to the future is more complex than this, incorporating planning, goals, hopes, expectations, and predictions (Aspinwall, 2005). For example, in chapter 2 it was noted that people may anticipate stigma towards Alzheimer's disease and therefore fear seeking or disclosing a diagnosis. As such, the way people view the future impacts on everyday-life decisions as well as more specific events, highlighting how multiple systems may shape future outlook (Beal, 2011).

Several theories have emerged which consider future outlook within them. For instance, the model of possible selves (Markus and Nurius, 1986) suggests that how we view ourselves guides how we look to the future. Possible selves evolve across the life course and can include both hoped-for and feared-for possible selves (Whitbourne, 2005). Similar concepts of hoped-for selves have been discussed within sociological literature in relation to aspirations and expectations (Beal, 2011), which focus on idealistic future attainment (Messersmith and Schulenberg, 2008). A longitudinal study by Frazier et al. (2000) found that hoped-for selves and feared-selves were largely continuous over time, although health-related selves became increasingly prevalent with age. In relation to Alzheimer's disease, Frazier et al. (2003) discuss how the condition can impact on feared-for future selves including loss of independence, and becoming dependent on others. The research discussed suggests that internalisation of stigma-driven assumptions and fears of Alzheimer's disease may affect how people adjust to living with the condition and see themselves in the future.

The complexity of future outlook may explain the limited research in the field of dementia. As the neurobiological research highlighted, the processes involved in 'mental time travel' raise questions about whether people affected by Alzheimer's disease are able to think ahead. However, the intricacy of future outlook suggests it is unlikely to be an 'all or nothing' phenomenon. Research into future outlook in the context of lifespan development and stressful events has suggested several insights into how people look to the future and manage adversity. For instance, the role of 'controllability' of the stressor may influence the extent to which the stressor impacts on future outlook, with people showing greater reluctance to look ahead if the outcomes are seen as uncontrollable (Skinner, 1997). A lack of control does not necessarily mean that people do not look ahead, but that factors such as hope become increasingly important in facilitating the process (Bruininks and Malle, 2005). In addition, whether events are long-lasting can influence future outlook relative to events which take place

in a shorter time period, with ‘going with the flow’ being associated with better outcomes for longer-lasting events (Aspinwall et al., 2005).

As noted throughout the previous chapters, much of the driving force behind early-diagnosis of Alzheimer’s disease is in enabling people to plan for the future (Social Care Institute of Excellence, 2013). However, evidence across disciplines presented so far in the review suggests that this may not be happening for people affected by Alzheimer’s disease. Small and Rhodes (2001) found that people who were seriously ill were reluctant to think about future needs, and preferred to focus on a ‘day at a time’ approach. Similarly, Brown and Graaf (2013) observed that people facing high levels of vulnerability and uncertainty due to progression of cancer, were more likely to focus on the day-to-day present than the future. This was particularly evident when people did not feel they had control over the outcome of their condition, as noted previously (Skinner, 1997). When control is taken away, it is more adaptive to focus on situations that you can have mastery over (Brown and Graaf, 2013). Further, hope can play a key role in time-orientation. Future time was a place where hopes could be directed towards, and where negative futures could be ‘bracketed away’ (Brown and Graaf, 2013).

For the people in Brown and Graaf’s (2013) research, there was a ‘certainty and inevitability of death’ but the time-frame in which this would occur was unclear. This level of uncertainty in time-frame is often mirrored in the experiences of people affected by Alzheimer’s disease, as the trajectory of the condition is hard to predict (Doody et al., 2010). One of the ways of managing the unpredictable timescale is to focus on the near future, and ‘bracket away’ the negative outcomes which may lie further ahead. Such strategies may be particularly useful in cases such as Alzheimer’s disease where the progression of the condition leads to an inevitable difficult future in terms of a decline in independence and increased care needs (Jalbert et al., 2008; Feldman et al., 2005). It is worth reiterating at this point that despite this progressive decline, quality of life does not always follow the same path, and people across the journey of dementia can still experience high quality of life (Trigg et al. 2010; Conde-Sala et al., 2014).

In keeping with socioemotional selectivity theory, Brown and Graaf (2013) found that if people were able to reimagine their futures and focus on the emotional experiences in

daily living, they were better able to adapt to their condition (Brown and Graaf, 2013). However, the ability of people with Alzheimer's disease to reimagine futures may be dependent on neurological mechanisms, and a person's ability to understand the implications of their diagnosis (Schacter et al., 2013). Overall, these findings highlight that looking to the future is not one-dimensional. The level of active and passive engagement in such practice changes over time, and may be affected by the level of both physiological and psychosocial resources a person has available.

In addition, it is important to recognise that although deliberate avoidance of negative information and focusing on the present day may be adaptive for people, it may have unintended negative consequences. Lockenhoff and Carstensen (2004) note that as people face health conditions which restrict their perception of time, the subsequent shift in motivational goals affects health choices. Evidence suggests that older people or people facing 'time-limiting' conditions may avoid negative information, as their primary motivation is to maintain positive emotional states (Lockenhoff and Carstensen, 2004). A consequence of this is that people may avoid information that although unpleasant may be necessary to consider for future planning. For instance, people may be more likely to avoid advance care planning, power of attorney, and deciding on preferences for community or institutional care. However, it is not clear whether making such plans will lead to better outcomes overall for people with Alzheimer's disease. Robinson et al. (2012) argued that the current evidence for advance care planning positively influencing future care and wishes is variable.

The previous sections have focused on literature largely from the neurobiological and psychological literature. Mische (2009) argues that 'imagined futures' is a generally neglected topic in sociology; however, Mische's (2009) discussion goes on to highlight how considering future projections may allow for increased knowledge and understanding about the ways in which people think and behave. How people think about the future and when they plan ahead are questions of particular interest to this thesis, which aligns more closely with psychological literature (Aspinwall et al., 2005; Frazier et al., 2000; Schacter et al., 2012).

In addition, Mische (2009) highlights that the work in this area mostly uses questionnaire and interview methods to consider future outlook, further supporting a similar design for this thesis. Despite the lack of sociological focus specific to imagined

futures (Mische, 2009), there is relevant literature related to how people experience illness and their futures living with chronic conditions. Nettleton (2013), for example, explains that chronic illness can impact on daily life, social relationships, identity and sense of self. The impact of chronic illness is explored in more depth within sociological theory.

Biographical disruption (Bury, 1982) is one theory from a more sociological perspective which explores chronic illness in the context of self and identity. Early writings using the theory focus on the experiences of people living with rheumatoid arthritis; however, there are theoretical overlaps with other conditions. Biographical disruption describes chronic illness as being a critical disruptive event in people's lives, whereby the underpinnings of everyday life are unsettled leading to awareness of pain, suffering, and potential death (Bury, 1982). This potentially paints a very bleak picture, and has potential dissonance with the current focus on 'living well' with conditions such as Alzheimer's disease (Department of Health, 2009). However, the discussions of Bury (1982) and others (Charmaz, 1983, 1995; Robinson, 1988) highlight that, when faced with critical situations a person is required to re-think their biography and sense of self, and re-examine views of the future (Bury, 1982; Charmaz, 1983, 1995; Robinson, 1988). Alternatively it may be that people do not wish to engage with the potential for negative changes and instead actively minimise their thoughts about change, the future, and the consequences of Alzheimer's disease on their lives. Focusing on the present to deliberately avoid thinking about the future is suggested to be dissonant with Bury's (1982) notion that an unexpected event disrupts a 'taken for granted' life course (Larsson and Jeppsson-Grassman, 2012). Active avoidance of the future may thus suggest awareness that the event or change is a possibility (Larsson and Jeppsson-Grassman, 2012).

Recent research by Larsson and Jeppsson-Grassman (2012) raises additional concerns over the applicability of biographical disruption to conditions that involve repeated disruption. For example, the symptoms of Alzheimer's disease are progressive and likely to be continually disruptive. Further, much of the work on biographical disruption focuses on the onset of a condition, but as Larsson and Jeppsson-Grassman (2012) highlight, for some conditions the risks of worsening symptoms can increase over time. Williams et al. (2009) similarly argue that biographical disruption may not be as

relevant when focusing on future illness trajectories, due to the continual biographical revisions needed over time.

Based on critical reading and appraisal of the literature presented across the two literature review chapters, Socioemotional Selectivity Theory (Carstensen, 1991) has been chosen over alternative theories discussed. This decision is based on Socioemotional Selectivity Theory's relevance to younger and older people living with a chronic illness, in particular the possibility of similar experiences not captured in previous literature, and due to the gaps currently not addressed in relation to the theory and people with Alzheimer's disease (Mark, 2012). Other perspectives such as biographical disruption are one of several 'lenses' that could have been used to explore experiences, although this may have been more beneficial if a life-history perspective had been taken, exploring the impact of stigma on the self and future self. Although an interesting angle, this was not the primary aim of the research. Instead, this thesis focuses on perceptions of stigma and the associations between stigma and the ways in which people view and plan for the future. The complexity of these two issues suggests that multiple approaches could be taken to explore them. This thesis, using a psychological lens and framed within a biopsychosocial perspective, as discussed in chapter 1, has led to the decision of a mixed-method approach, capturing a 'snap shot' of people's experiences living with Alzheimer's disease in relation to stigma and future outlook. Alzheimer's disease is viewed as a physical condition impacting on physical and psychological health, with psychological and societal factors altering the experience of this.

This review serves to emphasise the complexity of looking to the future for people with Alzheimer's disease. It may be that in order to be able to take on practical future planning, a person has to go against the instinctive preference to avoid negative experiences. The avoidance of negative information also gives maximum resources to focus on emotionally meaningful activities and interactions with loved ones (Lockenhoff and Carstensen, 2004). Such findings support the proposition that across age groups, people with Alzheimer's disease and their supporters are likely to be reluctant to plan ahead, instead choosing to focus on their emotional goals. This would suggest a greater focus on living in the present moment, thereby supporting the need to shift focus from end of life care to the journey between diagnosis and this point.

The literature reviewed suggests people are not planning for the future to the extent that current policy promotes. However, the consequences of this avoidance are unclear in terms of the benefits of future planning. Neurobiological literature previously discussed may suggest that people have limited future outlook due to decreased ability to ‘mentally time travel’. However, this does not explain the variation seen, or the challenges supporters face in looking to the future (Sampson et al., 2010). It appears that the way people look to the future is influenced by the way people manage their experiences.

Managing experiences of Alzheimer’s disease: Stigma and Future outlook

The literature presented across this chapter illustrates that despite the good intentions behind diagnosis as an opportunity to plan ahead, there appears to be limited engagement with this process. The discussion highlighted that much of this is due to the way people manage challenging experiences, with a focus on maintaining positive emotional states as much as possible. This has been seen to influence how people manage experiences of stigma as well as feared futures.

In relation to stigma and ageing, socioemotional selectivity theory (Carstensen, 1991) can be seen as a bridge between debates over experiences of early-onset or late-onset Alzheimer’s disease. Seemingly, the literature discussed in chapter 2, such as Chaston (2010) and Scodellaro and Pin (2013), suggested that the experience of stigma were likely to be skewed towards either older or younger people. However, based on the understandings of socioemotional selectivity theory there may in fact be similar levels of stigma reported, due to the shared experience of the condition. Further, the principles of the theory may support the idea that regardless of the public stigmatisation of Alzheimer’s disease, the focus is shifted in favour of actively narrowing social networks to those who provide positive emotional support. This pruning of networks can be used as a way of separating from people who have treated them negatively. In keeping with this, previous research has highlighted that the response of family and friends is much more important to those affected, than that of the public (Benbow and Jolley, 2012).

Finally, possible age-based differences in looking to the future appear to be dependent on how people with Alzheimer's disease and their supporters view time. The limited literature available suggests that there may be cognitive challenges in looking ahead; however, general avoidance may be reflecting management of the situation over cognitive inability. The change in motivational goals leading to a 'day at a time' approach also reiterates the continued futures of people with Alzheimer's disease, rather than focusing on a distant future.

Conclusions and key gaps in the literature

For both the person with Alzheimer's disease and their supporter, focusing on the negative changes that are experienced as a result of the condition may restrict positive outcomes. This is the case for negative reactions of others, through to changes in possible futures. The positivity bias allows people to focus on positive circumstances as much as possible, and promotes avoidance of situations where their emotional state may be threatened. Despite the conflicting evidence relating to age-based differences in experiences of Alzheimer's disease, the reviewed literature suggests that these differences may be mitigated through shared methods of managing challenging situations. This is both for looking to the future and experiencing stigma.

Across chapters 2 and 3, the strengths and limitations of research presented have been discussed. Before moving on to the research questions and methodology, the key studies that have informed this thesis are noted. Burgener and Berger (2008) are highly relevant to the stigma focus as their research suggests a need to consider the perception of stigma by the person with Alzheimer's disease, moving beyond a passive experience to an acknowledgement of insight of stigma. Their research validated the questionnaire being used in this thesis, as a tool for measuring stigma in people with Alzheimer's disease. Further, the questionnaire has been developed with Modified Labelling Theory (Link, 1987) as its underlying framework. Two other illustrative papers in relation to stigma and age were Chaston (2010), and Scodellaro and Pin (2013). It should be noted that both of these papers are secondary literature, bringing together previous research in their respective areas (Machi and McEvoy, 2012), and summarising the key challenges in the field relating to younger people with Alzheimer's disease (Chaston, 2010), or age

more generally (Scodellaro and Pin, 2013). Their discussions highlight the conflicting findings surrounding age, stigma, and Alzheimer's disease, which this thesis aims to explore in more detail by considering similarities and differences across both age groups.

In terms of the future outlook research, Carstensen (1991) and the subsequent research into Socioemotional Selectivity Theory were key to the way future outlook was conceptualised in this thesis. The theoretical literature explores how people of all ages manage an experience like Alzheimer's disease, where time becomes more restricted. However, as Mark's (2012) discussion piece has emphasised, this has not been researched in relation to Alzheimer's disease due to the possible neurological issues in terms of being able to view time as restricted, or imagine the future. As discussed earlier in chapter 3, there are several lenses through which stigma and future outlook could be viewed with the biopsychosocial perspective allowing for flexibility in terms of how much each domain is represented (see chapter 1), including topics such as 'the self' and 'identity', which other theories into experiences of chronic illness such as biographical disruption (Bury, 1982) would prioritise. Instead, this thesis aimed to explore how negative experiences such as stigma could be associated with future outlook from a psychological perspective.

For the purpose of this study, several areas of research have been identified in relation to experiences of Alzheimer's disease. Current literature separates the experiences of people with early and late-onset Alzheimer's disease. However, research which considers management of 'time-limiting conditions' suggests there may be overlooked similarities. Current policy focuses on how the exposure to stigma through diagnosis is potentially justifiable due to the increased ability to plan. However, the research literature reviewed emphasises that people may not be taking advantage of this. In addition, greater research is needed to understand planning and looking to the future across the journey of Alzheimer's disease rather than an end point. Understanding more about subjective experiences of Alzheimer's disease can therefore influence how people can be best supported to manage their circumstances. Accordingly, the aims and research questions have been formulated as follows.

Aims and Research Questions

Overall this research study aimed to explore people's experiences of living with Alzheimer's disease, with a particular focus on stigma and future outlook, as well as whether age plays an important role in outcomes. Experiences have been viewed from a biopsychosocial perspective, and aimed to recognise the distinct and entwined experiences of people with Alzheimer's disease and their supporters. This aim has been broken down into four research questions:

1. Do people with Alzheimer's disease and their supporters experience stigma?
2. How do people with Alzheimer's disease and their supporters view and plan for the future?
3. Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters?
4. Are there differences in experiences, in terms of both stigma and future outlook, for people experiencing early-onset Alzheimer's disease and late-onset Alzheimer's disease?

Chapter 4- Methodology

The following chapter presents the methodology for this study. An overview of the study will be provided, before a discussion of where the research places itself within research paradigms. Ethical and practical considerations have been noted throughout the discussions on research design, inclusion criteria, and sampling methods. This is followed by reflections on recruiting people affected by Alzheimer's disease to the study. Throughout, the decisions made were based on how best to answer the research questions generated in the previous chapter.

Ethical approval for this study was granted by NHS Research Ethics Committee (West of Scotland, REC 5, Appendix 1). This was followed by site-specific approval across five NHS health boards. Research register access was granted by the Scottish Dementia Clinical Research Network, and full risk assessment (Appendix 2) was approved by the School of Applied Social Science, University of Stirling, before research visits commenced. People with Alzheimer's disease and their supporters were sampled using purposive sequential sampling from the Scottish Dementia Clinical Research Network research register, supplemented by two NHS referrals. All participants had capacity to consent, with the model of process consent (Dewing, 2007) applied throughout the study. A mixed method design was chosen to include the most appropriate measures to address the research questions. People with Alzheimer's disease (n=22: 7 people with early-onset, 15 people with late-onset) and their supporters (n=22) completed questionnaires which looked at perceived stigma. Additional questionnaires explored variables which may influence stigma, including quality of life, insight, and activities of daily living. A subsample of participants took part in semi-structured interviews (n=14: 12 paired, 2 supporter only), exploring experiences of stigma in more depth, and future outlook. A full discussion of measures will be provided in chapter 5. All study visits took place in people's homes, and included additional time for sharing a cup of tea and informal conversation. Analysis of questionnaires included a range of statistical tests, supported by SPSS software. Interview data were analysed using thematic analysis, supported by NVivo software. The findings will be presented across chapters 6, 7, and 8, reflecting the first three research questions respectively. The fourth research question, exploring age-based influences, has been amalgamated into the three chapters.

Epistemology and Ontology

In order to choose a research design, a researcher should be aware of their epistemological and ontological position, placing themselves within a particular paradigm. In this context a paradigm is synonymous with a worldview, which is based on assumptions and beliefs about knowledge (Creswell and Plano Clark, 2011). Mixed method designs have become known as the third methodological movement (Tashakkori and Teddlie, 2003). They are defined as a type of research which combines elements of quantitative and qualitative approaches, for increased breadth and depth of understanding (Johnson et al., 2007). There is ongoing debate as to whether mixed methods designs are compatible as they may be considered to be combining opposing paradigms (Guba and Lincoln, 1994).

Several paradigm options have been suggested to resolve the possible conflict of mixed methods bridging incompatible concepts. For instance, a paradigmatic stance can be taken, which refers to research that does not declare a particular paradigm (Tashakkori and Teddlie, 2003). However, Hall (2012) argues that research is implicitly or explicitly positioned within a research paradigm, regardless of whether this is declared. Alternatively, Gorard (2007) observes that paradigms themselves are too restrictive, and argues that there should not be a divide in quantitative and qualitative methods. Similarly, Johnson et al. (2007) suggest that mixed methods do not necessarily need a detailed philosophical and methodological position. Rather, the variation in philosophical commitments should be embraced. This promotes a reintegration of qualitative and quantitative methods (Hammersley, 2004). A single paradigm approach which encompasses both quantitative and qualitative methods is discussed by Tashakkori and Teddlie (2003), who prioritise the research question over a particular method or philosophical stance (Creswell and Plano Clark, 2011). Therefore, although this research identifies itself as a mixed method design, it does not seek to debate one paradigm against another, or argue for superiority of either method. Instead, the focus is on producing a wide range of data using multiple methods, to reflect people's experiences of living with Alzheimer's disease. This stance is also reflected in the analysis section through presentation of data by research questions, rather than quantitative versus qualitative data.

Research Design

As discussed in the literature (chapters 2 and 3), there have been few studies looking into the experiences of people with Alzheimer's disease and their supporters, in terms of perceived stigma and future outlook. The majority of the research discussed uses either a quantitative or qualitative approach. However, by using only one of these approaches, several questions remain unanswered. The third methodological movement, mixed method design, enables some of these limitations to be addressed, whilst providing a unique perspective overall (Tashakkori and Teddlie, 2003). The increasing drive to support the inclusion of people with dementia also encourages methods which allow for diversity and flexibility in how people are asked to express their views (Wilkinson, 2002). A mixed method design may be the most suitable approach to allow for this diversity, particularly in an area of research which has supportive evidence across research paradigms.

Mixed methods as defined by Creswell and Plano Clark (2011) focuses on collection and analysis of data from quantitative and qualitative measures in a single study, with the aim of providing a richer understanding than is possible from either approach alone. This is not to say that having a quantitative or qualitative design alone would be a weaker study than when the two are combined, rather they lead to different outcomes. This further reinforces the suggestion of Tashakkori and Teddlie (2003), prioritising the research questions. One of the advantages of choosing a mixed method approach is that the limitations of individual measures can be partially addressed. Such as, the lack of clarity for why people give a particular answer on a questionnaire, or the difficulty in generalising interview data. Further, including both questionnaires and semi-structured interviews gives people the opportunity to have their voices heard in different ways.

Mixed method research is described by Johnson and Onwuegbuzie (2004) as being a promising research design for methodologies more in line with what researchers use in practice. Mixed method designs are reiterated as having the ability to minimise weaknesses of single research studies and maximise strengths (Brown et al., 2015), however, this arguably takes away from the strengths of mixed method research in its own right, suggesting it is a compensatory research paradigm (Tashakkori and Teddlie, 2003). There is increasing use of mixed method research (De Lisle, 2011) and a move

away from the different paradigms debate (Sale et al., 2011). Although this it is not without critics (Bazeley, 2004; Sale et al., 2002), the increased use highlights the progression of mixed-method research in social science. Importantly for this thesis, Johnson and Onwuegbuzie (2004) emphasise that mixed method research designs are needed as the ‘research world’ is increasingly complex and multidisciplinary. A mixed method research design is suggested to facilitate communication and collaboration, and fits well with the collaborative nature of this PhD between the SDCRN and University.

Similarly, a mixed-method research design is supported by the biopsychosocial perspective which, as outlined in chapter 1, represents understandings of the physical experience of illness as something objective that can be measured, with a need to consider how such experience is perceived and interpreted by the individual based on various psychological factors and societal inputs. This type of research design allows for use of quantitative scales which are more reflective of the clinical environment and the way stigma would be measured in practice environments, combined with more in-depth interviews which give room for understanding more about the social context and psychological experience of stigma and future outlook.

Mixed method design, as with quantitative or qualitative design, can be approached in many ways. Bryman (2006) brings together various researchers’ work to highlight five key dimensions of mixed method decision making. Firstly, will the data be collected simultaneously or sequentially? Secondly, does quantitative or qualitative data have priority, or are they equal? Thirdly, what is the purpose of combining the data? For instance, is data being combined for triangulation, exploration, or explanation? The final two stages outlined by Bryman (2006) question where in the research process the multi-strategy takes place, and whether there is more than one data strand; although if there is only one strand its classification of mixed-method or multi-method is debatable (Bryman, 2006). Figure 2 presents a ‘decision tree’ outlined by Creswell (2003), which incorporates the dimensions previously noted, and aims to guide researchers through the different options available to them. The decision tree shows the various pathways towards mixed method designs. Sequential timing was chosen for this study, separating the questionnaires and interviews into visit one and visit two. As not all participants could be interviewed, this allowed preliminary analysis of questionnaires before selecting people for interview. Further, separate visits enabled a relationship to build up

between researcher and participants, allowing for greater familiarity at interview (McKillop and Wilkinson, 2004). Equal weighting was given to qualitative and quantitative measures, reflecting the underlying assumption that neither method is superior, but contributes differently to the outcome. The data across measures were then combined for the final analysis based on the research questions. This allowed for a more comprehensive understanding of people’s experiences, as well as possible similarities and differences in findings to be observed. Therefore, the research strategy employed was a sequential exploratory design, as described by Creswell (2003).

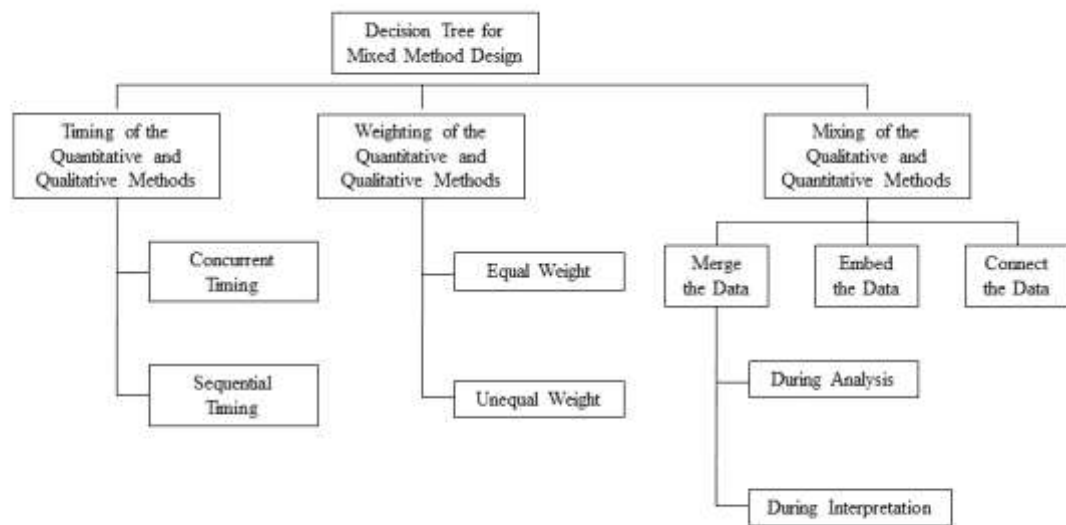


Figure 2. Decision tree for mixed methods design, as discussed by Creswell (2003)

Of note, a typical exploratory design collects qualitative data first, followed by quantitative data collection; this is useful when little is known about the topic area (Andrew and Halcomb, 2009). Whereas, a sequential explanatory design typically collects quantitative data and uses the qualitative data to confirm and expand on the findings (Ivankova et al., 2006). Based on the sequencing of the two study visits in this thesis it could be argued that the design is a sequential explanatory design, however, these designs typical prioritise the quantitative data. Instead, this thesis aimed to give equal weight to the two methods, with more of the research questions reflecting an exploratory approach. For example, how people look to the future, and whether there is an association between peoples experience of stigma and future outlook. Therefore, the sequential exploratory design best describes the overall design of this study while not

privileging one set of data over another. Onwuegbuzie and Teddlie (2003) suggest that instead of framing research in terms of quantitative and qualitative, we should reconceptualise these as exploratory and confirmatory methods (Onwuegbuzie and Teddlie, 2003). This conceptualisation may make it easier to highlight how the sequential methods have been used. However, for clarity and transparency the terms quantitative and qualitative have been used in the thesis.

The combination of methods is a topic of considerable debate in the literature surrounding mixed method research designs (Bryman, 2006, 2007; Fielding, 2012; Olsen, 2004; Onwuegbuzie and Leech, 2007). One key aspect of this debate is how the quantitative and qualitative data are combined. Quantitative and qualitative research can be combined during the formulation of research questions, sampling, data collection and data analysis (Bryman, 2006). The degree of freedom within this process may help explain why it is difficult to establish clear, consistent guidelines for mixed-method research. Several justifications are outlined by Greene et al. (1989) for the combination of methods that are applicable to this thesis. Firstly, 'development' is applicable where the aim was to use scores from the quantitative data to inform sampling for the qualitative data collection. As noted in the reflections at the end of this chapter, the ability to do this was limited due to the lack of dispersion between scores, and the numbers of people with early-onset Alzheimer's disease taking part in the research. Secondly, 'triangulation and complementarity' are used together to explore how the results from the two methods fit together, elaborating on the initial findings and exploring consistency. Discussion of the quantitative and qualitative findings is presented in chapters 6 and 8. Thirdly, the combination of mixed methods is justified through 'expansion' where the breadth of knowledge is increased by using multiple methods (Greene et al., 1989). Expansion is demonstrated within this thesis by considering stigma and future outlook separately and together as part of a possible association.

Finally, it is important to recognise the limitations of mixed-method designs in order to try to minimise the impact of these. Many of the criticisms presented in the literature focus on the 'paradigm debate' where quantitative and qualitative methodologies are seen as incompatible (Doyle et al., 2009). However, this debate does not recognise the similarities between paradigms, where both methods are seeking to describe data, construct arguments and speculate over outcomes (Sechrest and Sidiini, 1995).

Focusing on the differences between paradigms is argued by Onwuegbuzie and Leech (2005) to be counterproductive in progressing social science research. Several practical challenges which if not addressed can limit mixed-method research have been noted by Bryman (2007). For example, writing for different audiences can result in the weighting of the two methods changing during write up or dissemination. It is also important to reflect on preferences for quantitative or qualitative methodology and to make sure this is not creating bias in how the data is combined or reported. For instance, if a researcher's background is more quantitative they may have more faith and confidence in this aspect of the mixed-method work, due to this greater familiarity and expertise (Bryman, 2006). It is therefore important to reflect on background and skills to make sure that if equal weight is being given to the two methods, the confidence in them is equal. In this thesis, this potential bias is part alleviated from collaboration with a multidisciplinary team of qualitative and quantitative researchers, therefore enabling both sets of skills to develop in parallel. Bryman (2006) also suggests that challenges may arise when data is generated at different speeds, leading to one aspect being analysed separately to another. However, this is alleviated by having a sequential design from the beginning of the research process.

Overall, mixed-method research design has been chosen for this thesis as a way of exploring stigma and future outlook in a way that can create in-depth information as well as numerical data. As with all research designs there are limitations, however, as outlined in the previous paragraph efforts have been made to alleviate these as much as possible.

Power and Sample Size

When determining the most appropriate sample size to include for a mixed method study, both statistical power and data saturation need to be considered. As the study design included the collection of quantitative data, a sample size calculation (Brant, 2013) was used to make sure that the number of people completing questionnaires was sufficient to generate suitable power for the study results. Power analysis considers the likelihood of a type I or II error, which indicate false-positives and false-negatives respectively (Halpern et al., 2002). Further, conducting a study without appropriate

power size could have ethical implications for the people involved (Halpern et al., 2002). Saturation in this context refers to the state where increasing the number of participants does not add anything new to the data or theory (Bowen, 2008). There is not a calculator for saturation, although several factors have been identified to help researchers decide the ideal number of participants. These include the breadth of the topic, where with increasing breadth the time taken to research saturation increases (Morse, 2000). The nature of the topic is also important, as it may affect the accessibility of information. Highly emotive data may be more difficult to gather, and therefore requires a greater sample size to try and get a full picture (Morse, 2000). In addition, previous literature was considered to estimate the ideal sample size for both questionnaires and interviews.

There remain challenges in operationalising data saturation and establishing a sample size, as ideally the sample size would be dependent on the information coming out of interviews, with more interviews being conducted until there was no further information being added about a particular topic (Mason, 2010). However, this raises challenges in time-limited research or research where a clear protocol is needed from the outset which determines the number of participants being included (Green and Thorogood, 2004). The challenge for PhD research is argued to be that the pre-meditated focus on numbers of people detracts from the focus on true data saturation and qualitative enquiry (Mason, 2010). The issue of data saturation is suggested to be neglected due to the difficulty in defining it, and a lack of 'one size fits all' option (Fusch and Ness, 2015). However, Guest et al. (2006) suggest the aim should be to have no new data, themes, or codes, with the ability to replicate the study. The process of data analysis and reflections on the interviews which will shape data-saturation are presented in chapter 5. For calculating statistical power and sample size, a power level, alpha level, and expected population means and standard deviations are input. In this case a power level of 0.80 was chosen, which reflects a large effect size. This was based on the potential sample size being relatively small, and the focus on an effect that is consistent or large enough to be observed by 'naked eye' (Sullivan and Fenn, 2012). An alpha level of 0.05 was selected in line with typical significance levels (Erdfelder et al., 1996). This is followed by population mean values and expected standard deviation values. These values are based on the dependent variable within the questionnaires, in this case, perceived stigma. At the time of calculating sample size, there was very limited

research surrounding perceived stigma and people with Alzheimer's disease. Further, the literature had not used the Stigma Impact Scale or equivalent to measure perceived stigma in people with early-onset Alzheimer's disease or their supporters. As such there was minimal or no data to provide mean values of the different groups within this study. The literature search was widened to include stigma and 'age associated conditions'. For example, research which looked at comparisons of perceived stigma between younger and older people for conditions such as HIV. However, there was not any research which focused on experiencing stigma of a condition, where age may have a significant effect.

As Table 2 highlights, the only values in the literature at the time of sample selection, allowed a comparison between people with late-onset Alzheimer's disease, and supporters of people with late-onset Alzheimer's disease. Based on the values collected from two previous papers (Burgener and Berger, 2008; Liu, 2011), sample size calculations showed a minimum of 15 people was necessary in each group for a power of 0.80. For this study, the proposed sample size for questionnaires was increased to 20 participants per group. This allowed for greater data collection, as well as attrition. The direction of results was not stated within the research questions, as there were several possible outcomes and insufficient literature to assume a given direction due to the opposing hypotheses. For instance, Chaston (2010) suggested people with early-onset Alzheimer's disease would experience greater stigma than people with late-onset Alzheimer's disease. Whereas, Scodellaro and Pinn (2013) suggest the opposite direction of effect, hypothesising that people with late-onset Alzheimer's disease will experience more stigma.

	People with early-onset dementia	People with late-onset dementia	Supporters of people with early-onset dementia	Supporters of people with late-onset dementia
Predicted mean SIS scores	Data unavailable	42.7	Data unavailable	29.58
Predicted SD for SIS scores	Assume ~9/10	9	Assume ~9/10	10.8
Ideal power			0.8	
Minimum number for power		15		15
Ideal number for this study	20	20	20	20

Table 2. Illustrated sample size calculation, based on the information available in the literature at the time of calculation.

On the assumption that 80 people would participate in the questionnaires, completing interviews with every participant would not have been feasible. This is due to the time constraints of the data collection period, and the need for multiple visits. To address this, all of those who completed questionnaires were asked if they were happy to be contacted at a later date regarding a possible interview. Participants were reminded that not everybody would be able to complete interviews, but that if they were not contacted at this point they would still be contacted when the overall study was complete. It was also reiterated to all those involved that selection was not based on ‘right or wrong’ answers to questionnaires. This was to reduce possible anxiety over their answers. As one of the main outcomes of the study was experiences of stigma, and the consequences it could have on future outlook, the scores of the Stigma Impact Scale were to be used for interview selection. In accordance with mixed method design protocol, it was anticipated that extreme and deviant cases would be selected from each group (Patton, 1990). This was to highlight the breadth of experiences, and allow for greater exploration of the factors which affected people’s perceptions and experiences of stigma.

If the extreme and deviant scores from each group were selected, it would provide a minimum sample of 8 people for interview. This mirrors the number of people affected by Alzheimer's disease in previous research, such as Pison-Young (2011). However, as future outlook is a largely unexplored area, a greater number of participants may be needed. This is supported by Morse's (2000) discussions on topic breadth. Therefore, 16 interviews were proposed to generate novel data, and increase the likelihood of data saturation. Of these 16, 8 were to be people with Alzheimer's disease (4 people with early-onset, 4 people with late-onset) and 8 supporters of people with Alzheimer's disease (4 supporters of people with early-onset, and 4 supporters of people with late-onset). This is supported by Guest et al. (2006), who suggested that saturation generally occurred within twelve interviews, depending on the data set. Further, similar sample sizes for semi-structured interviews can be seen in dementia research literature (Clare, 2003; Harman and Clare, 2006; Robinson et al., 2005).

As well as considering the number of interviews, dementia research literature calls for flexibility over whether interviews are with people with dementia and their supporters together or separately (Wilkinson, 2002). Therefore the total sample size for interviews was based on people's preferences about who was present for the interviews. This suggests a minimum of 16 participants for interviews, and a maximum of 32 people. Further, the actual number of interviews remained flexible to the questionnaire data, in order to be responsive to the data collected and the variance between individual scores. The following section looks at how the discussed sample sizes worked in practice, taking into account inclusion and exclusion criteria for study participation. Reflections on the sampling methods and participation rates will be presented.

Use of research registers for recruiting people with Alzheimer's disease

Recruiting people with Alzheimer's disease to research is notably difficult, with Alzheimer's Society (2015) reporting that despite around 700,000 people experiencing dementia in the UK, researchers have difficulty recruiting more than 50 people to a study. People with dementia can be viewed as a 'hard to reach population' for research purposes. Shaghghi et al. (2011) describe 'hard to reach' populations as subgroups of people who are difficult to involve in research. There are many different examples of

'hard to reach groups'. Noteworthy for people with Alzheimer's disease, is the difficulty in sampling from stigmatised groups (Sadler et al., 2010), and those living in difficult social or economic situations (Shaghghi et al., 2011). When compared to research participation for conditions such as cancer, public engagement in dementia research is low (Department of Health, 2012). One such approach for improving participation rates has been the use of research registers, which aim to bridge the gap between people affected by dementia and research studies (Avent et al., 2013). Sampling from a register has the potential to increase acceptance rate, due to people already having expressed interest in research (Avent et al., 2013). In addition, if people have previously expressed an interest in dementia-related research, they may be more willing to share their potentially difficult experiences. This would help to address concerns of reaching data saturation where topics are highly emotive, as outlined in the previous section.

Research registers also allow researchers the opportunity to screen for potential participants based on the pre-set inclusion or exclusion criteria. This may save time, and reduce the likelihood of people being contacted about research that they are not suitable for, which could be unethical. Despite the benefits of using this sampling method, there are some limitations which are important to acknowledge. Previous research such as Avent et al. (2013), suggests that as research registers appeal to people who are motivated to help themselves and others living with the condition, results may be biased. However, this does not mean that those who avoid participation in research do not wish to help themselves or others. Rather, that the negatives appear to outweigh the benefits for some. It is useful to know what reasons people have for engaging in research, but it is also important to consider who declines. This may help to better understand who may be missing from the research, and could therefore have implications for generalising findings (Brintnall-Karabelas et al., 2011).

As discussed previously, Alzheimer's disease can expose people to a range of stigma. Therefore, motivation to identify with the condition and participate in research may be low (Sadler et al., 2010). Other reasons explored in research literature for declining research participation have included specific protocol features, and inconvenience in timing or circumstances (Brintnall-Karabelas et al., 2011). Additionally, competing commitments, clarity of benefits, and previous negative experiences of healthcare and/or research have all been cited as reasons to avoid research participation (Taylor et

al., 2007). Taking these findings into account, it was important to make sure that people's experiences of participating in this study were as positive as possible. This meant spending extra time with participants for informal conversations, and sharing a cup of tea, as will be highlighted in the study protocol (chapter 5).

Inclusion and Exclusion criteria for study participation

Participants for this study were recruited from the Scottish Dementia Clinical Research Network (SDCRN) research register, supplemented by two additional NHS referrals. Other organisations were also approached and adopted the study, but were unable to be included due to time limitations. This will be discussed more within reflections on sampling. As discussed in chapter 1, the SDCRN research register holds the details of people with various types of dementia and their 'carers', who have expressed interest in dementia research participation. Following NHS ethical approval, the ensuing inclusion and exclusion criteria were provided to the SDCRN to filter potential participants from their research register. This process resulted in a list of potentially eligible participants who could then be sampled and contacted. As highlighted in the introduction (chapter 1), this PhD has been part funded by the SDCRN. To avoid any conflict of interest or bias when sampling, the study went through review by the network, in accordance with SDCRN study adoption protocol. Further, the register was not accessed by the researcher.

The study focused on people with Alzheimer's disease over other types of dementia. There were several reasons for this inclusion. Firstly, Alzheimer's disease is the most common type of early and late-onset dementia (Alzheimer's Society, 2014). Given that people with dementia are already viewed as a 'hard to reach population', selecting people with the most prevalent type was likely to increase sample size. In addition, as noted within the introduction (chapter 1) it was also important to separate 'Alzheimer's disease' from 'dementia' which is made up of several types of neurodegenerative conditions. Different types of dementia are associated with different symptoms (Knopman et al., 2003; Gure et al., 2010; Chiu et al., 2006). For example, one of the subtypes of dementia is known as frontotemporal dementia. This subtype is associated with reduced inhibition, which can lead to socially inappropriate behaviours and impulsivity (Alzheimer's Society, 2013b). Such symptoms could potentially intrude

more on a person's life and social interactions, making the attributes more discrediting, and therefore potentially affecting stigma experiences (Goffman, 1963; Kelly and Field, 1996). Based on these conclusions, people with other types of dementia were not included in the study.

Diagnosis of Alzheimer's disease could have been given either before or after the age of 65. Age at diagnosis, as opposed to current age, was used for categorisation of early or late-onset Alzheimer's disease, in line with clinical diagnosis (Koedam et al., 2010). A minimum age of participants was set at aged 18, as different ethical considerations are associated with people younger than this. The maximum age of participants was not specified. Previous studies have capped the age limit at around 75 years old, however, as age was of particular interest to this study this may have been too restrictive. The probability of having many people within the 'oldest old' category of 85 years old and onwards was predicted to be low (Brumback-Peltz et al., 2011), due to an increased likelihood of people with dementia in this age range having mixed dementia pathology (James et al., 2012). In spite of this, over half of the people with Alzheimer's disease in this study were over the age of 75, with nearly 30% within the 'oldest old' category. Full characteristics of the sample are presented later in the chapter. Importantly, had an age cap been in place the majority of people with late-onset Alzheimer's disease in this study would not have had the opportunity to participate, thereby losing valuable insight into their experiences.

All of the participants in this study had to be able to give informed consent themselves. Other studies have used proxy consent, whereby the supporter consents on behalf of the person with Alzheimer's disease if they are unable to consent themselves. However, this was not done for this study as the person with Alzheimer's disease was being asked to complete several self-report measures. Therefore, they would need to feel able and comfortable doing so. When deliberating capacity to consent, there is a need for judgement and considering each person individually. There is insufficient evidence to relate cognitive capacity and ability (Warner et al., 2008). Situational factors and the complexity of the decision to be made have both been shown to influence capacity to consent (Dewing, 2007). For example, making a decision regarding taking part in a new drug trial has different considerations for a person with dementia, in comparison to completing a survey.

Mild to moderate stages of Alzheimer's disease have been associated with a greater level of capacity to consent. This is due to relative preservation in ability to reason and decide (Karlawish, 2008), as well as increased insight (Rankin et al., 2005). Therefore, this 'staging' was used as a filter for the SDCRN. To fit with the design of the register, MMSE scores were used to indicate 'mild to moderate' Alzheimer's disease. MMSE is a type of cognitive assessment regularly used within clinical practice to stage Alzheimer's disease and other types of dementia. A possible score range for mild-moderate Alzheimer's disease is 10-26 (Alzheimer's Society, 2012). Although MMSE scores were used for the filtering of participants, they were not used in the analysis or updated during this study. This will be discussed within study measures (chapter 5).

All participants needed to be able to speak and understand English to take part in the study. The measures used such as the Stigma Impact Scale had not been validated in other languages, and it was not within the study scope to be able to do this. Secondly, given the complexity of the biopsychosocial underpinnings of Alzheimer's disease, cultural differences are to be expected (Sayegh and Knight, 2013; Johl et al., 2014). Finally, limitations such as time and money were not viable for including people who did not speak English. Importantly, this reinforces that much of the psychosocial discussion is focused on social constructions within British society.

The SDCRN research register holds less information about the supporters of people with dementia. Therefore, there were minimal inclusion or exclusion criteria specifically for supporters. However, as several of the study measures required perspectives of both the person with Alzheimer's disease and their supporter, several considerations were noted. Supporters needed to have regular contact with the person with Alzheimer's disease. This was important as courtesy stigma or family stigma is hypothesised on the basis of a clear connection with the person with Alzheimer's disease (Larson and Corrigan, 2008). Close contact did not necessarily mean that the person with Alzheimer's disease and their supporter needed to live together. Previous research which considers the reliability of proxy-ratings have not found clear links between hours of contact, or living with the person with Alzheimer's disease (Huang et al., 2008). However, the person with Alzheimer's disease could not be living within a care home, due to the difference in ethical procedures for researching within these settings (Luff et al., 2011). As such, 'regular contact' was not operationalised in terms of time, however, all carers had identified themselves on the research register as a study

partner. In practice, 18 of the research pairs were spouses, and 3 were adult-child supporters, who identified themselves as the main informants for the person with Alzheimer's disease.

Finally, the location of participants was restricted. In 2014, the Scottish Dementia Clinical Research Network register included 1401 people with dementia, and 1427 supporters of people with dementia (SDCRN, 2015b). For the purpose of this research, the location of participants was restricted to five NHS health boards: NHS Forth Valley, Lothian, Grampian, Tayside, and Greater Glasgow and Clyde. The numbers of potential participants available by health board area is presented in Appendix 3. These health boards were chosen based on the numbers of potential participants on the research register, as well as the feasibility of travelling to home visits. Originally, NHS Lanarkshire was included due to proximity; however, administration within this area was particularly slow. Therefore it was discounted to prevent significant delay.

Sampling Methods

The outlined inclusion and exclusion criteria resulted in a list of potential participants from the SDCRN research register to contact. The use of research registers, and the mixed method design across separate visits, is best classified as purposive sequential sampling. This type of sampling allows for participant selection before and during the study, in-keeping with the sequential research design (Teddlie and Yu, 2007). For instance, people completed questionnaires before being selected for interviews. The flexibility of purposive sampling also allows for multiple sampling techniques to be adopted within it. For example, selections of extreme and deviant scores of the Stigma Impact Scale for people with late-onset Alzheimer's disease, and opportunistic sampling of people with early-onset Alzheimer's disease. This was necessary due to the challenges faced in recruiting equal numbers of people with early and late-onset Alzheimer's disease. This is discussed in more depth within reflections of sampling later in the chapter. Figure 3 illustrates the sample selection process for questionnaires and interviews, for people with early and late-onset Alzheimer's disease and their supporters.

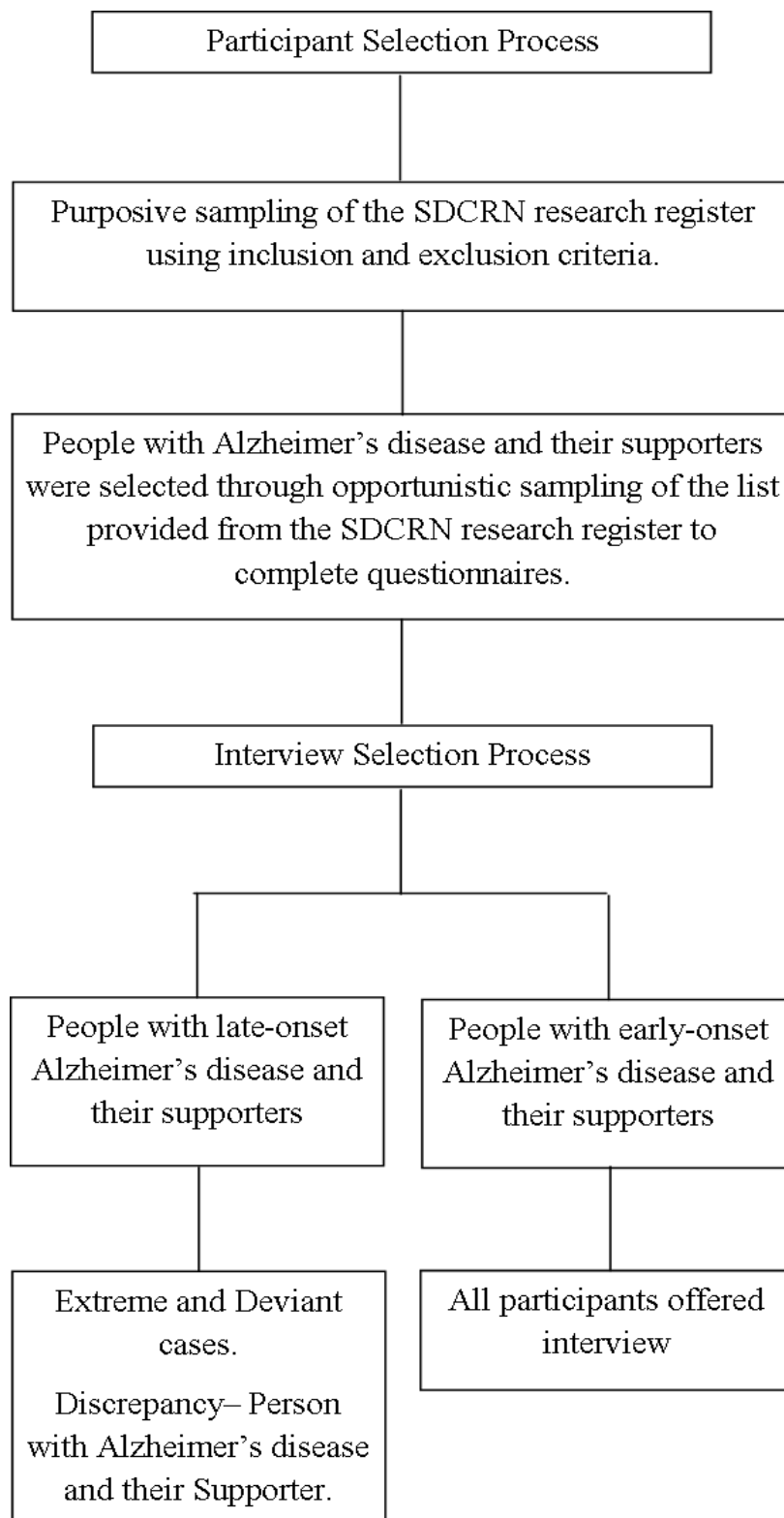


Figure 3. Illustration of the participant selection process for questionnaire and interview based data collection.

The SDCRN research register provided details of 120 eligible people with late-onset Alzheimer's disease, and 17 people with early-onset Alzheimer's disease. All of the possible participants with early-onset Alzheimer's disease were contacted, with an additional two contacts made from NHS referrals. Of the 19 people with early-onset Alzheimer's disease and their supporters, 7 pairs agreed to participate in the research. Therefore, all participants were invited to interview. As the number of people with late-onset Alzheimer's disease available for contact was higher, additional sampling was needed.

Out of the 120 potential participants with late-onset Alzheimer's disease, 73 were contacted for participation. Selection from the list for contact was opportunistic, with potential participants being contacted until a feasible amount of data had been collected. The 73 participants contacted were then analysed against the remainder of potential participants for possible selection bias, taking account of the variables available from the register including age, socioeconomic status, years living with Alzheimer's disease, and MMSE scores. Discriminant analysis of the 120 people with late-onset Alzheimer's disease suggested that none of these variables significantly predicted whether participants were contacted. This suggests that the sample chosen was representative of the observable characteristics from the overall sample available (Wilks $\lambda = .921$, Chi-square = 8.767, $df = 4$, Canonical correlation = .280, $p = 0.067$).

People with late-onset Alzheimer's disease were selected for interview using deviant and extreme cases, as discussed earlier (Patton, 1990). It was also noted that interview selection must be sensitive to the data. There was minimal dispersion of Stigma Impact Scale scores for people with late-onset Alzheimer's disease and their supporters. Therefore, discrepancy between paired scores was also included, for example, the person with late-onset Alzheimer's disease whose perceived stigma score was most different to their supporter.

A discriminant analysis compared people with late-onset Alzheimer's disease who completed questionnaires and people with late-onset Alzheimer's disease who completed both questionnaires and interviews. Scores were compared across eight variables: age, socioeconomic status (SIMD), time living with diagnosis, gender, and questionnaire scores (Stigma Impact Scale, DEM-QOL, MARS-MFS score for the person with Alzheimer's disease and the discrepancy with supporters). The overall Chi-

square test was non-significant (N= 15, Wilks $\lambda = .524$, Chi-square = 5.822, df = 8, Canonical correlation = .690, p = 0.667). This suggests there was no evidence of differences between the people with late-onset Alzheimer's disease selected for interview and those who were not, based on the variables available.

Similarly, for the nine comparable variables available for supporters of people with late-onset Alzheimer's disease (age, socioeconomic status, time living with diagnosis, gender, and questionnaire scores (Stigma Impact Scale, MARS-MFS for supporter and discrepancy with person with Alzheimer's disease, Zarit Burden Interview, and Bristol Activities of Daily Living) no significant differences were found between those selected for interview and those not (N=15 Wilks $\lambda = .249$, Chi-square = 11.809, df =9, Canonical correlation = .866, p = 0.224). The lack of significant differences suggests the interviewed sample were reflective of the sample of people with late-onset Alzheimer's disease participating in the study. As all those affected by early-onset Alzheimer's disease were offered interviews, and all but one pair agreed, discriminant analysis was not conducted for this group.

Study Participants

The summary characteristics of people who took part in this study are shown in Table 3. More detailed explanation for why each characteristic was reported is provided in the following chapter on study measures. Overall 22 people with Alzheimer's disease and 22 supporters were recruited, of which 26 took part in interviews. Twelve were paired interviews, and two were supporter only. Despite the challenges recruiting people to the study at the beginning, the retention of people across the study was high, with all but one pair of participants invited to interview agreeing, giving a retention rate of 93%. The final section will reflect on the sampling and recruitment process, and the possible implications of the challenges faced.

	Number of participants- Questionnaires	Number of participants- Interviews	Mean age in years /Range	Mean time with diagnosis in years /Range	Mean socioeconomic status by SIMD decile /Range	Gender	
						Male	Female
People with Alzheimer's disease	22	12	76.05	5	7.23	16	6
Early-onset	7	5	63.29 52-69	3.57 1-8	6.71 3-10	7	0
Late-onset	15	7	82.00 73-91	5.67 1-11	7.46 3-10	9	6
Supporters	22	14	68.45	5	7.41	5	17
Early-onset	7	6	59.43 47-67	3.57 1-8	6.71 3-10	0	7
Late-onset	15	8	72.67 53-88	5.67 1-11	7.73 3-10	5	17
Total sample	44	26				21	23

Table 3. Summary table for sample characteristics of people with Alzheimer's disease and their supporters included in the study.

Reflections on study recruitment

The study aimed to recruit a sample of 80 people for the questionnaires (20 people with early-onset Alzheimer's disease; 20 people with late-onset Alzheimer's disease; and their 40 supporters), and a minimum of 16 interviews. However, achieving these numbers was not possible within the time of the study. This was particularly true for recruiting people with early-onset Alzheimer's disease and their supporters. The initial contact list of people with early-onset Alzheimer's disease provided by the SDCRN detailed 17 people. As a result, Alzheimer's Scotland and The Scottish Dementia Working Group were both approached for additional recruitment, and adopted the study. However, time restrictions of the PhD meant it was not feasible to pursue these routes. Overall, the difference in numbers of people available led to the different sampling methods for people affected by early and late-onset Alzheimer's disease, as previously displayed in figure 3.

The reduced sample size impacts on the overall power of comparisons, indicating that there is an increased chance of type I or type II errors. As highlighted in table 2, the minimum number of participants for ideal power was 15, based on the population norms available at the time of power calculations. This means that valid comparisons could be calculated between people with Alzheimer's disease and their supporters (n=22 per group), but that age-based comparisons should be interpreted more cautiously. This is not to say that the results would be invalid, rather that they should be interpreted cautiously.

The reduced sample size and its impact on internal validity is in part counteracted by the inclusion of semi-structured interviews. Based on the study design, the same participants were able to expand on their experiences and potentially corroborate the questionnaire data. Therefore, the risks of error may be reduced, based on the increased validity from triangulating data (Zohrabi, 2013) as can be seen in chapter 6. Importantly, researchers such as Slonim-Nevo and Nevo (2009) and Moffatt et al. (2006) highlight that mixed-method data can produce conflicting findings and that this should not invalidate the results; rather, they discuss how the presence of conflicting results reflects a strength of a mixed-method approach in capturing a level of complexity that may have been missed in a single-method study.

Of the 92 people with Alzheimer's disease contacted to take part in the study, 90 from the SDCRN research register and 2 from NHS referral, 22 were recruited. This gives a response rate of 22.2%. It is difficult to draw conclusions from the response rate alone. Galea and Tracy (2007) discuss how many studies fail to report response rates through concerns over low response rates being indicative of study inferiority. However, the lack of transparency in response rates does not allow for more in depth consideration of why people may choose to be involved in research. There may also be differences between people that are difficult to reach, and people who decline taking part in research (Patel et al., 2003). Although these considerations can influence generalizability, it also demonstrates the need for providing as much detail as possible about a study sample. The reduced generalizability should also not take away from the subjective experiences and voices of those who were involved.

Due to the challenges faced in recruiting people with Alzheimer's disease, possible variables which may have affected study uptake were explored. The discriminant

analysis compared those who were contacted and agreed to take part, with those who did not respond or declined. The variables age, number of years since diagnosis, and socioeconomic status were included as possible predictors. These variables were available without any additional information needed from people who declined. The analysis included 92 people with Alzheimer's disease (73 people with late-onset Alzheimer's disease, 19 people with early-onset Alzheimer's disease). The overall chi-square test was non-significant (Wilks $\lambda = .963$, Chi-square = 3.302, df = 3, Canonical correlation = 0.191, $p = 0.347$). The results of the discriminant analysis suggested that age ($p=0.321$), socioeconomic status ($p=0.103$) and length of time since diagnosis ($p=0.707$) did not predict whether people with Alzheimer's disease agreed to take part in the study. Due to the minimal information available about supporters on the SDCRN research register, discriminant analysis could not be done with their data. This may have yielded useful insight, given that supporters are often considered 'gatekeepers' to such activities (Beattie et al., 2004).

The discussion highlights that there were clear challenges in recruiting people with Alzheimer's disease. In many respects this is surprising given that participants have previously signed up to the SDCRN research register, thereby expressing their interest in taking part in research studies. Having worked within the SDCRN, there are several factors that I would suggest may impact on this. This is speculative, as participants who turned down the study were not asked to explain as this would violate their right to decline without giving a reason (APA, 2010). Firstly, participants contacted may already be involved in research studies and therefore feel they could not commit to an additional study. Galea and Tracey (2007) support this assumption, discussing how participation rates in studies have been declining and this may in part be due to the people being offered more research options. Further, the types of study offered by the SDCRN include pharmaceutical intervention studies as well as psychosocial interventions, and observational studies. Although pharmaceutical interventions may be prioritised by participants given the potential for more direct benefits, they are associated with higher risk, and it is unknown how prospective participants may weigh this up. Finally, prior to recruitment, it was acknowledged that the way the study was framed may impact on recruitment, in particular whether stigma was mentioned. Therefore, the study was called 'Experiences of Alzheimer's disease: Looking to the future' on all information sheets. As noted within chapter 2, there is considerable

stigma attached to the terms ‘Alzheimer’s disease’ and ‘dementia’ with some people being reluctant to identify themselves as having the condition. This is less likely to be the case for people who have chosen to be part of a dementia research register.

Despite the challenges of recruitment, the retention rate for the study was high. A retention rate of 93% is particularly positive given the difficulty in recruiting and retaining participants in health-related research (Provencher et al., 2014). As with response rate, there are limited guidelines on the classification of high or low retention rates. This is potentially due to concerns over invalidating results. Research has considered strategies which contribute to studies with higher retention rates. A review by Provencher et al. (2014) suggested several strategies which had positive effects on retention rates, many of which were used in this study and will be discussed in more details within the study measures and protocol (chapter 5). These included conducting face-to-face interviews, and using simple language. Materials were also adapted to potential needs, for example including large font due to the increased likelihood of visual difficulties (Van Boxtel et al., 2000). Further, it was important to remain flexible about the time and location of the study, with in-home interviews generally being preferred (Provencher et al., 2014).

In addition to considering the numbers of people within the sample, it is important to be aware of the sample characteristics. As discussed in the previous section, Avent et al. (2013) note several positives to using recruitment registers to reach a target population, such as increased motivation, and self-identifying as potential participants. However, it is important to be aware of the possible biases within such a sample, and the challenges dementia research faces in general recruiting a representative sample (Rockwood and Gauthier, 2005). For instance, it may be that people who experience high levels of stigma are more reluctant to get involved in research. This might lead to lower levels of stigma being reported by participants than are present within the general population of people with dementia. Conversely, people who experience significantly more stigma may have increased motivation to be involved in research and support change, thereby leading to findings of higher than expected stigma. Such skewing of results based on the sample population could also be the case for future outlook and age-based experiences. A representative sample is ideal (Ritchie et al., 2015), however, not to have this should not invalidate the research; rather, it means the conclusions drawn should include awareness of the sample used and its limitations.

Possible sample qualities to be aware of include the socio-economic status of participants. Socio-economic status was measured by Scottish Index of Multiple Deprivation (SIMD) scores. Participants' decile scores ranged from 3-10, which highlights that people within the least deprived areas were included, as shown by an SIMD of 10, however, the levels of highest deprivation (SIMD of 1-2) were not included. The importance of this finding is discussed within study measures in chapter 5, noting the potential impact of socioeconomic status on outcomes. In addition, the population sample was entirely based in Scotland. This has implications in terms of the policy frameworks impacting on the support and care available to people with Alzheimer's disease, such as Scotland's policy for one year of post-diagnostic support (Scottish Government, 2013). Gender has been considered as there were no female participants with early-onset Alzheimer's disease in this study, and only 27% of participants with late-onset Alzheimer's disease were female. This is surprising given that gender-based statistics of Alzheimer's disease would predict more women than men with the condition. For instance, Knapp and Prince (2007) report that that 67% of women are diagnosed with Alzheimer's disease, compared to 55% of men. A possible reason for the disproportionate number of men in the study could be based on the gender prevalence on the SDCRN research register. There were more males (n=285) with Alzheimer's disease on the register than females (n=279). Despite these differences, gender was not expected to have significant implications for stigma results (Corrigan et al., 2003; Prenda and Lachman, 2001), but it worth noting when considering possible generalisation of findings.

Finally, one of the limitations to the study was the time delays between questionnaire and interview visits. The delay meant that for some pairs, the person with Alzheimer's disease was no longer able to engage fully in the interview. In these circumstances, interviews with the supporter still took place. This was the case for Katie (SE3) and Toby (PE3), and Millie (PL12) and Holly (SL12). Further, on some occasions the person with Alzheimer's disease was present but did not contribute to the interview questions. However, they were included in general conversation so as not to feel excluded. This was the case for Michael (SL2) and Grace (PL2), Poppy (SL1) and David (PL1), and Sophie (SL15) and Angus (PL15). The remaining interviews included both the person with Alzheimer's disease and their supporter. Despite this limitation, the interviews conducted reached data saturation, as discussed earlier in chapter 4.

The time-delay between visits 1 and 2 was up to six months for some participants, due to the delay in getting more people with early-onset Alzheimer's disease participating in the research. Interviews were delayed due to the sequential design and the aim of having a larger sample of questionnaires for extreme and deviant case sampling as set out in the sampling method plan. The delay is likely to have led to increased likelihood of participants no longer feeling able to participate in the interview; although the unpredictable nature and progression of Alzheimer's disease means that there is not a clear way of predicting the speed or likelihood of decline over a study period. It could be argued that a qualitative-quantitative sequence would have worked better for these participants, with interviews first followed by questionnaires, as interviews are likely to be harder and involve the ability to think in a more open-ended way. However, this would have changed the thesis in that questionnaires after interviews would not have given participants as much opportunity to expand on their questionnaire answers. In addition, questionnaires following interviews would not have allowed for deviant/extreme sampling from the quantitative data. Further, having the questionnaire visits first allowed a relationship to build up with participants, and if an interview had been carried out first, participants might not have been as open with their discussion. Therefore, the discussion outlines the support for a questionnaire to interview sequential design.

Conclusions

Overall, this chapter has provided an outline of the decision-making process and methodology behind this research study. These decisions have been made based on how best to answer the research questions derived from the literature reviews presented in chapters two and three. Supportive evidence has been used to increase the validity of the decisions made. Based on these decisions, the following chapter illustrates how the design was implemented for data collection. This will focus on the study measures, as well as reflect on conducting the research study.

Chapter 5-Methods Chapter

This chapter will expand on the methodological framework presented in chapter 4. The measures used for data collection are discussed with reference to relevant literature, before a step by step protocol, including reflections on the research process. Finally, the data analysis procedure is described, with an introduction to the findings chapters which follow. Throughout the data collection, the experience of participants was prioritized. This is particularly important for research where people may not directly benefit from the study outcomes (Berghmans and Muelen, 1995; Higgins, 2013).

Study Measures

The following section outlines the measures used to answer the research questions of this study. The decision-making process for each measure is provided based on theoretical, methodological, and ethical considerations. For measures that were adapted or created specifically for this study examples are provided in the Appendices (4a and 4b). A summary of the study measures and when they were used is provided in Figure 4. These will be discussed in turn.

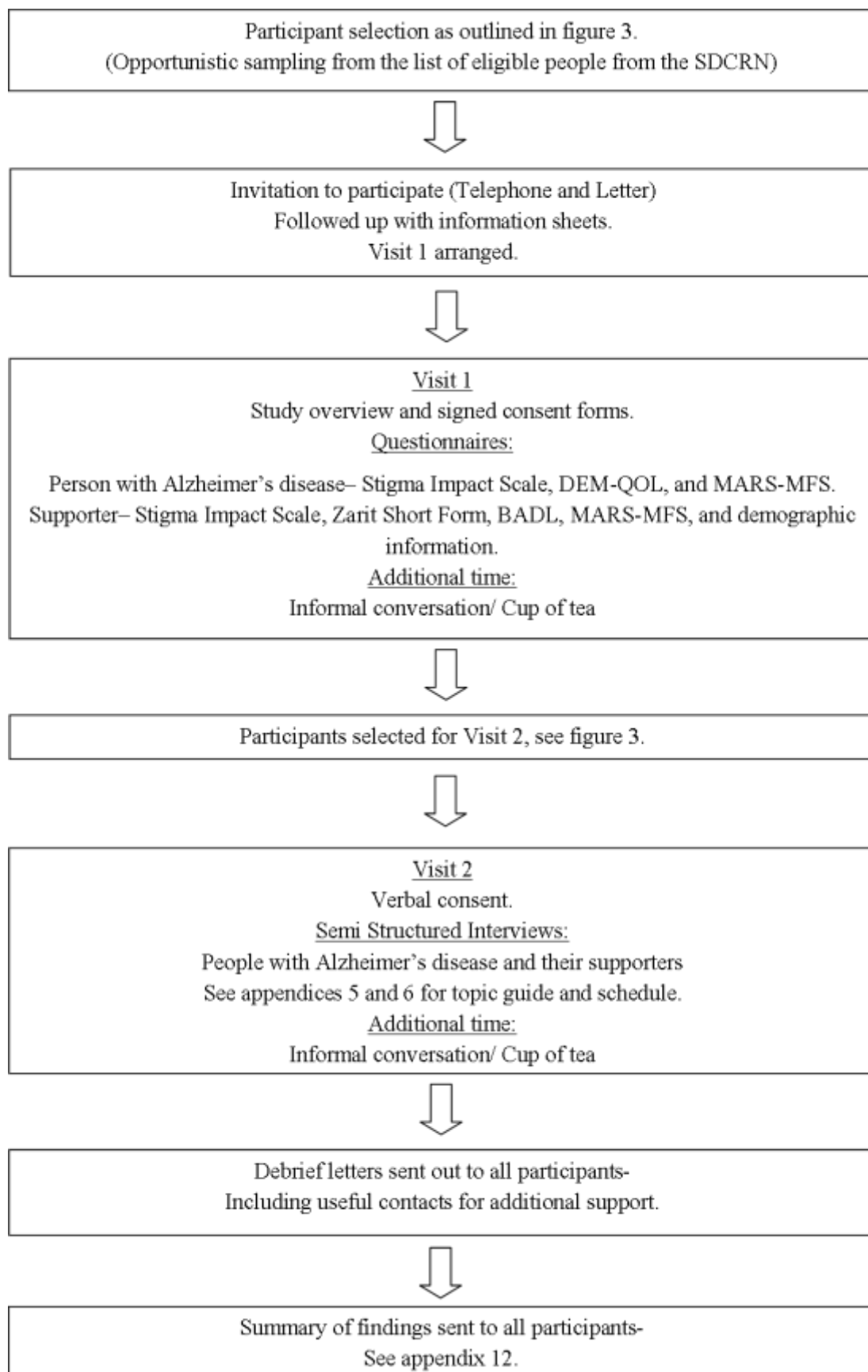


Figure 4. Summary of study measures and protocol.

Demographic information of people with Alzheimer's disease was taken from the SDCRN register. By using register data, the number of questions people completed was minimised, prioritising the core study measures. The research register does not hold as much information about supporters, therefore a demographic information questionnaire was provided for them to complete. Demographic data allows for a range of information to be gained about people, which can be compared to other people in the study, as well as to other studies with similar research aims and objectives. Further, the variables noted have been suggested to influence experiences of Alzheimer's disease and should therefore be measured for possible effects on the study outcomes. Measures included: age, socioeconomic status, and time of diagnosis. The reasons for which are outlined below.

As outlined across the previous chapters, age may influence experiences of stigma and future outlook, although the direction of effects is unclear. Therefore, age of people with Alzheimer's disease was recorded and categorised people as having early-onset or late-onset Alzheimer's disease. People who had been diagnosed with Alzheimer's disease before the age of 65, who at the time of study were older than 65 years old, were included in the early-onset Alzheimer's disease category.

The date people with Alzheimer's disease began taking cholinesterase inhibitors was used as a consistent measure for dating diagnosis, and is provided on the register. Although time of diagnosis was not controlled for it was measured as a possible factor in experiences. For example, as discussed in the chapter 3, the literature highlights that positive memories are more likely to be retained over time than negative memories (Mather and Carstensen, 2005). Therefore, this could affect the reporting of negative experiences such as stigma over time. Additionally, research suggests that the experience of stigma is stronger at the point of diagnosis, with people adjusting over time, further implicating the amount of stigma people report (Vernooij-Dassen et al., 2005).

The final demographic variable included for analysis was socioeconomic status, which was measured using neighbourhood deprivation scores. Fischer et al. (2009) highlighted that there are large amounts of consistent evidence to support the view that low socioeconomic status increases the prevalence of dementia. Further, socioeconomic status has been linked to attitudes and behaviour, including future planning. For

instance, Wardle and Steptoe (2003) compared various attitudes, beliefs and behaviours around healthy living, and found lower socioeconomic status was associated with less future planning and thinking less about ways of staying healthy. Various measures of socioeconomic status can be seen across research. Neighbourhood deprivation can be particularly important among older people as they have an increased risk associated with the effects of the neighbourhood, and they are less likely to be able to move from an area (Lang et al., 2008). These data are available by postcode using the Scottish Index of Multiple Deprivation (SIMD, Scottish Government, 2013b). The Scottish Government provides a full database of postcodes, with overall deprivation, quintiles, deciles and vigintiles, population estimates and health board classifications (Scottish Government, 2013b). The database is open access and can be downloaded to personal computers, which allows for specific postcodes to be input with the database generating all of the necessary SIMD information to be exported. Decile scores were chosen over quintile scores used by Fischer et al. (2009) as they allow for greater diversity, giving a more robust sense of socioeconomic status. Although both education and income levels have also been used in research as markers of socioeconomic status (Fischer et al., 2009), they were not seen as appropriate across all participants, due to the increased likelihood of being retired, and reliance on memory for education levels. Additional data collection methods are discussed below in relation to individual research questions.

Research Question Measures- Do people with Alzheimer's disease and their supporters experience stigma?

Perceived stigma was measured using the Stigma Impact Scale (Burgener and Berger, 2008), and thematic analysis of interview data. The scale was conceptualised based on Modified Labelling Theory (Link, 1987), as discussed in chapter 2, and has been widely used within the psychological literature to explore stigma in mental and physical health from a biopsychosocial perspective since its development by Fife and Wright (2000). It was adapted for use with people with Alzheimer's disease by Burgener and Berger (2008). The questionnaire is made up of 24 questions, which are answered on a Likert scale from strongly disagree (scoring 1), disagree (scoring 2), agree (scoring 3), and strongly agree (scoring 4). Questions could also be scored as non-applicable (scoring

0). This gives an overall score range of 0-96. In their original study Burgener and Berger (2008), as well as Liu (2011), reported the mean Stigma Impact Scale scores. However, more recently and in line with the original scale (Fife and Wright, 2000), subcategory scores have also been reported (Burgener and Berger, 2013). This reflects a more comprehensive view of stigma. Presenting mean scores on their own risks a skewed view, particularly when the different subcategories are not equally weighted.

The scale is made up of four subcategories: social rejection, financial instability, internalised shame, and social isolation. Cronbach's alphas for the four subcategories based on populations of people with HIV and cancer, ranged from 0.85 to 0.90 (Burgener and Berger, 2008). For people with Alzheimer's disease, Cronbach's alphas ranged from 0.56 to 0.82. Although 0.70 and above is generally considered to be reliable (Santos, 1999), the low range due to the financial instability subcategory (0.56) is discussed as acceptable when considered as part of the total scale, which has an overall Cronbach alpha of 0.87 (Burgener and Berger, 2008). In addition, Burgener and Berger (2008) discuss how 'financial instability' may be less relevant to the age range of people living with dementia, in comparison to the study populations using the Fife and Wright (2000) scale. However, Burgener and Berger's (2008) discussion does not acknowledge people with early-onset Alzheimer's disease, which may complicate age-based comparisons in this thesis. The evidence available from Burgener and Berger (2008) suggests that this scale is suitable for use with people with Alzheimer's disease, and it has since been used with this population by others (Burgener et al., 2013; Chapman, 2011; Liu, 2008; Riley, 2012).

Examples of subcategory questions include: 'Some family members have rejected me because of my condition', which represents social rejection, and 'I have experienced financial hardship that has affected how I feel about myself', which represents financial instability. Questions were the same for the supporter's questionnaire with wording changed to reflect their role, for example, 'I do not feel I can be open with others about my family member's condition', which represents internalised shame, and 'Changes in the appearance of my family member with Alzheimer's disease have affected my social relationships', which represents social isolation. The order of questions matched the Burgener and Berger (2008) scales. Adaptations specific to this study included changing the word 'impairment' to 'condition', and 'neurological impairment' to 'Alzheimer's disease'. This was to move away from the medical perspective, and

clarify focus on people with Alzheimer's disease over other types of dementia. The layout was also modified to be clear and accessible to people with Alzheimer's disease, including increased font size and spacing of words. This is due to the higher likelihood of visual difficulties (Van Boxtel et al., 2000). Copies of the adapted questionnaires, with corresponding subcategories can be found in Appendix 4(a -c).

The use of questionnaires with people with dementia has been explored by a range of research. For instance, Small and Perry (2005) found that communication was more successful between people with Alzheimer's disease and their supporter, when closed-ended questions (yes-no) were used compared to open-ended questions, particularly if the answer required episodic memory. Conversely, Moore and Hollett (2003) noted that there is supportive evidence for use of both open and closed-ended questions. The evidence supports the use of a research design which includes a variety of ways of gathering information, depending on what best suits the needs of the person with dementia. As such, a mixed-method design including quantitative and qualitative methods of different structures with open and closed ended questions has been used in this thesis.

Further, the use of a stigma questionnaire allowed for comparisons of scores with similar studies, as well as between participants. It also included a restricted time-frame which spanned two weeks. As such, it provided an indication of the current situation for people with Alzheimer's disease and their supporters in relation to perceived stigma. However, to get a more comprehensive understanding of people's experiences of stigma, a broader time-frame was also considered useful. Therefore, the interview topic guide included questions such as 'How do you feel about others' reactions to yourself and/or your diagnosis of Alzheimer's disease?' A full interview topic guide and schedule can be found in Appendix 5 and 6. Open ended questions relating to stigma experiences gave people the opportunity to expand on their questionnaire answers, particularly if more than one response was appropriate. For example, the questionnaire requires either a positive, negative, or non-applicable response. Comparatively, interviews allowed people to disclose examples of both.

In order to draw conclusions from measures of stigma, possible factors which may influence differences in scores beyond stigma alone were considered. Research

literature suggests that stigma is made up of multiple layers, and can be influenced by a variety of factors including quality of life and people's level of insight into their situation and people's reactions to it. Assumptions include that people diagnosed with Alzheimer's disease cannot have a high quality of life (see Bond et al., 2002), and that they will not have insight into their situation (see Baste and Ghate, 2015) therefore will not perceive stigma.

Evidence from mental health literature indicates that lower insight could reduce the negative consequences of stigma (Boyer et al., 2012), however, there is not sufficient evidence within the field of dementia to support this. Insight was therefore measured using the MARS-MFS (Clare et al., 2002). The questionnaire was completed by people with Alzheimer's disease, reporting on how able they felt in managing a particular memory-based scenario. For example, 'You have an appointment and need to remember to go along'. How frequently would you be able to manage this situation? Response cards were given to participants with 5 possible answers, never, rarely, sometimes, often, and always. The same scenarios are answered by the supporter in relation to the abilities of the person with Alzheimer's disease. This provides scores which reflected both the person with Alzheimer's disease and the supporter's view, as well as a discrepancy score which could be used to suggest an overall picture of functioning. The use of separate scores as well as a discrepancy moves away from the cognitive focus (Clare and Wilson, 2006) and is more encompassing of the subjective experience of the person with Alzheimer's disease. Scores of the MARS-MFS were included in analysis of Stigma Impact Scale scores to see if they influenced the overall outcome.

Additionally, quality of life measures were included as a possible covariate to perceived stigma. Research literature suggests that people who report increased stigma are more likely to experience poor quality of life in comparison to people who report lower levels of stigma (Mashiach-Eizenberg et al., 2013; Burgener et al., 2013). The DEM-QOL (Smith et al., 2005) and Zarit Burden Interview- short form (Bedard et al., 2001) were used to assess quality of life and how it may affect stigma scores for people with Alzheimer's disease and their supporters respectively. The DEM-QOL was developed specifically for using with people with dementia (Smith et al., 2005). It is made up of 29 questions, which focus on a person's experiences over the past week in terms of

emotions, memory, and everyday life. Example questions include, ‘In the last week how worried have you been about your physical health?’. The use of the DEM-QOL for people with Alzheimer’s disease is supported by the Royal College of Psychiatrists (2012). The proxy measure of the DEM-QOL was not used with the supporter, as the study aimed to include the supporter’s quality of life, rather than their view of the person with Alzheimer’s disease. Therefore, The Zarit Burden Interview- short form (Bedard et al., 2001) measured quality of life for supporters, to see if it influenced their perceived stigma scores. The original scale made up of 22 questions is one of the most consistently used scales in similar research (Bedard et al., 2001). The short form is made up of 12 questions, with a correlation of 0.92 and 0.97 with the original version (Bedard et al., 2001). Example questions include ‘Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?’ A shorter version was developed to reduce the number of questions supporters had to answer, particularly as quality of life was not the primary outcome measure. Other quality of life measures were considered for supporters, such as the Short Form Health Survey (Ware and Sherbourne, 1992). However, these measures are not specific to experiences of dementia, and the Zarit Burden Interview is more in-line with supporter outcomes, such as well-being (Royal College of Psychiatrists, 2012). Further, a significant correlation between burden and quality of life has been found across health literature (Isaac et al., 2011; Rha et al., 2015; Santos et al., 2014). Consequently, the Zarit Burden Interview has been used as a proxy measure for quality of life in this thesis.

The final questionnaire used was completed by supporters, and refers to the daily functioning of the person with Alzheimer’s disease. Many studies use memory assessments as an indicator of functioning. These require the person with Alzheimer’s disease to answer questions which rely on memory, such as remembering and recalling a fictional name and address. The most commonly used assessments being the MMSE and ACE-R or ACE III (Simard, 1998; Mioshi et al., 2006; Sheehan, 2012). These assessments provide a cognitive functioning score which is often used to classify somebody as having mild, moderate or advanced stage of dementia. Although this can be useful from a clinical perspective, it does not provide insight into a person’s lived experiences with the condition. Further, completion of memory assessments can expose people to feelings of failure and unnecessary harm (Mograbi et al., 2012). As noted in chapter 4, the SDCRN research register used MMSE scores to filter potential

participants for this study. However, this was not used as a study measure, as there was variation in when people completed the MMSE. As an alternative that is more reflective of lived experiences, the Bristol Activities of Daily Living (Bucks et al., 1996) was chosen. The questions reflect the focus on people's daily experiences moving beyond cognitive ability. During study visits, many participants expressed their frustration over cognitive tests, and how they did not feel they reflected daily living. This does not mean that cognitive assessment does not have its place, but that it needs greater contextualising to understand overall experiences.

Research Question Measures- How do people with Alzheimer's disease and their supporters view and plan for the future?

Looking to the future was explored through semi-structured interviews. As discussed in the literature reviews (chapters 2 and 3), there has been limited research into future outlook which considers the journey between diagnosis and end of life care. As such, a more exploratory method was needed. Interview topic guides were formulated based on the gaps in the research literature and areas of interest identified within the literature review (see Appendix 5). These guides were provided to participants prior to interview, as well as during visits. This gave people the time and opportunity to consider the topics and how much information they wanted to share about them. The interview schedule which accompanied this had more specific questions including, 'How do you view the future with Alzheimer's disease?' and 'Have your thoughts about the future changed since having Alzheimer's disease?' These questions were used to facilitate discussion (see Appendix 6).

Research Question Measures- Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters?

The remaining research questions were explored within the analysis using the data collected across research measures. As discussed within the literature reviews (chapters 2 and 3), diagnosis of Alzheimer's disease exposes people to stigma. Despite this,

diagnosis is encouraged to allow people to plan for the future. Therefore, the findings relating to both stigma and future outlook were considered together, to understand more about how people look ahead and whether experiences of stigma impact on this.

Research Question Measures- Are there differences in experiences, in terms of both stigma and future outlook, for people experiencing early-onset Alzheimer's disease and late-onset Alzheimer's disease?

Age differences were not explicitly asked about at interview, to reduce the likelihood of leading questions or eliciting stereotypes. Rather, during analysis the similarities and differences in experiences between age groups were explored. Although age differences were not raised by the researcher, age was repeatedly brought up by participants at interview, relating to the support services available and when comparing their experiences to others. This has been explored in more depth within the findings chapters.

Overall, people with Alzheimer's disease and their supporters completed a range of measures to explore the four research questions identified through the literature review. Demographic information was collected from all participants, either from the SDCRN research register or through a demographic information sheet. All participants completed the Stigma Impact Scale and measures of quality of life and insight, as previous literature has indicated these could influence stigma reporting. Semi-structured interviews allowed people with Alzheimer's disease and their supporters to expand on their questionnaire responses, as well as explore future outlook in more depth. The subsequent section provides a discussion on quality assessment of measures before moving on to a more structured description of how these measures were used, following people through their study visits, through to the end of data collection and the beginnings of data analysis.

Selection of measures: Quality assessment

Establishing research rigour is a fundamental aspect of demonstrating strength of outcomes in research (Brown et al., 2015). Combining methods can be time-consuming

and is often done in research where a team of researchers are involved (Tariq and Woodman, 2013). However, the key benefit of a solo researcher as part of a PhD study is a consistent approach. The literature surrounding ‘research rigour’ considers quantitative, qualitative, and mixed method research, and how they differ in their approach to establishing quality (Seale and Silverman, 1997). Quantitative research is described by Seale and Silverman (1997) as focusing more on representative data; whereas, qualitative research favours authenticity and the need to accurately capture experiences (Seale and Silverman, 1997). Although Seale and Silverman make note of mixed-method research, Brown et al. (2015) argue that there remains little consensus for establishing rigour in mixed-method research designs.

Despite this lack of consensus, there is general agreement that the quantitative and qualitative methods used within a mixed-method study can be evaluated, with ‘reliability and validity’ applied to quantitative elements and ‘dependability and conformability’ applied to qualitative elements (Bryman et al., 2008). The different terms can lead to an assumption that reliability and validity cannot be applied to qualitative research; however, Tobin and Begley (2004) highlight that qualitative research should still consider these concepts as to reject them could reject rigour and the applicability of the scientific process to qualitative methods.

Interestingly, although there is a tendency to apply reliability and validity to quantitative methods a recent paper by Lilienfeld et al. (2015) suggests that researchers should be more cautious of using the terms ‘reliable’ and ‘valid’, since the nature of science as ‘work in progress’ leads to an inability for findings to be conclusively validated or invalidated. Further, the concepts are not unitary; instead they are made up of different types of reliability and validity, such as internal and external validity, and test-retest reliability. Finally, the reliability and validity of research is not inherent to the test itself but conditional on the specific sample (Lilienfeld et al., 2015). The following discusses rigour in relation to the mixed-method research carried out in this thesis.

Reliability of the questionnaire data will be considered through comparison with other studies using the same scale in a similar research population. For instance, the Stigma Impact Scale scores available for the studies, previously used in power calculations (Burgener and Berger, 2008; Liu, 2008; Riley, 2012) will be discussed in relation to the

findings of this study in chapter 6. For the interview data, reliability is reflected as ‘dependability’ (Tobin and Begley, 2004) where a clear ‘auditing trail’ has been kept throughout the research process. For instance, interviews were transcribed by the researcher, and examples were discussed and reviewed with the supervisory team to confirm a logical and clearly documented process for coding and thematic analysis (as discussed in chapter 5).

The validity of questionnaire measures has been discussed in the previous section on study measures. Of note, the questionnaires chosen were all previously used in the dementia field, and have been adapted for their use with people with Alzheimer’s disease and their supporters (Burgener and Berger, 2008; Clare et al., 2002; Sheehan, 2012). This increases the trustworthiness of scales, which also requires trust in past researchers to accurately document their use. According to Golafshani (2003), the involvement of several researchers can reduce the validity of a test, and this further supports having a consistent, single, researcher administering the questionnaires. All questionnaires given to the person with Alzheimer’s disease were read aloud and recorded by the researcher. In addition, the questionnaires had all been practiced in order to be prepared and consistent when administering them.

Validity in relation to interview data can be viewed as ‘trustworthiness’ (Tobin and Begley, 2004) and incorporates dependability and conformability as previously outlined by Bryman et al. (2008). As with reliability discussions, dependability relates to providing an ‘auditing trail’ with reflexivity central to this (Tobin and Begley, 2004). Throughout the research process, supervision with PhD supervisors allowed for continued reflections on the research from initial conception to study visits, analysis, and overall write up of the thesis. In addition, separate field notes were made on study visits for personal reflections on the visits, as well as study data and summary of visits. As well as being reflexive of the research process, experiences of working with people with dementia as a Clinical Studies Officer for the SDCRN impacted on the research visits. For instance, through SDCRN work, sharing a cup of tea with people with dementia and their families to help build relationships was strongly beneficial (Ashworth, 2014). In addition, working with people with dementia and recognising the importance of familiarity led to small changes such as including a photograph of the researcher on all written correspondence, as well as keeping notes about general likes and dislikes of participants, allowing for familiar topics of conversation and trust to

build. Throughout study visits it was important to participants that the researcher had worked with people with dementia previously, as this supported the idea that the situation was understood, and that it would not be the first time such stories had been heard. This is likely to reduce the risk of people feeling they may ‘shock’ the researcher, and therefore withholding important information. Further reflections on study visits have been discussed following the study protocol.

Reflexivity is a concept regularly noted in qualitative research as a way of validating research, but less so in quantitative research (Walker et al., 2013). Further, the use of reflexivity in quantitative methods may be counterintuitive given the discrepancy between objective measures and subjective experience (Ryan and Golden, 2006). Despite this, when conducting research with people with dementia, the researcher needs to overcome barriers to communication, such as cultural differences, gender, social class (Ryan and Golden, 2006), as well as potential symptom-related communication difficulties (Alzheimer’s Association, 2015). In order to do this, reflexivity is needed across the research process. Reflections on study measures and protocol are discussed at the end of chapter 5, before data analysis. Other aspects of reflection are noted in the following discussion.

In addition to reflexivity, confirmability is noted by Bryman et al. (2008) and Tobin and Begley (2004) as being an important aspect of trustworthiness and validity of research. Confirmability requires researchers to demonstrate that the findings presented are clearly evident in the data (Tobin and Begley, 2004). Within this is a need to be aware of personal biases and how they may affect the findings (Bryman et al. 2008). As with the previous discussions, regular supervision and clear documentation of thought processes helped to maintain awareness of such biases and establish agreement that the findings were accurately reflecting the data. This included field work diaries, mind-maps of analysis and potential themes, recorded supervisions and discussion summaries. These processes are not without critiques, with some arguing that the nature of validity and reliability being tested ‘post-hoc’ means that it may be too late to do anything to alleviate error (Morse et al., 2002). However, being aware of these challenges from the outset of research should help to alleviate this as much as possible.

Finally, triangulation is worth noting within quality assessment given its importance in mixed method research. Triangulation is often used to address the differences between

qualitative and quantitative methods (Tobin and Begley, 2004). However, Olsen (2004) argues that triangulation goes beyond validation, and leads to a wider understanding of the topic area. In order to achieve this, the findings from questionnaire data and interview data will be combined with reference to the research questions in chapters 6 and 8. As will be discussed in the analysis section, there was an a priori set of codes based on the type of questions being asked in the questionnaires and the interview schedule (see appendix 6). In addition to this, open coding was used, allowing for previously unexplored areas to emerge. Following the quantitative and qualitative analysis, conducted separately, the data was brought together by research question and is presented across three findings chapters.

In the following section the study protocol will be outlined to provide a step-by-step guide to researchers for how the mixed method study was carried out, before reflections in practice, and an overview of data analysis. The level of detail within the protocol is an aspect of establishing quality and trust through transparency (Bryman et al., 2008). Transparency has been established in this thesis across the two methods chapters, as well as through supervision with PhD supervisors, and consultation with a statistician with regard to the data analysis intentions and outcomes to reduce the risk of statistical errors (Bridge and Sawilowsky, 1999). The quantitative and qualitative data has been analysed separately to preserve the integrity of each type of data (Tariq and Woodman, 2013), before bringing them together based on the research questions, to give an overall enhanced understanding of the research phenomenon (Tariq and Woodman, 2013).

Study protocol

People with Alzheimer's disease and their supporters were invited to take part in a study which explored people's experiences of living with Alzheimer's disease. A particular focus on attitudes of others, and looking to the future was highlighted. All written correspondence with participants contained contact information, and a photograph of the researcher to make it easier for people to place the information they were receiving with the study. This was particularly important for participants in this study, as being part of the SDCRN research register meant that some participants had contact from several researchers over the study period. Having clearly identifiable

information helped to ease some of the confusion of this, and further added to the personalisation of research. The first visits included study information and consent. People with Alzheimer's disease completed the Stigma Impact Scale, MARS-MFS, and DEM-QOL with the researcher, whilst supporters completed Stigma Impact Scale, MARS-MFS, Zarit Burden Interview, Bristol Activities of Daily Living, and the demographic information questionnaire.

Second visits were organised with those selected for interview (see Figure 3). The visits were kept informal and open, with the topic guide providing a broad structure for experiences to be shared. On completion of the study, all participants were debriefed verbally and by letter, including useful contacts such as Alzheimer Scotland (Appendix 11). A summary of results was sent to all participants following analysis and write up of results (Appendix 12). Although the primary purpose of study visits was the completion of research measures outlined previously, it was important to make the research experience as positive as possible for participants. This is particularly important in non-therapeutic research, where people may not directly benefit from the study outcomes (Berghmans and Muelen, 1995; Higgins, 2013). Further, there is an increased likelihood of social isolation amongst this participant group (Alzheimer's Australia, 2014). Therefore, to help people feel that their voices were being heard, additional time was added to all visits to allow for general conversation. Taking time to share a cup of tea aimed to alleviate some of the social isolation, which has been suggested to impact on cognitive functioning (Cacioppo and Hawkley, 2009). In addition, sharing in cultural practices such as tea drinking encourages positive relationships to form (Ashworth, 2014). The aim was to make sure people were left in a positive frame of mind, which is particularly important when the study involves emotive topics. The protocol is discussed in more detail, with inclusion of the practical and ethical considerations which influenced the process.

Initial contact

All potential participants were sent an initial contact letter (see Appendix 7) and phoned using the telephone number listed on the SDCRN research register. Letters were sent out in hand-addressed envelopes to add personalisation and encourage uptake (Choudhury et al., 2012). The letter informed people that they were eligible for a study

looking into experiences of Alzheimer's disease. If they wished to know more about the study they could reply using stamped-addressed envelope, phone or email. For those who agreed to learn more about what the study involved (see chapter 4 for study uptake), information sheets were sent out (Appendix 8a/b). The time, date and location of visits were kept as flexible as possible to meet people's needs. A couple of restrictions included, no more than 2 visits in any one day, to reduce researcher fatigue, and allow time for processing visits without too much overlap. Additionally, Friday afternoon visits were not offered as it was felt that this could leave people with less contact opportunity after the visits, should it be needed.

Participants were offered multiple visits to reduce the pressure of completing the study in one go. Three possible visits per participant were included in the study design; this was deemed enough to make sure there was plenty of time to answer research questions and spend time with participants. Finally, people were offered visits in their homes or at the University of Stirling. All participants preferred to be seen in their own home. For supporters who did not live with the person with Alzheimer's disease, visits were completed at the person with Alzheimer's disease's home based on the pair's preferences.

Visit one

Before the first visit, participants were called within 48 hours to confirm that the time and date were still suitable. Everyday life can be unpredictable and it was important to give people the opportunity to change their visit if they wished. Upon arrival, people with Alzheimer's disease and their supporters were engaged in general conversation before focusing more specifically on their current situation. The first visits were not audio recorded, although a summary was written after visits. These were particularly useful to review before interview visits, by re-familiarising the researcher with the situation. They also provided conversational cues which could reinforce feelings of familiarity, such as dogs' names or favourite hobbies.

The purpose of the study was discussed in more detail with both the person with Alzheimer's disease and their supporter, what the study involved, and the ability to pause or stop the study at any time without negative consequences was made clear

throughout. This discussion fed into the consent process. As noted within inclusion criteria (chapter 4), people with Alzheimer's disease had to have capacity to consent to take part in the study. Proxy consent was not deemed appropriate given the measures being used. Capacity is not necessarily fixed or predictable based on one factor. It is based on a continuum (Cacchione, 2011) and can vary based on daily performance, and situational factors such as time of day (McKeown et al., 2010), mood and tiredness (Wilkinson, 2002). Therefore despite the list of potential participants provided by the SDCRN being of people with capacity, the overall decision was not made without further context, and discussion with both the person with Alzheimer's disease and their supporter.

Once it was established that somebody had capacity to give their consent, the secondary consideration was that consent was given based on an informed decision. Informed consent is defined as the provision of voluntary authorisation given by an individual who has the capacity to understand the research protocol, and decide whether to participate in research (Black et al., 2008). For people with Alzheimer's disease it was important to make sure they agreed to consent throughout the process. This was addressed by applying the model of process consent (Dewing, 2007). This model challenges the cultural stereotypes of dementia, which suggest people are not able to give consent. Dewing (2007) outlines how consent can be more inclusive and appropriate to the needs of people with dementia, and comprises 5 key stages, background and preparation, establishing a basis for capacity and other abilities, initial consent, on-going consent monitoring, and feedback and support. In essence this brings together skills of communication and working together with people with dementia to understand how their subjective experiences may influence their ability to consent. A copy of the consent form used can be found in Appendix 9.

After obtaining consent from both the person with Alzheimer's disease and their supporter, questionnaires were given to both. Supporters completed the demographic information, the Stigma Impact Scale, the MARS-MFS, the Zarit Burden Interview, and the Bristol Activities of Daily Living. The researcher was available throughout to answer any questions. The person with Alzheimer's disease completed the Stigma Impact Scale, MARS-MFS, and the DEM-QOL. The questionnaires were completed with the researcher reading the questions aloud, and each questionnaire came with a

laminated response card for people to refer to. Participants' energy levels and engagement with the questions was monitored throughout, with people regularly being asked whether they were happy to continue.

Completion of all questionnaires took around 30 minutes, although all visits were a minimum of an hour long to give sufficient time to get to know people, and complete measures without them feeling under pressure or rushed. After the questionnaires had been completed, the next stage was explained again to all participants. Particular focus was on whether people were happy to be contacted about a second visit. It was important that everybody understood that they may not be interviewed, but that they would hear from the researcher before the end of the study for a more formal debrief regardless. Finally, before leaving any of the visits, it was important to recognise that much of the discussion could elicit negative memories and emotions for people. It was therefore vital to make sure that people felt positive before ending the visit, and knew who they could contact if needed. This was another reason to exclude people who could not be seen as a pair, as this supportive relationship was important for the wellbeing of both the person with Alzheimer's disease and their supporter.

Visit two

Following the selection of people for interview, participants were contacted and asked whether they were still interested in taking part in the second stage of the research. As with visit one, time and dates were left as flexible as possible to meet participants' preferences, and confirmed within 48 hours of the visit. A topic guide (Appendix 5) was sent out to participants so that they would have an overview of what the interview involved, and feel more control over the discussion. All interviews were audio recorded to allow the researcher to stay engaged in the conversation and avoid note-taking. As with visit one, summaries of the visits were made afterwards to keep note of any additional information. These were included in transcript summaries to provide as much context to the interview data as possible.

Visits began by recapping what had been happening in people's lives between visit one and visit two. It was important to take the time to let people settle into the interview and feel comfortable sharing their stories, particularly as many of the interview topics were

emotive and involved sharing personal experiences. As with the first visit, it was important that people felt they were being listened to beyond just question answers. Having summary notes of previous visits helped to facilitate general discussion and emphasised the focus on overall experiences as well as research-specific outcomes. Interviews followed a general structure, although they were deliberately left open to the subjective experiences of people with Alzheimer's disease and their supporters. For some participants, following the schedule more rigidly was their preferred style, whereas others discussed topics through elaborate stories. Remaining responsive to individual preferences in communication allowed people to share information in the ways that suited them most.

As with the first visits, around one hour was allocated for discussion, however this was left flexible to the preferences of participants. As part of ethical practice it was important to be aware of fatigue, and both verbal and non-verbal communication of wishes to pause the study. For this reason multiple visits were planned into the research design. When conducting the research, interviews lasted a minimum of 1 hour, up to 2.5 hours. For the longer interviews, participants were regularly asked if they wished to pause or stop the interview. However, the response was always a preference to continue unless the researcher had to leave. This in part reflects the relaxed atmosphere of interviews, aiming to learn more about people whilst addressing the study aims. Further, it reinforced how for many people the study visit was a significant amount of social contact, relative to their normal routine, and as such was encouraged.

When designing the study it was decided that formal compensation would not be issued. Monetary incentives can lead people to feel under pressure to participate, or to continue in a study when they may wish to withdraw (The Research Ethics Guidebook, 2013). Therefore, a thank you gesture was deemed the most appropriate way of acknowledging people's involvement whilst not adding unintended pressure. All interview visits included a token gesture of strawberries and gluten-free biscuits. These were chosen as foods which should be inclusive of a range of different diets and food preferences.

At the end of the interview, the schedule was looked over to check that all of the topics had been picked up, although they did not require equal time spent on each. The final processes of the study were explained to people. This included who could be contacted

if they had any questions, and when they could next expect to hear more about the study. A verbal debrief was given, which included an overview of the study, as well as a more general debrief to make sure people were left in a positive frame of mind. People were then sent written debrief letters by post, which included additional contacts for support should it be needed. Finally, a summary of results was sent to participants once the study had been completed and written up. Research such as Law et al. (2014) highlighted that people felt strongly about having clear feedback of results. Further, if people participated in research where results were not fed back they felt less inclined to participate in future projects (Law et al., 2014). A copy of the debrief letter, useful contacts, and summary of results is available in Appendices 10, 11 and 12 respectively.

Reflections on study measures and protocol

The following section reflects on the experiences of data collection, from consent through to final visits. The consent process was not always straightforward. For instance, Harris¹ (person with late-onset Alzheimer's disease, PL3) was very eager to take part in the study, and showed clear understanding of what was involved. However, when the consent form was presented to Harris he showed significant distress. It was explained to Harris that we could share a cup of tea, and I could come back at a later date if he wished to consent another time. Whilst sharing a cup of tea, Harris repeatedly asked to start the questionnaires. When asked about his previous discomfort over the consent form, he disclosed fear of being unable to spell his name. Once he had seen his name written down he eagerly signed and continued with the study. Scenarios such as this emphasise the complexity of conducting research with people with dementia, and supports the use of process consent (Dewing, 2007).

Including additional time for sharing a cup of tea and getting to know participants enabled a relationship to build up. The benefits of engaging with participants through sharing a cup of tea has been discussed in more detail by Ashworth (2014), which highlights the importance of cultural practices in facilitating research visits. It was

¹ Harris is a pseudonym for PL3. See Table 5 for full list of participants and their pseudonyms.

important for participants to have time to get used to the researcher and the study protocol, as well as helping people feel valued as participants.

As noted within the discussion of study measures, multiple questionnaires were included in the first study visit. The Stigma Impact Scale was used as a quantitative measure of perceived stigma. This scale has previously been adapted and validated for use with people with Alzheimer's disease (Burgener and Berger, 2008), and was therefore chosen to capture people's experiences. However, it should be noted that at the time of study design there were no alternative scales (following literature review) to measure perceived stigma, validated in this population. There is limited previous research with the scale, and the research available does not provide detailed critique of its use (Chapman, 2011; Liu, 2008; Riley, 2012). As will be discussed in more detail within the results (chapter 6), the scale is missing areas such as the negative attitudes of healthcare professionals, which were important to the participants within this study. Despite the potential challenges of the scale, first study visits, which included questionnaires, demonstrated several positives which support the use of the Stigma Impact Scale for exploring stigma. In terms of time feasibility, more people could be involved in visit 1 than visit 2, leading to a wider range of data being available. In addition, the less intrusive nature of the questionnaires compared to interviews (Benjamin Darling, 2006) enabled relationships to build up with participants in order to develop trust and openness for the second visits. This is particularly beneficial when conducting interviews on emotive topics. Therefore, in addition to providing relevant data, visit 1 supported an ethical approach to introducing stigma before exploring the topic in-depth at visit 2.

During the study visits the time-referencing of questionnaires emerged as an interesting aspect of the tools that was potentially important. For instance, the DEM-QOL (Smith et al., 2005) asks participants to describe their emotions over the past week. When documenting the development of the scale, Smith et al. (2005) highlight that the appropriateness of the time-frame question was assessed. However, they go on to note that pre-testing indicated variation in the ability of people with dementia to use this specified time. It was concluded that although data from some people with dementia may be unreliable, it was still important to keep a time reference for people with dementia who were able to use it (Smith et al. 2005). The DEM-QOL specifies a period

of a week as being a practical time reference for people with mild dementia, and the time reference is indicated in each question to maintain its salience.

Other scales which have been adapted for use with people with dementia use longer time references, including the Stigma Impact Scale (Burgener and Berger, 2008), which measures perceived stigma, and asks participants to describe their experiences from the past three to four weeks. Similarly, scales used by a supporter to rate a person with dementia's daily activities, such as the Bristol Activities of Daily Living scale (Bucks et al., 1996), have a two-week time reference. Of interest, is whether people are using this time reference, and if variation in its use amongst participants is a problem. Scales such as the Bristol Activities of Daily Living (Bucks et al., 1996) includes items which relate to time orientation, such as how aware a person is of the date/time of day. Such symptomatology suggests that considering how people place themselves in time may influence the way they answer questionnaires with a specific time reference.

Despite acknowledging the reliability concerns of including a time reference, Smith et al. (2005) kept it in the questionnaire design. Other questionnaires used for people with dementia have not included such time restrictions, such as the Memory Functioning Awareness scale (Clare, 2002). However, when discussing the development of such measures, Clare et al. (2011) do not mention whether this exclusion was a deliberate choice. The importance of time reference is largely dependent on what questions are being asked. For example, if a cross sectional study looking at people's experiences of stigma was conducted, different participants' use of the time reference might not affect reliability. However, if a longitudinal study wanted to look at whether the experiences of stigma have changed over time for a person or group, the time-frame becomes an important variable. Similarly, if cross sectional research was looking at stigma relative to length of time since diagnosis, participants would need to be reliable in their time referenced recall. McDonald et al. (2003), in their discussion of questionnaire design, noted that assuming that respondents are able to answer questions relating to their past is a mistake, acknowledging that participants may not have access to the information to recall, or have the information but cannot recall it from the fixed time reference given. The literature highlights that future research with these measures could benefit from including greater discussion on the importance of time-frame references, as this could have implications for the validity of scales. Although it is important to be aware of these limitations, the BADL scale (Bucks et al., 1996) is world-leading for research

with people with dementia (Sheehan, 2012), and DEM-QOL (Smith et al., 2005) is noted to have ‘comparable psychometric properties to the best available instruments’ and is validated with a UK population (Sheehan, 2012:354). Therefore, these tools were chosen for this study.

During questionnaires, people often went into great detail about the reasons behind their answers, with some expressing frustration that the questionnaires did not always give them room to include these experiences. However, they were reassured that the study included interviews, whether with them or others. They also appreciated having the opportunity to share their stories while doing the questionnaires, even if these stories would not be included in the findings data. Further, several people added that they appreciated questionnaires being completed in the presence of the researcher. Many had experience of postal questionnaires, but had felt frustrated by these as they did not give them the opportunity to share their views adequately. It was noted when deciding which questionnaires to use in this thesis, that cognitive tests would not be used, as recent research emphasises the distress that people with Alzheimer’s disease can experience doing these tests (Mograbi et al., 2012). Further, cognitive test scores were not seen as being reflective of everyday experiences, compared to scales such as activities of daily living, which are more functionally focused (Sheehan, 2012). Not using cognitive tests was acknowledged by many participants as something they were pleased about, with several participants suggesting more appropriate ways of ‘testing’ the memory difficulties they were facing. For example, Lily (SL3), Holly (SL12) and Sophie (SL15) all noted that questions such as the cost of bread or handling money would be better indicators of the difficulties they are experiencing. Lily and Holly both added how Harris (PL3) and Millie (PL12) had ‘sailed through’ their memory assessments when seeking a diagnosis, scoring highly on the cognitive tests, despite their memory difficulties significantly impacting on everyday life. Importantly, not using cognitive assessments does not necessarily mean that participants did not feel ‘tested’ by the other questionnaires, which may have led them to answer differently to how they did in interview where the format is more conversational. Despite the limitations of questionnaires, in particular the fixed-choice answers which may not reflect the participants’ underlying concerns, they allow for a structured approach to collecting data quickly and give more time for the researcher to focus on getting to know the participants and surrounding context, which is particularly useful when building up

relationships for multiple-visit research. Questionnaires also allow for direct comparisons with previous research and relevant applications to time-pressured clinical environments, which is a common feature of health research (Westbrook et al., 2008).

Finally, although interviews were audio-recorded, on a couple of occasions the supporter added comments as the researcher was leaving. This was mainly due to wanting to share additional information away from their loved one, for fear of upsetting them. With the permission of the supporter, this information was also recorded as part of the transcripts whilst noting it was collected without the audio recording.

Data Analysis Procedure

Once all of the data had been collected, the data were analysed using various methods based on the measures used. The following outlines the data analysis procedure used to address the four research questions this study aimed to explore and answer. An overview by question is provided in Table 4, before a more detailed explanation of the analysis. This is followed by the findings chapters, presented by research question in keeping with the epistemological stance of mixed methods research prioritising the research questions over the quantitative or qualitative nature of measures.

Research Question	Study Measures	Data Analysis
Do people with Alzheimer's disease and their supporters experience stigma?	Stigma Impact Scale Semi-Structured Interview <i>Covariates:</i> DEM-QOL Zarit Burden Interview MARS-MFS Demographic Information Bristol Activities of Daily Living	ANCOVA and MANOVA– Differences between Stigma Impact Scores (mean and subcategory) for people with Alzheimer's disease and their supporters.
How do people with Alzheimer's disease and their supporters view and plan for the future?	Semi-Structured Interviews	Thematic analysis of interview data
Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters?	Stigma Impact Scale Semi-Structured Interview <i>Covariates:</i> DEM-QOL Zarit Burden Interview MARS-MFS Demographic Information Bristol Activities of Daily Living	Bringing together results from the Stigma Impact Scale for interviewed participants with themes generated at interview. Possible relationships between findings, including theoretical and methodological discussion.
Are there differences in experiences, in terms of both stigma and future outlook, for people experiencing early-onset Alzheimer's disease and late-onset Alzheimer's?	Stigma Impact Scale Semi-Structured Interview <i>Covariates:</i> DEM-QOL Zarit Burden Interview MARS-MFS Demographic Information Bristol Activities of Daily Living	T-Tests and Multiple Regression – Differences between Stigma Impact Scores (mean and subcategory) for people with early and late-onset Alzheimer's disease . T-Tests and Multiple Regression – Differences between Stigma Impact Scores (mean and subcategory) for supporters of people with early and late-onset Alzheimer's disease . Thematic analysis of interview data.

Table 4. Summary of data analysis process by research question

Analysis process

To assist with the data analysis process, two software programmes were used. SPSS 21 statistics software was used for statistical analysis of questionnaire data, as well as for discriminant analysis of group variables. NVivo 10 was used as a data management tool for the interview data. NVivo 10 does not analyse the data but contains tools which can facilitate the analysis, such as coding matrices. In order to use the software effectively, the qualitative analysis procedure had to be chosen beforehand. The type of analysis chosen depends on the methodology, the research questions being addressed, and the timing of the analysis within the research design. For instance, if an ethnographic approach is taken, the data is more likely to be analysed simultaneously with the data collection (Marshall and Rossman, 1999), whereas this thesis included sequential analysis as part of the mixed-method design. For the purpose of this study, thematic analysis was chosen, the reasons for which are discussed in the following section. Other similar approaches to analysis were also considered. For example, content analysis, which has many overlapping features with thematic analysis (Vaismoradi, 2013), could allow for quantification of interview data (Smith, 2000) but would potentially make it more challenging to notice unexpected themes in the data, relying more heavily on preset codes. Additionally approaches which require a higher level of interpretation such as grounded theory were also noted (Vaismoradi, 2013). However, these approaches were discounted as the research aimed to limit the level of interpretation put on the data by the researcher, so that people's voices and experiences were not lost.

A final alternative that could have been used for this type of research is interpretative phenomenological analysis. The strength of this approach is that it aims to 'give voice' to participants, allowing them to tell their story (Smith et al., 1997) and make sense of their concerns (Larkin et al., 2006). Alongside this the approach is interested in how the researcher's interpretation influences the analysis and data (Cassidy et al., 2011).

Interpretative phenomenological analysis is based upon phenomenological theory, interpretation or hermeneutics, and ideography (Smith et al., 2009). The approach is concerned with the individual's perception of a phenomenon (Smith et al., 1997), and has been applied to conditions such as dementia (Clare et al., 2008), as well as research which sits within a biopsychosocial perspective (Biggerstaff and Thompson, 2008).

Despite many positive aspects of interpretative phenomenological analysis, this thesis does not take a purely phenomenological approach where the subjective is focused on over objective accounts, (Brocki and Wearden, 2006). Instead, the thesis considers experiences of Alzheimer's disease as containing both objective and subjective realities. Interpretative phenomenological analysis avoids prior assumptions and explores the meaning of experience (Reid et al., 2005). Whereas, this thesis aims to be both explanatory and exploratory in terms of stigma and future outlook, and as such the interviews are not only acting as a prompt, but are in part prescriptive in answering specific questions, which does not fit with interpretative phenomenological analysis (Biggerstaff and Thompson, 2008). Further, this thesis is exploring specific aspects of the experiences of Alzheimer's disease, which is more structured than a focus on overall lived experiences. Therefore, thematic analysis is more appropriate for this thesis, with interpretative phenomenological analysis potentially being more applicable to a study exploring experiences more generally. Thematic analysis will now be discussed in more detail including the process used in this thesis, before moving onto the findings chapters.

Thematic analysis

Thematic analysis is “a method of identifying, analysing and reporting patterns within data.” (Braun and Clarke, 2006:79). This approach was chosen as the preferred method of data analysis in this study for several reasons: firstly, the approach is flexible, without needing to be fixed by a particular theory (Braun and Clark, 2006). This is useful in the case of this study where the research questions explore an area with novel focus. Further as the study used mixed methods, the interview data are more structured, based on the need to confirm/refute the evidence collected from the questionnaires. The combination of inductive and deductive coding and theme development has been supported by research such as Fereday and Muir-Cochrane (2006), who used the approach to understand data from interviews as well as organisational documents.

Secondly, Braun and Clark (2006) argue that thematic analysis is a useful approach to PhD research, given its accessible nature. It is important to be realistic about what can be done with the data, given the time and resources available. As such, an accessible approach allows for as much time as possible being allocated to analysis, rather than

focusing more heavily on the theoretical and technological knowledge (Braun and Clarke, 2006).

Previously, it has been argued that thematic analysis is not an appropriate stand-alone approach for analysis, despite the fact it is a widely used approach (Spencer et al., 2003). The main reason cited for this is a lack of transparency in discussing qualitative data analysis (Spencer et al., 2003), with thematic analysis being implied rather than explicitly stated. In order to challenge this, the process by which the analysis of this study has been done has been kept as clear as possible, enabling others to see how each step was reached.

Thematic Analysis Process

The following describes the thematic analysis used in this study in more detail. Firstly, all interviews were transcribed by the researcher during the data collection process. This made it easier for areas of audio which were harder to transcribe to be remembered and accurately recorded. Further, non-verbal communication when appropriate could be added. Transcribing as soon as possible after the interview enabled focus on individual interviews, and meant that had there been any problems with hearing the audio, participants could be contacted fairly easily to confirm answers. All participants expressed they would be happy to be contacted for this purpose. The transcriptions were written verbatim.

Following transcription, an initial code book was developed. There are various approaches to coding qualitative data: A theoretical approach is a 'top down' approach, meaning there are predetermined codes to look for based on the theoretical background of the study. Comparatively, an inductive approach is data driven, or a 'bottom-up' approach, where there is not a set coding frame. Such an approach is aimed at removing the researcher's theoretical position before the data have been analysed. However, Braun and Clarke (2006) highlight that it is not possible to remove this completely. It is important that having an a priori set of codes does not blinker the researcher from considering conflicting or miscellaneous data (King, 2004). Despite the concerns raised about having a priori codes, an initial code book was chosen over open coding as there

were already set questions asked in each interview. These reflected the research questions of the study, and were informed by previous research literature. It was felt that by acknowledging that these codes would be there, additional codes were more likely to be noticed.

The initial code book was made up of 11 codes, based on the interview schedule: Family relationship changes, friend relationship changes, public perception of Alzheimer's disease, reaction to diagnosis, information received, support services, advance care planning, changing futures, hopes, fears, and coping. These were not meant as fixed codes, but as starting points for looking through the data. Following the transcription, additional codes were added to cover areas which had emerged throughout the interviews. Acknowledging that such codes had already formed for the researcher while transcribing, keeps the process transparent. A summary of codes can be seen in Appendix 13.

The next stage was to read through each script twice and write a summary of the interview in order to facilitate being fully immersed in the data, as well as correct any typing errors. The interview scripts were then separated into people with early and late-onset Alzheimer's disease to allow for more exploration of possible age differences. Each script was taken one at a time and initial coding took place. This included noting the codes previously outlined as well as any additional codes. Some data was assigned multiple codes. Some of these were allocated a singular code upon further revision; others were kept across multiple codes. Further, during revisions the key statements within larger chunks of coded text were highlighted.

Following the generation of initial codes, potential themes were considered based on the collation of codes, as discussed by Braun and Clarke (2006). The themes were then reviewed to reflect both the chunks of data and the entire data set. Once themes had been identified and refined, they were named and prepared for reporting (Braun and Clarke, 2006). These themes have been separated into the research questions which they answer, and are discussed in more detail within the findings. Finally, throughout the analysis process PhD supervisors reviewed samples of transcripts and the assigned codes. Group discussions strengthened the overall analysis, increasing the validity of the process and findings. The remainder of the chapter focuses on how the discussed analysis has been applied to the individual research questions.

Do people with Alzheimer's disease and their supporters experience stigma?

Several research measures were used to explore whether people with Alzheimer's disease and their supporters experienced stigma. Firstly, the mean scores from the Stigma Impact Scale for each person within the four groups were generated (people with early and late-onset Alzheimer's disease, and supporters of people with early and late-onset Alzheimer's disease). These scores were compared to previous studies scores on perceived stigma to consider similarity of findings. Descriptive statistics were brought together with demographic information to consider possible interactions. These interactions were explored using a covariate analysis (ANCOVA), a frequently used method for research designs when there are variables which could not be controlled, but may impact on the outcomes (Rutherford, 2001). ANCOVAs allow for the possible influence of the additional measures taken on Stigma Impact Scale scores including: demographic information, quality of life and insight. As discussed within study measures, mean scores of the Stigma Impact Scale alone do not provide a comprehensive picture of stigma using this measure. As such, a multivariate analysis of covariance (MANCOVA), an extension of ANCOVA, was conducted to compare the experiences of people with Alzheimer's disease and their supporters across the four subcategories of the Stigma Impact Scale.

As well as the questionnaire measures and subsequent analyses, thematic analysis of the interviews explored experiences of stigma. Several of the topic guide ideas related specifically to stigma including reaction of family and friends to diagnosis, and experiences of Alzheimer's disease. The guide allowed for several codes to be made before open coding. A full list of codes is available in Appendix 13. Interview data were synthesised to reflect experiences of stigma, as well as provide examples to illustrate the stigma categories of the Stigma Impact Scale.

How do people with Alzheimer's disease view and plan for the future?

Semi-structured interviews explored how people look to the future. Accordingly, a level of analysis which allows for greater understanding theoretically, whilst preserving the voices of people affected was preferred. Thematic analysis was therefore the primary route to understanding how people with Alzheimer's disease view and plan for the future. Preliminary codes were created from the literature, and additional codes were formed following data collection, as shown in Appendix 13.

Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters?

Analysis of this research question required bringing together the data from questionnaires and interviews discussed in the previous questions. The scores on the Stigma Impact Scale and the stigma reporting at interviews were looked at to see if there was any correlation with how a person views and plans for the future.

Are there differences in experiences, in terms of both stigma and future outlook, for people experiencing early-onset Alzheimer's disease and late-onset Alzheimer's disease?

Finally, the fourth research question aimed to get an overall picture of age-based differences in perceptions of stigma, and future outlook. Stigma Impact Scale scores (mean and subcategory scores) were compared for people with early and late-onset Alzheimer's disease, and for supporters of people with early and late-onset Alzheimer's disease. This included t-tests, multiple regression analysis, and ANOVAs. Notably, there was limited statistical power due to difficulties in recruiting the desired sample size. Therefore, the generalizability of the significance of age-based questionnaire results should be treated cautiously. As with the questionnaire measures, interview data were also explored for age-related similarities and differences between experiences people shared for stigma and future outlook.

Analysis Chapters Overview

The findings chapters have been structured according to the first three research questions, with age-based differences presented across the three findings chapters to show how they weave through experiences as a whole. Importantly, it was preferable to have quantitative data presented with qualitative data, as numbers alone can depersonalise the findings. Further it reflects the discussions in chapter 4, which support prioritisation of research questions over research paradigms.

As it was central to the research to hear the voices of those affected, maintaining a sense of the person across methods was key. Table 5 provides an overview of characteristics for people with Alzheimer's disease and their supporters, with summary scores presented in the analysis. All of the participants' names were changed to protect their privacy and anonymity. Further, during transcription of interviews some of the details were changed if they were identifiable. Table 5 also presents the pseudonyms of all of the participants who took part in the study. Identifiers were attached to data for example PE5 and SE5, or PL5 and SL5, with 'P' referring to person with Alzheimer's disease and 'S' referring to supporter. 'E' identifies early-onset Alzheimer's disease, and 'L' identifies late-onset Alzheimer's disease. Participants in bold took part in both questionnaires and interviews. All other participants completed questionnaires only.

People affected by late-onset Alzheimer's disease					People affected by early-onset Alzheimer's disease				
Pseudonyms and ID	Age	Gender	Time living with diagnosis /years	SIMD score	Pseudonyms and ID	Age	Gender	Time living with diagnosis /years	SIMD score
David (PL1)	74	M	8	10	James (PE1)	60	M	1	9
Poppy (SL1)	66	F			Eva (SE1)	61	F		
Grace (PL2)	73	F	8	9	Stewart (PE2)	67	M	7	8
Michael (SL2)	74	M			Jean (SE2)	67	F		
Harris (PL3)	87	M	8	7	Toby (PE3)	69	M	8	3
Lily (SL3)	58	F		8	Katie (SE3)	55	F		
Isla (PL4)	77	F	2	6	Charlie (PE4)	66	M	2	8
Hamish (SL4)	77	M			Emma (SE4)	66	F		
Oliver (PL5)	80	M	8	3	Murray (PE5)	66	M	2	10
Isobel (SL5)	56	F		5	Lucy (SE5)	60	F		
Bernie (PL6)	86	M	6	8	Jack (PE6)	52	M	1	4
Janice (SL6)	82	F			Olivia (SE6)	47	F		
Alfie (PL7)	77	M	5	8	Matthew (PE7)	63	M	4	5
Theresa (SL7)	77	F			Olivia (SE7)	60	F		
Graham (PL8)	91	M	1	6					
Morag (SL8)	64	F							
Archibald (PL9)	83	M	2	3					
Edith (SL9)	78	F							
Emily (PL10)	80	F	9	7					
Cameron (SL10)	77	M							
Morag (PL11)	88	F	11	6					
Nigel (SL11)	88	M							
Millie (PL12)	89	F	5	9					
Holly (SL12)	53	F		10					
Dorothy (PL14)	85	F	4	10					
Stephen (SL14)	83	M							
Angus (PL15)	80	M	6	10					
Sophie (SL15)	82	F							
Douglas (PL16)	80	M	2	10					
Ginny (SL16)	75	F							

Table 5. Summary of all participants from the study including age, gender, time living with diagnosis, and socioeconomic status shown by SIMD score.

As well as providing demographic information that could be recorded quantitatively as shown in Table 5, short biographies of people interviewed are presented in Table 6 to increase their salience throughout the following analysis chapters.

David and Poppy (L1)

David and Poppy are husband and wife. Their faith is very important to them, and they are very active members in their community. Poppy has managed many of the challenges associated with Alzheimer's disease by empowering herself to take on new skills.

Grace and Michael (L2)

Grace and Michael are husband and wife. Grace enjoys painting and takes great pride in sharing her work. Michael is very independent and hardworking, with traditional values for his family. He was very keen to know lots of information and be well informed.

Harris and Lily (L3)

Harris and Lily are father and daughter. Harris is described as a 'family man', who cares a lot about being a good father and making sure those around him are happy. Lily enjoys socialising with friends, and supports both her mother and father.

Isla and Hamish (L4)

Isla and Hamish are husband and wife. They like to be actively involved in the community and the groups available in their area. They have had experience of social discrimination in the past, and as such have built up a lot of resilience to the challenges they now face.

Oliver and Isobel (L5)

Oliver and Isobel are father and daughter. They are from a very close-knit family and work together to support each other. Isobel is very protective of Oliver and finding activities which make him happy. Oliver likes to be the person people ask for advice, and likes to stay well informed.

Emily and Cameron (L10)

Emily and Cameron are husband and wife. They are a very independent couple. Cameron is very practical, and enjoys gardening and golf. Emily enjoys painting, as well as activities such as tennis and swimming.

Millie and Holly (L12)

Millie and Holly are mother and daughter. They have a strong sense of family values and responsibility. They both have a strong faith which has given them strength throughout the challenges they have faced.

Angus and Sophie (L15)

Angus and Sophie are husband and wife. They are very driven by their faith, and actively engage in charitable opportunities. Although they had different avenues of support, they prefer to do things 'their way'.

Eva and James (E1)

Eva and James are husband and wife. They were very keen to show how people can continue to 'live well with dementia'. James likes to stay active, and prefers one-to-one activities. Eva and James enjoy travelling, and go on holiday as much as possible.

Toby and Katie (E3)

Katie and Toby are husband and wife. Katie has used many of the challenges she and Toby have faced to empower herself as much as possible. Both Katie and Toby adore their pets, who have acted as a great source of comfort through the difficult times.

Emma and Charlie (E4)

Emma and Charlie are husband and wife. Emma enjoys spending time with a close group of friends, meeting up for tea and coffee on a regular basis. Charlie finds his reduced independence very difficult as he is a very active independent man, who is very proud of his sporting achievements.

Murray and Lucy (E5)

Murray and Lucy are husband and wife. Murray enjoys entertaining, and being in front of an audience. Lucy and Murray have focused on what they can do despite the condition, both having a 'bucket list' of things they hope to do.

Jack and Olivia (E6)

Jack and Olivia are recently married. They have shown a lot of strength and resilience, having to face multiple hurdles in a short space of time. Jack was very proud of his work, and the camaraderie that comes with it. Both Olivia and Jack were keen to change stereotypes of what it meant to live with dementia.

Matthew and Jennie (E7)

Matthew and Jennie are husband and wife. They both find humour is very important in managing their situation. Both chose to focus on the positives in their situation, and grounded themselves with their faith. There was a strong sense of partnership between them, and working together to make the best of things.

Table 6. Summary of interviewed participants' biographies

Chapter 6- Do people with Alzheimer’s disease and their supporters experience stigma?

The following chapter presents findings from the study relating to experiences of stigma. As described in the data analysis overview (chapter 5), a range of statistical tests were completed using SPSS 21 software. SPSS outputs can be found in Appendix 14. Questionnaire answers were then explored in combination with interview data, before a broader thematic analysis of interview data in relation to stigma.

Table 7 provides a summary of Stigma Impact Scale scores for people with Alzheimer’s disease and their supporters. Scores are presented alongside mean scores and standard deviations for the covariates used in the subsequent analysis. Measures explored perceived stigma, quality of life, insight, and activities of daily living. The choice of covariates and their supporting literature can be seen in chapter 5.

	Perceived Stigma /Mean stigma impact score	Insight MARS-MFS/ mean scores			Quality of Life/ mean scores		Bristol Activities of Daily Living/ mean scores
		Person with Alzheimer’s disease (Self-Report)	Supporter (Informant)	Discrepancy	DEM-QOL	Zarit Burden Interview	
People with Alzheimer’s Disease	38.36 (SD 6.41)	30.41 (SD 10.69)	-	18.72 (SD 11.58)	97.73 (SD 11.18)	-	-
Supporters	29.45 (SD 15.70)	-	15.14 (SD 12.15)	18.72 (SD 11.58)	-	17.00 (SD 8.73)	23.86 (SD 12.23)

Table 7. Summary scores for people with Alzheimer’s disease and their supporters used for multiple regression analysis of Stigma Impact Scale scores.

Firstly, comparative analysis of perceived stigma for people with Alzheimer’s disease and their supporters was conducted. When comparing the two groups, they could be viewed as independent or matched based on the relationship they share, therefore it was deemed appropriate to include ‘independent-sample’ and ‘matched-sample’ analyses for the initial comparison. A correlation analysis for people with Alzheimer’s disease and their supporters suggested a significant correlation between Stigma Impact Scale scores

($r(42) = -0.355$, $p = 0.018$). The scores were considered in more detail with t-test analyses.

A matched-sample t-test found significantly different results between people with Alzheimer's disease and their supporters, $t(21) = 2.643$, $p = 0.015$. This significance remained when the two groups were considered separately with an independent-samples t-test, $t(42) = 2.464$, $p = 0.007$. The t-tests suggest that there is a significant difference between the amount of stigma reported on the Stigma Impact Scale by people with Alzheimer's disease and their supporters, when viewed independently and as matched pairs. For the remainder of the analyses the people with Alzheimer's disease and their supporters have been considered as independent groups. This was viewed as the most suitable option as different questionnaires were completed for covariates such as quality of life, and perceived stigma reflected their own experiences of stigma, as opposed to their view of their loved one being stigmatised. Further, a discriminant analysis of the demographic variables for people with Alzheimer's disease and their supporters was carried out. Variables age, gender, and socioeconomic status were included in the analysis. The overall Chi-square test was significant ($N = 44$, Wilks $\lambda = 0.701$, Chi-square = 14.372, $df = 3$, Canonical correlation = 0.547, $p = 0.002$), suggesting that the two groups can be viewed independently.

Table 8 presents the variables which were included in an analysis of covariance (ANCOVA) for comparing Stigma Impact Scale scores of people with Alzheimer's disease and supporters. This test explored whether the significant difference observed in the t-tests remained when possible covariates (age, socioeconomic status, and gender) were included. ANCOVA produced significant results, $F(1, 39) = 2.895$, $p = 0.034$, with an observed power of 0.729. The findings suggest people with Alzheimer's disease reported higher levels of stigma than their supporters. Further, this difference is not explained by age, socioeconomic status or gender. These findings match the direction of difference in previous research (Batsch and Mittleman, 2012; Werner and Heinik, 2008).

	Mean Stigma Impact Scale score	Mean Age /Years	Mean socioeconomic status / SIMD Decile	Gender Ratio/ Male: Female
People with Alzheimer’s disease	38.36 (SD 6.41)	76.05	7.23	16:6
Supporters	29.45 (SD 15.70)	68.45	7.41	5:17

Table 8. Mean scores for people with Alzheimer’s disease and their supporters used for ANCOVA of Stigma Impact Scale scores.

Perceived stigma and age-based experiences

Age-based differences in mean stigma impact scores were explored for people with Alzheimer’s disease and supporters, before looking at questionnaire scores in more depth. Table 9 presents the summary scores on the Stigma Impact Scale by age category. However, conclusions from this analysis should be taken with caution given the sample size and difference between group numbers.

	Mean Stigma Impact Scale score	Standard deviation
People with Alzheimer’s disease	38.36	6.41
Early-onset	37.86	10.45
Late-onset	38.60	3.83
Supporters	29.45	15.70
Early-onset	36.29	11.87
Late-onset	26.20	14.48

Table 9. Summary scores of Stigma Impact Scale, for people with early and late-onset Alzheimer’s disease and their supporters.

An independent-samples t-test suggested significant differences in perceived stigma reported by people with early and late-onset Alzheimer’s disease ($t(20) = -0.247, p = 0.005$). This suggests higher reporting of stigma for people with late-onset Alzheimer’s disease. The comparison was explored more robustly through the inclusion of possible

covariates. As discussed within study measures in chapter 5, several variables have been identified as potentially influencing stigma reporting. Therefore, scores from the covariate questionnaires were included in a regression model to observe whether the significant difference between people with early and late-onset Alzheimer's disease remained.

Perceived stigma, measured by Stigma Impact Scale mean score was the dependent variable, with insight scores (self-report and discrepancy), quality of life, socioeconomic status, gender, time since diagnosis in years, age, and activities of daily living included as variables. A significant association was found for socioeconomic status measured by SIMD decile, and quality of life measured by DEMQOL score, $F(8,13) = 3.146, p=0.033, R^2 = 0.659$. The direction of the coefficients in the regression model suggests that as socioeconomic status decreases, indicating increased levels of deprivation, perceived stigma reporting increases ($\beta = -0.511, p=0.030$). Similarly, as quality of life decreased, perceived stigma reporting increased ($\beta = -0.526, p=0.041$). The multiple regression analysis for people with Alzheimer's disease suggests that perceived stigma is influenced by socioeconomic status and quality of life. Further, age was not significantly associated with stigma reporting in this model ($\beta = 0.051, p=0.795$).

These findings suggest that although the t-test produced significant results between the two age groups, stigma reporting is associated more with the quality of life and socioeconomic status of participants over age itself. Figure 5 illustrates that people with late-onset Alzheimer's disease had higher scores on average for quality of life (Mean= 98.67, SD=9.62) than people with early-onset Alzheimer's disease (Mean= 95.74, SD=14.66). Further, people with late-onset Alzheimer's disease had higher socioeconomic status scores (Mean= 7.47, SD=2.36) as shown by SIMD decile, compared to people with early-onset Alzheimer's disease (Mean= 6.71, SD=2.69). Overall the findings suggest that the difference in perceived stigma reporting on the Stigma Impact Scale for people with Alzheimer's disease is based on quality of life and socioeconomic status.

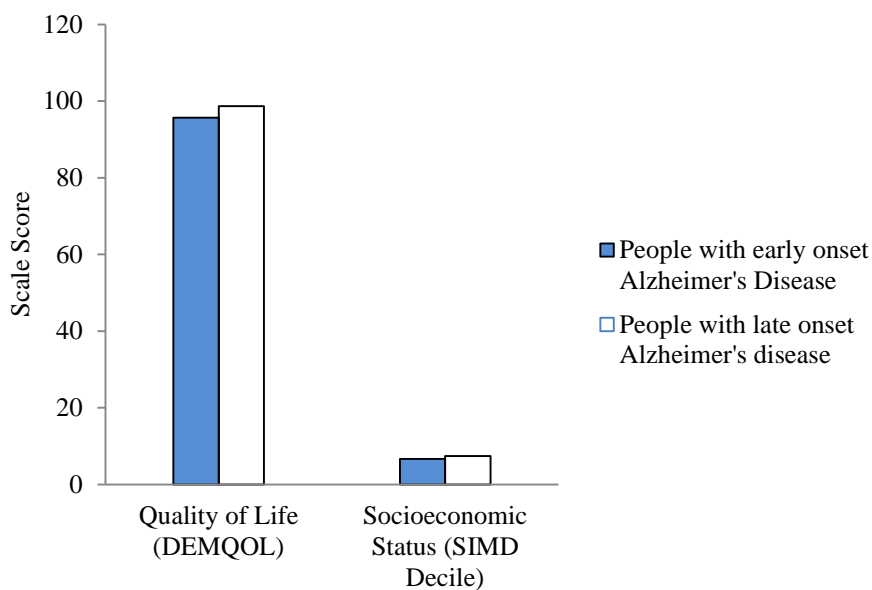


Figure 5. Average quality of life and socioeconomic status scores for people with early and late-onset Alzheimer’s disease.

The previous analyses were repeated for supporters’ data. An independent sample t-test produced non-significant differences for perceived stigma, measured by Stigma Impact Scores, for supporters of people with early and late-onset Alzheimer’s disease ($t(20) = 1.428, p = 0.420$). This was followed by a multiple regression with the variables age, socioeconomic status, gender, quality of life, time since diagnosis in years, activities of daily living, and insight (informant and discrepancy), considered in relation to perceived stigma. The multiple regression analysis showed significant results overall, $F(8,13) = 2.705, p = 0.05, R^2 = 0.625$ (see appendix 14 for SPSS outputs). The difference in significance between the t-test and regression analysis can be explained through inclusion of quality of life scores, as this was the only significant variable within the model ($\beta = 0.512, p = 0.026$). Increased quality of life measured by the Zarit Burden Interview, was associated with a reduction in Stigma Impact Scale scores, reflecting perceived stigma. This supports the pattern seen for people with Alzheimer’s disease. Overall, the findings suggest there were not significant differences in the amount of stigma reported by supporters of people with early and late-onset Alzheimer’s disease based on age.

Finally, in order to draw conclusions from the mean results presented, scores were compared to previous literature. Mean Stigma Impact Scale scores for people with Alzheimer’s disease and their supporters are presented in Table 10, alongside mean scores obtained from previous research using the Stigma Impact Scale in this area. For people with Alzheimer’s disease, mean Stigma Impact Scale scores from the literature were 42.7, 39.93, and 39.94, with standard deviations of 9.0, 10.33 and 9.89 respectively. Mean scores from the Burgener and Berger (2008) and Riley (2012) papers suggest similar results to this study. Similarly, scores for supporters of people with Alzheimer’s disease were compared to those obtained by Liu (2011), showing mean scores differing by 0.13. The similarity of the study findings to those in previous literature support the validity of conclusions that people with Alzheimer’s disease and their supporters experience stigma.

	Number of participants	Mean Stigma Impact Scale score	Standard deviation
People with Alzheimer’s disease			
This study	22	38.36	6.41
Burgener and Berger (2008)	26	42.70	9.0
Riley (2012)	43	39.93	10.33
(Mean scores for two study visits)		39.94	9.89
Supporters of people with Alzheimer’s disease			
This study	22	29.45	15.70
Liu (2011)	51	29.58	10.83

Table 10. Summary of mean scores and standard deviations of study against scores from the literature.

Although the mean responses appear similar across studies, the interpretation has to be taken with caution. Burgener and Berger (2008) discuss the mean score of people with Alzheimer’s disease relative to the score of people with Parkinson’s disease. Similarly, Riley (2012) and Liu (2011) discuss how Stigma Impact Scale scores correlate with

other variables. However, there has not been clear discussion on the score threshold for experiencing stigma. For instance, if the mean results are considered on their own, they could be interpreted as reflecting low levels of stigma. As discussed within study measures (chapter 5), the Stigma Impact Scale is made up of 24 questions, with 5 responses: not applicable (scores 0), strongly disagree (scores 1), disagree (scores 2), agree (scores 3), and strongly agree (scores 4). The highest score is 96, which indicates that people have strongly agreed with all statements, and therefore reported the highest amount of stigma. If the threshold is considered as the majority of answers reflecting experiences of stigma, the minimum score for agreeing to more questions than disagreeing would be 50 (13 agree, scoring 3 each, and 11 disagreeing, scoring 1 each). This presents an inconsistent picture given that the mean scores for all of the studies presented were below 50. If stigma reporting was high, it would be conceivable to expect a higher mean. This does not mean that the conclusions drawn from previous studies are incorrect. Rather it suggests a need for clearer guidelines on the interpretation of scores. In order to explore this further, the subcategories of the scale were looked at, including an exploratory analysis of the answers through inclusion of interview data.

Subcategories of the Stigma Impact Scale

To understand the meaning behind the subcategories of the Stigma Impact Scale, examples from interview data have been selected for illustrative purposes. Firstly, ‘social rejection’ refers to people feeling discriminated against, particularly in terms of assumptions of competence, or people avoiding being around them (Fife and Wright, 2000). For example, Isla (PL4) felt that friends were treating her as incompetent:

“Short of saying ‘get your hand off me’ you know? You’ve got to just go along with it.”

Other participants such as Jack (PE6), describe experiences where symptoms of Alzheimer's disease, in this case speech difficulties, have led to being treated negatively,

“...couldn't get the words out and then that lass started laughing, another one started laughing, I'm saying what's going on?”

The second category, 'financial instability' refers to the consequences of job or financial insecurity as a result of the condition (Fife and Wright, 2000). Financial worries can be seen across the journey of Alzheimer's disease, particularly in terms of funding care. For example, Emma (SE4) shared her concerns over future costs,

“...it's expensive, there's private care, I don't know if I would get help locally, and personal care for him when the time comes...”

Similarly, Poppy (SL1) shared financial concerns,

“I did panic at one stage because there was all this talk about care homes and funding, and as I say I would hope very much wouldn't have to happen.”

Previous literature focuses on financial concerns as more relevant to younger people with dementia (Chaston, 2010), whereas interview data highlights it may be a concern across age groups, particularly in relation to futures.

'Internalised shame' focuses on how experiences such as social rejection and financial insecurity affect the way a person views themselves (Fife and Wright, 2000). These experiences are associated with blame and fear of disclosing a diagnosis. Examples include, Oliver (PL5) who Isobel (SL5) describes as avoiding accepting the condition due to pride, and fear of its meaning,

“And it was so hard because he wasn't really telling you, he was hiding, and if you brought it up he would change the subject, he was so awkward.”

Similarly, Katie (SE3) discusses regularly reassuring Toby (PE3) and challenging his feelings of stupidity,

“...something that Toby kept saying to me at the beginning was, he kept saying I'm, I feel so stupid, I'm stupid, I wish I wasn't stupid.”

The final subcategory, ‘social isolation’, incorporates feelings of loneliness, and inequality in relationships (Fife and Wright, 2000). Sophie (SL15) discusses that some of this loneliness is a result of people not being able to understand the situation if they have not lived through it,

“unless you’re really dealing with it 24 hours a day, I don’t think anybody can really do an awful lot.”

Further, Lucy (SE5) highlights feelings of inequality in relationships when discussing her relationship with Murray (PE5),

“...for quite some time now I’ve accepted on the whole Murray’s world revolves around Murray, and although we still enjoy being a couple in most ways, obviously Murray is fixated on what’s going on in his head.”

This change in experiences can therefore lead to feelings of isolation. The subcategories of the Stigma Impact Scale were explored in more detail through quantitative analysis. A detailed breakdown of subcategories by questions and subsequent score ranges are presented in Appendix 4a-c with the adapted scale.

Exploratory analysis of the scores within the subcategories took place for people with Alzheimer’s disease and supporters. Table 11 presents a summary of scores by subcategories, with the number of items and score ranges presented to illustrate the unequal weighting of mean scores.

Subcategory of Stigma Impact Scale	Number of items within subcategory	Range of possible scores for each subcategory	People with Alzheimer's disease		Supporters	
			Mean	Standard Deviation	Mean	Standard Deviation
Social Rejection	9	0-36	15.72	3.67	11.05	6.21
	Early-onset Alzheimer's Disease		14.14	5.70	13.13	4.42
	Late-onset Alzheimer's Disease		15.33	1.40	10.40	7.57
Financial Insecurity	3	0-12	1.27	1.93	1.73	2.21
	Early-onset Alzheimer's Disease		3.14	2.34	2.88	2.75
	Late-onset Alzheimer's Disease		0.40	0.83	1.60	2.56
Internalised Shame	5	0-20	8.36	1.89	5.90	3.35
	Early-onset Alzheimer's Disease		7.14	2.19	6.75	2.05
	Late-onset Alzheimer's Disease		9.07	1.87	6.33	3.96
Social Isolation	7	0-28	13.00	2.47	10.77	5.89
	Early-onset Alzheimer's Disease		13.43	3.60	12.75	3.99
	Late-onset Alzheimer's Disease		13.80	1.90	9.93	6.45
Total	24	0-96				

Table 11. Summary scores by subcategory for people with early and late-onset Alzheimer's disease and their supporters.

The results from comparing mean scores on the Stigma Impact Scale suggested that people with Alzheimer's disease report significantly more stigma than their supporters. A multiple analysis of variance (MANOVA) was computed to compare people with Alzheimer's disease and their supporters across the four subcategories. Significant differences between people with Alzheimer's disease and their supporters were highlighted across subcategories, $F(4, 39) = 3.605$, $p = 0.014$, Wilk's $\Lambda = 0.730$, partial $\eta^2 = 0.270$. Figure 6 illustrates the average percentage scores for the four subcategories. Percentage scores are presented over raw scores, as the unequal weighting of subcategories could lead to a skewed picture of results.

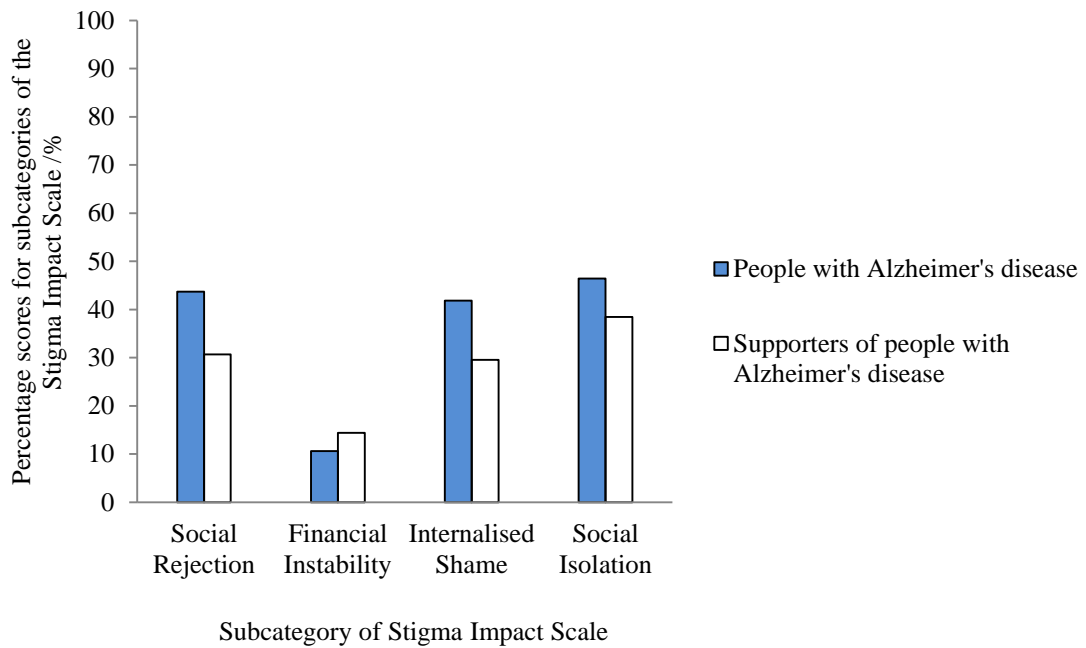


Figure 6. Percentage scores for People with Alzheimer’s disease and their supporters for subcategories of the Stigma Impact Scales

Significant differences were found between people with Alzheimer’s disease and their supporters for social rejection, $F(1,42)= 9.246$, $p= 0.004$ and internalised shame, $F(1,42)= 8.953$, $p= 0.005$. This suggests that people with Alzheimer’s disease report higher levels of stigma than their supporters, in relation to social rejection and internalised shame, but not social isolation ($F(1,42)= 2.672$, $p= 0.110$) and financial instability ($F(1,42)= 0.528$, $p=0.471$). The difference in subcategories may be linked to the impact of the symptoms of Alzheimer’s disease itself on social reactions and self-stigma, compared to everyday experiences which may affect people with Alzheimer’s disease and their supporter together such as financial concerns, and mutual isolation. Across subcategories, social isolation was highest for people with Alzheimer’s disease and supporters of people with Alzheimer’s disease. This supports earlier discussion within the study protocol (chapter 5), that people affected by Alzheimer’s disease are likely to experience high levels of social isolation (Alzheimer’s Australia, 2014).

It should be noted that these results support the pattern of answers, but are not necessarily indicative of high or low stigma. Across the subcategories, people with Alzheimer’s disease answered ‘disagree’ or ‘strongly disagree’ 66.8% of the time, with

supporters ‘disagreeing or strongly disagreeing’ 57.3% of the time. Comparatively, levels of agreement with statements were 9.3% for people with Alzheimer’s disease and 11.1% for Supporters. These results suggest stigma reporting using the Stigma Impact Scale is low overall.

Covariate Questionnaires and Stigma Impact Scale Subcategories

The subcategory analysis between people with Alzheimer’s disease and their supporters suggests a more complex picture of stigma can be seen across patterns of reporting. To build on this further, subcategory analysis within-groups have been explored. Previous regression models for mean Stigma Impact Scale scores suggested that quality of life and socioeconomic status were significantly associated with stigma for people with Alzheimer’s disease , $F(7,14) = 3.85, p=0.015, R^2 = 0.658$. As levels of deprivation decreased, levels of perceived stigma decreased. As quality of life increased, perceived stigma scores decreased. The significance of these covariate questionnaires supports their inclusion in an analysis of variance with Stigma Impact Scale subcategories.

Quality of life scores for people with Alzheimer’s disease produced near significant results for internalised shame ($F(15, 6) = 3.89, p=0.051$) but did not significantly predict the other three subcategories. As quality of life scores increased, scores for internalised shame decreased. The findings suggest that decreased quality of life is associated with increased stigma for people with Alzheimer’s disease. This is supported by studies such as Burgener et al. (2013) who found quality of life to be significantly associated with stigma for three of the four subcategories of the Stigma Impact Scale: Social rejection, social isolation, and internalised shame. The difference in number of subcategories associated with quality of life between Burgener et al. (2013) and the current study may be the use of 8 different measures of quality of life in the Burgener et al. (2013) research, compared to the single scale (DEM-QOL) in this study. Further, there may be ceiling effects: quality of life scores on DEM-QOL can range from 28-112, with higher scores indicating higher quality of life. Within this study, people with Alzheimer’s disease scores ranged from 74 to 110, with a mean score of 97.7. A sample with greater diversity with respect to quality of life ratings may have produced

significant results in the additional subcategories of the Stigma Impact Scale shown by Burgener et al. (2013).

For socioeconomic status, as measured by SIMD decile, ANOVA results found socioeconomic status significantly predicted financial instability for people with Alzheimer's disease ($F(7, 14) = 5.78, p=0.03$). Higher levels of deprivation were associated with higher scores for financial instability but not the remaining three subcategories. The significance of socioeconomic status and financial instability is supported by the overlap in focus of the two measures.

For supporters, multiple regression analysis of perceived stigma scores produced significant results for the quality of life, but not for the additional covariate questionnaires, $F(8, 13) = 2.705, p=0.05, R^2 = 0.625$. As with people with Alzheimer's disease, data collected from supporters were explored across the subcategories of the Stigma Impact Scale. Supporters' quality of life, as measured by Zarit Burden Interview was found to be a significant predictor of scores for Social Rejection ($F=6.04, p=0.01$), Internalised Shame ($F=17.19, p=0.01$), and Social Isolation ($F=4.60, p=0.03$). These results suggest that supporters' quality of life could influence how much stigma is reported. Decreased quality of life was associated with greater stigma reporting across the three subcategories. These findings are supported by previous research literature, where higher stigma has been associated with increased 'caregiver burden' (Werner et al., 2012), which is often used with reference to supporters' quality of life.

Age and Stigma Impact Scale subcategories

As well as subcategory differences between people with Alzheimer's disease and their supporters, age-based differences in Stigma Impact Scale subcategory scores were explored as age is a variable of interest throughout the study. The results have been illustrated in the following bar graphs. As with previous figures, percentage scores were chosen over raw scores as the unequal weighting of subcategories could lead to a skewed picture of results.

Firstly people with early and late-onset Alzheimer's disease were compared by Stigma Impact Scale subcategory scores. Figure 7 illustrates that financial instability scored the least for people with Alzheimer's disease. For people with early-onset Alzheimer's disease, social isolation yielded the highest percentage score (48.0%), followed by social rejection (39.3%). People with late-onset Alzheimer's disease showed the same pattern, with social rejection and social isolation both producing average percentage of 45.7%.

Analysis of variance between groups produced a significant difference in scores for people with early and late-onset Alzheimer's disease for financial instability and internalised shame. People with early-onset Alzheimer's disease scored significantly higher than people with late-onset Alzheimer's disease for financial instability, as shown by a significant analysis of variance, $F(1,20) = 16.9, p = .001$. This is supportive of previous literature on age based differences (see chapter 2), which suggests younger people are more likely to be affected by financial difficulties following diagnosis of Alzheimer's disease (Chaston, 2010). People with late-onset Alzheimer's disease scored significantly higher than people with early-onset Alzheimer's disease for internalised shame, $F(1,20) = 5.12, p = 0.035$. This may reflect the accumulated self-stigma of older adult stereotypes and Alzheimer's disease stereotypes as suggested in previous literature (Scodellaro and Pin, 2011). As noted previously, it is difficult to draw firm conclusions from the data given the sample size. However, the pattern of results suggests it would be interesting to follow-up with a larger sample to see whether the significance remains. Further, the inclusion of interview data later in the chapter adds support for the conclusions made.

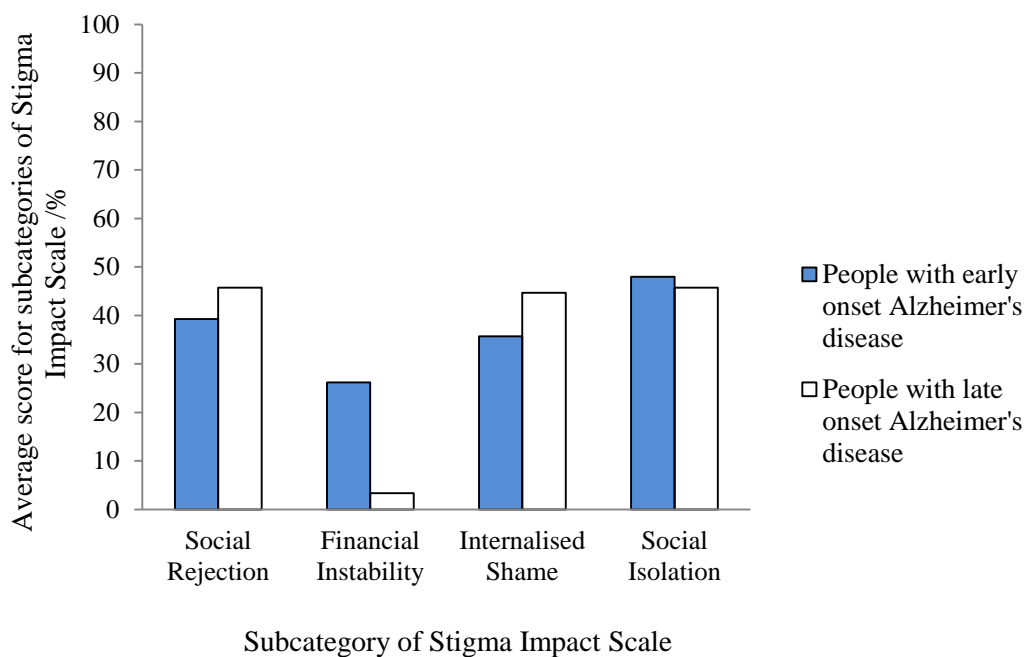


Figure 7. People with Alzheimer’s disease percentage scores for subcategories on the Stigma Impact Scale

The pattern of results for supporters of people with early and late-onset Alzheimer’s disease is illustrated in Figure 8. Scores are given as a percentage of the total score for each subcategory. Supporters of people with early-onset Alzheimer’s disease had the highest percentage score (45.95%) for social isolation followed by social rejection (39.7%). Similarly, social isolation was the highest for supporters of people with late-onset Alzheimer’s disease (35.0%). This is followed by internalised shame at 29.3%.

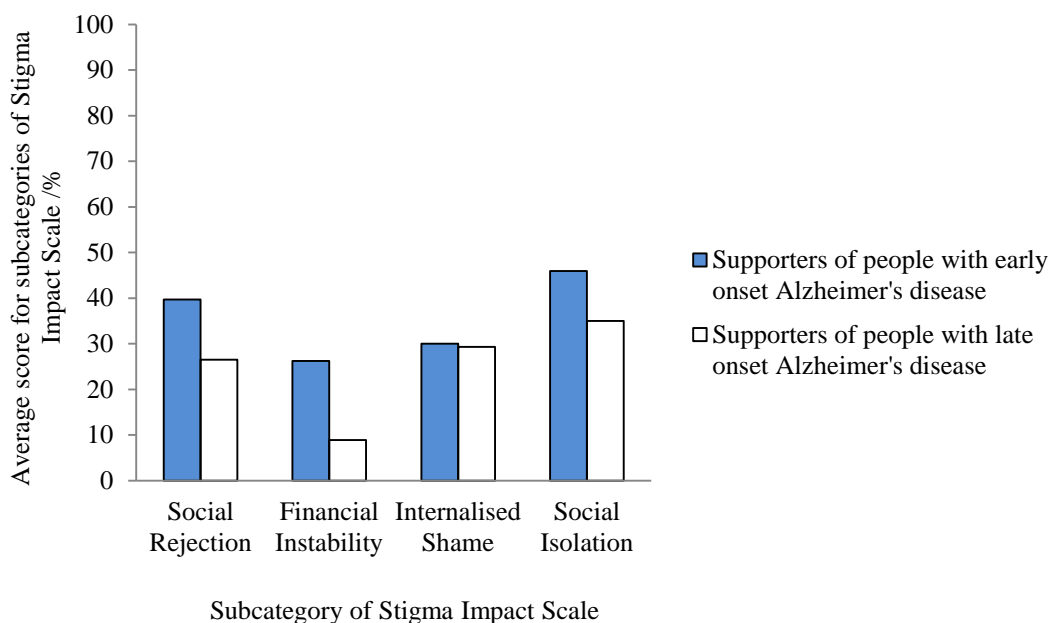


Figure 8. Supporters of People with Alzheimer’s disease percentage scores for subcategories on the Stigma Impact Scale

Supporters of people with late Alzheimer’s disease scored lower across the 4 subcategories than supporters of people with early-onset Alzheimer’s disease. This suggests that supporters of people with late-onset Alzheimer’s disease report less stigma than supporters of people with early-onset Alzheimer’s disease. As with people with Alzheimer’s disease, scores for financial instability were significantly different between supporters, with scores for supporters of people with late-onset Alzheimer’s disease scoring significantly lower ($F(1,20) = 5.03, p = .036$). This provides further empirical evidence for people affected by early-onset Alzheimer’s disease experiencing greater financial consequences (Chaston, 2010).

The answers given by both people with Alzheimer’s disease and their supporters suggests that stigma reporting is low, however, a criterion is not available to determine a threshold between reporting stigma and not reporting stigma. The analysis of subcategories emphasises that stigma is multifaceted, with mean scores from the Stigma Impact Scale not necessarily reflecting people’s experiences of stigma. For example, the low scores for financial instability would bring the overall mean down. Results have been consistent with the numbers reported in previous literature, particularly with increased levels of agreement for social isolation, for both supporters and people with

Alzheimer's disease (Alzheimer's Australia, 2014). Further, a significant difference between the scores of people with Alzheimer's disease and their supporters is also supported by the literature, with supporters reporting lower stigma than the person with Alzheimer's disease (Batsch and Mittelman, 2012).

The pattern of results supports the hypothesis that people with Alzheimer's disease and their supporters experience stigma. However, results from the Stigma Impact Scale itself do not present a clear answer to whether people experience stigma, due to the lack of clarification over a threshold. Across the literature using the scale, mean scores appear relatively low (Burgener and Burger, 2008; Liu, 2011; Riley, 2012). Despite the low mean scores, stigma surrounding Alzheimer's disease is present in a range of research literature (Burgener and Berger, 2008 and 2013; Vernooij-Dassen et al., 2005; Werner et al., 2012; Batsch and Mittelman, 2012). Further the statistical tests, particularly those which explore age-based differences should be taken with caution, given the limit in sample size, and the non-significance of age within multiple regression models. Therefore in order to increase understanding and draw conclusions for the research questions, it is important to explore the data in more depth for both experiences of stigma, and possible age-based similarities and differences.

Experiences of stigma- Interviews

Interview data provide a more comprehensive understanding of stigma from the perspectives of those involved in this study. Themes which emerged from the experiences of stigma are discussed within this chapter, with the consequences being explored in more depth within chapter 8. As noted within the data analysis overview in chapter 5, the interviews contained topics specifically aimed at understanding stigma including, reaction of family and friends to diagnosis. Researcher prompt questions included people being asked whether their relationships with people had changed, and how they felt about this (see Appendix 5 and 6).

During thematic analysis, examples which related to experiences of Alzheimer's disease and stigma were identified. Experiences of stigma were mixed and unpredictable. People's experiences differed across relationship groups, including

family and friends, public perceptions and healthcare experiences. The presence of self-stigma draws attention to the inaccuracy of stigma-fuelled misconceptions surrounding Alzheimer's disease which imply that people do not have insight into their experiences. Additionally, the mixture of responses emphasises the heterogeneity of the group and the subjectivity of experiences.

Previous research on stigma and Alzheimer's disease has a tendency to focus on whether stigma is present in society, rather than the experience of this for the person with the condition. Interview data supports this presence of stigma within society. Matthew (PE7) discussed how the public hold misconceptions about how somebody with Alzheimer's is expected to act,

“They expect you to be all... [Imitates vegetative state]”

Further, Jennie (SE7) highlights that this may be linked to a lack of accurate knowledge about the condition among the general public,

“...I think it's just been left in the dark too long, and now suddenly there's all this rush, it's splashed over the telly and the papers...there's very few facts, sadly, but there's plenty of speculation.”

The lack of facts is argued to lead to ignorance, which the majority of people cite as the underlying cause of stigma, evidenced by Eva (SE1) who points out that Alzheimer's disease is an 'invisible illness' which makes it harder for people to recognise and understand. However, increased visibility of the condition may also increase exposure to stigma (Goffman, 1963). Rather, increasing accurate understanding of the condition may be of most benefit.

Although the examples suggest that a lack of knowledge among the public is associated with increased stigma, experiences with healthcare professionals suggests that knowledge itself does not always negate stigma. Within current services in the UK, people with dementia are likely to receive support from psychiatry and/or psychology (Alzheimer's Society, 2013). However, despite the increased dementia-related knowledge among people in this field, experiences are not always positive. For example, Poppy (SL1) describes experiences of hospital appointments with David (PL1),

“... ironically enough the only occasions I’ve felt not quite so happy has been at hospital appointments...and I’ve actually said that to one of the staff that I find it really ironic...”

Experiences such as this led to anger and frustration, feeling that people in this position should know better. Similarly, Eva (SE1) and James (PE1) discuss the delivery of diagnosis,

“... The doctor who delivered the diagnosis was very blunt and umm all he said to James after looking at scans on his computer was ‘so has anybody else in your family got dementia?’”

Such blunt delivery of a diagnosis emphasises the stigma-fuelled assumption that people do not have insight into their experiences. Further, experiences of stigma from healthcare professionals, who are assumed to be more informed, may add to self-stigma and anticipated-stigma from others.

Self-stigma fuelled by healthcare experiences can be seen from people with Alzheimer’s disease’s discussion of appointments and memory assessments. Several people spoke about feeling stupid and a failure. Others said they were not bothered by their difficulties, however, supporters reported significant physiological and psychological stress at the time. For example, Emma (SE4) and Charlie (PE4) discussed memory testing and its impact,

“You said to her right away, I know I’m going to be no use at this.” (Emma). “I just tell them that I can’t do it and that’s it, not worried about it.” (Charlie).

“Yeah, but deep down you are...although he was smiling and saying I can’t do it, and it’s not bothering me, I could see” (Emma).

Overall there was agreement that memory testing not only failed to accurately reflect their experiences of Alzheimer’s disease but fuelled self-stigmatisation.

There are also examples in the interview data that self-stigma may be one of the earliest experiences relating to stigma and Alzheimer’s disease. This is based on how anticipated stigma may make it difficult for people to share their symptoms. For example, Isobel (SL5) discussed how Oliver (PL5) tried to hide symptoms of Alzheimer’s disease for quite some time,

“I think at the start dad tried to cover up and hide it, and he was very stressed about it...I think it was affecting his pride, and he was trying to cover up.”

Isobel went on to discuss how Oliver always tried to look after his health and was particularly aware of memory,

“He always said was look after your brain, and I don’t know why, his whole life, he did all these memory and brain books, puzzles and games...”

Fear of developing memory problems and their consequences highlights the pervasiveness of public understandings of Alzheimer’s disease, and how these can go onto to influence people who develop the condition. Similarly to Oliver, Holly (SL12) discussed how Millie’s (PL12) fear of dementia made it very difficult to use the term Alzheimer’s disease around her for fear of the self-stigmatisation it would cause,

“She used to say if I go like that, shoot me. It was always her worst nightmare.”

The complex relationship between stigma, terminology, and identity emerging from examples like Oliver and Millie illustrates how people can be reluctant to seek a diagnosis, and take on an identity of ‘person with Alzheimer’s disease’ for fear of its consequences. However, others in the study were more willing to take on the label, seeing it as a way of explaining their difficulties. Jack (PE6) exemplifies this adoption of Alzheimer’s disease identity following negative experiences of stigma from the public. Jack has early-onset Alzheimer’s disease, and a prominent symptom of the condition for him is speech difficulties (known as aphasia). Jack describes a situation where he was laughed at whilst using a petrol station,

“...they don’t do tokens anymore but they couldn’t tell me that and I’m saying...[stammers]...couldn’t get the words out and then that lass started laughing, another one started laughing, I’m saying what’s going on??” (Jack).

Experiences such as this led to Jack carrying around information cards with him,

“My name is Jack, I have an illness called dementia. I would appreciate your help and understanding...I like to be independent, but sometimes I need help. Here’s how you can help: Be patient and try to understand me. Ask how you can help me. If I seem very confused or distressed, contact Olivia.”

Having these cards on him increased Jack's confidence, particularly in public situations. Without the information he was concerned that people would think he was drunk and act negatively towards him. Across the interview with Jack and Olivia (SE6) it appeared that public stigma was more prevalent than stigma experienced through family and friends.

Overall, the discussion highlights that participants felt that there was stigma relating to Alzheimer's disease. Stigma was prevalent within society, and explained by participants as the public misunderstanding what it meant to have the condition. This stigma impacted on how people viewed themselves and how they reacted to Alzheimer's disease. Experiences of stigma from other sources are considered in the following section, before revisiting age-based similarities and differences.

Sources of Stigma- Family and Friends

A lot of research focuses on experiences of stigma from a more public perspective; however interview data suggest that there was generally higher reporting of stigma among family and friends. Although this is not to say that quantitatively there is more stigma from these groups, it may be that the impact of experiencing stigma from people closer to you is greater. This hypothesis is in-keeping with previous literature (Benbow and Jolley, 2012) presented in chapter 2. Further, theories such as socioemotional selectivity theory discuss how our social networks become smaller and more emotion-focused across the life course (Carstensen, 1991). As such, stigma from people within these networks is likely to have a greater impact. This is not to undermine the negative experiences of public stigma; rather if multiple experiences of stigma have taken place, family and friend stigma may be reported more.

Despite there being a lower amount of research which looks at stigma perpetrated by family and friends, compared to the general public, interview data included several examples of such experiences. In addition, the reactions of family and friends exemplified the unpredictable nature of responses. Jennie (SE7) and Matthew's (PE7) discussion typifies this,

“The people that we expected to offer support...disappeared off the face of the earth, and the people that we had, I would say we weren’t close friends with but we were friends, they are the people that I’ve...” (Jennie) “They’ve come through and we see a lot more of” (Matthew).

Jennie and Matthew (PE7) , Katie (SE3), and Michael (SL2) all shared examples of how very close friends, who they would expect to be supportive had treated them negatively. For example, Katie talks about a friend of nearly 30 years who “was kind of like a sister” had stopped coming to visit or getting in touch,

“she just stays very close, within walking distance, and I thought right well I’ve been along a couple of times, I’ve phoned every day nearly, I’ve text, right I’ll just see what happens, I’ve never heard from her since.”

Further Katie added that she was not given an explanation for this social rejection. Michael shared a similar experience,

“our bridesmaid who was on the phone maybe 3, 4, 5 times in the year, umm she hasn’t phoned at all, the same with the people who [possible identifier removed] used to come and stay with us here, they’ve gone, I’ve had to phone them three times in a row over a period of 4, 5, months, but there’s no coming, no phone call back to us.”

The examples highlight how people have been socially rejected as a result of living with Alzheimer’s disease, without the reasons being made clear.

Additionally there were examples where family and friends were supportive, but their lack of understanding of the condition potentially fuelled self-stigma. For example, Isla (PL4) and Hamish (SL4) discuss how although there was a lot of social support, people didn’t always know how to help, which led to avoidance from some, and ‘overly fussing’ from others,

“Sometimes you actually complain about support...Isla says ‘they’re treating me like an idiot’...some of the friends don’t know how to deal with it so they say nothing...others overreact, like mother hen.” (Hamish) “Short of saying ‘get your hands off me’ you know? You’ve got to go along with it.” (Isla) “She meets her friend every [weekday], she’ll come in sometimes...with steam

coming out of her ears [*Isla laughs*] and it's simply because her friend is trying to be helpful." (Hamish).

Generally, families were described as supportive as Harris (PL3) exemplifies,

"I have an exceptionally good family."

Further, families can provide support to both the person with Alzheimer's disease and their supporter in different ways, as Lucy (SE5) highlights,

"my kids are great, they love Murray, they're very fond of Murray, and do everything they can to keep everything, you know... he's [son] often around, it means that sometimes, in fact quite often he has been there when I've been really upset on odd occasions."

There was variation across groups as to whether families were local or more spread out geographically, although there did not appear to be a clear correlation between geographical proximity and family-based stigma towards Alzheimer's disease. For instance, Isobel (SL5) talks about how,

"There's always family members that have stepped in... as a family we would try and work our way around every problem individually as long as we could."

Comparatively, people like Cameron (SL10) and Emily (PL10), and Michael (SL2) and Grace (PL2) had family close by, but they would rather do things on their own. For example Cameron notes,

"...one of the sons is married with the two grandchildren, and daughter in law, but both sons work, and I'm not, I'm not looking for support from them you know? I like to be independent, I like to do my own thing, on behalf of Emily I do things..."

Similarly, Michael describes having local family but still being fairly isolated,

"I mean we have a daughter who lives less than a mile away, and she'd be lucky if she comes and sees her mum once a week."

The examples presented highlight the mixed experiences of both stigma, and support from family and friends. Further, the interactions between people affected by

Alzheimer's disease and those around them are not passive. Both the amount of support available and the willingness to accept support vary. This reinforces the subjectivity in experiences, even when similarities are present.

Possible age related differences

Thus far, age-related differences have not been specified from interview data. However, several possible differences between age groups emerged related to experiences of stigma. As previously highlighted, self-stigma may influence whether people identify themselves as being a 'person with Alzheimer's disease'. Interviews suggested that people with early-onset Alzheimer's disease were more likely to adopt the label of Alzheimer's disease than people with late-onset Alzheimer's disease. By identifying themselves as having an illness, people were arguably able to see the condition outwith their control. People such as Jack (PE6) wanted others to know exactly what condition he had, carrying around a card to notify people of Alzheimer's disease. Similarly, Matthew (PE7) and Murray (PE5) were very open about their condition and felt it was important for people to understand the symptoms so that their behaviour could be explained if necessary. In these scenarios they have identified themselves as people with Alzheimer's disease in order to make their interactions with others easier. Comparatively, for people with late-onset Alzheimer's disease such as Millie (PL12) and Oliver (PL5), their fears of developing such a condition influenced the terminology they used. Oliver spent a long time trying to hide his symptoms, and tried to do everything he could to prevent getting dementia. Similarly, Isla (PL4) saw the condition as something she should try to conquer,

“I think there's an element of denial in it, you know? I don't really have, or I have this but I'm going to conquer it [*Isla agrees*]” (Hamish) “Is that not a good idea?” (Isla).

Not being able to 'beat the condition' led to significant frustration,

“She feels a failure, that I think is one of the main trigger points for the frustration.” (Hamish).

People with late-onset Alzheimer's disease appeared to be more reluctant of the term 'Alzheimer's disease', preferring to use 'memory problems', Holly (SL12) explains Millie's experience (PL12) and her avoidance of terms,

“... she thinks oh I'm in my 80s I'm bound to have a bad memory and that's ok, and I think that goes with a lot of them, and because they've got dementia they don't remember, so each time you mention them having dementia, it's like you're hitting them straight again.”

Although these examples suggest possible age differences, this difference is not consistent. For example, supporters such as Michael (SL2) and Cameron (SL10) repeatedly referred to Grace (PL2) and Emily (PL10) as 'patients' with Alzheimer's disease. This is more consistent with the illness identities adopted by many of the people with early-onset Alzheimer's disease. Further, they appeared to adopt the 'caregiver' identity. For example, Cameron discusses one of the support groups he attends with Emily (PL10),

“...we break up half way through, the carers go out and have a coffee... and the patients stay.”

Similarly, when Michael (SL2) asked a question,

“Experience of living with Alzheimer's disease, is that from the patient's point of view or carers?”

This use is despite the terms not being on the information sheets provided, which suggests a general adoption of the 'patient/carer' identity. Although other participants used the term 'carer' they did so more reluctantly, including Poppy (PL1) who acknowledges that she uses the term because she feels she has to,

“Primarily I still am his wife but I suppose I do care for him, it's just a silly label [*laughs*].”

Further, their choice of terminology varied in terms of how much it reflects their role, as Michael talks about his role as a 'carer' in line with that of paid/formal carers, focusing on the very practical aspects of care; whereas others spoke more about their relationship as husband/wife/daughter/son. It is possible that the choice of term reflects

particular coping styles. For example, Michael expressed concerns that Grace was no longer aware of their relationship,

“She’s actually forgotten for the last fortnight to a month, it’s gradually come in, she’s actually asked, who are you?”

The use of the term ‘patient’ may therefore emphasise the caring role, whilst separating from the husband relationship and accompanying sense of loss.

Additional age-based differences emerging in relation to stigma were age-based expectations of Alzheimer’s disease. For example, people affected by early-onset Alzheimer’s disease highlighted that there was public ignorance around ‘being too young to have an older person’s disease’. Jennie (SE7) exemplifies this when describing disclosing Matthew’s (PE7) condition to others,

“Although quite honestly, quite a lot of people expect, you know, they say ‘what does your husband do?’ I say oh he’s retired, he, he has Alzheimer’s disease, ‘oh, he’s much older than you?’”

Similarly, Olivia (SE6) discusses public misunderstandings,

“It’s for older people, people don’t realise that people as young as Jack can get that.”

However, these differences do not necessarily mean that younger people experience more stigma than older people. Alternatively, it may be that the types of stigma differ. For example the discussed evidence suggests older people may be more exposed to self-stigmatisation, compared with younger people who are more likely to experience public stigma.

The synthesis of answers from the interviews with people with Alzheimer’s disease and their supporters suggest that they have experienced stigma from a range of sources, whether that be public understanding, family and friends’ reactions, or experiences of healthcare. Further, for the majority of people this stigma had been internalised to some extent. This led to feelings of stupidity and frustration. Although supporters of people with Alzheimer’s disease give examples of social rejection and isolation, the examples focus on the stigma being directed at the person with Alzheimer’s disease more so than themselves. This supports the questionnaire findings of significantly lower stigma

reported by supporters than people with Alzheimer’s disease. However, although the stigma may be directed at the person with Alzheimer’s disease, it is felt as a couple, impacting on both identities.

Synthesising questionnaires and interviews- Perceived stigma

The data collected during interviews would predict higher scores on the Stigma Impact Scale questionnaires; however reporting stigma using this measure was relatively low. The pattern of scores for those interviewed has been considered in the following figures. Firstly, people with early-onset Alzheimer’s disease who were selected for interview are shown in Figure 9. The four subcategories of the Stigma Impact Scale are shown, with the percentage scores given for ease of comparison across subcategories. As with mean scores, there is not a clear threshold which indicates high or low stigma, however percentage scores allow for a visual representation with over 50% conceivably indicating higher rates of stigma.

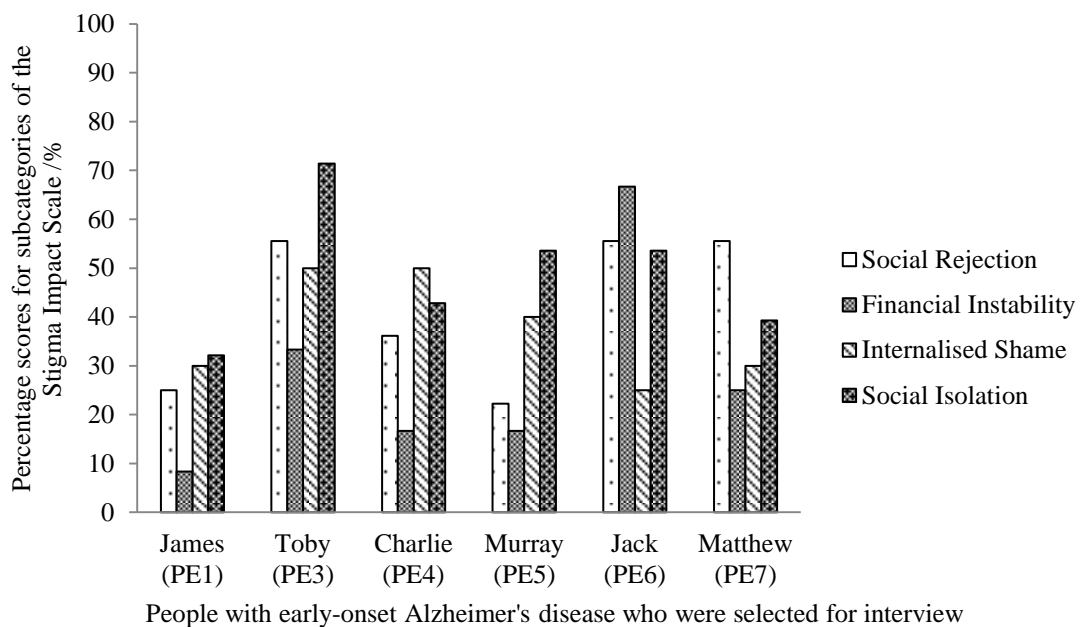


Figure 9. Percentage scores for the four subcategories of the Stigma Impact Scale, for people with early-onset Alzheimer’s disease selected for interview

Toby (PE3) had the highest percentage scores for social isolation, and joint highest score for internalised shame with Charlie (PE4). Toby (PE3) was unable to take part in the interview due to transitioning into a care home between study visits. However, the pattern of his responses fits the experiences discussed by Katie (SE3) within the interview. Toby (PE3) had experienced a lot of social isolation (which was scored as the highest of the four subcategories) due to limited mobility excluding him from activities and group support. Further, Katie (SE3) discussed having to repeatedly tell Toby he wasn't stupid when he got frustrated by his condition, which is mirrored in the highest internalised shame score,

“Something that Toby kept saying to me at the beginning was, he kept saying I'm, I feel so stupid, I'm stupid, I wish I wasn't stupid, you know? I used to have to keep saying to him, you're not stupid, you're ill”.

Interestingly, Charlie had the joint highest score for internalised shame, despite repeatedly saying to Emma (SE4) that his circumstances didn't affect him,

“It doesn't bother me Emma, honestly, it doesn't bother me at all... I don't care a damn, that's how I feel, because I know I can do this, I know it like it is” (Charlie)... “Deep down you are” (Emma).

Therefore, potentially supporting Emma's belief that it does bother Charlie underneath.

Financial instability was previously noted as the subcategory which did not show significant differences between people with Alzheimer's disease and their supporters. Across all participants bar Jack (PE6) and Olivia (SE6) it was the lowest subcategory. Whereas, for Jack and Olivia financial instability was highest, this is reflected in interview data,

“See what other people are doing, I could have been doing with that when I had nae money, I had to get my sisters, my sisters came and did my mortgage and that for me.” (Jack).

The couple talk about the number of forms they have had to fill in and the difficulty they have had with people understanding Jack's situation, as he developed Alzheimer's disease young,

“Fighting all the time ain't we? We should go and see them again ey?” (Jack).

Further, Jack scored the highest for social rejection, which may be explained by experiences of the general public relating to Alzheimer's disease, particularly relating to his communication difficulties, as discussed previously.

For James (PE1), Toby (PE3), and Murray (PE5) social isolation was the highest of their four subcategories. Lucy (SE5) discusses how Murray initially isolated himself from friends and colleagues after the diagnosis, but reengaged over time,

“I mean first you missed it for a few months, once the diagnosis you didn't want to go, you thought it was the end of all of that sort of thing, and then gradually your colleagues were saying why don't you come back Murray?”

James and Toby's high scores appear to be less associated with initial withdrawal and more linked to the limited support services available to fit their preferences. For example, Eva (SE1) discusses the group activities James has tried,

“He didn't like it, and I think that became obvious after a couple of visits, remember you went to that wee group? I took you over on a [weekday] or something, and it was mostly ladies and the idea was very good but it's just not James's cup of tea.”

As a result James and Eva tended to spend the majority of their time doing things together or with a support worker, rather than group activities.

Finally, Matthew (PE7) scored highest on social rejection, relative to the other 3 subcategories, as did his wife Jennie (SE7). This is in keeping with their interview, where they talked about experiencing very mixed reactions from people. For instance, Jennie discussed how some friends started treating Matthew,

“almost like you [Matthew] were contagious.”

Whereas, other friends have been increasingly supportive,

“They've been much much more supportive. (Matthew)” ... “Which I wasn't expecting 'cus I didn't know them well.” (Jennie).

The inclusion of questionnaire answers with interview answers supports a similar pattern of responses, even if the degree to which this is reported varied across measures.

The discrepancy between the amount of stigma reported at interview and with questionnaires will be discussed in more detail towards the end of the chapter.

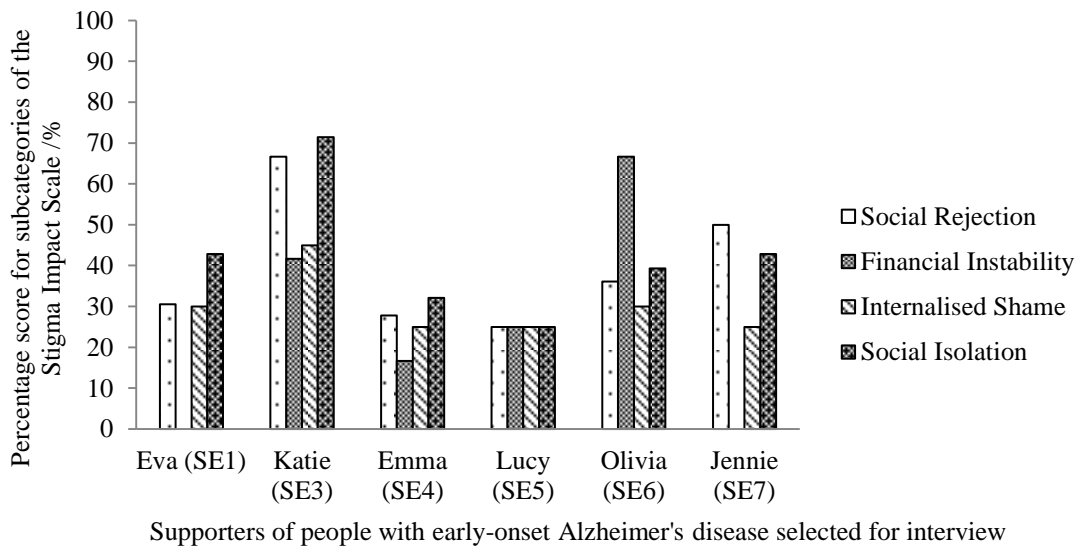


Figure 10. Percentage scores for the four subcategories of the Stigma Impact Scale, for supporters of people with early-onset Alzheimer’s disease selected for interview.

NB: Eva(SE1) and Jennie (SE7) scored 0= non-applicable to all questions relating to financial instability.

Supporters of people with early-onset Alzheimer’s disease showed similar patterns of responses to the person they support, as shown in Figure 10. Katie (SE3) had the highest scores for three out of the four subcategories, with Olivia (SE6) having the highest score for financial instability. Katie (SE3) scored particularly high for Social Isolation (20 out of 28) and Social Rejection (24 out of 36). This pattern was strongly reflected in her interview, with her circumstances leading to a loss of friends and family, as well as limited support services which met her and Toby’s (PE3) needs. This isolation was particularly evident following Toby’s transition into a care home,

“I mean it’s like a bereavement, but he’s still there, and there’s days that you don’t see anybody, which is why I’ve kept busy, because some of these groups could have made a bit more effort.” (Katie, SE3).

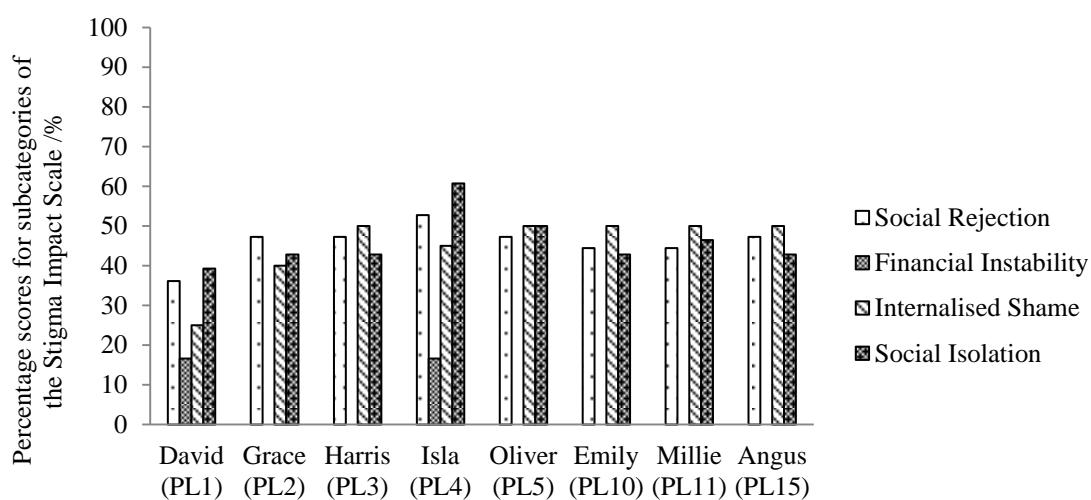
Social Isolation was also the highest subcategory for Eva (SE1) and Emma (SE4), although they scored 12 and 9 out of 36 respectively, which suggests that they do not feel significant social isolation. This is supported by discussion in interview, where they both talk about maintaining social groups as much as possible,

“I’ll just phone around, round robin, and say anybody free for coffee? And see who can come over.” (Emma, SE4).

Interestingly, although Lucy (SE5) showed consistently low percentage scores in the questionnaire, the interview data suggest fear of social rejection. This fear resulted in avoidance of being open with people early on,

“...’cus I suppose initially for me, one of my main feelings as you said before, I didn’t want people feeling sorry for us, I really didn’t, I just wanted us to be as normal as possible for as long as possible” (Lucy).

Further, Lucy discusses how she has benefited from being able to continue in work, and maintain her social connections. The fact her work and social life had been largely uninterrupted compared to some of the other supporters may contribute to overall lower scores for Lucy. As with the data presented for people with early-onset Alzheimer’s disease, there is a need to consider the difference in reporting across measures when drawing overall conclusions. Further, the discrepancy adds support for using multiple research measures to build a comprehensive picture of experiences.



People with late-onset Alzheimer's disease selected for interview

Figure 11. Percentage scores for the four subcategories of the Stigma Impact Scale, for people with late-onset Alzheimer’s disease selected for interview

NB: Grace (PL2), Oliver (PL5), Emily (PL10), Millie (PL12) and Angus (PL15) scored 0= non-applicable to all questions relating to financial instability.

Questionnaire scores for people with late-onset Alzheimer’s disease invited to interview can be seen in Figure 11. Unlike people with early-onset Alzheimer’s disease, only 2 of the 8 people with late-onset Alzheimer’s disease saw questions on financial instability as applicable. Additionally, the scores for David (PL1) and Isla (PL4) were still low, both scoring 2 out of 12, which suggests they didn’t agree to any of the statements.

For 5 of the 8 participants with late-onset Alzheimer’s disease, internalised shame was the highest scoring subcategory, scoring 10 out of 20. This may be reflected in their fears of developing a condition like Alzheimer’s disease, with Holly (SL11) describing how Millie (PL11) felt about dementia,

“it was always her worst nightmare, she says I could cope with heart, stroke, cancer anything...”

Similarly, Isobel (SL5) notes that for Oliver (PL5),

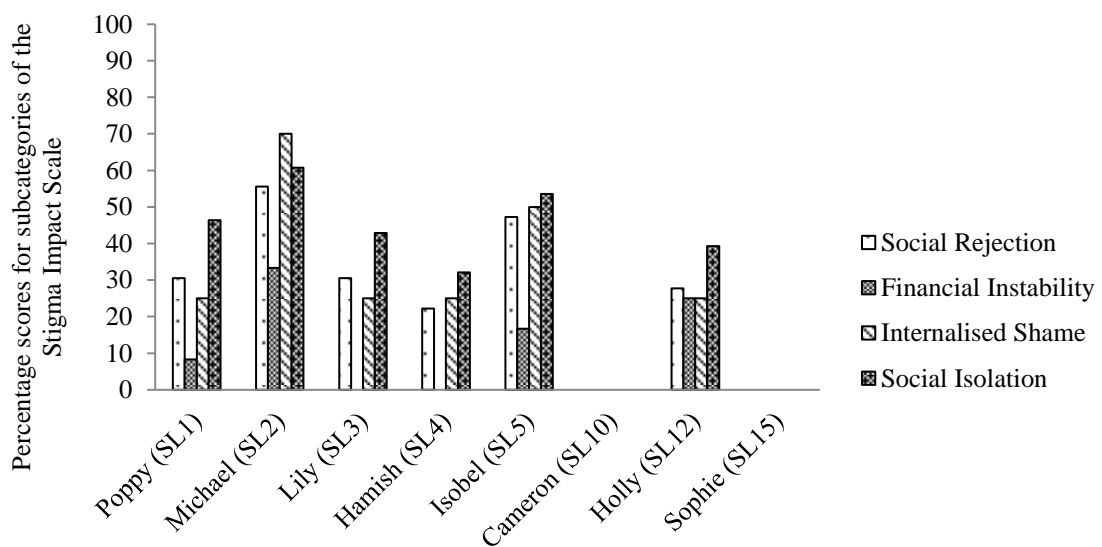
“it was the one thing he feared and didn’t want.”

Emily (PL10) expressed internalised shame through a reduction in confidence, with Cameron (SL10) commenting on how she no longer feels able to paint, despite it previously being a much loved hobby.

Isla (PL4) scored highest across participants with late-onset Alzheimer’s disease for social rejection and social isolation. In interview, both Isla and Hamish (SL4) expressed concerns over social isolation in terms of care within the community and residential care,

“I think care in the community is condemning an awful lot of people to a life of isolation and loneliness and poor level of support.” (Hamish).

Although Isla scored higher within these subcategories than others, when talking to her, the majority of her frustration stems from wanting to be able to ‘beat’ the condition, and feeling the symptoms of Alzheimer’s disease such as memory loss have affected how she views herself and her abilities, which does not come across in the questionnaire scores alone.



Supporters of people with late-onset Alzheimer's disease selected for interview

Figure 12. Percentage scores for the four subcategories of the Stigma Impact Scale, for supporters of people with late-onset Alzheimer’s disease selected for interview

NB: Lily (SL3 and Hamish (SL4) scored 0= non-applicable to all questions relating to financial instability. Cameron (SL10) and Sophie (SL15) scored 0= non-applicable to all questions on the Stigma Impact Scale.

Finally, supporters of people with late-onset Alzheimer's disease showed quite a distinct pattern, as illustrated in Figure 12, to that displayed in Figures 9-11. This is due to Cameron (SL10) and Sophie (SL15) scoring zero across all subcategories. A score of zero indicates that Cameron and Sophie felt that the questions on the Stigma Impact Scale were not applicable to them. A possible similarity between the two of them, which may explain their scores, is in the strong sense of independence and responsibility within their supporting role. Cameron notes,

“I'm not looking for support from them you know, I like to be independent, I like to do my own thing, on behalf of Emily I do things...”

Similarly, Sophie spoke about her frustration of other people being involved and making suggestions,

“... I've been married 60 years surely, sometimes that kind of thing, I want to say don't tell me.”

There is a sense from them both that they are separated from any possible stigma by focusing on themselves and the person they support, and not focusing on how others react, with Sophie adding,

“Unless you're really dealing with it 24 hours a day, I don't think anybody can really do an awful lot.”

It should be noted that scoring 'non-applicable' across questions does not mean that they did not believe Alzheimer's disease was a stigmatised condition, rather that they did not feel it affected them in ways that the questionnaire reflects.

Out of the 6 supporters who did score on the scale, 5 of them had social isolation as the highest scoring subcategory. For Michael (SL2), internalised shame was highest, followed by social isolation. Michael scored higher than other supporters of people with late-onset Alzheimer's disease across all four categories. There are several examples within the interview which help to contextualise this. Michael has very limited contact with support from family, friends, or support groups,

“I mean I don't really, I mean we've all got our problems but I don't think sharing this problem would be of any help to me.”

Further, he sees the support he provides Grace (PL2) with as part of his role as a husband,

“Don’t feel sorry for me, umm, because that’s what I’ve got to do, that’s what I’m doing”.

The higher score on financial instability is likely to be linked to the money he puts towards helping care for Grace, and his avoidance of accessing public money if he doesn’t have to,

“I don’t really need hand-outs, and yet I should have it, you know?”

Social isolation and rejection were also highest for Michael, which is reflected in his experiences of friends no longer contacting or visiting,

“I have a cousin who hasn’t phoned up for 8, 9 months to find out how Grace is; I’ve got a sister who hasn’t phoned me to find out how Grace is...”

For the other 4 supporters social isolation was highest of the subcategories, with a mixture of possible explanations. Lily (SL3) and Isobel (SL5) were generally positive about the reactions of family and friends, and the support available for groups and activities. Part of the isolation they experienced may be a result of being adult-child supporters, rather than spousal supporters. As such, they are balancing their own home lives with that of the person with Alzheimer’s disease they support. Further Lily gave up work to help look after Harris (SL3). Despite the prevalence of supporters being adult-children of people with dementia (Brodaty and Donkin, 2009), only 3 of the 22 supporters in this study were (Lily, Isobel, and Holly). Isobel noted that challenging Oliver’s (PL5) behaviour early on was difficult, and conflicting with her role as daughter,

“but I think you don’t have the confidence to challenge your parent initially and things have to get to a stage where you think no, before you do it.”

The difficulty Isobel felt may also be linked with her having the second highest score of internalised shame.

Holly and Poppy (SL1) also scored highly on social isolation, relative to their other scores. For Holly, much of this could be linked to her own health, where she

experiences significant anxiety, which limits her activities. For Poppy, social isolation may be linked more to her avoidance of groups relating to Alzheimer's disease, she explained her fears in relation to worrying about the future,

“I just feel that groups, I feel personally that that would depress me... I can see the benefit and some ...but I also feel too that people are obviously going to be at different stages... I think I could start to panic, and really worry about the future, about things that might never happen.”

Overall the pattern of results on the Stigma Impact Scale appears to mirror much of the interview data for people with Alzheimer's disease and their supporters. Considering interview data along with the Stigma Impact Scale scores allowed for the more complex picture of stigma to be captured, with patterns between subcategories reflecting the experiences of participants more accurately than the mean score and quantitative data alone.

In addition, the discussed findings highlight an interesting discrepancy between the extent of stigma reporting on questionnaires and interviews. The questionnaire scores alone would suggest that stigma is low, with people with Alzheimer's disease agreeing or strongly agreeing to 9.3% of statements on the Stigma Impact Scale, and supporters agreeing or strongly agreeing 11.1% of the time. However, interview data show multiple examples of stigma being experienced, including public awareness, family and friends' reactions, experiences of healthcare, and self-stigma. Possible reasons behind such a discrepancy will be discussed before addressing the second research question in chapter 7, which explores people's future outlook.

Exploring the discrepancy between reporting of stigma in questionnaires and interviews

The methodology within the research literature relating to stigma and Alzheimer's disease is mixed, including questionnaires (Burgener and Burger, 2008), focus groups (Vernooij-Dassen et al., 2005), and interviews (Werner et al., 2012). However, as has been discussed previously, scales such as the Stigma Impact Scale (Burgener and Burger, 2008) did not present a clear answer as to whether people experience stigma. Across the literature using the scale, mean scores appear relatively low (Burgener and

Burger (2008); Liu (2011); Riley (2012)). However, other studies have shown higher response to stigma, for example, Alzheimer's Disease International (Batsch and Mittelman, 2012) surveyed 127 people with dementia and 1716 supporters of people with dementia, across 54 countries, with 75% of people with dementia answering 'yes' to "in your opinion, do you think there are negative associations (i.e. stigma) about people who have dementia in the country where you live?" (Batsch and Mittelman, 2012:28). Similarly, 64% of supporters believed that there was stigma surrounding dementia, although when asked about stigma related to being a supporter, 60% of supporters within the English survey did not feel there were negative associations (Batsch and Mittelman, 2012).

It is possible that this difference in reporting is based on differing sample characteristics and size. However, an alternative hypothesis is that the difference is due to whether the question contains 'the self'. People with Alzheimer's in the Batsch and Mittelman (2012) survey, were asked their views about whether people with dementia are stigmatised. Whereas, the Stigma Impact Scale is worded from the person's perspective, for example, "I feel I have been treated with less respect than usual." (Question 5, Stigma Impact Scale, Appendix 4a). As a result, the person with Alzheimer's disease may be more, or less, able to separate themselves from the situation. This is further supported when Batsch and Mittelman's (2012) data are looked at more closely. Questions where the person with dementia was asked to report their experiences, for example, "Have you concealed or hidden the diagnosis of dementia from others?" and "Have you been avoided or treated differently because of the diagnosis?" yielded agreement of 24% and 40% respectively. Further suggesting people with dementia will report lower stigma when they are answering about themselves compared to others with dementia. This phenomenon has been more widely explored within social psychology, as discussed within personal/group discrimination discrepancy theory (Taylor et al., 1990). As noted within chapter 2, the theory suggests that people acknowledge higher levels of stigma towards the group 'people with Alzheimer's disease' compared to their own experiences. The minimisation of personal stigma is a way of managing and avoiding the negative consequences of stigma.

Additional explanations for low stigma reporting include a bias in responding when having to make a choice between a positive or negative answer, if only one answer can be given. As discussed in field notes, participants were keen to elaborate on

questionnaires with stories to support them, and noted frustration at times where multiple answers would have been appropriate. For example, if asked whether family members have treated them differently, some participants commented that they wanted to respond ‘disagree and agree’. Where both answers were appropriate, participants favoured disagree over agree answers. This direction of effects is discussed in more detail as part of the theoretical considerations. As the literature review (chapter 3) highlighted, the presence of a positivity bias in the way people process information has been discussed across several disciplines. For instance, Berntsen et al. (2011) suggest that positive events are more central to older adults’ life story and identity and increase in salience over time, whereas negative events are less central and decrease over time. As such, the findings support that people with Alzheimer’s disease and their supporters are more likely to focus on positive reactions of those around them, with the strength of this increasing over time, compared to the negative experiences they have experienced. As interviews were less structured, negative experiences were given the space to be shared, leading to the discrepancy in stigma reporting.

Research suggests that as people get older, they show a preference for processing positive memories, and show better recall of positive stimuli, relative to their younger counterparts (Mather and Carstensen, 2005). This would suggest that people affected by late-onset Alzheimer’s disease would report lower stigma in the questionnaires than people with early-onset Alzheimer’s disease. This is interesting as the direct comparison of age categories suggested higher reporting of stigma for people with late-onset Alzheimer’s disease, with further exploration suggesting that age differences were non-significant compared to covariates such as quality of life and socioeconomic status.

The non-significance of age when considered within multiple regression analysis suggests a similarity in the way people affected by early and late-onset Alzheimer’s disease report stigma. As introduced within socioemotional selectivity theory (chapter 3), people facing ‘time-limiting’ conditions may equally be influenced by the positivity bias. The relatively low reporting of stigma on the Stigma Impact Scale for both age groups provides contradictory evidence to Reed and Carstensen (2011) who concluded that age-related positivity bias is less likely to be seen in people with cognitive impairment, as it is an active process requiring cognitive resources. Rather, it supports that people with Alzheimer’s disease choose to focus their attention on the positive stimuli as much as possible (consciously or unconsciously).

Possible explanations for the discrepancy between questionnaires and interviews may also include the design and corresponding protocols which differ between the two. For instance, first study visits were the questionnaire visits with people with Alzheimer's disease and their supporters. For people who were interviewed, there was increased familiarity with the researcher as it was the second meeting. Seeing participants more than once has been evidenced as an important part of building up relationships (McKillop and Wilkinson, 2004). Therefore, interviews may have revealed higher reports of stigma due to people feeling better able to share their difficulties. Additionally, all interviews were with people with Alzheimer's disease and their supporter, which may have increased feelings of comfort and familiarity (Wilkinson, 2002) as well as aiding with memory retrieval cues.

In addition, differences between questionnaire scores and interviews may be due to participants not feeling their experiences of stigma were included on the Stigma Impact Scale. Such experiences could include negative interactions with healthcare professionals, which are not currently included as a topic on the scale. The feeling that questionnaires cannot accurately reflect their situation may also explain why Sophie (SL15) and Cameron (SL10) scored non-applicable to all questions from the Stigma Impact Scale, given that in interview many of the elements the Stigma Impact Scale aims to pick up on were evident.

A final consideration for the discrepancy between questionnaire scores and interview answers is the inclusion of a time-frame reference in questionnaires, discussed in chapter 5, that is not present at interview. The DEM-QOL, Stigma Impact Scale, and Bristol activities of daily living, all have time-frames to which people are to base their answers. For example: In the last week have you felt cheerful? (DEM-QOL question 1). Smith et al. (2005) acknowledged that some people with dementia felt they were unable to provide reliable information within the time-frame, suggesting that data would be unreliable for these participants. However, Smith et al. (2005) argued that the time-reference was important for those who could visualise time in this way, whereas, McDonald et al. (2003) noted that assuming that respondents are able to answer questions relating to their past is a mistake. They suggest acknowledging that people may not have access to the information to recall, or have the information but cannot recall it from the fixed time-reference given. Further, recent events are more likely to be recalled (McDonald et al., 2003) which could potentially skew the results relating to

stigma reporting. However, if time-frame references were having a significant impact on results, the time since diagnosis would have been more likely to produce significant results when included as a covariate. Further, the accuracy of time-based recall may also affect interviews. Therefore, the discrepancy between questionnaires and interviews appears to be underpinned by a range of factors, rather than specific to the measures themselves.

Finally, regardless of the reason for the discrepancy, it is important to consider the implications for stigma reporting in practice. If interview data reports high levels of stigma but the Stigma Impact Scale is not reflecting this, it may suggest a more effective questionnaire is needed to measure stigma. For instance, during clinical assessments a short tool which captures experiences may be preferable over completing a more in-depth interview. At present, if the Stigma Impact Scale was used for this purpose it may suggest stigma is low, rather than acknowledging that had the questions been worded differently or focused on other aspects of stigma, reporting may have been higher.

Conclusions

Overall the findings presented in this chapter support the conclusion that people with Alzheimer's disease and their supporters experience stigma. The extent of this stigma varies across participants, as well as within individual circumstances. For some, stigma was more evident in public reactions. For others, negative reactions of family and/or friends were more prevalent.

Statistical analysis evidenced a higher reporting of stigma by people with Alzheimer's disease compared to their supporters. Further, these differences remained across subcategories of the Stigma Impact Scale. Possible age-based differences emerged relating to financial instability, and internalised shame. People affected by early-onset Alzheimer's disease scored higher for financial instability, reflecting previous literature on financial concerns of younger people with dementia (Chaston, 2010). People affected by late-onset Alzheimer's disease reported higher internalised shame which

would support a ‘double stigma’ of ageing and Alzheimer’s disease (Scodellaro and Pin, 2011).

Interview and questionnaire data complimented each other in terms of pattern of responses. However reporting during questionnaires was substantially lower. A range of possible reasons for this discrepancy have been discussed. These include ease of responding during interviews, based on flexibility of answers, and increased familiarity with the researcher. Further, bias processing of positive information, and dissociating with the group identity may skew questionnaire results. The findings reinforce the benefits of including multiple methods to answer the research questions, as the discrepancy seen between questionnaires and interviews provides interesting insights for how people report their experiences.

Despite the range of negative experiences reported, people generally remained very positive. The possible age-based differences in stigma appeared to be reduced when considered in the context of how people manage their experiences. Both older and younger participants showed shared motivations to focus on the positive aspects of their experiences. For instance, people focused on considering the friends and family who remain supportive. Such mechanisms will be discussed in more detail when looking at the consequences of stigma on looking to the future in chapter 8.

Chapter 7- How do people with Alzheimer's disease and their supporters view and plan for the future?

The question of how people with Alzheimer's disease and their supporters view and plan for the future, was a largely unexplored topic outside of advance care planning. Therefore, unlike with the stigma-focused questions, there were not appropriate quantitative measures to look at future outlook more generally. As such, a range of topic guide questions were used to ground answers in what was already known, and address the gaps in knowledge to broaden understandings.

As advance care planning and end of life care have received greater focus than looking to the future more broadly, these topics were included with several interview schedule questions including: Have you been involved in advance care planning? Have you thought about future care? It was important to keep these questions given that much of the drive behind early diagnosis of Alzheimer's disease, and the subsequent exposure to stigma is justified through advance care planning. Further, it would allow a baseline in literature for similarities and differences in findings to emerge. The focus was then widened to include hopes and fears about the future, and how Alzheimer's disease may influence future outlook. For example, Have your thoughts about the future changed since having Alzheimer's disease? (full topic guide in Appendix 6). By moving beyond end of life care, it brings to light the ongoing future thoughts which can influence people across the journey of Alzheimer's disease. Similarly, by seeing Alzheimer's disease as a journey it highlights how future outlook can influence people's experiences pre-diagnosis, through to learning to manage their condition.

Thematic analysis was used to synthesise answers relating to looking to the future. Across people with Alzheimer's disease and their supporters two key themes emerged: Focusing on 'one day at a time' and maintaining a positive outlook. These themes overlap where the focus on 'one day at a time' is a way of managing their concerns about the future and thereby remaining positive. The following discussion brings together examples from the interview data to demonstrate how people in this study looked to the future. These experiences have been considered in relation to research literature, before being brought together with stigma-related findings in chapter 8.

What do we do now?

Following the diagnosis of Alzheimer's disease, all participants expressed a feeling of 'What now?' Getting over the initial shock and distress of diagnosis was the first hurdle. This is exemplified by Eva (SE1) describing the moments following diagnosis,

“...had a cup of coffee in the hospital cafe and thought what do we, what do we do? Where do we go from here?”

The presence of uncertain futures early on in the journey of Alzheimer's disease contributes to the need to move beyond an end of life focus. However, several participants asked, 'why do people need to know the diagnosis?' Following initial adjustment almost all participants expressed that they were glad to know in order to move forward with their lives. As Poppy (SL1) highlights,

“Actually it was a relief that there was an explanation, I mean you know, very sad about the diagnosis, but a lot of close friends and family had been concerned because there was obviously something wrong.”

These extracts support previous literature which discusses how distress from diagnosis reduces over time, as people adjust to the situation (Robinson et al., 2011).

Across participants there was varying amounts of previous experience of Alzheimer's disease, with some families having several family members being diagnosed with the condition at some point, and other families having never spent much time with somebody who has the condition. This did not appear to impact on whether participants felt they knew what to do next or what was ahead of them. This was largely explained by viewing the condition as unique and unpredictable. For example, Isobel (SL5) notes that Oliver's (PL5) aunt had dementia,

“It was the one thing he feared and didn't want, I think he had an aunt ...”
(Isobel)...“So he had an idea of what it would mean?”(Researcher)...“Yes, I think it was her who possibly, who, uh huh...” (Isobel)

Isobel goes on to add that the trajectory is unique,

“And it’s different for everyone when it comes, it doesn’t necessarily, because aunt went downhill quite quickly.”

Separating experiences based on their unique nature may suggest that future outlook is not being affected by knowing others with the condition. However, there may be more indirect mechanisms around fear of what has been observed in others and what may be influencing views. For instance, Emma (SE4) notes that previous experiences may have led to avoidance,

“His mother had it you see, so I don’t think, you know the alarm bells were there, maybe chose to ignore them for a bit ...”

Similarly, Sophie (SL15) highlights the general view of participants, that whether you have seen others living with Alzheimer’s disease or not, you hope it would be different when you have to deal with it,

“Well his mum had it, and all her family had it... Well you can’t really prepare yourself for it, just have to hope it’s not going to happen...”

Even if people had not had direct experience of people with Alzheimer’s disease beforehand, their discussions mirror those who had. For instance Poppy (SL1) and Cameron (SL10) discussed reading books about another supporter’s experience of living with Alzheimer’s disease to learn more. They conclude with a similar acceptance of unpredictability seen in previous quotes, as Poppy explains,

“by the time it came to the end I thought maybe I shouldn’t have read this..., sometimes I think you have to shut your mind off to things because I had to think well that might not happen, just the way she’d [book reference] gone, that might not necessarily happen so really there is no point dwelling on that.”

Overall, participants did not appear to be heavily influenced by having had previous family members with the condition, as their responses were much the same as those without previous experience. However, as Kristiansen et al. (2015) note, it may have influenced feared futures which could change the way people manage their experience.

Initial future outlook revolved around lifestyle changes which needed to be implemented as a result of symptoms, such as loss of driving licenses and job roles. For all of those who had to make these changes, there was a clear sense of loss and

uncertainty about how this would affect their lives, noting both the change in independence and the boredom of not being busy. Such differences appeared to have age-related differences, with previous research suggesting that loss of driving licences can affect younger people more than older people (Taylor and Tripodes, 2001). Although, this does not mean older people will not be affected by a loss of license (Carr and Ott, 2010). All but one of the participants with early-onset Alzheimer's disease discussed the loss of their driving license and the impact this had on their confidence and feelings of independence. Both Matthew (PE7) and Jack (PE6) talked about how they had been driving all of their lives, and having this taken away had caused significant distress as highlighted in the conversation between Jack and Olivia (SE6),

“I've driven all my life and then...” (Jack)... “Aye, but he dinnae feel confident to drive” (Olivia).

This discussion also highlights how it is not necessarily the symptoms themselves that have an impact, but how they are understood and managed. For example, studies have shown that psychometric profiles of people with Alzheimer's disease who continued to drive, or had stopped driving did not significantly differ (Carr et al., 2005). This suggests that factors such as confidence levels, discussed by Olivia and Jack, have a greater impact than the physical changes.

Unlike the other participants with early-onset Alzheimer's disease, at the time of interview Murray (PE5) was still driving but waiting to find out if his license was to be renewed. Discussing the impact of this possibility further illustrated how much these participants saw driving as part of who they are, and a symbol of their independence. Comparatively, driving was very rarely mentioned in the interviews with people affected by late-onset Alzheimer's disease, other than references from supporters highlighting that they appreciated still being able to drive. For example, Poppy notes how her ability to drive kept her optimistic,

“A lot of friends can't drive, and that would be awful, and I thought right you can drive and that's a positive from there.”

All of the participants with Alzheimer's disease were no longer in employment, as were the majority of supporters. As with driving, changes in employment were largely discussed by people with early-onset Alzheimer's disease. These changes had clear

impacts on how they viewed themselves and considered their plans for the future. Both Jack (PE6) and Murray (PE5) talked about how they had to leave work due to fears such as burdening colleagues, or no longer being as capable of maintaining the standard necessary. It was particularly evident for Murray and Jack how important colleagues' reactions to their diagnosis were to them, particularly in treating them the same,

“...there's 18 years in my work, and when they found out about it, they come up and shook my arms, worst of luck, wee laugh, wee joke, come on Jack, so I was always Jack...”

Being out of work was something which caused concerns over the future, both financially and through fear of boredom as Olivia (SE6) and Jack's (PE6) discussion highlights,

“I mean you've never ever been out of work, never” (Olivia). “Nah, this is new to me, know what I mean? What's gonna happen in winter? ... financially I panic, don't I?” (Jack).

The impact of changes in employment was also evident from the supporters, for instance, Lily (SL3) had given up work to support Harris (PL3) more,

“Well I was working before...I took early retirement with a view to getting a part-time job ... but I don't have time for that.” (Lily, SL3).

Interestingly, Michael (SL2) refers to his role as similar to that of being in employment, comparing the time he gets off to formal support workers,

“They allow me 2 weeks holiday in a year, or 2 weeks respite but the workers get 5...”

Noting that he gets very little time to himself,

“While we were away on holiday I was able to have a lot of time on my own because [formal support] was there all the time with Grace, whereas when I'm here I'm with Grace all the time so. I think that that's probably the most difficult part of it, apart from the number of hours I've got to put in every day...”

Several other supporters mirrored Michael's discussion over lack of time to themselves; with Cameron (SL10) describing how doing things for himself was self-centred,

recounting how fitting in activities he wanted to do on the same day as Emily (PL10) had appointments was “selfish me.”

Emma (SE4) and Lucy (SE5) also discussed the need for time to themselves, and the change that Charlie (PE4) and Murray’s (SE5) employment had on the relationship dynamics. Charlie had previously worked away from home for periods of time, and adjusting to being home full-time was difficult for both of them. It should be noted that Charlie retired prior to the onset of Alzheimer’s disease, something which in hindsight they both appreciated as it gave him some time being retired without the condition. This may have meant he was protected from some of the distress experienced by the likes of Matthew (PE7) and Jack (PE6) by having to leave before they were ready. However, his greater distress was related to now feeling he was capable of returning to work, and Emma (SE4) disagreeing.

“You wouldn’t have had a great retirement, because you finished work early...you’ve had a good few years...I doubt if you could of [carried on working] now could you? You couldn’t wire up tools and use a computer?”(Emma)...”Oh well, I don’t know” (Charlie, PE4)... “Be honest Charlie, I mean, I know you would like to.” (Emma)... “I would have a go at it anyway...I was a [job title] for goodness sake, I used to do that every day” (Charlie).

This dialogue highlights the challenges faced by Emma and Charlie, particularly in terms of differing views over capability and the loss of work roles. This challenge was also noted by Lily (SL3) when explaining that Harris (PL3) sometimes thought he should be working, and that it could be difficult to explain that he was retired now. Others, such as Matthew (PE7) and Jennie (PE7), used the situation to focus on finding new ways of using their time together, considering volunteering as a way of filling the gap of employment. As well as the change in the person with Alzheimer’s disease’s employment status, supporters such as Katie (SE3), Lily (SL3) and Poppy (SL1) had given up work to look after Toby (PE3), Harris (PL3), and David (PL1). Lily had taken early retirement and planned to work part-time but was unable to do this given the circumstances. For both Katie and Lily, losing this employee role had a clear impact, affecting their confidence and feelings of connection. However, Poppy (SL1) tried to

focus on what she was now able to do with the time when she would have been working,

“...because I can't do that [work] now, but that's the other thing, things fill the gaps and you don't sit thinking oh I used to be [working], I sometimes think oh gosh I would have been [working], I wouldn't have been able to do such and such...”

Unlike the other supporters, Lucy (SE5) was still in employment, and it was evident how important maintaining this for as long as possible was for her, as shown by the following extract,

“I would hate at this point in time to be retired and with Murray 24/7, because we would drive each other mad, I, I currently still need my job, I still enjoy working, most of my, my colleagues who are my age have gone, so I'm one of the most senior ones there now....”

The interviews highlighted that following the diagnosis of Alzheimer's disease, people had to adapt to the losses associated with the condition. This process was particularly evident for people affected by early-onset Alzheimer's disease, as they were more likely to have been in employment prior to disease onset. Examples such as Poppy (SL1), Matthew (PE7) and Jennie (SE7) looking into volunteering roles, highlight a general preference to focus on the positive, and what is still possible. This supports the theoretical framework discussed in the literature review (chapter 3), where people are motivated to remain positive as a way of managing challenging circumstances (Walker et al., 2003).

Part of the push for early-diagnosis of Alzheimer's disease is to allow people with dementia and their families to plan for the future (Luengo-Fernandez et al., 2010). In terms of planning, timing was paramount. When should people start planning for the future? And how can you know what the time scale will be? For example, Jack (PE6) points out,

“I've not done it yet, know what I mean, I've still two arms, two legs.”

He went on to talk about waiting for the dementia to “kick in”. Other participants expressed similar views to Jack, talking about preferring to deal with things as they

come. As Isobel (SL5) discusses, it wasn't until Oliver (PL5) started going "downhill" that they started to think about help and making plans. These shared experiences fit well with previous literature on help-seeking, and waiting for a 'crisis point' situation (Adams, 2008). At this point, people are less likely or able to avoid the situation, and therefore override the preference for positive information.

Knowing when something may happen was another issue discussed across interviews, as Holly (SL12) exemplifies,

"You haven't got a timescale to know whether they're going to go downhill weekly, monthly, annually, so there's no way you can predict."

This uncertainty was mirrored across participants, feeling that planning was difficult to do as you never know what might happen. Uncertainty around Alzheimer's disease progression has also been evidenced in challenges to advance care planning in the research literature (Sampson et al., 2011; Denning et al., 2012; Poppe et al., 2013; Davies et al., 2014b). Further, Katie discussed how the unpredictability of the condition makes it harder to predict over time so she learned to stop planning what her and Toby (PE3) would do,

"You really couldn't plan too far ahead, especially, maybe at the beginning you could plan a little bit more, but nearer the end you just couldn't because things change so rapidly."

These discussions suggest that participants were generally reluctant to initiate planning for the future. Instead, they chose to focus more on specific changes to everyday life. Age-based differences may be present in terms of what the initial changes made were, however age itself was not salient to future planning.

Can we continue normally?

Although there was a general avoidance of planning across people with Alzheimer's disease and their supporters, more immediate plans were discussed, such as, continuing with activities, staying active and busy, and having a routine. For Cameron (SL10), routine had become a significant feature in their everyday lives. He discussed how

Emily (PL10) always wanted to know what was happening next, and that he had to keep a plan of the day in his head to make sure that they were always aware of what they had left to do; as evidenced in the following quote from Cameron (SL10),

“It hasn’t changed from the question, what are we doing tomorrow? Have you any idea? Have you any plans? What are we going to do tomorrow?”

Questions over everyday activities, or what they will do tomorrow, highlights how looking to the future does not need to be a distant future. Rather, it can be near future planning which is evident in thinking about how to continue ‘normally’.

Eva (SE1), Poppy (SL1), and Sophie (SL15) also talked about how they did not feel the need to be involved in a lot of the local dementia support groups, as they currently did a lot of the activities offered as part of their normal routine. For example, Poppy notes,

“...we’re fortunate we can do these things ourselves, and that’s what we enjoy, going out for coffees, lunches, town, you know? So we can do that, you know?”

However, other supporters, such as Holly (SL12) and Emma (SE4), mentioned how difficult it can be to keep busy, particularly if Millie (PL12) and Charlie (PE4) do not feel motivated to do activities, or know what they would like to be doing. As Holly notes,

“... [they] all seem to have this, I can’t be bothered attitude, you try and encourage them to do things and they just think, ‘I can’t be bothered’ ...”

The lack of engagement expressed by Holly and Emma may add to the challenges of planning for the future, particularly if the decision-making is one sided.

Generally, in terms of looking to the future and finding ways to continue normally, most of the time everyday lives were much the same as they were previously. Over time there was an introduction of gradual changes to make things easier. These included the supporter doing the shopping, or introducing day-care services and groups to keep busy. However, there was a separation over how the gradual changes were discussed, compared to the more practical but greater-scale changes towards planning a future with Alzheimer’s disease. These will be described in the following sections. The reasons behind differences in the smaller to large-scale changes appear mostly down to learning to manage the condition.

What changes will I need to make?

Throughout the study, participants highlighted that they focused on one day at a time, choosing to avoid thinking about the future. It was viewed as both unpredictable and distressing to consider the possible outcomes. However, despite this approach many had made practical changes. Interestingly, when these changes were discussed they were still qualified with statements about unpredictability. Hoyle and Sherrill (2006) support the use of these qualifiers by highlighting that nobody knows what is going to happen in the future; therefore making predictions is not necessarily realistic.

Despite the condition being unpredictable and unique, Alzheimer's disease does limit people's future (Kristiansen et al., 2015), and therefore changes will inevitably be made at some point. The main changes discussed for the future included home-based adaptations, and securing their financial situations. All but two participants talked about their desire to stay at home, with their first answer to looking to the future regularly emphasising this preference. For example, Lily (SL3) stated,

“I want dad to be able to stay at home, but there needs to be the right support for this.”

In order to make it easier to stay where they were several participants had made changes to their homes. Sophie (SL15) had moved their bedroom downstairs, although she talked frankly about how hard this was to do, due to the restricted space and the emotional impact of having to leave the bedroom herself and Angus have always shared together,

“I was saying to one of the ladies I was thinking of moving the bedroom downstairs...but there was an awful lot against us moving downstairs, for a start the bedrooms tiny, can't take our bed down. “

Her continued discussion highlights how much the bedroom is more than just a room,

“You’ve more or less had everything in those drawers from when the kids were little, they needed space in there as well, but you get so used to everything, Angus’s shirts hanging in the wardrobe and trousers hanging in the next bit... there’s an awful lot of things folk don’t understand unless you’re actually working with others, nobody can say what you can and can’t do.”

It was evident that such changes made it harder for participants like Sophie (SL15) to avoid the increased needs of the person they support. Lucy (SE5) had renovated the kitchen, noting how much she had tried to keep it similar to before to reduce disorientation for Murray (PE5). As well as this they spoke about removing Murray’s office and making the space more open plan to avoid him secluding himself. In addition, Lucy (SE5) and Murray (PE5) had bought a summer house to allow Lucy (SE5) her own space, whilst knowing that Murray (PE5) was happy in the familiar environment of the home. Similarly, Michael (SL2) spoke about renovating an unused space to become a self-contained studio for ‘formal carers’ to stay when Grace (PL2) needed more continuous care. These bigger changes showed awareness of the potential challenges that could happen in the future, and finding practical ways to deal with them. However, there was a lot more detachment from these discussions to the rest of the interviews, with conversation returning back to the idea of ‘it could be worse’ or ‘it might not be necessary’.

In terms of lifestyle changes, the most frequent example was the reduction in holidays, or the shorter distance and duration that holidays now took, although, many participants still went away fairly regularly. Michael (SL2) talked about how much more he would like to go away but there were many practical limitations to this. Similarly, Emma (SE4) expressed sadness and regret over missing the opportunity to go away when they were more able to,

“Going away for a weekend I think the downside of it outweighs the benefits, it’s easier not to do it, so, no I wouldn’t say the future’s looking rosy, I just, there’s a lot of regrets, and opportunities lost I think, that’s the way I look at it.”

Comparatively, Murray (PE5) and Lucy (SE5), and Eva (SE1) and James (PE1) talked about going on more holidays following the diagnosis of Alzheimer’s disease, as a way

of making the most of life. Murray and Lucy's bucket list exemplifies this focus, having chosen to visit all of the places they wished to see following Murray's diagnosis,

“...this bucket list that started all that in the first place... because it suddenly took me away from what I was...” (Murray).

Both Murray and Lucy discuss the various holidays they have managed across the world in recent years,

“So we've done a good bucket list and we've filled a lot of bucket!” (Murray).

As with previous discussions, timing was important to the variation in experiences, with all participants talking about changes in opportunity and type of holiday across time. There were also concerns over future holidays, feeling that it was safer to plan trips that were nearby or with other people for additional support. Hamish's (SL4) discussion highlights these changes,

“Our holiday taking pattern changed because we used to do a lot of travelling, that has stopped because we weren't going on package holidays, we were just taking off travelling around, and I suddenly realised that we can't do that anymore.”

Many supporters expressed concerns over how the person with Alzheimer's disease would cope with any unforeseen problems. Lucy (SE5) shares these fears about travelling,

“I've always watched and waited, and usually a couple evolve that I feel, you know what I can tell you, just in case anything happens to me, that's always my fear, if something happens to me, Murray would be lost, he absolutely wouldn't know what to do”.

Despite changes in the type of holiday people go on, the ability to go away has helped people like Eva (SE1) and James (PE1) look to the future and feel they are 'living well'. Further, they acknowledge that they are lucky to be able to do this. This reinforces how positive comparisons can help in managing their situation,

“We’re lucky in many ways, we’re in a position to be able to do these things, because there are lots of people who, who obviously can’t and, perhaps if you’re not in a position to be able to, to go on nice holidays and you’re kind of stuck in worrying about things, that makes things worse...”

It should be noted that not all of the participants were in a financial position to go on such holidays. Financial concerns were discussed further by participants when thinking about the future, with some participants such as Jack (PE6) and Olivia (SE6) discussing their immediate concerns over financial instability and the complications they have faced over support for Jack who had to leave work early due to his condition. Other people’s financial fears were discussed much more in relation to the prospect of increased care and moving to a care home in the future. Emma (SE4) describes these fears for the future,

“I don’t think physically we’d be able to afford it, I worry about the finances of let’s say Charlie going into care, because I’m physically not able to cope with him, you know you hear about people having to sell their homes to finance, that bothers me.”

Implicit within the changes made is a need to make decisions based on the new situation and the related consequences. Making these decisions was challenging for people over time, particularly due to the reduction in shared decision-making between people with Alzheimer’s disease and their supporters. Increased dependency on supporters to make decisions was seen fairly early on in people’s journey with Alzheimer’s disease, with Hamish (SL4) stating that it was one of the first changes he noticed in Isla (PL4). Further, changes in decision-making can have a marked effect on the person they support. Poppy (SL1) discusses these changes,

“One of the most tiring things in a way, sometimes, is the fact that I know that every decision has to be mine, absolutely everything, and sometimes that’s fine, most of the time, but I, sometimes I think you know I’m really tired of that, because even the arrangement for [upcoming event]... it’s all my decision, but, I suppose it has its advantages as well I get what I want [laughter] so sometimes I do think well, look at it that way...but just the fact there’s nobody to refer to, and I do miss sometimes, things I would quite like to run past, decisions about things, or what to do about silly things...”

Emma (SE4) shares similar experiences and the impact of this in more detail, highlighting how she had previously been a very decisive person, but not being able to share decisions with Charlie (PE4) led to avoidance,

“I don’t like it, you know, you tend not to make a decision because you’re not sure what the other person would do about it, so it’s easy to put it off, and that’s, that goes against the grain because I was never that type of person, I always dealt with things as they came along, now I’m very aware I bury my head in the sand.”

The apparent disinterest Charlie shows over decisions fuels Emma’s feelings of loneliness within their relationship, a feeling mirrored by Lucy (SE5). The challenges expressed here related to decision-making and understanding the needs of both the person with Alzheimer’s disease and their supporters have been explored in more detail within research such as Livingston et al. (2010). Similar observations are noted, such as the challenge of decision-making from onset of Alzheimer’s disease through to end of life care (Livingston et al., 2010), reiterating the on-going challenges people may face.

There were also examples of where the preferences of the person with Alzheimer’s disease and their supporter differed. This was highlighted by Lucy (SE5) and Murray’s (PE5) experience of a clinical trial. During the trial Murray decided he wanted to stop due to the side effects. This caused great upset to Lucy, who felt that the trial was a lifeline to them. Such hope for clinical trials, and emotions attached to their involvement is mirrored in literature which explores motivations to be involved in research more generally (Black et al., 2013; Karlawish et al., 2001; Sugarman et al., 2001). Lucy felt that had Murray had a different condition, he would have made a different decision. Despite his reservations, Murray decided to continue the trial, putting his change in decision down to seeing himself as part of a family as well as an individual,

“The thing again... which finally made a big thing in there... yes [identifier removed] pills and everything else but what I forgot, or didn’t fathom out, that it’s not just me but it is us and therefore it’s not just about me, there’s a wife who also has to be part and parcel.”

For Lucy, this provided a moment of Murray seeing himself as a husband, a feeling which she felt was being lost. It also demonstrated much of the challenges faced by people when having to make decisions while accounting for what people currently wish for, and what they may have wanted prior to the condition.

If people are facing a scenario which as a pair they have not anticipated or discussed, or their previous discussions could not be implemented, people may become increasingly avoidant of making decisions. A supporter's fear over making a decision which accurately reflects the wishes of the person they support is exemplified in Emma's (SE4) earlier quote, where she acknowledges 'burying her head in the sand'. This can be seen in avoidance of advance care planning literature, where people worry that the person's prior decisions are being honoured, whilst also balancing their current preferences. This contributed to the 'take a day at a time' focus seen throughout the interviews for this study, and within research literature (Van der Steen et al., 2014; Black et al., 2009; Dickinson et al., 2013) as discussed in chapter 3.

Can we manage?

Underlying how people with Alzheimer's disease and their supporters look to the future is how they manage the challenges faced. As Poppy (SL1) exemplifies,

“I think it's just a question of, you know, taking it as it comes, and just hoping that, you know, you can still cope with it.”

Although there is repeated reference to the unpredictable and unique nature of the condition, this does not mean people are in denial over the potential difficulties. This can be seen by the practical changes participants have made to their daily lives and their futures. However, despite awareness of what may happen, there are many examples of avoidance of thinking too much about it, therefore avoiding thinking too far ahead. As Jennie (SE7) states,

“You know we tend to kind of think ahead so far, but obviously, none of us can tell, we can get run down by a bus tomorrow...”

This philosophy was evident across all participants. There is a clear acknowledgement and fear towards the future, and therefore in their everyday lives people focused on dealing with each day at a time. As noted, this does not mean people cannot look to the future, as hypothesised by some of the neurobiological literature (Addis et al., 2010). Rather, due to awareness of what the future could hold or fear of such circumstances, people chose not to.

Due to the lack of control participants felt over their futures, they tried not to worry about what could lie ahead. Many participants talked about how you could easily get overly worried and panicked about the future. Focusing on the present moment helped people to manage the lack of control. This is shown by Isobel (SL5) when discussing potential changes in Oliver's (PL5) condition,

“I think once you accept it and stop worrying and imagining what it could be, you just have to take it as it comes.”

The ‘day at a time’ way of coping with Alzheimer's disease further reinforces the preference for gradual change. Participants talked about their preference for receiving information slowly, and adapting to situations as they happen. As Jennie (SE7) explains,

“I mean we know that eventually things will change, but for the moment...”

Jennie adds that they know where to go if they need more information and support. This is reflected in other people's stories, such as Eva (SE1) and Poppy (SL1) who have an information drawer/folder which they can go to when needed. Thus emphasising the importance of knowing what is available, but not necessarily accessing it at that particular time. Further, Eva (SE1) was avoidant of James (PE1) being exposed to too much unfiltered information without sufficient time to process their situation. She discusses ‘banning’ James searching ‘Alzheimer's disease’ after a while reasoning that,

“There's so much out there and you are maybe not always reading the right thing.”

This is supported by previous literature, which emphasises knowledge can lead to increased anxieties (Proctor et al., 2002) and fears for future selves (Kristiansen et al.,

2015). Further, health-related information can compromise positive emotional states (Lockenstoff and Carstensen, 2004).

Focusing on a day at a time also made it easier to manage plans changing unexpectedly. Holly (SL12) discussed how no matter how much you plan, you never know whether that plan will end up in place or whether the circumstances will change. Further, Katie (SE3) talked about how she used to make plans but felt this was problematic in hindsight,

“I used to often say to myself, one day at a time, one day at a time, and just try and, I mean I did make some mistakes in maybe forward planning holidays and things that didn’t occur, because you really couldn’t plan too far ahead.”

Understandably there were several incidences where people feared whether they could manage their circumstances. This fear led to avoidance of situations where they may have to think about or plan for such a time. For instance Poppy (SL1), Emma (SE4) and Lucy (SE5) avoided support groups, fearing meeting people who may have advanced symptoms of Alzheimer’s disease. Emma explains,

“There’s different types, and people are at different stages, and it can be if you’re in with a poorer group, oh lord is this what’s in front of me? I don’t want to be like that, you know?”

This sentiment is mirrored by Poppy,

“I just feel that groups, I feel personally that that would depress me, I really, I’m not saying, I never like to say never, but I just, I can see the benefit and some people can find great comfort and support and all the rest of it from that, but I also feel too that people are obviously going to be at different stages, and also everyone’s different, I think I could start to panic, and really worry about the future about things that might never happen.”

Poppy’s discussion supports theories of positivity bias, and the need to maintain positive emotional states, therefore minimising exposure to negative information (Carstensen et al., 2003). Further, it reiterates people’s fears of the ‘advanced stages’ of Alzheimer’s disease, reflecting the interaction between stigma and future outlook.

Katie (SE3) also discussed her difficulty with thinking ahead, and exemplifies how participants managed this,

“I tried not to look too far ahead, cos if you do look too far ahead it becomes too difficult, so you tend to try and deal with what you’re dealing with at the time”.

Similarly, Cameron (SL10) found it frustrating and distressing when members of the group he attended continually asked him whether he had made plans,

“They say, ‘what have you done? Have you organised a maid? Someone to come in?’ ...Give it a rest, please don’t, they’re always ‘you should do this’...”

Cameron, Poppy, and Emma talked openly and frankly about their fears over not coping with thinking about the future, and wanting to keep their situation at a level they could handle. They believed that thinking about a time where things may be worse would lead them to anxiety/depression very quickly, as supported by previous literature surrounding salience of the situation and feared futures (Szpunar and Schacter, 2013).

Emma (SE4) summarises the feelings shared by herself, Poppy, and Cameron,

“I couldn’t cope with it, literally, you know, our situation just now is at a level I can just handle, you know? I don’t know what’s going to happen if it gets worse... I just have to take it day by day, week by week, otherwise I’m, I’m sure I would get depressed...not just down in the dumps, I think I could get really, yeah genuinely upset and not able to cope.”

As well as not feeling able to cope with thoughts of the future, others expressed fears about how they would manage the changes expected in the future. Michael’s (SL2) statement exemplifies this fear when talking about Grace’s (PL2) care needs increasing,

“There may be a time comes when I can’t do it, and I fear that day... the fact that maybe I won’t be able to do it, and that will be a sad day”.

Similarly, Katie (SE3) talks retrospectively about Toby (PE3) transitioning to a care home and how she had never thought that would have to happen. Katie goes on to add how difficult it has been to manage this change, and how limited, or in some cases non-existent, the support has been in helping cope and prepare for this transition. These discussions highlight how people with Alzheimer’s disease and their supporters’ fears

of the future both need considering. Further, it is important to consider how people manage these fears if they are being encouraged to think ahead by others.

Advance care planning

Despite the heavy focus on advance care planning within the research literature compared to broader thoughts about the future, advance care planning was unrecognised by participants. Most said that they had not heard of the term, and very few had spoken with healthcare professionals or other informants about potential care needs. Plans were identified more in terms of having a will and whether or not the supporter had power of attorney. Further, many reinforced the fact they had wills and other such documentation but this was irrespective of having Alzheimer's disease, and was more to do with securing theirs and their families' futures. Not all supporters had power of attorney, for Jack (PE6) completion was not necessary whilst he still had "two arms, two legs" but he did see the importance of it in the future for Olivia (SE6) to be 'his voice'. Again, the timing of this was mentioned with some participants feeling there was no need to rush into such formalities, particularly as it takes a lot of work and costs.

As discussed in terms of making changes to their homes, the main aspect of advance care planning highlighted was a preference to stay at home as long as possible. Oliver (PL5) and Millie (PL12) were already living in supported accommodation, with their daughters Isobel (SL5) and Holly (SL12) acting as their main supporters. Isobel and Holly generally felt that advance care planning was taken care of in the sense that they could increase the care support their parents received if and when they needed to. Both expressed a wish for them not to have to move again, although this would be dependent on the support available where they currently lived.

Many reasons were given for the preference of both people with Alzheimer's disease and supporters wishing to remain in their own homes, largely based around care home stigma. This stigma may be a key reason for avoiding future care planning. People worried that the level of care would never be as good as more individualised care within their own homes, as well as the inevitable impact on their identity and roles. All but one

participant disliked the idea of going into a residential care home if their needs increased, and their fears of this were given as reasons to not consider future possibilities. Reasons behind the stigma included previous experiences of care homes, stories heard in the media, and fears over how they would be treated by care home staff. Matthew (PE7) highlighted that if he got to a stage where he needed a care home, he hoped to have no awareness of the fact it had happened. Similarly, Isobel (SL5) ponders Oliver's (PL5) awareness of future changes,

“I'm quite hopeful that really he can finish out his days in his own home and not have to go anywhere...my sister keeps saying it would only ever happen if he went downhill so badly that he wouldn't know where he was anyway, but I do still think they do no matter, I don't know though.”

Although there didn't appear to be an age difference in attitudes towards care homes, for younger participants, the age range of people using care homes was mentioned. People such as Emma (SE4) expressed fears that people using care homes would be older and sedentary, suggesting younger people need more stimulation. Emma's statement exemplifies this,

“These people are in their 80s and 90s, we're not that age, you know, they don't have ones for younger people, I mean, I would die if I had to go into somewhere like that.”

Unlike the rest of the participants, Hamish (SL4) felt expressively more positive towards care homes. He spoke in depth about his dislike of 'care in the community' and how if there was ever a time where he or Isla (PL4) needed more help, they would want to move into a care home.

Generally discussion of what life would be like following transitions into care homes was very limited, with participants often diverting the conversation back by focusing on the unpredictability of the situation. However, Katie (SE3) and Michael (SL2) spoke in more detail about their futures aside from living with Alzheimer's disease. For instance, Michael talked about whether he would have a future where he wasn't caring for Grace (PL2), noting that there were many things he wished he could do. He shared these thoughts and the sadness that they bring,

“Well I often think, believe it or not, that is this it? Is this all I can expect out of my life for the next, I don’t know how many years I might have... Can I slip away and enjoy what’s left of my life, since I’ve already devoted a lot of years to her? And can I slip away and just live the way I want to do?”

Following this, Michael goes on to discuss how despite these thoughts he is not sure he could cope with a life where he was not with Grace, they are “inseparable”.

For one of the couples, Katie (SE3) and Toby (PE3), the transitional period into a care home facility happened between study visits. Katie stressed how difficult it is to think about the future, and how it feels just as uncertain as before. Although she now has more control over what she does, Katie emphasises how difficult it is to think about moving forward. She expresses the guilt that comes from considering a future away from Toby, or being involved in things which Toby was unable to do,

“I’ve not had a great deal of pleasure since Toby went into the home, but if I’m doing something that I am enjoying a bit, I feel, that’s when I’ll maybe feel guilty, I’ve booked, I was going on a break... I feel guilty that I’m looking, in a way I’m looking forward to going to somewhere I’ve not been, I do feel guilty because we never went there together and there’s one or two places that we still wanted to go...”

This excerpt highlights the opposite end of the spectrum in the journey of Alzheimer’s disease and looking to the future.

Current focus on advance care planning does not take into account the complexity of the situation for both the person with the condition and their supporter.

“I’ve lost it all... I’ve not got an identity... then I was able to say well I’m looking after Toby, I’m a carer, what do I say now?” (Katie, SE3).

Much more research is needed into how people manage the transition from being a supporter to building a different identity following such a transition. Overall these examples highlight that the avoidance of looking to the future doesn’t have a clear end point but continues across the journey of dementia. Within the literature there is acknowledgement of the challenges supporters may face following a loved one’s transition in a care home (Milligan, 2005; Davies and Nolan, 2004; Nolan and

Dellasega, 2001; Cronin et al., 2015; Mullin et al., 2011). However, Katie's experiences suggest that the research literature is not currently impacting on lived experiences, such as increased support options available.

Age-based differences in looking to the future

Finally, age-based differences relating to future outlook seem to emerged from the interview data. However, the pattern was not unidirectional. There were mixed responses for how the situation was for the age group people were in compared to the opposite age group. This emphasises the subjectivity of experiences, over age itself. For example, there were instances of people affected by early-onset Alzheimer's disease suggesting their futures had been 'snatched away', but this loss of future was also present for some affected by late-onset Alzheimer's disease. Olivia (SE6) states,

“Your future's been snatched away, your plans have grandly altered, and where the elderly, the over 75s, they've had that time”(Olivia)...“We're nowhere near it yet.” (Matthew, PE7).

Similarly, Holly (SL12) talking about how much harder it must be for people diagnosed young, seeing memory problems as understandable “once they come to a certain age”. She continues to say,

“If you or I were diagnosed it would be absolutely devastating, but at that age, I don't know, the thing is, different people are diagnosed at different points.”

However, there were also cases where people affected by late-onset Alzheimer's disease felt their future had been lost. Michael (SL2) represents this view,

“Well I often think, believe it or not, that is this it? Is this all I can expect out of my life for the next, I don't know how many years I might have.”

Lucy (SE5) agrees with the increased difficulty for people such as Michael, arguing that the scenario is easier to manage for younger people. She states,

“I think we’re maybe one of the lucky ones, ‘cus what I thought at the beginning, it’s awful that we’re young and it’s happening, but imagine if you’re old and it’s happening, how much harder is that to handle, how much harder for a carer, the whole thing must be a nightmare.”

The presence of similar challenges across age groups suggests overarching themes, rather than being reduced to age-specific experiences. Importantly, across age groups there appears to be a shared method of managing the situation: focusing on one day at a time. As with previous discussions, the similarities seen across age groups add further support to theories such as socioemotional selectivity theory (Carstensen, 1991). As explained in chapter 3, the theory suggests that people affected by ‘time-limiting’ conditions, in this case Alzheimer’s disease, will have a similar sense of time being restricted. If Alzheimer’s disease were not present, older participants would be expected to have a different view of time to younger participants (Carstensen et al., 1999). The change in perception of time experienced by people affected by the condition, leads to a shift in focus from knowledge-focused to emotion-focused goals. Overall, this can be seen to influence how people affected by early and late-onset Alzheimer’s disease manage their experiences, and will be discussed further in the following chapter.

Conclusions

Synthesis of interview data demonstrates the continuous nature of looking to the future. Participants were seen to think about their immediate futures, and small practical changes, over looking ahead to an ‘end point’. Their discussions highlighted that future outlook is not restricted to focusing on ‘care’. Rather, it can be seen as something that is fluid and changing throughout people’s life-course. How people look to the future can therefore influence the whole journey of dementia, from pre-diagnosis and fears about anticipated futures, through to continuing ‘normally’ and making the most of the situation you are in.

Age-related differences were present but bi-directional, with people affected by early and late-onset Alzheimer’s disease arguing that the future looked better/worse for their group, or the opposite group highlighting the lack of clear direction. As with the stigma-

related findings presented in chapter 6, possible differences between age groups were overarched by shared methods of managing the situation.

Future planning from the perspective of current policy and practice was unfamiliar to the majority of people. Choosing not to engage in advance care planning did not seem to be limited to awareness of its existence, or neurological inability to look ahead (Schacter et al., 2013; Addis et al., 2009). Instead consideration of such plans was more intertwined with an avoidance of thinking about a feared future. This deliberate diverting of attention to positive stimuli and avoidance of negative events is supported through the theoretical literature and research evidence (Carstensen, 1991; Kristiensen et al., 2015). For instance, looking too far ahead or acknowledging negative information led people to worry about the future and what may happen. Worrying was seen as unhelpful, particularly as the future was viewed as unpredictable and out of one's control. Therefore, as will be discussed in the following chapter, focusing attention on more positive experiences allowed people to maintain a positive emotional state, and manage their everyday experiences.

Chapter 8- Is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer’s disease and their supporters?

The final findings chapter brings together what has been learned about stigma experiences and future outlook for people with Alzheimer’s disease and their supporters. There is particular focus on the overarching themes which have enabled people to manage the difficult situations they have faced. Figure 13 provides an illustration of the thematic analysis which has guided the findings and how they have been presented.

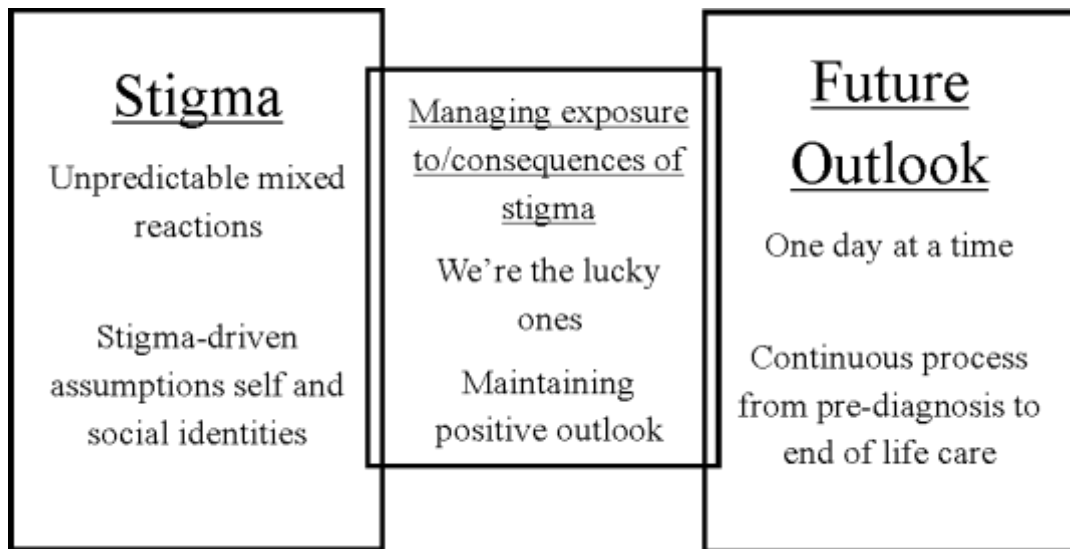


Figure 13. Illustration of the key findings from the thematic analysis

The following discusses the findings evidenced so far, before proposing how these findings interact with each other. The study results suggest that people with Alzheimer’s disease and their supporters experience stigma. The source of the stigma ranged from the reaction of the public, healthcare professionals, family, and friends. These reactions were unpredictable and mixed. Further, there were many examples of the person with Alzheimer’s disease internalising the stigma-driven assumptions of the condition. This can affect how they view themselves now and in the future.

The findings described in the previous chapter emphasise that future planning is not an ‘end point’ rather it is an on-going process across people’s journey with Alzheimer’s disease. Thoughts about the future are evident from pre-diagnosis through to end of life care. The most prominent finding within this is that although people are aware of the challenges they may face, there is general avoidance of thinking too far ahead. Across all participants there was a preference for taking one day at a time. Small changes may have been put into place, but generally changes were downplayed substantially to lessen their emotional impact. As the previous chapter notes, some of this avoidance is linked to stigma-fuelled fears relating to what the future may hold, such as care home stigma.

In addition, literature indicates that a loss of future is a widely held stereotypical assumption relating to Alzheimer’s disease (McParland et al., 2012). Despite this, there is a drive towards early diagnosis as a facilitator of future planning (Luengo-Fernandez et al., 2010). It could be argued that the drive towards early diagnosis for future planning is challenging the stigma-driven assumptions of ‘no future’. However, as the majority of the future planning focus is on advance care planning and end of life care, it may inadvertently be reinforcing the stigma-fuelled assumptions.

Both people with Alzheimer’s disease and their supporters have expressed fear over what the future may hold, and therefore chose to avoid situations where they may have to confront it, as the following quotes exemplify,

“... the sleepless nights, or you wake early or something, you can, your mind can, you really just try to rein it in and think oh well, nobody knows what’s going to happen, so.. but just you know as long as you know what’s available, and what’s there and hoping you won’t have to...” (Poppy, SL1)

This can lead to avoidance of activities, as discussed in chapter 7, or more generally choosing not to think about how the future may be,

“...there’s a great unknown out there, what I do know is there’s a lot of variables, and so I could frighten myself to death or not, and I’ve decided not to frighten myself to death.” (Lucy, SE5).

Recent research suggests that fears of the future are likely to be fuelled by stigma (Kristiansen et al., 2015). This supports the interplay between stigma-based assumptions and future outlook emerging from this study. Several core strategies were

seen across participants for managing these fears and possibilities. Firstly, where possible, people tried to maintain a positive focus. This was seen throughout stigma reporting, as well as when looking to the future. Secondly, people can be seen to have actively separated from the group identity of ‘people with Alzheimer’s disease’. Therefore, separating from the stigma and anticipated futures of the group. This is evidenced by people seeing their situation as unpredictable and unique. These two strategies are discussed in more detail in relation to socioemotional selectivity theory (Carstensen et al., 1991) and personal/group discrimination discrepancy (Taylor et al., 1990). These theories help to ground the thesis’s findings in terms of living with a condition like Alzheimer’s disease for both younger and older people, by highlighting that the presence of a ‘time-limiting’ condition can minimise the age-based differences expected along a ‘typical’ life-course trajectory. Additionally, they offer explanations for why people may separate themselves from a group identity, skewing the reporting of negative experiences and influencing how they look to the future.

Socioemotional selectivity theory

As discussed in more detail within the literature review (chapter 3), socioemotional selectivity theory (Carstensen, 1991) is underpinned by motivational goals. These goals change across the lifespan from knowledge-seeking to emotion-seeking. Knowledge-seeking in this context refers to engaging in social interactions for the primary purpose of acquiring knowledge. Comparatively, emotion-seeking refers to looking for interactions to regulate emotional states. This includes avoiding negativity and focusing on positive interaction (Carstensen et al., 1999).

Socioemotional selectivity theory offers compelling evidence for how people affected by Alzheimer’s disease manage stigma and future outlook. The underlying principle is that people are motivated to maintain a positive emotional state (Carstensen, 1991). As a result, social networks are actively narrowed to those that provide positive experiences. Therefore, people that react negatively are acknowledged but compartmentalised, focusing on those who continue to support them. Jennie’s (SE7) response to stigma from friends highlights this,

“It’s their problem; I mean if they can’t deal with it, quite honestly I’d rather they stayed away.”

Similarly, possible negative futures are ‘bracketed off’ (Brown and Graaf, 2013), by focusing on one day at a time. Looking further ahead may compromise the positive focus, and therefore potentially expose people to significant distress. Examples of this can be seen throughout the study data, such as Cameron’s (SL10) fears of looking ahead,

“See what happens, not in a position mentally to consider that one, or emotionally.”

Despite a range of negative experiences reported in relation to stigma, reporting of this was low when making a ‘forced-choice’ in one direction during the questionnaires. For example, Katie (SE3) discussed a variety of negative responses from family and friends, such as Toby’s (PE3) son,

“Yes, they’ve detached, and the sad thing is, we did get on fine, we all, we, I mean they were really close to him, he was really close to Toby.”

Despite describing this within the interview, on the questionnaire Katie disagreed with the question, ‘Some family members have rejected me because of my contact with family member with Alzheimer’s disease’. Similarly, Sophie (SL15) and Angus (PL15) talk about how the support they have had from their social group has been largely gestures such as sending chocolates at Christmas, rather than spending time visiting. Despite this limited contact following Angus’s diagnosis, Sophie scored zero on the Stigma Impact Scale and Angus answered disagree or not applicable to 23 out of 24 questions. These findings suggest a possible bias in reporting when having to decide between a positive or negative response. Further, the findings support the strength of including multiple measures within the study to capture the complexity of experiences and how they may be reported.

Interestingly, as discussed in chapter 3, there is evidence to suggest that positivity bias does not always work for people with cognitive impairments; due to the amount of cognitive resources it requires (Reed and Carstensen, 2012). This may explain examples such as Toby (PE3) who strongly agreed to ‘some family members have rejected me because of my condition.’, whereas, others although having similar experiences of

family rejection to Toby, reported lower scores. For instance, David's (PL1) brother is described as being avoidant following the diagnosis of Alzheimer's disease,

“...but David's brother definitely, I don't think he can cope with it, think that's the bottom line.” (Poppy, SL1).

However, both David and Poppy answered 'strongly disagree' to the Stigma Impact Scale question. Toby may have had greater cognitive impairments than other participants, given that he transitioned into a care facility between visits, as well as scoring the highest for the Bristol Activities of Daily Living. Therefore, being at a slightly more 'advanced' stage of his condition may have reduced the presence of the bias seen in others. The bias is also less likely in people who are experiencing depression and anxiety (Walker et al., 2003; Taylor and Brown, 1988), which may be reflected by Toby having the lowest score for quality of life compared to other participants with Alzheimer's disease. These conclusions are limited in that the findings should not be generalised from one person, however they suggest an avenue for future consideration. Further, the results demonstrate the complexity of separating biological and psychosocial factors to draw conclusions, and therefore add further support for the use of a biopsychosocial approach.

Age, Stigma, and Future Outlook

The literature review (chapter 2) highlighted several possible directions of age differences for stigma and future outlook. Scodellaro and Pin (2013), among others, suggested that younger adults with dementia will experience less stigma than older adults as they will not be exposed to the stigma of ageing (Milne, 2010; Benbow and Reynolds, 2000). Whereas, researchers such as Chaston (2010) reviewed the current understandings surrounding younger adults with dementia, and found that stigma was resulting in a loss of opportunities and independence (Roach et al., 2008; Ducharme et al., 2014). The literature provided by Chaston (2010) and Scodellaro and Pin (2013) suggests that the experience of stigma will be different based on age. Alternatively, socioemotional selectivity theory may be a bridge between debates over experiences of people with early and late-onset Alzheimer's disease. According to the theory people

who are experiencing ‘time-limiting’ conditions will experience similar views of time and the future, compared with people without health conditions (Carstensen et al., 1999).

The theory suggests that people with early and late-onset Alzheimer’s disease are likely to share similar views, despite possible differences in circumstances. For instance, younger participants including Jack (PE6), Matthew (PE7), and Murray (PE5) discussed loss of driving licenses and changes in employment status more so than older participants. However, despite these differences, the findings presented throughout suggest a similar attitude to managing stigma and future outlook. Therefore, although there are debates in the literature about stigma and age-based experiences of Alzheimer’s disease, the shared experience of the condition across age groups appears to override these effects. As discussed within chapter 2, previous research focuses on differences between the two age groups, whereas the similarities emerging from this study are likely to have been missed by not considering people across age groups together.

Managing feared futures

The discussion across the findings chapters has highlighted that generally participants avoided negative information, and focused on taking each day at a time. The salience of positive memories is seen to be stronger due to the cognitive-processing bias, with negative memories appearing further away (Walker et al., 2003). As such, people are more likely to recall scenarios where people have responded positively towards them, than negatively. This appears to be particularly true when reporting on questionnaires, as discussed in the previous section.

Similarly, people are more likely to avoid situations where they may be exposed to negative scenarios, or information that will potentially fuel stigma. Several examples of this avoidance are available within the interview data, including accounts of Poppy (SL1) and Emma (SE4) who discuss avoiding group activities. Emma exemplifies avoidance of groups by people like herself and Poppy,

“There’s different types, and people are at different stages, and it can be if you’re in with a poorer group, oh lord is this what’s in front of me? I don’t want to be like that, you know.”

Despite the avoidance and negativity associated with the future, people spoke about their hopes and how these helped them to manage their fears. These hopes included considering what they were still able to do, and goals they hoped to achieve. This is exemplified by Murray (PE5) and Lucy’s (SE5) bucket list, and hopes for research discussed in the previous chapter. Many participants talked of their hopes for new medications and new technology to help people with Alzheimer’s disease now or in the future, as Cameron (SL10) explains,

“...I have faith in technology that something will happen, we will improve, we will learn, we’ll experience, and there’s all sorts of people beavering away in labs up and down the country.”

Such hopes contributed to people wanting to be involved in research, with them expressing how this helped them maintain a positive outlook for the future. Such findings can be seen in similar research literature which considers research participation for Alzheimer’s disease and other ‘time-limiting’ conditions (Black et al., 2013; Karlawish et al., 2001; Sugarman et al., 2001). Further, Matthew (PE7) and Jennie (SE7) discuss how research participation keeps them involved,

“It brings in other people, and it keeps us abreast with what’s going on...if there’s something gonna happen, or something available, somebody in that group is gonna tell us.” (Jennie)

As well as providing hope for the future, even if they won’t directly benefit from research outcomes,

“Got nothing to lose...but it could help somebody else, that’s the thing and the future, it might not help me, but it might help.” (Matthew)

Similarly, as presented in chapter 3, hope enables people to look ahead when facing challenging circumstances (Bruininks and Malle, 2005).

As well as discussing general hopes for the future, there were times where people had to acknowledge the future possibilities. For instance, Michael (SL2) and Katie (SE3)

shared their fears of a time in the future when they would be separated from the person they support,

“There may be a time comes when I can’t do it, and I fear that day, that’s the only thing I would say about advance care planning, is the fact that maybe I won’t be able to do it, and that will be a sad day, because I will never rest, because of the attention that Grace needs, and because I’d always be worried that people wouldn’t understand what she needs.” (Michael, SL2).

Despite the challenge of looking ahead, Katie’s (SE3) interview illustrated that avoiding thinking about the future does not necessarily help in the long term,

“I didn’t predict I would feel like this, I didn’t predict I’d be in this situation and it isn’t a situation that any family member, partner, carer, you know, none of us want to think about this, umm, however, I didn’t think I’d feel as bad as I do, I didn’t think I’d be as sad.”

Katie’s distress reflects the concerns raised by Lockenhoff and Carstensen (2004), who note that whilst avoiding negative information can reduce distress in the short-term, it may lead to negative long-term outcomes. Further, interviews such as Katie’s (SE3) reinforces how futures of people with Alzheimer’s disease and their supporters are entwined. For example, Katie talks about how Toby (PE3) no longer being able to participate in the same things as she is doing makes her feel,

“I feel guilty that...I’m looking forward to going to somewhere I’ve not been, I do feel guilty because we never went there together.”

As a result of their supporting role, many of the supporters’ pursuits had changed, such as stopping work (Lily, SL3), or having less time for themselves (Cameron, SL10). To focus on this would be maladaptive to emotion regulation. Therefore in order to remain positive, the smaller things in life become appreciated (Hicks et al., 2012). Most importantly, people focused on the positive relationships with those around them such as family and friends (Benbow and Jolley, 2012).

Managing unpredictability

The thesis findings emphasise that looking to the future exposed people to their fears about what could happen. As a result, people avoided looking ahead as much as possible, choosing to focus on their current situation. The unpredictable trajectory of the condition encouraged people to see it as out of their control, and avoid worrying as much as possible. As Holly (SL12) notes,

“You haven’t got a time scale to know whether they’re going to go downhill weekly, monthly, annually, so there’s no way you can predict.”

This sentiment is mirrored across previous literature which considers how people manage adverse and unpredictable circumstances (Hoyle and Sherrill, 2006; Dickinson et al., 2013). The need to ‘just get on with it’ was unanimous amongst participants, feeling that the only way to manage was to accept it for what it was, and try to focus on what they could still do, instead of worrying about what you cannot do now, or in the future. This approach was seen across participants, regardless of age.

The management strategies employed are being increasingly reported, as noted in the literature review chapters. The current findings build on this body of literature further by highlighting how experiences of people with Alzheimer’s can be similar despite affecting a diverse range of people. The acceptance of unpredictability was most adaptive for participants, and is supported by motivations to maintain positive emotions. However, this process takes time. Participants talked about the gradual process of change, and learning to move forward. For instance, Lucy (SE5) notes how initially she did not necessarily think people should be diagnosed, whereas she now sees the benefits as it led them to create the ‘bucket list’,

“... if there’s nothing you can do, why do we need to know?, and [doctor’s wife] she felt that you know, why tell people when there’s nothing we can do? But once we got over that, we decided that actually we were glad that we did know, because we could plan.”

This is supported by research into how people experience their diagnosis (Vernooij-Dassen et al., 2006). The focus moved from diagnosis to thinking about what they enjoyed doing, emphasising how planning in practice was focused on life-goals over

'care' concerns. Eva (SE1) spoke passionately throughout the interview about this viewpoint,

“Go with the flow; do as much as we can, when we can, live well.”

For some couples this was continuing activities they had done before, for others it was engaging in new activities or services to help support this transition. Similar findings have been seen in relation to 'couplehood', and preservation of joint activities (Hellstrom et al., 2005, 2007; Sorensen et al., 2008).

The unpredictable nature of Alzheimer's disease was also used as protection from future fears. Poppy (SL1) highlights this view,

“I think it's just a question of, you know, taking it as it comes... certainly sometimes something will happen and I really panic and think oh no it's a slippery slope, but then I've learnt to realise that that's not necessarily even going to occur... you can't dwell on it, just hope for the best and keep going.”

Such feelings were also expressed in terms of the unique nature of the condition, where each person is different; therefore unpredictable. This is exemplified by Eva (SE1),

“Why worry about something that might never happen?...nobody knows, so, you I think you just have to get on, and as I say, we concentrate on the positive things in life, and what we enjoy doing, and what we can do, and you know, just get on with it.”

The discussion highlights how across age groups people with Alzheimer's disease and their supporters manage unpredictable reactions and fears of the future through focusing on each day. Further, within this unpredictability is a sense that each experience is unique. As Sophie (SL15) notes,

“You wouldn't get two stories the same”

Poppy (SE1) mirrors this,

“You could have a dozen people with Alzheimer's who are all completely different...and they might have come across somebody who's completely different to the next.”

By separating individual experiences to those expected by the group, people have learned to maintain a positive emotional state as much as possible. The findings have been supported throughout by socioemotional selectivity theory for people affected by Alzheimer's disease, irrespective of age. This is explained through a shift in motivation towards emotion-focused goals when people face 'time-limiting' conditions. The unique nature of the condition has also been discussed as a way of helping people separate from the group identity, associated stigma, and anticipated futures, as will be discussed in the following section.

The personal/group discrimination discrepancy- 'We're the lucky ones'

The separation from the group identity of 'people with Alzheimer's disease' can be explained using personal/group discrimination discrepancy theory (Taylor et al., 1990). Further, it can be applied to both stigma and future planning, under the framework of socioemotional selectivity theory (Carstensen, 1991). The following discussion has brought together evidence from this study with the research literature presented in chapters 2 and 3, to show how findings build on current understandings of experiences of Alzheimer's disease, and consider how people manage exposure to stigma and the consequences to future planning.

Personal/group discrimination discrepancy, as discussed in more detail within the literature review, was developed to explain the emergent finding that people perceived a higher level of discrimination towards their group, compared to themselves as an individual within the group (Taylor et al., 1990). By seeing others as worse off, people may be able to dissociate themselves from the group norm, thereby protecting their identity (Taylor et al., 1990). This allows people to separate from the stigma toward the condition and the feared futures, to maintain emotional stability.

Across interviews, people regularly described themselves as being the 'lucky ones'. When negative events were reported, they were followed by an event which affected somebody else, and was perceived as worse. Examples include Sophie (SL15), who mentions finding things difficult at times, but follows this by describing her neighbour's circumstances,

“Oh I keep it together, Sunday really wasn’t very good, but I just hold it together, saw my neighbours, saw my grandchildren...feel sorry for my neighbour, I think it’s easier for a female to cope with an illness than a male, and neighbour says life is not what it was like when his wife could do it....she has an awful lot of health problems...I think, I don’t have that to contend with...”

Other examples to support the discrepancy include, Holly (SL12) and Lucy (SE5). Holly talked about how much harder it must be for people diagnosed with Alzheimer’s disease when they are younger. Whereas, Lucy felt it was better to be dealing with it whilst young and able. Their differing views also emphasise the complexity of age-based hypotheses relating to experiences of Alzheimer’s disease. Other participants compared their situation to health problems other than Alzheimer’s disease. For instance, Sophie (SL15) discussed one of her friends,

“He’s had two heart attacks and also had prostate cancer, so I think we’re lucky, when I compare myself, I think we’re ok.”

In addition, the process of seeing themselves as lucky relative to others may have contributed to low reporting of stigma in questionnaires. For example, Jennie (SE7) and Matthew (PE7) talk about knowing people with dementia who have “dropped off the radar” and ended up very isolated, whereas they didn’t feel that was the case for them. Knowing about other people’s experiences may have increased the motivation for employing the positivity bias. If participants had not known of other people’s experiences, or focused on these comparisons, reported stigma during questionnaires may have been higher.

Throughout all of the interviews, participants were continually comparing their situations to others, both with Alzheimer’s disease and with other health conditions. The majority of the time this was to suggest that their situation could be worse. Matthew (PE7) exemplifies the positive comparison to other health conditions,

“At the end of the day it’s something that happens, it’s not, I’m not the only person that’s got it, there’s an awful lot of other people out there that have it as well, you know, and there’s a lot of things a lot worse than Alzheimer’s, so you know, if you’ve got to have something, I don’t mind because you can forget things, it’s convenient you know!”

However others, such as Millie (PL12) and Oliver (PL5) felt that Alzheimer’s disease was the worst condition to be diagnosed with, and others were in easier situations. As Holly (SL12) describes,

“It was always her worst nightmare, she says I could cope with heart, stroke, cancer anything...”

Isobel (SL5) also discusses how Oliver expressed similar feelings,

“It was the one thing he feared and didn’t want.” (Isobel, SL5).

These differences in response may link back to previous discussions on stigma and labelling of the condition (chapter 2). There may also be age differences, with younger participants being more likely to see Alzheimer’s disease as an illness outside of their control. Whereas, as the questionnaire data alluded to, older participants may be at more risk of internalising the stigma of the condition and therefore expressing greater anticipatory fear. In addition, the experiences may differ due to how Millie and Oliver used to talk about the condition before developing it themselves. Whereas, Matthew’s response may be a result of seeing the condition differently since the diagnosis, as his experiences have challenged the stigmatised view. The range of possible explanations highlights the complexity of the topic and suggests future research which considers people’s view of Alzheimer’s disease before and after diagnosis may be insightful.

Participants’ ability to see their situation as better off is captured in the interviews with references to being the ‘lucky ones’. The sense of being lucky may contribute to the significant difference seen between people with Alzheimer’s disease and their supporters in the questionnaires. During the interviews, the shared experience of Alzheimer’s disease is evident,

““It didn’t just happen to Matthew, it happened to me too.” (Jennie, SE7).

However, in terms of questionnaires relating to stigma, supporters may have felt that the level of stigma they have experienced was marginal to that of the person they support. Taking account of the possible positivity bias and the sense of being lucky relative to others, the experiences of Alzheimer's disease appear to be affected by how people manage their situation. Results may have been different for people who felt that they were unable to manage, or did not have the psychological or physical resources to do so. For example, if people did not have the resources available to use the positivity bias, or they focused on their feared futures, a different picture may have emerged. This is reflected in the case studies presented by Kristiansen et al. (2015) who highlighted that the participant who focused on the feared future had poorer outcomes overall than the participant who was able to focus on maintaining positivity.

Part of the focus on being the 'lucky ones' enabled people to separate themselves from the group identity. Weiss and Lang (2012) found that such dissociation could be self-protective. Early research by Weinstein (1980) found people rated positive future events as more likely to happen for themselves than others, and negative future events as less likely to happen. This is an attribution bias known as unrealistic optimism. McKay and Dennett (2009) note, that although this view of the future can be a misperception, it can still be highly adaptive. In keeping with this, separating from the rest of the group can change the way people consider their future. Functional MRI (fMRI) imaging has shown people processing less information that challenges their optimistic view compared to that which supports it (Sharot, 2011). An example of this from interview data can be seen when Lucy is discussing a clinical trial Murray (PE5) is involved in. Lucy (SE5) talks about changes which make her hopeful that he is on the active drug, although noting that it's not consistently the case,

“...sometimes you do things or say things and I think, oh he's definitely not on the tablet, and then there will be something else you'll think, wow I wasn't expecting that...” (Lucy, SE5).

By focusing on the potential signs the drug is working, Lucy can direct her hopes towards this. Lucy highlights the distress resulting from Murray considering stopping the trial, and therefore losing hope of changing their anticipated future,

“I was absolutely devastated that Murray couldn’t grasp that it was our only hope of a future that was longer, and yes it might not work, but it’s the only hope we’ve got.”

The fMRI research by Sharot (2011) highlighted that as well as a reduction in processing challenging information, people showed increased processing of information which supports their view. These findings would suggest that people affected by Alzheimer’s disease are more likely to process experiences which suggest they are managing better than they expected, as shown by Isobel (SL5),

“We’ve been really pleasantly surprised that dad, after all these years, you expect when you get the diagnosis that they’re going to go downhill very quickly, but that hasn’t been the case with dad at all, dad’s still very active and very, just memory problems.”

However, across the visits and stories shared, changes in Oliver’s (PL5) abilities were evident. The extracts from interviews reinforce the subjective nature of people’s experiences, with the need to consider how people appraise their own situations relative to their expectations for themselves and others.

The literature surrounding unrealistic optimism highlights how neurological processes can impact on the way people view their situation. Such processes can influence how they anticipate their future, relative to their own beliefs, and others’ situations. Similarly, it could add further explanation for why people would rate their own experiences of stigma as low, given the reduction in negative information processing.

Overall, personal/group discrimination discrepancy and the attribution biases discussed go some way to explaining why people may report less stigma being directed at themselves. This does not take away their awareness of stigma towards the group, rather it places greater emphasis on others who they feel are more affected, leading them to feel the ‘lucky one’. This dissociation is thought to improve people’s ability to manage stigma. Acknowledging the group stigma without self-identifying appeared to have the best outcomes for people in this study; it allows them to maintain positivity whilst not denying the existence of negative circumstances.

Despite these findings, dissociating with the group may not necessarily be the best outcome in the long term. When it comes to looking to the future, such dissociation

may be making it harder to acknowledge the changes they may have to face, as discussed within socioemotional selectivity theory (Lockenhoff and Carstensen, 2004). Generally, a lot more research is needed to consider the current dissonance between looking to the future in policy, and in practice (Robinson et al., 2010; Godfrey and Hackatt, 2015; Denning et al., 2011), and how to manage the avoidance which has protective effects in the moment (Lockenhoff and Carstensen, 2004). The current literature is not conclusive over the benefits of advance care planning (Robinson et al., 2012) and in line with the current study's findings, suggests focusing on daily living is more optimal (Dickinson et al., 2013). However, if planning ahead can be of benefit, findings ways to support this could improve outcomes for people affected by Alzheimer's disease.

Conclusions

Overall, this chapter has brought together the findings relating to stigma and future outlook to highlight how they interact and shape people's experiences of living with Alzheimer's disease. Exposure to stigma can lead to feared futures, with a focus on increased 'care' and reduction in capabilities. In order to manage the negative experiences they had been exposed to and their fears for the future, participants employed a range of mechanisms to help manage their situation. These included separating from the group identity, and considering themselves as 'lucky' relative to others. The concept of being 'lucky' enabled people to focus on how things could be worse, further facilitating the positive focus and the minimising of negative experiences. These techniques are considered to be particularly helpful when people are faced with unpredictable circumstances that are outside of a person's control.

Socioemotional selectivity theory provides a useful lens to explore the interaction between stigma and future outlook by highlighting how people are motivated to maintain their positive emotional state. As such, participants separated themselves from the negative reactions of others and focused on those who remained close to them. Further, participants chose to avoid looking far ahead, instead focusing on taking one day at a time.

Finally, emerging findings brought together with the research literature emphasise how age-based differences are minimised when focusing on the interaction between stigma and future outlook. The findings suggest that some experiences may differ between age groups including, the impact of diagnosis on employment and driving license affecting confidence and finances of younger participants, with internalised shame impacting more on older participants. Despite these differences, the way people have learned to manage a diagnosis of Alzheimer's disease encompassed all participants. As with previous discussions, these findings are supported by shared experiences of people living with 'time-limiting' conditions, irrespective of age.

Chapter 9-Discussion and Conclusion

The following chapter synthesises what has been discussed across the thesis, and how the PhD contributes to wider understandings of living with Alzheimer's disease. Firstly, the study results will be considered in relation to the gaps in the research literature discussed within the literature review chapters. The potential for generalisation of findings has been noted in terms of replications of the research. Finally, gaps which have emerged as a result of the findings will be explored with recommendations for future directions of research.

Perceptions of Stigma and Future Outlook

This study explored the experiences of people with Alzheimer's disease and their supporters. The aims and objectives were to consider people's perceptions of stigma and future outlook, including the possible age differences previously unexplored in the research literature. The development of Alzheimer's disease can expose both people with the condition and their supporters to stigma, the source of which can range from public perceptions through to family, friends, and self-stigmatisation. One of the core stigma-driven assumptions explored was that people do not have a future following the development of Alzheimer's disease. This assumption may be fuelled further by current understandings of future planning which focus on advance care planning and end of life care (Denning et al., 2011; Robinson et al., 2010; Dickinson et al., 2013).

The results presented across the three findings chapters considered four research questions. Firstly, do people with Alzheimer's disease and their supporters experience stigma? Secondly, how do people with Alzheimer's disease and their supporters view and plan for the future? Thirdly, is there an association between levels of perceived stigma and how a person views and plans for the future: for both people with Alzheimer's disease and their supporters? Finally, across the findings chapters the differences in experiences of stigma and future outlook, for people experiencing early and late-onset Alzheimer's disease were explored. These questions were examined through questionnaires and interviews, to give an in-depth account of the complexities

of experiences. Further, theoretical and methodological understandings were considered through a biopsychosocial lens, which acknowledged the biological underpinnings of the condition whilst focusing on the psychosocial experiences of Alzheimer's disease.

The findings presented highlighted that people with Alzheimer's disease and their supporters had various experiences of stigma. These experiences were mixed and unpredictable, with inconsistent age differences seen across participants. Questionnaire and interview methods produced different outcomes. Stigma reporting in questionnaires was generally much lower than that expressed at interview. Several explanations were suggested to explain this. The positivity bias, explained with socioemotional selectivity theory, highlights how people affected by 'time-limiting' conditions are motivated to maintain positive emotional states. As such, when making 'forced choices' between positive and negative answers on questionnaires, people were more likely to focus on the positive. The interview data suggest that the Stigma Impact Scale may not be accurately capturing people's experiences of stigma, which is considered in relation to whether stigma is being discussed towards oneself or the group 'people with Alzheimer's disease'. By separating from the group and seeing other people's situations as worse off, reporting of stigma was lower in questionnaire responses than when discussing experiences more broadly in interviews.

The positivity bias and pursuit of emotion-focused goals can also capture broader experiences of living with Alzheimer's disease and looking to the future. Instead of planning post-diagnosis, people chose to focus on one day at a time, and hope for a future that was different to that feared through stigma. By comparing themselves to others and seeing themselves as unique, people with Alzheimer's disease and their supporters were better able to separate themselves from the 'typical future' associated with developing the condition. As such, the interaction between stigma and future outlook is reinforced. These findings compliment socioemotional selectivity theory, as well as various attributional biases which help people to maintain this view (Taylor et al., 1990; Shepperd et al., 2013).

The theoretical literature warns that such attributional biases can lead people to avoid thinking about the future when negative events are likely to occur (Lockenhoff and Carstensen, 2004). As a result of this, people avoid information that disturbs their positive emotional state. This was evident amongst people with Alzheimer's disease

and their supporters. There was a lot of reluctance to consider a time where care needs would increase for the person with Alzheimer's disease, as well as more generally the changes that may take place practically and emotionally. Several participants acknowledged that this avoidance was deliberate and necessary to avoid fear and anguish. Despite fears of thinking about the future, many participants had begun to make more practical changes, such as moving their bedrooms to the ground floor. However, these changes were generally segregated from being considered in relation to the person with Alzheimer's disease's health. These findings are consistent with recent work by Dickinson et al. (2013) who found people were reluctant to make plans relating to care, but were more likely to consider aspects such as finances.

Finally, age differences were explored given the lack of research which included people with early and late-onset Alzheimer's disease together. Although differences in experiences were evident, particularly in relation to finances and occupational change, the differences focused on in previous literature do not seem to accurately reflect the overall similarity in experiences of people in this study. Interestingly, people across age groups learned to manage their situation in similar ways, which influenced how they lived their everyday lives and looked to the future. Participants showed positivity bias and pruning of social networks to surround themselves with those who continued to support them. Further, although their circumstances differed in the sense of having been retired or working before diagnosis, across age groups the 'day at a time' perspective and avoidance of looking to the future was consistent.

Applying research findings to previous literature

The literature review presented in the earlier chapters of the thesis highlighted several gaps within the research, which have been addressed in this study. Firstly, there was minimal research in experiences of stigma from the perspective of people with Alzheimer's disease and their supporters. Previous research focused more on public understanding of Alzheimer's disease. This has led to considerable drives to challenge the stigma attached to the condition internationally. This is demonstrated by the World Health Organisation report on overcoming the stigma of dementia (Batsch and Mittleman, 2012). Within this report is recognition that the voices of people with

dementia are often missing in the literature to date; an acknowledgement shared among other researchers in the field (McKeown et al., 2010). The findings from the thesis support the presence of stigma from the perspective of people with Alzheimer's disease and their supporters. Further, the increased stigma reported in this study by people with Alzheimer's disease compared to their supporters, mirrors the figures from the Batsch and Mittleman (2012) survey data. The presence of stigma challenges the stigma-driven assumption that people with Alzheimer's disease will not have insight into their circumstances (Bond et al., 2002). Further, the findings support the limited research currently available into insight and perceptions of people with Alzheimer's disease, with a focus on stigma (Burgener and Berger, 2008; Riley, 2012). Based on these findings, interventions may be needed that target both public awareness and people already affected, to reduce internalised stigma.

The reviewed literature in chapters 2 and 3 suggested several possible directions of results relating to age, stigma, and Alzheimer's disease. Chaston (2010) suggested that younger people were likely to experience more stigma than older people affected by Alzheimer's disease. This was hypothesised due to 'inverse ageism' and the presence of an 'older person's' disease. However, researchers such as Scodellaro and Pin (2013) argued that older people are likely to be exposed to greater amounts of stigma due to the 'double stigma' of ageing and Alzheimer's disease. Despite these opposing views, there was very limited research into the psychosocial experiences of the two age groups together. Examples of age-based differences have been reported in relation to biological differences and symptomology (Toyota et al., 2007), time to diagnosis (Van Vliet et al., 2013) and supporters' perspectives on challenging behaviour (Arai et al., 2007), which begins to bridge biomedical and psychosocial factors. The findings from the thesis highlight that although age may influence aspects of experiences, such as financial insecurity and internalised shame, the impact of age was inconsistent in relation to stigma and future outlook. Further, the thesis findings emphasise the benefit of including both age groups together;

Other research has included both people with early and late-onset dementia, but without noting that participants are classified as having different ages of onset. This has made it difficult to separate out possible age based differences. For instance, Caddell and Clare (2013) included people with dementia over the age of 60 as one group, despite the current diagnostic cut off of age 65 years old for early and late-onset dementia (Koedam

et al., 2010). Given that across areas of dementia research, different experiences have been evidenced for the two age groups (Tolhurst et al., 2014), it seems an oversight for research to not acknowledge when people with early and late-onset diagnoses are included, even if the age cut off itself is arbitrary (Woods and Clare, 2015). This thesis helped to address the challenges of this by considering the results by age groups, separately and together, helping to understand more about age itself as a variable.

Age differences highlighted through the subcategories of the Stigma Impact Scale suggested that people affected by early-onset Alzheimer's disease were more likely to experience financial instability. This is in-keeping with the work of Chaston (2010) and discussions of the Alzheimer's Society (2015b). Comparatively, people with late-onset Alzheimer's disease reported higher stigma than people with early-onset Alzheimer's disease for internalised shame. This is discussed within chapter 6 as a possible reflection of self-stigma of older adult stereotypes and Alzheimer's disease (Scodellaro and Pin, 2011), supporting the presence of 'double stigma' (Milne, 2010; Benbow and Jolley, 2012). Despite the differences seen on the assessment scales, interview data highlighted that there were overarching similarities in the way people managed the exposure to stigma and its consequences. The findings show support for both sides of previous evidence, demonstrating the complexity of the topic area. They also help to illustrate the multifaceted nature of stigma, and suggest it cannot be considered as a unitary concept. The difference in reporting across measures demonstrates the strength of mixed method designs, as will be discussed in the ensuing section.

Another key gap in the research literature was how people look to the future, particularly if they have internalised the stigma-driven assumption that a future is not possible. Previous literature has focused almost exclusively on future planning from the perspective of advance care planning and end of life care (Robinson et al., 2012; Dickinson et al., 2013; Alzheimer's Disease International, 2014). This thesis aimed to move away from this focus and look at how people view and plan for the future across the journey of Alzheimer's disease. The findings presented in chapter 7 highlight that looking to the future was not an end point process. Rather, people's focus fluctuated from immediate to more long term futures, depending on how manageable the situation felt at the time. Smaller everyday changes in future planning and outlook were evident across participants. Larger changes were sometimes present, but downplayed to minimise the emotional impact. This led to people focusing on one day at a time,

acknowledging that Alzheimer's disease is an unpredictable, unique condition, which makes looking ahead difficult. Therefore, it is easier to focus on what can be done in the moment.

As well as adding to the psychosocial literature in relation to looking to the future, the findings add to the field of neurobiological research. As discussed in the literature review, cognitive impairment and ageing have been associated with increased difficulty in looking to the future. This has been explained through the additional challenge of projecting oneself into the future and reconceptualising past memories to anticipate the future (Schacter et al., 2013). Literature such as Mark (2012) sought to explore the applicability of socioemotional selectivity theory to people with Alzheimer's disease. It was noted that the symptoms of the condition may make it difficult for people to experience the adaptive biases discussed within the theory. Despite the discussions of these researchers, the results of this study suggest that such theory is applicable to people with Alzheimer's disease and their supporters. Further, the deliberate focus of emotion-focused goals and avoidance of negative information supports that people are not unable to look to the future. Rather they are deliberately choosing to avoid this and focus on daily living.

As with the stigma findings, age differences were mentioned in relation to looking to the future, but they were not consistent in direction. For example, some people affected by early-onset Alzheimer's disease felt they were worse off, having futures 'snatched away' whilst older people with the condition had been able to experience longer without Alzheimer's disease. This is in-keeping with theoretical literature discussed in chapter 2, where people may be adversely affected by events that appear 'off time' to the 'normal' life span (Heckhausen et al., 1989). Comparatively, there were other younger people who felt they were better equipped to deal with the condition due to their age. The alternative responses within and between-groups highlight the subjectivity of experiences and how age does not necessarily separate people with Alzheimer's disease as much as the previous literature suggests. Instead, there was a shared sense of focusing on each day and making the most of the opportunities available. The results suggest that although certain age differences may be present, these differences are overarched by shared management of the situation, in keeping with socioemotional selectivity theory (Carstensen, 1991).

Alternative explanations for findings

The previous section highlights how the findings from this thesis have been interpreted using a psychological lens within a biopsychosocial perspective. As noted within the literature reviews (chapters 2 and 3), this is not the only perspective that could have been taken to understand people's experiences of living with Alzheimer's disease. Therefore, alternative explanations for the key findings of this thesis have been considered in the following section.

Experiences of stigma

The first key finding was that people with Alzheimer's disease and their supporters experience stigma. As noted in the literature review (chapter 2), there was already significant evidence to suggest Alzheimer's disease is a stigmatised illness (Devlin et al., 2007; McParland et al., 2012; Mendez and Cummings, 2003). However, less research was available from the individual's perspective. In order to facilitate this focus, Modified Labelling Theory (Link, 1987) was used as the conceptual framework. Despite its origins in sociology, this framework has been developed and applied as a model of stigma in the field of psychology and mental health due to the continued focus on the individual within a social context (Olafsdottir, 2013; Yang et al., 2007). It may be controversial to apply a theory with its roots in sociology within a thesis where 'measurement' is included, as Scambler (2009) suggests people's experiences are too complex to operationalise. However, Link et al. (2004) assert it is crucial in the field of mental health, and the theory has been successfully used to develop stigma scales (see chapter 5).

Alternative psychological stigma theories which centre on models of stigma and mental health include Corrigan and Rusch's (2002) two-factor theory. Within their model, stigma is separated into socio-cognitive structures of stereotypes, prejudice, and discrimination. Although public and self-stigma follow the same structure they are presented independently. Taking this perspective, the extent to which participants endorse the stereotypes will influence the consequences of stigma for their everyday

lives. For instance, people who believe that Alzheimer's disease is equivalent to a 'social death' (Kirkman et al., 2006) are more likely to separate from the group identity. This could be a useful perspective when considered in light of personal/group discrimination discrepancy (Taylor et al., 1990), as discussed in chapter 2. However, the findings from this thesis highlighted that stigma is very complex and difficult to separate into two components. For instance, public stigma included the attitudes of friends, family and the general public, but the impact of stigmatised-responses from these groups varied across participants. Furthermore, it could be argued that Alzheimer's disease is not purely a mental health condition (Ticehurst, 2001), and therefore is less suited to a framework that does not include the physical and social aspects of the condition, as has been considered in this thesis using a socio-cognitive model (Corrigan, 2000).

From the sociological perspective of biographical disruption, it could be expected that people living with a chronic condition such as Alzheimer's disease would focus on the positives of their situation, minimising the impact of its effects to maintain a sense of hope for the future. This is discussed by Bury (1991) and others as strategic mobilisation of resources (Williams, 2000a). A strength of such an approach is that it is possible to understand the symbolic nature of the condition as it is expressed narratively, and to explore how people manage this through representing disruption or continuity in their identity. Some 'disruptive' events may actually be anticipated in later life, and the extent of adversity is likely to be further mediated by a person's material circumstances (Williams, 2000a) or 'emotional capital' (Williams, 2000b). Therefore, from this perspective, the experience of stigma would be contextualised through understanding dementia as an older person's condition (Mendez and Cummings, 2003; Werner, 2005), with younger participants expected to experience greater biographical disruption. This would explain why younger participants felt there was less public understanding, and their futures were more disrupted by having been diagnosed at a younger age. However, this approach does not address how younger participants in the current study also suggested that they may be better able to cope and had more resources to do so, than if they were older; thereby conflicting with literature suggesting that older people may be better able to manage stigma, due to repeated exposure to disruptive events across the life-course (Pound et al., 1998).

Overall, this sociological framework takes a different approach to what has been explored within the thesis by exploring how the person constructs the impact of the condition on their identity. Taking such an approach would have included identity as an explicit and integral characteristic from the outset (Hubbard et al., 2010), whereas this thesis focused on the socio-cognitive processes that influence people's perceptions of stigma and future outlook.

Looking to the future

A key reason for exploring the stigma of Alzheimer's disease was to consider the consequences it may have for future outlook. Participants' future outlook was explained using Socioemotional Selectivity Theory (Carstensen, 1991), a psychological perspective on the life-course. A weakness of the socio-cognitive approach, in this case Socioemotional Selectivity Theory (Carstensen, 1991), is that it focuses on the internalised world in terms of a person's thought processes, compared to understanding the sociocultural context framing the individual's experiences and the impact of this context on their identity.

Alternative theories which consider future outlook, with a particular focus on time, are also worth noting. As discussed above in relation to the sociological concept of biographical disruption, Alzheimer's disease acts as a critical event in a person's biography, leading to an awareness of the body, self and social world (Bury, 1982). Later work by Bury (2001) suggests that people manage this change by trying to maintain their previous lifestyle as much as possible and minimise symptoms, or alter their lifestyle to contain the chronic illness (Bury, 2001). This perspective also fits well with the work of Keady et al. (2009) who describes how people diagnosed with dementia undergo a balancing act between these two approaches of minimising and accommodating the condition. From this perspective, actively narrowing social networks to include only people who are supportive may enable participants to maintain as 'normal' a life as possible, minimising the overall disruption.

The extent to which a chronic illness is biographically disruptive has been argued to be based on context and expectations in terms of age and perceived life expectancy

(Hubbard et al., 2010), which Williams (2000a) argues the original theory fails to account for. This would suggest that older people, who may be more likely to expect Alzheimer's disease based on age-related risk factors, would be less disrupted by the condition, supporting the idea of biographical continuity (Williams, 2000a). However, the findings of this thesis suggested more similarity than difference in the experiences of people with early and late-onset dementia, as will be discussed further below in relation to the finding about age-related differences in perceived stigma and future outlook.

Recent research by Reeve et al. (2010) suggests that to understand the impact of a terminal illness, the biographical approach should combine the study of the narrative and the embodied emotional experience. However, this type of research may be better suited to a purely qualitative study with a more interpretive analysis of the lives of the participants and their surrounding context. Although such approaches have relevance in terms of explaining the subjective experience of chronic illness, this thesis has chosen to focus on theory which can explain the association between stigma and future outlook observed in terms of socio-cognitive processes (Corrigan, 2000). This provides an explanatory framework to understand the potential cognitive biases that influence perceptions and experiences, a notable gap in the current literature about stigma and future outlook.

Perceptions of stigma and future outlook

The third key finding from this thesis was the interaction between stigma and future outlook, which raised the importance of considering the two core topics together. Stigma of Alzheimer's disease and fear of the future led to an active avoidance of looking ahead to a time where the stigmatised-future may be realised. To maintain focus on positive experiences, social networks were actively 'pruned' and exposure to others with dementia was often avoided. The findings have previously been discussed using a biopsychosocial perspective.

A socio-political framework, as described in more detail by Bartlett and O'Connor (2010), provides an interesting alternative that may also capture the interaction between

stigma and future outlook. This perspective focuses on positioning people with dementia as ‘active citizens’ shaped by life events and broader socio-political systems (Bartlett and O’Connor, 2010). To facilitate citizenship, the Scottish Dementia Strategy (Scottish Government, 2013) promotes five ‘pillars’ of support recommended by Alzheimer Scotland (Simmons, 2011): planning for future decision making, understanding the illness and symptoms, supporting connections in the community, planning for future care, and peer support. Despite the suggested value of such support, there remain risks to diagnosis (Fox et al., 2013) which may alter the way the condition is managed, and the options people living with dementia feel they have. The findings of this thesis suggest that the currently cited benefits of future planning may not outweigh the negatives of stigma attached to the diagnosis of Alzheimer’s disease. More work is needed to enable person-centred support following diagnosis, advancing on the ‘one size fits all’ model currently available (Kelly and Innes, 2016), to give people more choice (Watts et al., 2013) and to better support ‘active citizenship’ (Bartlett and O’Connor, 2010).

From a socio-political perspective, Clarke and Bailey (2016) discuss how people with dementia can be socially excluded but have shown resilience in the face of such adversity. Participants showed awareness of being treated differently, and excluded themselves from some situations in order to minimise the risk of others ‘shunning’ them (Clarke and Bailey, 2016), mirroring some of the experiences described in this thesis. Taking this alternative perspective, the findings of this thesis may be explained through stigma disrupting the identity of people living with dementia, and their position within society (see Beard and Fox, 2008). People strive to maintain a certain degree of ‘normality’ despite the changes they face, withdrawing from social circumstances in order to minimise personal risk (Clarke and Bailey, 2016; Lee and Craft, 2002). Although social withdrawal appears to be a positive approach, correlational evidence suggests that it may also lead to lower self-esteem and therefore may not be protective in the longer-term (Ilic et al., 2011). From a psychological perspective, this would need further exploration in terms of the consequences of withdrawing socially on an individual’s perceptions about themselves and those around them. Finally, the potential for resilience to facilitate how people manage experiences provides an interesting avenue for future research, given how techniques for managing adverse circumstances were key to the thesis findings.

Age-based differences: Perceived stigma and future outlook

The final key finding explored throughout this thesis was the age-based differences in experiences of stigma and future outlook for people with early and late-onset Alzheimer's disease. Socioemotional Selectivity Theory (Carstensen, 1991) explained why people with early and late-onset Alzheimer's disease shared similar experiences. The findings present a different picture to previous literature by highlighting that there are overarching similarities across age groups that are missed when early and late-onset Alzheimer's disease are separated. As discussed previously, the age category is arbitrary and based on a clinical cut-off of older or younger than 65 years old for diagnosis of early or late-onset Alzheimer's disease (Woods and Clare, 2015); nonetheless, the separation is used consistently across literature which considers age-based experiences (e.g. Roach et al., 2008).

Alternative theoretical perspectives to Socioemotional Selectivity Theory around ageing and experiences of Alzheimer's disease include biographical disruption (Bury, 1982). As discussed previously, the theory reflects on the impact of chronic illness on a person's life trajectory. Much of the biographical disruption literature suggests younger people may be more affected by the onset of a chronic illness than older people (Pound et al., 1998; Sanders et al., 2002), although conflicting research is available (Larsson and Jeppsson-Grassman, 2012). This challenges the idea that Alzheimer's disease itself is universally disruptive, and supports the focus on context and timing (Grinyer, 2007; Hubbard et al., 2010; Wilson, 2007). Had a biographical disruption approach been taken, more pronounced age-based differences may have been expected from participants within this thesis. In support of this assumption, Roach et al. (2008) highlight that Alzheimer's disease may be more disruptive to the identity of younger people because of their life-stage and family dynamics; however, changes in family dynamics more generally (Swartz, 2009) may minimise these age-based differences. From this perspective, the similarities seen between younger and older participants in this study may be a result of similar family dynamics, or more generally a result of self-selection bias to research creating a more homogenous participant group. This is an area where further research would be helpful to explore these potential explanations.

As biographical disruption was not chosen as the theoretical framework, it is not possible to draw firm conclusions around the age-based similarities seen within this thesis. Grinyer (2007) notes the impact of illness on any age group can present profound challenges and is of significance for all age groups, but the specific difficulties people face may vary by age. It may have been that Alzheimer's disease was more disruptive to younger people in this study but they may have been better able to adjust their identities, leading to an overall similar level of disruption compared to the older participants. Alternatively, Alzheimer's disease may be equally disruptive for both older and younger people living with the condition. An approach which explicitly considered identity and adjustment to chronic illness may be better placed to answer this question.

Overall, the findings of this thesis do not intend to contradict the different experiences or potential levels of disruptiveness that a diagnosis of Alzheimer's disease can create based on age. There was evidence from both age groups to support different needs; importantly, there was also a need to consider the group similarities where age is one of many influential factors. In terms of practice implications, it may be more beneficial to separate dementia services from older adult psychiatry, as this may help to reduce the impact of age-based stigma (Richeson and Shelton, 2006), confusion around normal ageing (Whalley, 2002), as well as mental health stigma (Corrigan and Watson, 2002) that could all contribute to the experience of the condition. This separation could also ensure access to appropriate services.

Conclusion: Alternative Findings

Across the four findings, several alternative perspectives have been highlighted that could have been applied to this thesis, with a particular focus on biographical disruption due to its relevance to both stigma and future outlook. The alternatives have been discussed in terms of how the findings may have been framed differently had such approaches been taken. Of note, had alternative perspectives such as biographical disruption been used from the outset, the research questions are likely to have been different, particularly in terms of a more explicit consideration of identity. Therefore, the findings are interpreted using alternative approaches cautiously, as Hubbard et al. (2010) note it can be difficult to distinguish whether something is not relevant to a

participant, or whether it has not emerged since it was not raised as a topic during the data collection.

Although offering unique insights, there are strengths and limitations of all perspectives which were considered critically when selecting the most relevant approach.

Socioemotional Selectivity Theory (Carstensen, 1991) was chosen as it explains the findings from a psychological perspective, using a socio-cognitive model (Corrigan, 2000), within a biopsychosocial framework. As discussed across the thesis, this theory has allowed for two seemingly separate topics, stigma and future outlook, to be considered together to highlight the complexity of the 'benefits and costs of diagnosis' debate (Fox et al., 2013) and people's experiences of Alzheimer's disease. Further, the theory helps to address the overarching similarities between age groups which may be missed in alternative theories, and is particularly important when considering a condition such as Alzheimer's disease where there is a somewhat tangled relationship between age as a risk factor and age as a cause of Alzheimer's disease, with the added complexity of social constructions of age and stigma. The alternative explanations discussed above reflect different but relevant theoretical perspectives that merit further investigation in future research.

Supporting the use of mixed methods design

In order to generate the findings discussed, a mixed methods design was used. It is important to note that this choice of method is not without critics, and therefore the strengths and limitations should be acknowledged when drawing conclusions.

Commonly cited criticisms of mixed methods include, the lack of guidance relating to combination of methods and the integration of findings (Ostlund et al., 2011), as well as the underlying challenge of possibly opposing paradigms (Guba and Lincoln, 1994), considered in more detail within chapter 4.

The aim of this study was not to debate the use of mixed methods, but to show that they could be used effectively when the focus was on the research questions themselves (Tashakkori and Teddlie, 2003). Further, one of the issues highlighted in Ostlund et al.'s (2011) review of mixed methods research literature is a lack of clarity, particularly for the weighting of different methods. As such, this thesis aimed to make the research

process as transparent as possible, to support the validity of the research, as well as for ease of replicating the research in future.

Despite the limitations of mixed method designs raised, the results of this study support its use to capture the complexity of experiences. This is particularly the case for the discrepancy in stigma reporting between questionnaires and interviews. The discrepancy had been alluded to in previous literature, but through comparing separate studies, as opposed to studies which included both measures. For instance, Werner et al. (2012) documented that reported stigma was higher in qualitative studies than quantitative studies. This discrepancy remains after methodological differences, such as freedom of reporting, have been taken into account (Bergmann et al., 2004; McKillop and Wilkinson, 2004). The presence of a discrepancy that cannot be explained by measures chosen alone, suggests psychological mechanisms such as personal/group discrimination discrepancy may be skewing the responding (Taylor et al., 1990). It would not have been possible to observe the discrepancy as clearly had a singular approach been used. The discrepancy also suggests a more effective tool for capturing perceived stigma in questionnaires may need to be developed. The findings from this thesis and previous literature suggest low stigma reporting using the Stigma Impact Scale, therefore if the questionnaire had been used alone it would not have accurately captured people's experiences of stigma.

Finally, mixed methods designs are increasingly encouraged in dementia research as a field made up of multiple disciplines and research backgrounds (Robinson et al., 2011b). This is mirrored in the use of a biopsychosocial perspective. Driscoll et al. (2007) note that traditionally, quantitative measures focus more on biophysical features and qualitative measures focus on sociocultural data. In contrast to this view, Robinson et al. (2011b) emphasise that understanding well-being involves a holistic approach. Therefore there is a need to appreciate the impact of biology, whilst recognising the impact of psychosocial variables on people's everyday experiences. The findings of this study support this approach by emphasising that the changes that people have had to make, as a result of the symptoms associated with Alzheimer's disease, have been influenced by psychosocial factors. People have chosen to focus as much as possible on what their capabilities are and how they can adjust their everyday living to accommodate the changes. This process of change and adaptation provides a stark contrast to biomedical perspectives on dementia which focus on a journey of

deterioration from diagnosis to end of life care (Cuijpers and van Lente, 2015). Further, the biomedical explanation alone would not have reflected the experiences shared between people with Alzheimer's disease and their supporters.

Researching with people with Alzheimer's disease and their supporters

In addition to the gaps which led to research questions, a more general concern for dementia research is the limited inclusion of people with Alzheimer's disease (McKeown et al., 2010; Batsch and Mittleman, 2012). This inclusion was prioritised across the research process, including within initial design formulation, presenting ideas at conferences to people affected by dementia, and study protocol, as discussed within chapter 5. There is increasing awareness across the field of dementia that the voices of those affected by the condition can provide valuable insight into the experiences people face (Hellstrom et al., 2007; de Boer et al., 2007; Hubbard et al., 2003). An ever present concern for research which includes people with dementia is considering the additional ethical dilemmas that can be faced, which may be less prominent when researching other conditions (Higgins, 2013; Sadler et al., 2010; Shaghghi et al., 2011). These concerns include the therapeutic benefits of research and the capacity to consent. Discussion relating to capacity to consent to research has been covered in more detail within the methodology chapter (chapter 5). Therefore, the remainder of this section focuses on the therapeutic benefits of research. Berghmans and Ter Meulen (1995) note that for research with other age groups, or more treatable conditions, participants are more likely to benefit directly from the research. However, this is not to say that people with dementia should not be involved. Rather the focus is on how research participation itself can outweigh the potential negative aspects of involvement.

Psychosocial research tends to have fewer risks, but is associated with less direct benefits (Berghmans and Ter Meulen, 1995). The indirect benefits of research for people with Alzheimer's disease and their supporter have been evidenced both in this thesis as discussed in chapter 5, and in the research literature (Higgins, 2013; Law et al., 2014). Participation in research has not only been shown to benefit people with Alzheimer's disease and their supporters, but may indirectly help to challenge stigma, ageism and negative future outlook being explored in this thesis. Research which

focuses on strategies to overcome stigma include challenging the stereotypical view (Corrigan et al., 2012; Milne, 2010) and increasing social contact (Corrigan et al., 2001; Morgan et al., 2002). Challenging stigma-driven assumptions may increase general understanding of the ongoing journey people face with dementia. Assumptions to challenge include the view that there is no future post diagnosis, or that people cannot be actively engaged in activities such as research. These considerations emphasise the importance of disseminating research findings to a wide range of audiences.

Future directions of research

The following section takes account of the discussion across the thesis to consider future directions of research based on what has been learned so far. Firstly, the discussed limitations in sample suggest that an initial direction of future research would be to replicate the study with a more diverse, larger sample size. If more potential participants were available, stratified sampling could be used for a more proportionate representation of characteristics such as gender, age and socioeconomic status (Teddlie and Yu, 2007). As highlighted in the methods chapter, the low numbers of people with early-onset Alzheimer's disease in this study meant that statistical comparisons by age group did not have sufficient power. As such, there is greater risk of making a type I or type II error whereby the difference between the two age groups for Stigma Impact Scale scores may be concluded to be greater than it is or less than it is. For instance, a non-significant result between a small group of people with early- and late-onset Alzheimer's disease may become significant when more data is included, resulting in a different conclusion about the impact of age and stigma. This is in-part alleviated by the inclusion of interviews, as well as consideration of the findings against previous literature, but it would still be interesting to see whether the same results between age groups can be seen in a larger scale study.

Additionally, cultural differences were not considered in this study, given that the sample was made up of Scottish men and women. Therefore it would be an interesting comparison for future research given that cultural differences are expected in relation to stigma, ageing and future outlook (Mackenzie, 2006; La Fontaine et al., 2007; Hinton et al., 2005; Downs, 2000; Fung et al., 2008; Mezulis et al., 2004).

Scotland has a devolved health system to the rest of the UK. Within this is a national strategy which guarantees people diagnosed with dementia one year of post-diagnostic support (Scottish Government, 2013). Research suggests that increased support may influence perceptions of stigma, as well as potentially increased diagnosis rates and future planning strategies (Miller and Kaiser, 2001; Alzheimer's Disease International, 2012; MacLeod and Conway, 2005; Prenda and Lachman, 2001). Therefore a UK wide replication of this study may produce different findings given that this year of support is not currently offered elsewhere in the UK. For example, greater stigma may be expected for samples in the other areas of the UK due to the reduced post-diagnostic support. Alternatively, findings may not differ significantly given that the pattern of results found in this study has mirrored much of the similar literature in other countries such as America (Burgener and Burger, 2008; 2013). Further, although the increased rates of diagnosis and support may suggest greater future planning in Scotland compared to the rest of the UK, the results from this study suggest people are not utilising future planning, therefore differences may not be expected. The variety of potential findings when considered from a UK-wide context highlights an important future research opportunity, whilst also suggesting that any generalisation of results should proceed with caution. Further research would be needed to see whether the findings were similar or different to the outcomes of this thesis.

When considering the replication of research on a wider scale, it is worth considering the use of the Stigma Impact Scale itself. The scale developed by Fife and Wright (2000) and adapted for use with people with Alzheimer's disease by Burgener and Berger (2008) has produced conflicting findings when triangulated with the interview data. In practice this means that people with Alzheimer's disease may be reporting low levels of stigma when in fact they are experiencing much higher levels. Literature discussed in the literature review (chapter 2) and findings presented across chapters 6-8 highlight that stigma has negative consequences for the person affected, including loss of family and friends, lower self-esteem, and increased isolation.

Given the negative consequences of stigma, it is important in practice for those working within the field of dementia to be able to accurately capture the experiences of people with dementia in an efficient way. Questionnaires remain a suitable method for capturing information quickly, with the increased structure allowing for faster analysis (Zohrabi, 2013). In a clinical environment, healthcare professionals face significant

time pressure (Westbrook et al., 2008); as such, a questionnaire into perceived stigma may be particularly helpful, but the options available do not necessarily reflect key experiences of people with dementia, based on the data from this thesis. Therefore, further research could develop a new scale which is able to measure perceived stigma that would be consistent with levels reported using other methods.

As well as replication of this research on a wider scale, the findings of the study suggest multiple avenues of research which could be explored. Firstly, the study findings suggest that age differences expected based on the age-associated nature of Alzheimer's disease are overarched by shared methods of managing the situation. As was highlighted in the methodology, there was minimal research found to reflect similar age-associated patterns in other health conditions. Emlet (2006) considered experiences of older people with HIV, who were seen as 'too old' to have the condition, and acknowledged both age-related and illness-related stigma. However, this study did not directly compare experiences with younger people with the condition. Therefore, it would be interesting to see whether conditions which are associated with younger people are experienced in similar ways for older adults, when both groups are considered in the same study. The results of this thesis would suggest similar experiences of stigma and future outlook if the condition is 'time-limiting', regardless of the age of onset. Further, the findings indicate the relevance of this thesis to broader understandings of living with a chronic health condition.

Secondly, the findings suggest more research is needed into the diagnosis of Alzheimer's disease and the assumed future planning resulting from early diagnosis. It is widely recognised that a diagnosis can expose people with Alzheimer's disease to stigma (Bunn et al., 2012; Iliffe et al., 2003; Milne, 2010). This is supported by the findings of this thesis, with both people with Alzheimer's disease and their supporters sharing a number of experiences relating to stigma. Currently, one of the motivators behind diagnosis is the opportunity to plan for the future (Luengo-Fernandez et al., 2010). However, as the findings of this thesis show, people do not necessarily wish to engage in future planning. Instead the focus is on focusing on each day at a time, which has been discussed throughout the findings chapters as a way of maintaining a positive emotional state. This is supported by recent work into the impact of diagnosis and

avoidance of information about the future (Bunn et al., 2012; Lockenhoff and Carstensen, 2004).

Given these findings, future research is needed to explore ways of helping people to manage both exposure to stigma and planning for the future, whilst focusing on daily living. This is particularly advisable as despite the exposure to stigma, research highlights that the majority of people still wish to know their diagnosis (Pinner and Bouman, 2003, Robinson et al., 2011; Robinson et al., 2014). These conclusions may be biased, as people who are most fearful of the condition and its anticipated future trajectory may engage less with research; a limitation discussed in more detail within sampling (chapter 4). Current research which looks more specifically at future planning suggests that people benefit most from health care professionals instigating the discussion and supporting them through the decision-making processes (Engelhardt et al., 2006; Poppe et al., 2013). This may be particularly true for people affected by dementia who already face challenges with the shift in decision-making processes (Robinson et al., 2013). Therefore, shared responsibility relating to future planning may reduce avoidance.

The literature often assumes that both receiving a diagnosis of Alzheimer's disease and having the opportunity to plan for the future can be beneficial. The thesis findings of both perceived stigma and avoidance of future planning do not intend to contradict this. Rather, they illustrate that there remains a gap between policy recommendations and how people are managing their condition. The Scottish Dementia Strategy includes commitment to improving the rates of dementia diagnosis and access to a minimum one year post-diagnostic support (Scottish Government, 2013). The commitment is supported by Alzheimer's Scotland's "5 Pillar Model" (Scottish Government, 2013:7). Two of the five 'pillars' focus on future outlook: 'planning for future care' and 'planning for future decision-making' (Simmons, 2011). The results of this thesis suggest that while it is important to begin making changes, future research should aim to move beyond planning from the perspective of 'care'. The thesis illustrates that future outlook is an on-going, fluctuating process which is happening across the life course.

It should be noted that this thesis did not aim to focus on advance care planning; therefore the recommendations in terms of advance care planning and policy should be

taken with caution. Although the findings of this thesis suggest it may not be beneficial for people to look ahead due to the potentially negative futures they perceive, Lockenhoff and Carstensen (2004) warn that this can lead to potential difficulties in the long term. Therefore, future research which explores advance care planning in terms of long term benefits, as suggested by Robinson et al. (2012), would provide further context to these recommendations and the relevance of advance care planning in future outlook.

Considering a time where ‘care’ needs will increase exposes people to significant distress and activities such as group support are avoided, through fear of seeing people at more ‘advanced stages’ of their condition. As such, support services should be aware of the challenges people face in engaging in future planning and find ways of helping people to make appropriate plans whilst not compromising their emotional state. Recognising that the view of ‘no future’ is a stigma-driven assumption (Devlin et al., 2007) may help to reduce fear of looking ahead. Post-diagnostic support should be tailored to help people acknowledge that it is possible to live well and have a future which is not dominated by ‘care’, whilst not taking away from the challenges people face in learning to live with a condition like Alzheimer’s disease.

Finally, future research could explore possible therapeutic interventions to support people to maintain a positive focus and take one day at a time. ‘Mindfulness’ is one such intervention to help people develop and maintain this focus. Originating from Buddhist traditions (Whitebird et al., 2012) mindfulness is increasingly recognised as a way of improving health and wellbeing (Robertson, 2015) and refers to “the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment” (Kabat-Zinn, 2003:145). The evidence surrounding mindfulness interventions is generally positive, although there remains a need for a more rigorous approach to evaluation (Robertson, 2015). Previous literature highlights that such interventions may improve the experience of supporters (Hurley et al., 2014; Mackenzie and Pulin, 2013) and people with dementia (Larouche et al., 2015; Paller et al., 2015). The findings of this thesis, in particular the positive impact of maintaining a day at a time perspective, may support further research into mindfulness-based interventions for both people with dementia and their supporters. Although, as with the discussions surrounding cognitive resources for implementing the positivity bias (Mark, 2012), it may be that for some, the ability to

direct and engage attention makes it difficult to benefit from mindfulness-based interventions. Further research is needed in order to draw conclusions regarding this issue.

Overall Conclusions

The thesis sought to explore the experiences of people affected by early and late-onset Alzheimer's disease, with a particular focus on how stigma and future outlook interact. People with Alzheimer's disease and their supporters experienced a range of stigma. The reporting of stigma varied by research measure and begins to highlight the management of the condition, as participants actively chose not to identify with the stigmatised group as much as possible. One of the consequences of stigma is people being highly fearful of their future with Alzheimer's disease and what may happen. In order to manage fears, people chose to focus on one day at a time, deliberately avoiding planning or looking too far ahead. Alzheimer's disease was viewed by participants as unpredictable and unique, which helped them to manage the lack of control over the condition and to see themselves as 'lucky' relative to others. Across findings, age differences, such as financial concerns and internalised stigma, were minimised by a shared focus on preserving positive emotional states. The findings for both stigma and future outlook are supported by socioemotional selectivity theory and a range of attributional biases which help people to maintain the positive focus. Overall, there is a need to consider how best to explore the complex nature of future outlook in practice and policy, alongside managing stigma and its consequences. Of key importance is how to help people affected by Alzheimer's disease remain positive in the face of adversity. In the current context, taking 'one day at a time' appears to be the most adaptive strategy for managing everyday life with Alzheimer's disease, and minimising exposure to stigma-fuelled fears of the future.

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Appendices

Appendix 1- NHS REC Ethics approval

WoSRES
West of Scotland Research Ethics Service



Miss Rosalie Ashworth
Room 3S29
School of Applied Social Science
Colin Bell Building, University of Stirling
Stirling
FK9 4LA

West of Scotland REC 5

Ground Floor - Tennent Building
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Date 06 December 2013

Direct line 0141 211 2102
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Miss Ashworth

Study title: A comparison of the perceived stigma experienced by people with early onset Alzheimer's disease, late onset Alzheimer's disease, and their supporters: stigma and future planning.

REC reference: 13/WS/0291
IRAS project ID: 136750

Thank you for your email of 2 December 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 29 November 2013

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form	2	November 2013
Participant Information Sheet: Supporter	2	November 2013
Participant Information Sheet: Person with Alzheimer's Disease	2	November 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Evidence of insurance or indemnity		22 October 2013
GP/Consultant Information Sheets	1	
Interview Schedules/Topic Guides	1	October 2013
Investigator CV		24 September 2013

Letter from Sponsor		22 October 2013
Letter of invitation to participant	1	October 2013
Other: Debrief Letter	1	
Other: Participant Selection Flowchart	1	October 2013
Other: Interview Topics	1	October 2013
Other: Useful Contacts	1	October 2013
Other: Supporter Demographic Information	1	October 2013
Other: Letter from Funder		
Other: Supervisor CV (Bowes)		
Other: Supervisor CV (Kelly)		
Participant Consent Form	2	November 2013
Participant Information Sheet: Supporter	2	November 2013
Participant Information Sheet: Person with Alzheimer's Disease	2	November 2013
Protocol	1	October 2013
Questionnaire: BADLS		
Questionnaire: Zarit Burden Interview - Short Form		
Questionnaire: MARS-MFS Supporter		
Questionnaire: MARS-MFS person with Alzheimer's Disease		
Questionnaire: Sigma Impact Scale		
Questionnaire: Sigma Impact Scale: Caregiver		
Questionnaire: DEM-QOL	1	October 2013
Questionnaire: Adapted SIS	1	October 2013
Questionnaire: Adapted SIS Supporter	1	October 2013
REC application		05 November 2013
Referees or other scientific critique report		23 October 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

13/WS/0291	Please quote this number on all correspondence
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Yours sincerely



Mrs Sharon Macgregor
Committee Co-ordinator

Copy to: Daniela Bolle, University of Stirling
Ms Allyson Bailey, NHS Forth Valley

Appendix 2- SASS Risk Assessment**Risk Assessment**

School of Applied Social Science, University of Stirling

All those doing the work must be involved in the completion of this form. Complete all sections, marking clearly those that are not applicable. The form must be signed by all involved, and copies made for each person. Hard copies of the completed form, with original signatures, must be sent by the principal investigator to the School Administrator within 3 months of the start date of the project, or prior to the commencement of fieldwork, whichever is the sooner.

Head of School	<i>Professor Alison Bowes</i>
School Administrator	<i>Mrs. Morag Crawford</i>
University Safety Advisor	<i>Mr. David Duckett</i>
Completed by	Rosalie Ashworth
Date	13/11/13
Contact in Emergency, name & telephone number	Professor Alison Bowes, 01786 467795 Dr Fiona Kelly, 01786 466332

Research Activity

Dates of activity:	01/10/2013-01/10/2015
Activity: Give title and briefly summarise	<p>PhD fieldwork- “A comparison of the perceived stigma experienced by people with early-onset Alzheimer’s disease, late-onset Alzheimer’s disease, and their supporters: stigma and future planning”</p> <p>Visiting people with dementia and their supporters in their homes (or in the University of Stirling if they request). I will be completing questionnaires and interviews, across multiple visits.</p>

<p>People involved:</p> <p>Give individual name(s)</p>	<p>PhD Student- Rosalie Ashworth</p> <p>Supervisors- Professor Alison Bowes and Dr Fiona Kelly</p>
<p>Location(s) of the activity: Give specific locations, e.g. name of hospital, or town</p>	<p>People will be seen in their own homes or the University of Stirling, School of Applied Social Science.</p> <p>Peoples' homes will be across the central belt of Scotland: Forth Valley, Glasgow, Tayside, Lanarkshire and Lothian.</p>

	Hazard(s)	Control Measures	Severity of risk	Likelihood of risk	Overall Risk
<p>Working in a dangerous area: e.g. high crime area, area of civil unrest. Give contact details and measures in case of emergency</p>	<p>People will be seen at their homes the majority of the time: they may live in high crime areas etc.</p>	<p>The address of the visit will be given to supervisors prior to visits if the area is high risk, based on address given. The researcher will let the supervisors know when arriving/leaving the visit. Emergency contact details will be on the work phone of the researcher, and all visits will be done by car, with a Sat-Nav and breakdown cover with GreenFlag.</p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>
<p>Working in an isolated geographical area: Give contact details and measures in case of emergency</p>	<p>As above, peoples' homes may be in an isolated area.</p>	<p>The address of the visit will be given to supervisors prior to visits if the area is isolated. The researcher will let the supervisors know when arriving/leaving the visit. Emergency contact details will be on the work phone of the researcher, and all visits will be done by car, with a Sat-Nav and breakdown cover with GreenFlag.</p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input checked="" type="checkbox"/></p> <p>Low <input type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>

<p>Lone working: Give contact details and measures in case of emergency</p>	<p>The research involves lone working.</p>	<p>As above, the supervisors will be regularly contacted to ensure safety. The researcher will always have a charged work mobile phone, a Sat-Nav and breakdown cover on their car.</p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>	<p>High <input checked="" type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>
<p>Working with Equipment: Risks associated</p>	<p>N/A</p>		<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input type="checkbox"/></p>
<p>Environmental hazards: e.g. weather, terrain, animals, plants, earthquake, water quality</p>	<p>Weather</p>	<p>Weather conditions may affect driving: high winds. Snow etc. If the researcher feels that this is a risk the visit will be rearranged, particularly where people live in isolated areas where there is a greater risk of being affected by road conditions.</p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p> <p>Low <input checked="" type="checkbox"/></p>
<p>Chemical & Biological Hazards: e.g. laboratory chemicals, crop spraying, diseases</p>	<p>N/A</p>		<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p>	<p>High <input type="checkbox"/></p> <p>Med <input type="checkbox"/></p>

			Low <input type="checkbox"/>	Low <input type="checkbox"/>	Low <input type="checkbox"/>
Manual Handling: e.g. loading and unloading equipment	N/A		High <input type="checkbox"/> Med <input type="checkbox"/> Low <input type="checkbox"/>	High <input type="checkbox"/> Med <input type="checkbox"/> Low <input type="checkbox"/>	High <input type="checkbox"/> Med <input type="checkbox"/> Low <input type="checkbox"/>
Emotional Risks: e.g. Sensitive research	The nature of the research is sensitive-discussing experiences of living with Alzheimer's disease	<p>The researcher has regular experience working with people with dementia and their families, and listening to their experiences of dementia. In terms of support for the researcher, the university supervisors are always available and highly supportive, as well as social support from the Postgraduate Society at the University of Stirling.</p> <p>In terms of all of the participants, they will be made fully aware of the nature of the research and the fact that it will be covering sensitive topics. The researcher will be sensitive to the participant's situation at all time, with visits being allocated additional time for general conversation, as well as going at the pace</p>	High <input type="checkbox"/> Med <input checked="" type="checkbox"/> Low <input type="checkbox"/>	High <input type="checkbox"/> Med <input checked="" type="checkbox"/> Low <input type="checkbox"/>	High <input type="checkbox"/> Med <input checked="" type="checkbox"/> Low <input type="checkbox"/>

		of the participants, so they feel they can pause or stop at any time.			
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Legal compliance: Are there any specific standards relevant to the research activities?	Informed consent will be obtained from all participants, and this will be continually monitored across visits. People who do not have the capacity to consent will not be included in the research. People who lose their capacity during the study will not continue in the study- data collected so far will be kept unless they have not consented to this initially.
Training: Has special training been given for fieldwork activities in relation to safety?	The researcher is working as a Clinical Studies Officer for the Scottish Dementia Clinical Researcher Network; this role involves regular visits to the homes of people with dementia and their families. This involves lone working, in potentially isolated areas and areas of high risk. As will be done for the research study, a phone is used with emergency contacts, and the researcher will use their own car which has insurance and breakdown cover.
Supervision: What level of supervision is required, and are there sufficient supervisors for research?	The PhD supervisors, Professor Alison Bowes and Dr Fiona Kelly will be regularly involved throughout the fieldwork in keeping in touch with the researcher and being updated on progress. Both of the supervisors have experience with similar research projects and working with the target population.
Medical conditions/allergies: This information is to be kept confidential.	<i>Participants are asked to make a declaration that they are not knowingly in a condition that could compromise their health and safety (or the safety of others) during the proposed research activities</i>
First Aid: Will a First Aid box be available? If research involves a group, name the First Aider(s)	The researcher is not first aid trained, any injury that cannot be self-managed will be reported to supervisors or appropriate services. If the researcher is injured in any way they will seek appropriate action.
Disabled persons: Detail any special arrangements required	The researcher will be aware of any arrangements based on the information for each participant collected on the Scottish Dementia Clinical Research Network Register, where participants will be recruited from.

<p>Insurance: Are all activities covered by University insurance? Provide confirmation that this has been checked and approved.</p> <p>Give details of any additional personal insurance.</p>	<p>Attached is confirmation of University Insurance, contact Daniela Bolle.</p>
--	---

Risk assessment: Overall **LOW** **MEDIUM** **HIGH**

Safe system of work procedure (to be completed by research team on basis of above information. Continue on separate sheet if necessary)

Safety System: The researcher will complete a risk assessment and review this with the PhD supervisors. Following on from this, the steps given throughout the assessment will be implemented for each participant visit- getting the address and directions; making supervisors aware of where the researcher will be; maintaining awareness of the areas that will be visited and the weather conditions etc. Throughout the study, the researcher will keep a work phone on them, and be contactable at all times.

Throughout the study, the researcher will maintain contact with supervisors and support network of friends for wellbeing. If at any point the researcher feels the situation has changed/become a higher risk/or is having adverse effects, the supervisors will be contacted.

The safety of participants will be maintained at all times, through following the set out guidelines above, as well as this, NHS ethical approval is being sought for the study before it begins; this ensures that the researcher will act in the best interests of the participants, and that possible ethical considerations have been dealt with and acting on accordingly. The researcher will be continually aware of the health and wellbeing of the participants and any concerns for their safety will be raised with the supervisors (as outlined in participant consent forms).

Date:.....13/11/13.....

Agreed date for review...NHS Ethical Review 20th November.....

Appendix 3- SDCRN Research Register figures

Area	Gender	Number of people with early-onset Alzheimer's disease	Number of people with late-onset Alzheimer's disease	People with other types of dementia	Total	Percentage of males and females on the register /%
Register	Male	50	235	342	627	58.60
	Female	39	240	164	443	41.40
		89	475	506	1070	
Forth Valley	Male	1	9	16	26	72.22
	Female	0	3	7	10	27.78
		1	12	23	36	
Tayside	Male	6	58	41	105	51.98
	Female	6	64	27	97	48.02
		12	122	68	202	
Grampian	Male	8	17	26	51	41.46
	Female	11	25	36	72	58.54
		19	42	62	123	
Lothian	Male	11	35	46	92	48.17
	Female	4	56	39	99	51.83
		15	91	85	191	
Glasgow	Male	6	25	20	51	62.20
	Female	2	20	9	31	37.80
		8	45	29	82	

The number of people on the SDCRN research register based on 2014 figures. Numbers are presented by age of onset, type of dementia, gender, and health board.

Appendix 4a- Adapted Stigma Impact Scale- People with Alzheimer's disease**Stigma Impact Scale**

DIRECTIONS: Alzheimer's disease can affect many areas of a person's life. Please tick the response for each item that best describes your recent experiences (within the past 3 to 4 weeks).

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
1	I have experienced financial hardship that has affected how I feel about myself					
2	My job security has been affected by my condition					
3	My employer/co-workers have discriminated against me					
4	I have experienced financial hardship that has affected my relationship with others					
5	Some people act as though I am less competent than usual					
6	I feel I have been treated with less respect than usual by others					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
7	I feel set apart from others who are well					
8	I feel others are concerned they could “catch” Alzheimer’s disease through contact like a handshake or eating food I prepare					
9	I feel others avoid me because of my condition					
10	Some <u>family members</u> have rejected me because of my condition					
11	I feel others think I am to blame for my condition					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
12	I do not feel I can be open with others about my condition					
13	I fear someone telling others about my condition without my permission					
14	I feel I need to keep my condition a secret					
15	I feel some friends have rejected me because of my condition					
16	I have a greater need than usual for reassurance that others care about me					
17	I feel lonely more often than usual					
18	Due to my condition I have a sense of being unequal in my relationship with others					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
19	I feel I am at least partially to blame for my condition					
20	I feel less competent than I did before my condition					
21	I encounter embarrassing situations as a result of my condition					
22	Due to my condition others seem to feel awkward and tense why they are around me					
23	Due to my condition, I sometimes feel useless					
24	Changes in my appearance have affected my social relationships					

Appendix 4b- Adapted Stigma Impact Scale- Supporters**Stigma Impact Scale**

DIRECTIONS: Alzheimer's disease can affect many areas of a person's life. Please tick the response that best describes your recent experiences (within the past 3 to 4 weeks) in relation to the person you support with Alzheimer's disease.

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
1	I have experienced financial hardship that has affected how I feel about myself					
2	My job security has been affected by my family member's condition					
3	My employer/co-workers have discriminated against me					
4	I have experienced financial hardship that has affected my relationship with others					
5	I feel I have been treated with less respect than usual by others					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
6	I feel set apart from others whose family members are well					
7	I feel others are concerned they could “catch” Alzheimer’s disease through contact like a handshake or eating food I prepare					
8	I feel others avoid me because of my family member’s condition					
9	Some <u>family members</u> have rejected me because of my contact with my family member with Alzheimer’s disease					
10	I feel others think I am to blame for my family member’s condition					
11	I do not feel I can be open with others about my family member’s condition					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
12	I fear someone telling others about my family member's condition without my permission					
13	I feel I need to keep my family member's condition a secret					
14	I feel some friends have rejected me because of my family member's condition					
15	I have a greater need than usual for reassurance that others care about me					
16	I feel lonely more often than usual					
17	Due to my family member's condition I have a sense of being unequal in my relationship with others					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
18	I feel I am at least partially to blame for my family members condition					
19	I feel less competent than I did before my family member's condition					
20	I encounter embarrassing situations as a result of my family member's condition					
21	Due to my family member's condition others seem to feel awkward and tense why they are around me					
22	Some people act as though I am less competent than usual					

		NOT APPLICABLE	STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE
23	Due to my family member's condition, I sometimes feel useless					
24	Changes in the appearance of my family member with Alzheimer's disease have affected my social relationships					

Appendix 4c-Questions and Score Ranges for Subcategories of the Stigma Impact Scale

Subcategory of Stigma Impact Scale	Number of items within subcategory	Range of possible scores for each subcategory
Social Rejection	9	0-36
<p>My employer/ co-workers have discriminated against me.</p> <p>Some people act as though I am less competent than usual.</p> <p>I feel I have been treated with less respect than usual by others.</p> <p>I feel others are concerned they could “catch” my condition through contact like a handshake or eating food I prepare.</p> <p>I feel others avoid me because of my condition.</p> <p>Some family members have rejected my because of my condition.</p> <p>I feel some friends have rejected me because of my condition.</p> <p>I encounter embarrassing situations as a result of my condition.</p> <p>Due to my illness others seem to feel awkward and tense when they are around me.</p>		
Financial Insecurity	3	0-12
<p>I have experienced financial hardship that has affected how I feel about myself.</p> <p>My job security has been affected by my condition.</p> <p>I have experienced financial hardship that has affected my relationship with others.</p>		
Internalised Shame	5	0-20
<p>I feel others think I am to blame for my condition.</p> <p>I do not feel I can be open with others about my condition.</p> <p>I fear someone telling others about my condition without my permission.</p> <p>I feel I need to keep my condition a secret.</p> <p>I feel I am at least partially to blame for my condition.</p>		

Subcategory of Stigma Impact Scale	Number of items within subcategory	Range of possible scores for each subcategory
Social Isolation	7	0-28
<p>I feel set apart from others who are well.</p> <p>I have a greater need than usual for reassurance that others care about me.</p> <p>I feel lonely more often than usual.</p> <p>Due to my condition, I have a sense of being unequal in my relationships with others.</p> <p>I feel less competent than I did before my condition.</p> <p>Due to my condition, I sometimes feel useless.</p> <p>Changes in my appearance have affected my social relationships.</p>		
Total	24	0-96



Interview Topics

Below is a list of some of the things we will be talking about in the interviews. You are welcome throughout the interview to bring up anything you feel is important to you or your experiences of Alzheimer's disease. If at any point you feel uncomfortable or would like to stop the interview, please do say. The interview can also be stopped and restarted at another time if you wish.

- Experience of living with Alzheimer's disease
- Reactions of Family and Friends to Diagnosis
- Amount and type of information received about Alzheimer's disease
- Use of Support services
- Feelings of control
- Advance Care Planning
- Thoughts about the future
- Hopes and Fears

Appendix 6- Interview Schedule



**UNIVERSITY OF
STIRLING**



Interview

- Experience of living with Alzheimer's disease
 - Has your life changed?
 - If so, can you explain how?
 - What challenges do you face?
 - How do you feel about Alzheimer's disease?
- Reactions of Family and Friends to Diagnosis
 - Have your relationships changed?
 - In what way have they changed? If they haven't changed, what do you think is the reason for this?
 - How do you feel about others' reactions to yourself and/or your diagnosis of Alzheimer's disease?
- Amount and type of information received about Alzheimer's disease
 - Have you received information about Alzheimer's disease?
 - What sources of information have you used?
 - What type of information has been most useful?
 - Is there information that you would like but haven't received?
- Use of Support services
 - Do you currently use any support services?
 - Which ones?
 - What made you chose/discount particular services?

- How do you feel about receiving these services?
- Feelings of control
 - How do you feel about managing Alzheimer's disease?
 - What kind of support or help have you received to help you manage Alzheimer's disease?
 - Has this been useful? Could you explain why/why not?
- Advance Care Planning
 - Have you been involved in ACP?
 - Have you thought about future care?
 - Is ACP something you would like to do?
- Thoughts about the future
 - How do you view the future with Alzheimer's disease
 - Do you have future goals?
 - Have your thoughts about the future changed since having Alzheimer's disease
 - What helps/hinders you looking to the future?
- Hopes and Fears
 - Do you have any particular hopes and fears about Alzheimer's disease and the future?
 - What factors influence your thoughts about the future with Alzheimer's disease?
- Any other thoughts?

30/08/2015

Appendix 7- Initial contact letter



**UNIVERSITY OF
STIRLING**



Participant Name
Participant Address

Date

Dear _____

Involvement in a research study

I am writing to invite you to be included in a research study. The Scottish Dementia Clinical Research Network have given permission for you to be contacted, as the information you provided for the research register suggests you are eligible for this study. The study has ethical approval through the NHS ethics committee.

The study is looking into people's experiences of Alzheimer's disease, and looking to the future. It will involve completing a selection of questionnaires, and possibly an interview.

If you are interested in receiving more information or taking part, please get in touch using either the telephone numbers provided below or by filling in the response slip and sending it back in the stamped address envelope provided.

Many thanks for your time,

Yours sincerely

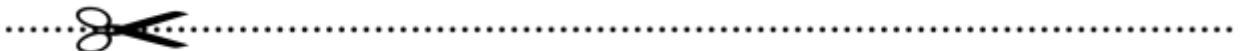
Rosalie Ashworth

Postgraduate Researcher- University of Stirling
Clinical Studies Officer- SDCRN

Email: rosalie.ashworth@stir.ac.uk

Tel: 01786 467728

Mob: 07816067066



Name: _____

I would like to be contacted with further information about this study.

If you have a preference over how best to contact you or the most suitable time to contact you please write in the space below:



Experiences of Alzheimer's disease: Looking to the future.

The purpose of the study

The purpose of the study is to look at people's experiences with Alzheimer's disease, and the possible consequences of the condition. The study aims to understand more about the effect of Alzheimer's disease on your life, and to help people affected by Alzheimer's disease have their voices heard.

The study has two core aims:

1. To explore how people with Alzheimer's disease and their supporters experience living with the condition
2. To explore how people with Alzheimer's disease and their supporters look to the future

Why have you been contacted?

The study is looking to learn more from people who have been diagnosed with Alzheimer's disease, and supporters of people with Alzheimer's disease. You have been identified as someone who may be eligible to take part in this study, if you wish.

Do I have to take part?

No, taking part in this study is completely voluntary.

If you choose to take part in this study you will be asked to sign a consent form to show you have given your permission to be involved. Your GP will be notified that you are taking part in a study.

What will I be asked to do?

- You will be asked to complete three questionnaires with the researcher, asking about yourself and your experience of Alzheimer's disease.
- Some people will be invited to take part in an interview. You will be asked whether you would like to take part in this.
- The interview would be with the researcher, and you will be asked about your experiences of Alzheimer's disease and your views about the future.
 - This interview can be done with your supporter or on your own
 - This interview can be done within your home or at the University of Stirling.
 - The interview will take place over one to three visits to make sure that you do not have to talk for too long at any one meeting.
 - All interviews will be audio recorded

What if I agree to take part, and change my mind?

If at any time during the study you wish to stop taking part, or you are unable to continue, all of the information collected about you up to that point will be retained unless you opt out of this on the consent form, in which case all information up to that point will be removed and destroyed. Withdrawing from the study will not affect your care or access to services in any way.

You can withdraw from the study, by asking the researcher to stop the study; or by contacting one of the other contacts linked to the research, as shown at the end of this document.

What will happen to information I give?

All information collected as part of the study will remain confidential. When the information is written up, your answers will not be identifiable: you will be given a pseudo-name. All

information will be kept securely at the University of Stirling, in a locked cabinet; audiotaped recordings will be stored in a password protected file, on a password protected computer to which only the researcher will have access.

If the researcher is concerned that you may harm yourself or others, confidentiality will need to be broken, the researcher will inform and the study supervisors, Professor Alison Bowes, and Dr Fiona Kelly, of the concerns; your GP will also be contacted. This means they will be able to contact you to check on your safety and wellbeing.

What will happen to the results of the study?

The results of the study will be written up as part of a PhD thesis at the University of Stirling. You will not be personally identifiable in any of the write up. The results may also be presented at conferences, as well as published in an academic journal. A summary of results will also be available for you if you would like to have a copy.

What is there is a problem during the study?

If you have any concerns at any point during the study, you can talk to the researcher who will do their best to answer any problems you may have. A list of other possible contacts has also been provided.

Who is funding this research?

The research is being funding by the University of Stirling, and the Scottish Dementia Clinical Research Network (SDCRN). It is being funded as part of a PhD at the University of Stirling.

Thank you for reading this information sheet. Contact details for all those involved in the study are provided on the next page.

Contact Details

Rosalie Ashworth



PhD Student (University of Stirling) and Clinical Studies
Officer (SDCRN)

Email: rosalie.ashworth@stir.ac.uk

Tel: 01786 467728

Mob: 07816067066

Address: Room 3S29, School of Applied Social Sciences,
Colin Bell Building, University of Stirling, Stirling. FK9 4LA

Professor Alison Bowes



PhD Supervisor

Head of School of Applied Social Sciences

Email: a.m.bowes@stir.ac.uk

Tel: 01786 467709

Dr Fiona Kelly



PhD Supervisor

Lecturer in Dementia Studies

Email: fiona.kelly@stir.ac.uk

Tel: 01786 466322

Emma Law



SDCRN Manager

Email: emma.law@nhs.net

Tel: 01738 562322



Experiences of Alzheimer's disease: Looking to the future.

The purpose of the study

The purpose of the study is to look at people's experiences with Alzheimer's disease, and the possible consequences of the condition. The study aims to understand more about the effect of Alzheimer's disease on your life, and to help people affected by Alzheimer's disease have their voices heard.

The study has two core aims:

3. To explore how people with Alzheimer's disease and their supporters experience living with the condition
4. To explore how people with Alzheimer's disease and their supporters look to the future

Why have you been contacted?

The study is looking to learn more from people who have been diagnosed with Alzheimer's disease, and supporters of people with Alzheimer's disease. You have been identified as someone who may be eligible to take part in this study, if you wish.

Do I have to take part?

No, taking part in this study is completely voluntary.

If you choose to take part in this study you will be asked to sign a consent form to show you have given your permission to be involved.

What will I be asked to do?

- You will be asked to complete five questionnaires about yourself and the person you support.
- Some people will be invited to take part in an interview. You will be asked whether you would like to take part in this.
- The interview is about your experiences of Alzheimer's disease and your views about the future.
 - This interview can be done on your own or with the person you support
 - This interview can be done within your home or at the University of Stirling.
 - The interview will take place over one to three visits to make sure that you do not have to talk for too long at any one meeting.
 - All interviews will be audio recorded

What if I agree to take part, and change my mind?

If at any time during the study you wish to stop taking part, all of the information collected about you up to that point will be retained unless you opt out of this on the consent form, in which case all information up to that point will be removed and destroyed. Withdrawing from the study will not affect your care or access to services in any way.

You can withdraw from the study, by asking the researcher to stop the study; or by contacting one of the other contacts linked to the research, as shown at the end of this document.

What will happen to information I give?

All information collected as part of the study will remain confidential. When the information is written up, your answers will not be identifiable: you will be given a pseudo-name. All information will be kept securely at the University of Stirling, in a locked cabinet; audiotaped recordings will be stored in a

password protected file, on a password protected computer to which only the researcher will have access.

If the researcher is concerned that you may harm yourself or others, confidentiality will need to be broken, the researcher will inform and the study supervisors, Professor Alison Bowes, and Dr Fiona Kelly, of the concerns; your GP may also be contacted. This means they will be able to contact you to check on your safety and wellbeing.

What will happen to the results of the study?

The results of the study will be written up as part of a PhD thesis at the University of Stirling. You will not be personally identifiable in any of the write up. The results may also be presented at conferences, as well as published in an academic journal. A summary of results will also be available for you if you would like to have a copy.

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If you have any concerns at any point during the study, you can talk to the researcher who will do their best to answer any problems you may have. A list of other possible contacts has also been provided.

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Thank you for reading this information sheet. Contact details for all those involved in the study are provided on the next page.

Contact Details

Rosalie Ashworth



PhD Student (University of Stirling) and Clinical Studies
Officer (SDCRN)

Email: rosalie.ashworth@stir.ac.uk

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Professor Alison Bowes



PhD Supervisor

Head of School of Applied Social Sciences

Email: a.m.bowes@stir.ac.uk

Tel: 01786 467709

Dr Fiona Kelly



PhD Supervisor

Lecturer in Dementia Studies

Email: fiona.kelly@stir.ac.uk

Tel: 01786 466322

Emma Law



SDCRN Manager

Email: emma.law@nhs.net

Tel: 01738 562322



Consent Form

Title of project: Experiences of Alzheimer's disease:
Looking to the future.

Researcher: Rosalie Ashworth, University of Stirling / SDCRN

Please Initial Box

1. I have read and understood the information sheet dated November, 2013 (version 2) for the above study. I have had the opportunity to consider the, information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that the relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Stirling, from regulatory authorities or from the NHSTrust, where it is relevant to my taking part in this research, I give permission for these individuals to have access to my records.

4. I agree to my GP being informed of my participation in the study

5. I agree that interviews can be audio-recorded

6. I understand that all information about me will be confidential and kept securely. My answers will be anonymised and not be identifiable to others

7. I agree to take part in the above study

Name

Date

Signature

Name of Person
taking consent

Date

Signature



Debrief Letter

Experiences of Alzheimer's disease: Looking to the future.

Thank You

Thank you for taking the time to take part in this study on the experience and consequences of stigma on your life.

The study is looking at experiences of Alzheimer's disease, for people of various ages, and whether their experiences affect how they plan for the future. At the heart of the study is making sure that people with Alzheimer's disease and their supporters have their voices heard. By being part of this study, you have helped to do this.

A summary of the results will be sent to you when the study is complete.

If you have any questions, please get in touch on the below contact details:

Rosalie Ashworth



PhD Student (University of Stirling) and Clinical Studies Officer (SDCRN)

Email: rosalie.ashworth@stir.ac.uk

Telephone: 01786 467728

Mobile: 07816067066

Address: Room 3S29, School of Applied Social Science, Colin Bell Building, University of Stirling, Stirling FK9 4LA

Appendix 11- Useful Contacts

Useful Contacts

Below is a list of possible information sources should you want to get more general information or advice about living with Alzheimer's disease.

- **Your local GP**
- **The Scottish Dementia Clinical Research Network**
 - www.sdcrn.org.uk
 - 01738 562322



- **Alzheimer's Scotland**
 - Alzheimer Scotland
22 Drumsheugh gardens
Edinburgh
EH3 7RN
 - Tel: 0131 243 1453
 - Email: info@alzscot.org



- **DSDC, Stirling**
 - Dementia Services Development Centre
Iris Murdoch Building
University of Stirling
Stirling
FK9 4LA
Scotland
 - Tel 01786 467740
 - Fax 01786 466846



30/08/2015

Appendix 12- Summary of results



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STIRLING



Dear _____

Experiences of Alzheimer's disease: Looking to the Future

Thank you once again for taking part in the research study conducted by myself last year. The stories you shared and the time generously given was incredibly helpful in allowing me to understand your experiences better, and hopefully the experiences of others in similar situations.

I have included a summary of the results for your interest. The results are currently being written up as part of the PhD thesis, with the intention of publishing the results as soon as possible so that other people will have the opportunity to learn from what you have shared.

If you have any questions about the study or its findings please feel free to get in touch.

It was lovely to meet you, and I am very grateful that you shared your experiences for this research.

Yours sincerely,

Rosalie Ashworth.



Postgraduate Researcher- University of Stirling

Clinical Studies Officer- SDCRN

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Tel: 01786 467728 / Mob: 07816067066.

Summary of Results

Living with Alzheimer's disease involves a range of experiences for both the person with the condition and their supporter (often referred to as a carer). The study focused on two main topics: Stigma and Looking to the Future.

Stigma refers to the negative attitudes of others relating to Alzheimer's disease. This was explored and compared between people with early and late-onset Alzheimer's disease and their supporters. The study went on to look at whether negative attitudes about what it is like to have Alzheimer's disease influenced how people look to the future.

All participants took part in questionnaires about their experiences, and a selection of people went on to be interviewed, where experiences were discussed in more depth. In particular interviews considered examples of how others have responded to the diagnosis of Alzheimer's disease, and explored how people view the future.

The results from the questionnaires suggested that people with Alzheimer's disease have experienced more negative attitudes towards their condition than supporters. Participants discussed that people's reactions could be unpredictable, with examples of friends, family members, health care professionals, and the general public treating them differently. Although all participants highlighted that they had experienced a mixture of both positive and negative experiences.

Although there were some differences in everyday lives for people with early and late-onset Alzheimer's disease, there were many similarities in the way people managed the condition and chose to deal with the reactions of others. People discussed how it was important to focus on the people who had supported them, and to not dwell on those who had reacted negatively.

Despite the negative experiences shared, people often saw themselves as the 'lucky ones' and thought about how their situation could be worse. People chose to focus as much as possible on what they could still do, staying positive, and trying not to think too far ahead. People tried to think about one day at a time, as the future is very hard to predict or control and many different things could happen. Therefore, thinking too much about possible changes was not helpful so changes in circumstances were dealt with as they arose.

The findings of this study suggest that greater support is needed to help people plan for the future, if that is what they wish to do. This support should reflect the unique nature of living with Alzheimer's disease, and personal preferences for how much information people want to take on board.

Appendix 13- Summary of codes

Initial Codes

Interview Schedule codes-

- Family Relationship changes
- Friend Relationship changes
- Public perception of AD
- Reaction to diagnosis
- Information received
- Support services
- ACP
- Changing futures
- Hopes
- Fears
- Coping

Additional codes following interviews and transcription

- Day-at-a-time approach
- Planning
- Comparison with others situations
- Unique experience
- Decision making
- Capability vs Inability
- Holidays
- Positive experiences of Healthcare
- Negative experiences of Healthcare
- Media
- Research
- Identity
- Role change
- Supporter and People with Alzheimer's disease relationship
- Terminology

NVivo Codes

Themes

Name	Sources	References
ACP	13	45
activities	10	41
Adaptation	8	32
Age stereotypes	6	35
avoidance	11	24
Awareness	13	49
Capability	8	29
Care	2	5
Care home stigma	6	15
Change	13	74
Changing futures	14	54
Choice	3	5
Church	4	7
Comparisons	12	71
Confidence	5	18
Continuing normally	9	40
Control	7	22
Coping	14	161
Day-at-a-time	10	23
Decision making	6	22
Denial	7	10
dependence	5	9
diagnosis	7	25
embarrassment	2	2
Empowering	3	9
failure	6	11
Familiarity	1	1
Family relationships	14	48
Fears	13	58
Finances	2	19
Friend Relationships	12	34
frustration	13	99
gender	1	6
guilt	1	3
Healthcare experiences	2	2
Helping others	6	17
Holidays	10	22
Hopes	8	16
Identity	14	96
Inconsistency	5	10

Name	Sources	References
Independent	10	26
Information	14	53
Invisible illness	1	4
Isolation	8	17
Label	2	9
Lifespan	5	9
Looking to Future	13	133
Loss	11	72
Media	7	11
Medication	6	7
normalise or validate experience	3	4
Occupation	4	20
Openness	4	12
Other Health	2	4
Planning	14	70
Pre-diagnosis	10	23
previous experience	9	31
Public Perceptions	8	29
PWD-S relationship	13	59
Reactions to Diagnosis	7	25
Regret	1	4
relentless	1	2
Research	6	25
Responsibility	8	38
Role Change	9	39
Routine	7	19
social support	12	38
Stigma	9	34
Support	14	38
Support services	14	126
Supporter health	4	10
Terminology	13	27
Time for self	9	26
Token Gestures	1	1
transition	2	16
Trapped	1	2
uncertainty	7	14
Unique	7	26
Unpredictable	11	42

Appendix 14- SPSS Outputs

Discriminant Analysis of Sampled Population- People with late-onset Alzheimer’s disease

Analysis Case Processing Summary

Unweighted Cases		N	Percent
Valid		111	92.5
Excluded	Missing or out-of-range group codes	0	.0
	At least one missing discriminating variable	9	7.5
	Both missing or out-of-range group codes and at least one missing discriminating variable	0	.0
	Total	9	7.5
Total		120	100.0

Group Statistics

		Valid N (listwise)	
		Unweighted	Weighted
Contacted			
YES	Age	77	77.000
	SIMD	77	77.000
	Time_diagnosis	77	77.000
	MMSE	77	77.000
NO	Age	34	34.000
	SIMD	34	34.000
	Time_diagnosis	34	34.000
	MMSE	34	34.000
Total	Age	111	111.000
	SIMD	111	111.000
	Time_diagnosis	111	111.000
	MMSE	111	111.000

Eigenvalues

Function	Eigenvalue	% of Variance	Cumulative %	Canonical Correlation
1	.085 ^a	100.0	100.0	.280

a. First 1 canonical discriminant functions were used in the analysis.

Wilks' Lambda

Test of Function(s)	Wilks' Lambda	Chi-square	df	Sig.
1	.921	8.767	4	.067

Discriminant Analysis of People with late-onset Alzheimer's disease who completed questionnaires

Group Statistics

Interviewed		Mean	Std. Deviation	Valid N (listwise)	
				Unweighted	Weighted
yes	SIMD	7.6250	2.38672	8	8.000
	Time_diagnosis	6.7500	2.31455	8	8.000
	Age	80.0000	5.65685	8	8.000
	Gender	1.5000	.53452	8	8.000
	SIS	38.8750	4.42194	8	8.000
	DEMQOL	100.8750	10.73629	8	8.000
	MFS	13.0000	10.71714	8	8.000
	MFSD	24.2500	15.78200	8	8.000
no	SIMD	7.2857	2.49762	7	7.000
	Time_diagnosis	4.4286	3.40867	7	7.000
	Age	84.2857	4.75094	7	7.000
	Gender	1.2857	.48795	7	7.000
	SIS	38.2857	3.35233	7	7.000
	DEMQOL	96.1429	8.21439	7	7.000
	MFS	13.5714	16.81128	7	7.000
	MFSD	19.7143	7.13476	7	7.000
Total	SIMD	7.4667	2.35635	15	15.000
	Time_diagnosis	5.6667	3.01583	15	15.000
	Age	82.0000	5.52914	15	15.000
	Gender	1.4000	.50709	15	15.000
	SIS	38.6000	3.83219	15	15.000
	DEMQOL	98.6667	9.61893	15	15.000
	MFS	13.2667	13.36556	15	15.000
	MFSD	22.1333	12.32226	15	15.000

Eigenvalues

Function	Eigenvalue	% of Variance	Cumulative %	Canonical Correlation
1	.910 ^a	100.0	100.0	.690

a. First 1 canonical discriminant functions were used in the analysis.

Wilks' Lambda

Test of Function(s)	Wilks' Lambda	Chi-square	df	Sig.
1	.524	5.822	8	.667

Discriminant Analysis of Supporters of people with late-onset Alzheimer's disease who completed both questionnaires and interviews

Group Statistics

Interviewed		Mean	Std. Deviation	Valid N (listwise)	
				Unweighted	Weighted
yes	Age	67.8750	11.12831	8	8.000
	SIMD	8.2500	1.98206	8	8.000
	Time_diagnosis	6.7500	2.31455	8	8.000
	Gender	1.6250	.51755	8	8.000
	SIS	26.0000	19.13113	8	8.000
	MFSS	37.2500	11.37353	8	8.000
	MFSD	24.2500	15.78200	8	8.000
	Zarit	16.6250	5.09727	8	8.000
	BADL	24.2500	10.41633	8	8.000
	no	Age	78.1429	7.60326	7
SIMD		7.2857	2.49762	7	7.000
Time_diagnosis		4.4286	3.40867	7	7.000
Gender		1.7143	.48795	7	7.000
SIS		27.2857	7.84675	7	7.000
MFSS		27.2857	7.84675	7	7.000
MFSD		19.7143	7.13476	7	7.000
Zarit		15.5714	10.90653	7	7.000
BADL		25.2857	12.20265	7	7.000
Total		Age	72.6667	10.71492	15
	SIMD	7.8000	2.21037	15	15.000
	Time_diagnosis	5.6667	3.01583	15	15.000
	Gender	1.6667	.48795	15	15.000
	SIS	26.6000	14.48546	15	15.000

MFSS	32.6000	10.84172	15	15.000
MFSD	22.1333	12.32226	15	15.000
Zarit	16.1333	8.01665	15	15.000
BADL	24.7333	10.87899	15	15.000

Eigenvalues

Function	Eigenvalue	% of Variance	Cumulative %	Canonical Correlation
1	3.012 ^a	100.0	100.0	.866

a. First 1 canonical discriminant functions were used in the analysis.

Wilks' Lambda

Test of Function(s)	Wilks' Lambda	Chi-square	df	Sig.
1	.249	11.809	9	.224

Descriptive Statistics- People with Alzheimer's disease (Questionnaires and Interviews)

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
MARSMFS	22	12.00	50.00	30.4091	10.68893
MARSD	22	4.00	50.00	18.7273	11.58892
Age	22	52.00	91.00	76.0455	10.46298
SIMD	22	3.00	10.00	7.2273	2.42864
Time_Diag	22	1.00	11.00	5.0000	3.07060
Gender	22	1.00	2.00	1.2727	.45584
SIS	22	25.00	54.00	38.3636	6.41089
SR	22	8.00	21.00	15.7273	3.67983
FI	22	.00	8.00	1.2727	1.93174
IS	22	5.00	11.00	8.3636	1.89097
SI	22	9.00	20.00	13.0000	2.46885
DEMQOL	22	74.00	110.00	97.7273	11.18324
BADL	22	4.00	54.00	23.8636	12.22525
Valid N (listwise)	22				

Descriptive Statistics- Supporters of people with Alzheimer's disease (Questionnaires and Interviews)

Descriptive Statistics					
	N	Minimum	Maximum	Mean	Std. Deviation
Age	22	47.00	88.00	68.4545	11.38390
SIMD	22	3.00	10.00	7.4545	2.36497
Time_Diag	22	1.00	11.00	5.0000	3.07060
Gender	22	1.00	2.00	1.7727	.42893
SIS	22	.00	58.00	29.4545	15.70177
SR	22	.00	24.00	11.0455	6.21425
FI	22	.00	8.00	1.7273	2.20782
IS	22	.00	14.00	5.9091	3.35104
SI	22	.00	20.00	10.7727	5.89537
Zarit	22	.00	38.00	17.0000	8.72872
MARS_MFS	22	.00	42.00	15.1364	12.15493
MARSD	22	4.00	50.00	18.7273	11.58892
BADL	22	4.00	54.00	23.8636	12.22525
Valid N (listwise)	22				

Discriminant Analysis- People with Alzheimer's disease and their supporters

Category: Person with Alzheimer's disease or Supporter

Variables: Age, SIMD, and Gender

Group Statistics					
PwAD_S		Mean	Std. Deviation	Valid N (listwise)	
				Unweighted	Weighted
PwAD	Age	76.0455	10.46298	22	22.000
	SIMD	7.2273	2.42864	22	22.000
	Gender	1.2727	.45584	22	22.000
Supporter	Age	68.4545	11.38390	22	22.000
	SIMD	7.4545	2.36497	22	22.000
	Gender	1.7727	.42893	22	22.000
Total	Age	72.2500	11.46709	44	44.000
	SIMD	7.3409	2.37176	44	44.000
	Gender	1.5227	.50526	44	44.000

Eigenvalues

Function	Eigenvalue	% of Variance	Cumulative %	Canonical Correlation
1	.426 ^a	100.0	100.0	.547

a. First 1 canonical discriminant functions were used in the analysis.

Wilks' Lambda

Test of Function(s)	Wilks' Lambda	Chi-square	df	Sig.
1	.701	14.372	3	.002

Correlation of Stigma Impact Scores for people with Alzheimer's disease and their supporters

Descriptive Statistics

	Mean	Std. Deviation	N
PwAD_S	1.5000	.50578	44
SIS	33.9091	12.67999	44

		PwAD_S	SIS
PwAD_S	Pearson Correlation	1	-.355*
	Sig. (2-tailed)		.018
	N	44	44
SIS	Pearson Correlation	-.355*	1
	Sig. (2-tailed)	.018	
	N	44	44

*. Correlation is significant at the 0.05 level (2-tailed).

Matched-sample t-test of Stigma Impact Scores for people with Alzheimer's disease and their supporters

Paired Samples Statistics

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	PWAD	38.3636	22	6.41089	1.36681
	S	29.4545	22	15.70177	3.34763

Paired Samples Test

		Paired Differences	t	df	Sig. (2-

	Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference		t	Sig.	tailed)
				Lower	Upper			
				Pair 1 PWAD - S	8.90909			

Independent-sample t-test of Stigma Impact Scores for people with Alzheimer’s disease and their supporters

Group Statistics

	PwAD_S	N	Mean	Std. Deviation	Std. Error Mean
SIS	PwAD	22	38.3636	6.41089	1.36681
	Supporter	22	29.4545	15.70177	3.34763

Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means							
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference		
								Lower	Upper	
SIS	7.898	.007	2.464	42	.018	8.90909	3.61591	1.61190	16.20628	
			2.464	27.812	.020	8.90909	3.61591	1.49999	16.31819	

Analysis of covariance (ANCOVA): Stigma Impact Scale scores of People with Alzheimer’s disease and their supporters

Descriptive Statistics

Dependent Variable: SIS

PwAD_S	Mean	Std. Deviation	N
PwAD	38.3636	6.41089	22

Supporter	29.4545	15.70177	22
Total	33.9091	12.67999	44

Tests of Between-Subjects Effects

Dependent Variable: SIS

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power ^b
Corrected Model	1582.840 ^a	4	395.710	2.895	.034	.229	11.580	.729
Intercept	1525.615	1	1525.615	11.161	.002	.223	11.161	.903
Age	159.248	1	159.248	1.165	.287	.029	1.165	.183
SIMD	300.580	1	300.580	2.199	.146	.053	2.199	.304
Gender	159.800	1	159.800	1.169	.286	.029	1.169	.184
PwAD_S	1157.793	1	1157.793	8.470	.006	.178	8.470	.810
Error	5330.796	39	136.687					
Total	57506.000	44						
Corrected Total	6913.636	43						

a. R Squared = .229 (Adjusted R Squared = .150) b. Computed using alpha = .05

Multiple Regression – People with Alzheimer’s disease

Dependent Variable: Stigma Impact Scale score (SIS)

Variables: Age, Socioeconomic status measured by SIMD decile, Time since diagnosis in years, Quality of Life measured by DEMQOL, Insight (self-report and discrepancy) reported through MARS-MFS, and Activities of daily living measured by BADL score.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
	PwAD_S = PwAD (Selected)			
1	.812 ^a	.659	.450	4.75547

a. Predictors: (Constant), BADL, MARS_D, Gender, SIMD, Age, QOL, Time_Diagnosis, MARS_MFS

ANOVA^{a,b}

Model	Sum of Squares	df	Mean Square	F	Sig.
1 Regression	569.102	8	71.138	3.146	.033^c
Residual	293.989	13	22.615		
Total	863.091	21			

a. Dependent Variable: SIS

b. Selecting only cases for which PwAD_S = PwAD

c. Predictors: (Constant), BADL, MARS_D, Gender, SIMD, Age, QOL, Time_Diagnosis, MARS_MFS

Model		Coefficients ^{a,b}				
		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	68.228	12.862		5.305	.000
	Age	.031	.117	.051	.266	.795
	SIMD	-1.350	.553	-.511	-2.440	.030
	Time_Diagnosis	-.213	.550	-.102	-.387	.705
	Gender	4.305	2.799	.306	1.538	.148
	QOL	-.301	.133	-.526	-2.271	.041
	MARS_MFS	-.032	.166	-.053	-.192	.851
	MARS_D	.153	.145	.276	1.053	.312
	BADL	.028	.139	.054	.203	.842

a. Dependent Variable: SIS b. Selecting only cases for which PwAD_S = PwAD

Independent Samples t-test: Stigma Impact Scale scores (SIS) for people with early and late-onset Alzheimer's disease

Group Statistics					
	EL	N	Mean	Std. Deviation	Std. Error Mean
SIS	Early	7	37.8571	10.44715	3.94865
	Late	15	38.6000	3.83219	.98947

Independent Samples Test										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
SIS	Equal variances assumed	9.756	.005	-.247	20	.807	-.74286	3.00238	-7.00572	5.52001
	Equal variances not assumed			-.182	6.766	.861	-.74286	4.07074	10.43660	8.95088

Independent Samples t-test: Stigma Impact Scale scores (SIS) for supporters of people with early and late-onset Alzheimer’s disease

Group Statistics

	EL	N	Mean	Std. Deviation	Std. Error Mean
SIS_S	Early	7	36.2857	11.87033	4.48656
	Late	15	26.2667	16.58944	4.28338

Independent Samples Test

	Levene's Test for Equality of Variances		t-test for Equality of Means						
	F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper
SIS_S Equal variances assumed	.677	.420	1.428	20	.169	10.01905	7.01576	-4.61558	24.65367
SIS_S Equal variances not assumed			1.615	16.166	.126	10.01905	6.20295	-3.11962	23.15772

Multiple Regression – Supporters

Dependent Variable: Stigma Impact Scale score (SIS)

Variables: Age, Socioeconomic status measured by SIMD decile, Time since diagnosis in years, Quality of Life measured by Zarit Burden Interview, Insight (informant and discrepancy) reported through MARS-MFS, and activities of daily living measured by BADLs.

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
	PwAD_S = Supporter (Selected)			
1	.790 ^a	.625	.394	12.22606

a. Predictors: (Constant), BADL, MARS_D, Age, QOL, SIMD, Gender, Time_Diagnosis, MARS_MFS

ANOVA^{a,b}

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3234.260	8	404.283	2.705	.054^c

Residual	1943.194	13	149.476	
Total	5177.455	21		

a. Dependent Variable: SIS

b. Selecting only cases for which PwAD_S = Supporter

c. Predictors: (Constant), BADL, MARS_D, Age, QOL, SIMD, Gender, Time Diagnosis, MARS_MFS

Coefficients^{a,b}

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	30.122	39.848		.756	.463
	Age	-.350	.298	-.254	-1.178	.260
	SIMD	.520	1.351	.078	.385	.706
	Time Diagnosis	-.759	1.353	-.148	-.561	.584
	Gender	2.572	8.997	.070	.286	.780
	QOL	.920	.366	.512	2.513	.026
	MARS_MFS	-.201	.395	-.156	-.510	.619
	MARS_D	-.228	.330	-.168	-.690	.502
	BADL	.434	.441	.338	.983	.344

a. Dependent Variable: SIS b. Selecting only cases for which PwAD_S = Supporter

Multiple Analysis of Variance (MANOVA): Stigma Impact Scale subcategory scores people with Alzheimer’s disease and their supporters.

Key:

PwAD- Person with Alzheimer’s disease, S= Supporter

SR= Social Rejection, FI= Financial Instability, IS= Internalised Shame, SI= Social Isolation

Multivariate Tests^a

Effect	Value	F	Hypothesis df	Error df	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power ^c
Intercept Pillai's Trace	.899	86.800 ^b	4.000	39.000	.000	.899	347.201	1.000
Wilks' Lambda	.101	86.800 ^b	4.000	39.000	.000	.899	347.201	1.000
Hotelling's Trace	8.903	86.800 ^b	4.000	39.000	.000	.899	347.201	1.000

	Roy's Largest Root	8.903	86.800 ^b	4.000	39.000	.000	.899	347.201	1.000
PwAD_S	Pillai's Trace	.270	3.605 ^b	4.000	39.000	.014	.270	14.421	.830
	Wilks' Lambda	.730	3.605^b	4.000	39.000	.014	.270	14.421	.830
	Hotelling's Trace	.370	3.605 ^b	4.000	39.000	.014	.270	14.421	.830
	Roy's Largest Root	.370	3.605 ^b	4.000	39.000	.014	.270	14.421	.830

a. Design: Intercept + PwAD_S b. Exact statistic c. Computed using alpha = .05

Levene's Test of Equality of Error Variances^a

	F	df1	df2	Sig.
SR	3.264	1	42	.078
FI	1.011	1	42	.320
IS	2.223	1	42	.143
SI	11.210	1	42	.002

Tests the null hypothesis that the error variance of the dependent variable is equal across groups.

a. Design: Intercept + PwAD_S

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power ^e
Corrected Model	SR	241.114 ^a	1	241.114	9.246	.004	.180	9.246	.844
	FI	2.273 ^b	1	2.273	.528	.471	.012	.528	.109
	IS	66.273 ^c	1	66.273	8.953	.005	.176	8.953	.832
	SI	54.568 ^d	1	54.568	2.672	.110	.060	2.672	.359
Intercept	SR	7884.568	1	7884.568	302.334	.000	.878	302.334	1.000
	FI	99.000	1	99.000	23.007	.000	.354	23.007	.997
	IS	2240.818	1	2240.818	302.707	.000	.878	302.707	1.000
	SI	6216.568	1	6216.568	304.356	.000	.879	304.356	1.000
PwAD_S	SR	241.114	1	241.114	9.246	.004	.180	9.246	.844
	FI	2.273	1	2.273	.528	.471	.012	.528	.109
	IS	66.273	1	66.273	8.953	.005	.176	8.953	.832
	SI	54.568	1	54.568	2.672	.110	.060	2.672	.359

Error	SR	1095.318	42	26.079				
	FI	180.727	42	4.303				
	IS	310.909	42	7.403				
	SI	857.864	42	20.425				
Total	SR	9221.000	44					
	FI	282.000	44					
	IS	2618.000	44					
	SI	7129.000	44					
Corrected	SR	1336.432	43					
Total	FI	183.000	43					
	IS	377.182	43					
	SI	912.432	43					

- a. R Squared = .180 (Adjusted R Squared = .161)
- b. R Squared = .012 (Adjusted R Squared = -.011)
- c. R Squared = .176 (Adjusted R Squared = .156)
- d. R Squared = .060 (Adjusted R Squared = .037)
- e. Computed using alpha = .05

ANOVA- Quality of Life scores measured by DEMQOL for people with Alzheimer’s disease across the four subcategories of the Stigma Impact Scale

		ANOVA				
		Sum of Squares	df	Mean Square	F	Sig.
SR	Between Groups	235.864	15	15.724	1.945	.211
	Within Groups	48.500	6	8.083		
	Total	284.364	21			
FI	Between Groups	67.864	15	4.524	2.585	.124
	Within Groups	10.500	6	1.750		
	Total	78.364	21			
IS	Between Groups	68.091	15	4.539	3.891	.051
	Within Groups	7.000	6	1.167		
	Total	75.091	21			
SI	Between Groups	100.500	15	6.700	1.462	.335
	Within Groups	27.500	6	4.583		
	Total	128.000	21			

ANOVA- Socioeconomic status measured by SIMD decile for people with Alzheimer’s disease across the four subcategories of the Stigma Impact Scale

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
SR	Between Groups	81.330	7	11.619	.801	.600
	Within Groups	203.033	14	14.502		
	Total	284.364	21			
FI	Between Groups	58.230	7	8.319	5.784	.003
	Within Groups	20.133	14	1.438		
	Total	78.364	21			
IS	Between Groups	27.424	7	3.918	1.151	.388
	Within Groups	47.667	14	3.405		
	Total	75.091	21			
SI	Between Groups	60.717	7	8.674	1.805	.164
	Within Groups	67.283	14	4.806		
	Total	128.000	21			

ANOVA- Quality of life measured by Zarit Burden Interview-short form for supporters of people with Alzheimer's disease across the four subcategories of the Stigma Impact Scale

ANOVA

		Sum of Squares	df	Mean Square	F	Sig.
SR	Between Groups	748.955	14	53.497	6.040	.012
	Within Groups	62.000	7	8.857		
	Total	810.955	21			
FI	Between Groups	65.864	14	4.705	.902	.590
	Within Groups	36.500	7	5.214		
	Total	102.364	21			
IS	Between Groups	229.152	14	16.368	17.186	.000
	Within Groups	6.667	7	.952		
	Total	235.818	21			
SI	Between Groups	658.197	14	47.014	4.592	.025
	Within Groups	71.667	7	10.238		
	Total	729.864	21			

ANOVA- People with early and late-onset Alzheimer's disease scores across the four subcategories of the Stigma Impact Scale

		ANOVA				
		Sum of Squares	df	Mean Square	F	Sig.
SR	Between Groups	25.773	1	25.773	1.993	.173
	Within Groups	258.590	20	12.930		
	Total	284.364	21			
FI	Between Groups	35.906	1	35.906	16.914	.001
	Within Groups	42.457	20	2.123		
	Total	78.364	21			
IS	Between Groups	15.300	1	15.300	5.118	.035
	Within Groups	59.790	20	2.990		
	Total	75.091	21			
SI	Between Groups	1.886	1	1.886	.299	.591
	Within Groups	126.114	20	6.306		
	Total	128.000	21			

ANOVA- Supporters of people with early and late-onset Alzheimer's disease scores across the four subcategories of the Stigma Impact Scale

		ANOVA				
		Sum of Squares	df	Mean Square	F	Sig.
SR	Between Groups	107.793	1	107.793	3.066	.095
	Within Groups	703.162	20	35.158		
	Total	810.955	21			
FI	Between Groups	20.573	1	20.573	5.031	.036
	Within Groups	81.790	20	4.090		
	Total	102.364	21			
IS	Between Groups	.085	1	.085	.007	.933
	Within Groups	235.733	20	11.787		
	Total	235.818	21			
SI	Between Groups	44.606	1	44.606	1.302	.267
	Within Groups	685.257	20	34.263		
	Total	729.864	21			