

The role of social support networks in the dementia literacy of older adults in Wales

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ABSTRACT

Dementia is a global and national priority although knowledge about it within the general public is low. Raising awareness of dementia has been established as an important area of public health policy. This thesis examined the relationship between general understandings of dementia and influences on attitudes towards risks and lifestyle behaviours, how views are shared, and how interactions with individuals are affected. These relationships are encapsulated within the concept of dementia literacy.

Dementia literacy is a relatively new area of investigation, set within the overarching construct of health literacy. Health literacy concerns the capacities of people to meet the complex demands of health, including promoting health and preventing illness, and is important for individuals and communities.

This study's mixed methods approach examined levels of population health literacy and explored understandings of dementia literacy within the older Welsh population. A health literacy measure was imputed using data from the Cognitive Functioning and Ageing Study Wales, a nationally representative survey of older adults. The measure enabled relationships between health literacy and social factors to be determined. In depth interviews with a subset of participants were conducted to provide a picture of dementia literacy and how it was shared within networks. Data were analysed using a qualitative framework approach.

Findings indicate that levels of health literacy differ by support network type and social participation. Interviews identified imbalanced, fragmentary and distorted dementia knowledge and an aversion to learning more. Negative attitudes towards dementia discouraged engagement in dementia literacy. Participant's social contexts did not facilitate knowing more about dementia, due to a mix of fear, fatalism and stigmatising attitudes. Participants reported that support network members frequently deflected attempts to discuss personal worrisome symptoms. Effective DL strategies must incorporate strategies to address fear, fatalism and stigma.

An enhanced definition and framework of dementia literacy is suggested.

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

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STATEMENT 1

This thesis is the result of my own investigations.

Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

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STATEMENT 2

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1 INTRODUCTION

Population ageing is associated with the increased prevalence of dementia. Age is the single biggest risk factor for dementia, which occurs mainly in people over the age of 65 years (Livingston et al., 2017). There is currently no cure for dementia and if prevalence rates were to remain the same, over one million people in the UK would have dementia by 2025, increasing to two million by 2050 (Prince et al, 2014). The growing numbers of people living with dementia has extensive economic and societal impacts (Wimo et al., 2017). Dementia is the most feared disease among older adults (Alzheimer's Association, 2014). Despite this risk and associated fear, or perhaps because of it, knowledge about dementia is low within the general population, and is, according to some studies, lower in older age groups than younger ones (McParland, Devine, Innes, & Gayle, 2012; Werner, 2003). There is limited research to suggest why this may be the case. The UK in general and Wales in particular face significant challenges with regard to early recognition, timely diagnosis and the best possible management of dementia (Welsh Government, 2018). It has been suggested when taking into account learnings from the health literacy and mental health literacy fields, that good public knowledge of dementia may facilitate engagement in risk reduction opportunities, improved symptom recognition improved condition management and foster greater public debate which may improve attitudes towards dementia and those living with it, (Low & Anstey, 2009; H. Zhang et al., 2017). Elevating knowledge and challenging beliefs about dementia, thus increasing 'dementia literacy', could be a route to such outcomes.

The picture of dementia in the UK

Dementia is a major cause of disability amongst older people and constitutes an on-going challenge with regard to disadvantage and service and support needs for those with the condition and their family and friends (A. Milne, 2010). The cost to the UK economy is estimated at £26 billion a year with the majority of costs (£11.6bn) attributed to informal care (Prince et al; 2014). In his Challenge on Dementia, the then Prime Minister, David Cameron, suggested that there is a moral as well as a financial imperative for improvements in dementia care (Department of Health, 2015). Broad statements underpinning this document included the desire to achieve:

“a society where the public thinks and feels differently about dementia, where there is less fear, stigma and discrimination; and more understanding”.

“Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily.” (Department of Health, 2015 p 4).

This ambition sounds like the achievement of improved population dementia literacy. Strategies to address dementia concerns have become a national priority (Rosow et al., 2011)

The older population in Wales is proportionately larger than any other country in the UK, with rural areas, in particular, having a disproportionate share of older persons with an expected accompanying higher dementia rate (Alzheimer’s Society, 2016). It is estimated that 45,000 people in Wales are living with dementia. However many of these people will be living without a formal diagnosis, as Wales currently has the lowest dementia diagnosis rate in the UK at 53% in 2016/7 (compared to England at 70%, Scotland 67% and Northern Ireland at 73%) (“Diagnoses in the UK | Alzheimer's Research UK”, 2018)

Political imperative and drivers

There are powerful policy motivations behind the management of dementia. Dementia has been described as the greatest challenge for health and social care in the 21st century (Frankish & Horton, 2017; Livingston et al., 2017). Globally there is a political imperative to address the cost of dementia to countries and individuals and families. An estimated 85% of dementia costs are attributed to family and social care, rather than medical care (Livingston et al., 2017). The Global action plan on the public health response to dementia 2017-2025 was adopted by World Health Organisation (WHO) Member States in May 2017 (World Health Organisation, 2017a). The plan includes requirements from signatories (including the UK) for the development of a public health response via public policies, dementia frameworks or strategies, public awareness campaigns, establishment of dementia friendly initiatives, targeting areas of potential risk reduction by addressing modifiable risk factors, increases in the numbers of those diagnosed, recommendations of support

provision for carers of people living with dementia and increases in research and innovation activities. Many countries (including Wales) have adopted national dementia strategies with priorities that include: raising awareness of the disease, combating stigma, providing dementia statistics regarding those affected by the disease, identifying and assessing services required to provide and ensure quality of dementia care (Welsh Government, 2018).

There have been recent political developments and commitments from the Welsh Government:

“Our vision is for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities”. Vaughan Gething, Cabinet Secretary for Health and Social Services, 2018 (Welsh Government, 2018 p3)

This vision includes a reference to the expectations of upholding “rights” for people living with dementia, implicitly acknowledging the current social and psychological obstacles that exclude or restrict full participation in their communities and society in general (Shakespeare, Zeilig, & Mittler, 2017). To achieve the meaningful involvement of people affected by dementia (and go some way towards a rights based approach) assumes an acceptance of the inherent “personhood” (Kitwood, 1997, p. 8) of the individual with dementia and that experiential knowledge - the lived experience of dementia, is valued, sought and incorporated into dementia action planning. This may require dementia literate infrastructures to facilitate this.

Over the last few years in particular there has been progress in achieving the recommended public health responses, as advocated by the World Health Organization (2017a), via a number of dementia initiatives in Wales. This has included, in 2018 the launch of the Dementia Action Plan for Wales: 2018-2022 (Welsh Government, 2018) and a Welsh Government dementia risk reduction campaign - ACT NOW (2017). However earlier research conducted on behalf of the Older People’s Commissioner for Wales (2016) suggested that many older people in Wales did not feel that their full needs for dementia care, support, and information were being met by services or that increased public awareness had translated to a full

understanding of what it was like to live with the condition - raising the issue of what type of knowledge is important. Concerns were also raised about the lack of understanding and knowledge that some health and care professionals had about dementia. Such local findings resonate with the broader discourses about dementia strategies and indeed about dementia literacy. While they have been touted as the single most powerful tool to transform dementia care and support within a country (Chow et al., 2018), evidence to substantiate some of the proposed actions within strategies remains weak.

The current context and why dementia literacy matters

There have been considerable research efforts and knowledge advancements in dementia over recent years in; risk reduction, protective factors, disease aetiology, improved diagnostic abilities and some pharmacological and non-pharmacological treatments (Brayne, Stephan, & Matthews, 2011; Livingston et al., 2017; Shah et al., 2016). A number of studies have suggested the effectiveness of a wide variety of interventions that can support the needs and quality of life of people living with dementia (Woods, Aguirre, Spector, & Orrell, 2012; Young, Camic, & Tischler, 2016) and of carers (Dickinson et al., 2017). However there are gaps in the general public's knowledge in several of these areas (Cahill, Pierce, Werner, Darley, & Bobersky, 2015; Cations, Radisic, Crotty, & Laver, 2018). Many do not recognise symptoms of dementia (Bond et al., 2005), are unaware of potential risk or protective factors (Cations et al., 2018; Friedman et al., 2015), current treatment and management options, are unable to differentiate dementia from normal age related cognitive decline and do not know how best to provide helpful responses to someone with the condition (Cahill et al., 2015; Low & Anstey, 2009). Such gaps in knowledge and misconceptions about dementia exist alongside widespread negative views and stigmatising attitudes towards the condition (McParland et al., 2012; A. Milne, 2010).

Dementia is frequently discussed in the main stream media and has been depicted in recent years by diverse media vehicles (including television, novels, films, newspaper articles, poetry) indicating its social impact and relevance (Peel, 2014; Van Gorp & Vercruyssen, 2012; Zeilig, 2015). The broader cultural framing of dementia heavily influences representations which: "become subconsciously

ingested and inform how we feel about dementia and even how we interact with people with dementia” (Zeilig, 2014, p. 265). The overwhelmingly negative cultural representations of dementia have become a commonly accepted viewpoint (Van Gorp & Vercruyse, 2012). Such opinions may then be reinforced within social networks when confronted by dementia in order to attribute meaning to the issues of concern. Limited alternative perspectives of dementia has powerful implications for the information available to be accessed and understood and attitudes to be formed and shared (McPherson, Smith-Lovin, & Cook, 2001).

What can health literacy contribute to conceptualisations of dementia literacy?

The idea of being literate about dementia comes from a tradition of conceptualising broadly-based literacies about health and more recent condition specific literacies such as with mental health literacy. Health literacy skills including information seeking, decision making, problem solving, critical thinking and communication alongside social personal and cognitive skills are required to meet the complex demands of modern society with respect to staying healthy, reducing risk of disease and managing illness (Van den Broucke, 2014). There is a substantial body of literature documenting the benefits and outcomes of good health literacy (N.D. Berkman et al., 2011; Chesser, Keene Woods, Smothers, & Rogers, 2016). Having good levels of health literacy has been thought of as necessary to improve health outcomes at both the individual and population level (Hernandez, 2013; Kickbusch, Pelikan, Apfel, Tsouros, & World Health Organization, 2013; Kutcher, Wei, & Coniglio, 2016) and is credited with improved abilities in the prevention and management of many chronic diseases (Poureslami, Nimmon, Rootman, & Fitzgerald, 2017). There appear to be increasing expectations of dementia literacy to deliver similar outcomes (Department of Health, 2015, Welsh Government, 2018).

Dementia literacy is a construct related to the overarching concept of health literacy and was adapted directly from the definition of mental health literacy which is focused more on knowledge and resultant actions related to specific mental health conditions (Low & Anstey, 2009). There is limited comparable research on older people’s dementia literacy to that conducted on health and mental health literacy. There are some key differences too, dementias are terminal conditions for which there are no current cures or clinically effective disease-modifying therapies

(Livingston et al., 2017). Whereas an outcome of achieving better health via improving health literacy may be viewed as desirable and potentially achievable, the reasons for and motivation to be dementia literate may not seem so apparent.

There are different theories of how health literacy may develop and is distributed, with potential applicability for dementia literacy. Recent models suggest that health literacy can be enhanced within people's social and support networks over their lifetime (Edwards, Wood, Davies, & Edwards, 2012) with individuals benefitting from past experiences and skills available within their social networks (Edwards et al., 2012; Edwards, Wood, Davies, & Edwards, 2015; S.-Y.D Lee, Arozullah, Cho, Crittenden, & Vicencio, 2009). Social networks may be used to benchmark the appropriateness of attitudes, beliefs and behaviours held, by comparing them with others in their social networks (McPherson et al., 2001; Thoits, 2011). There is evidence that the structure of support networks (e.g. network size, strong or weak ties) may influence social support, such as the provision and explanation of information about health in general (L.F. Berkman, Glass, Brissette, & Seeman, 2000).

Little is known about what being dementia literate means to older people or about what might influence them to become so. Older adults are not a homogenous group. Their health knowledge, experiences, attitudes and health behaviours are likely to have developed differently over their life course (Umberson, Crosnoe, & Reczek, 2010). In order to address current concerns regarding lack of dementia knowledge and persistent conceptualisations solely based on decline and loss, and to take advantage of the potential societal and individual benefits of improving dementia literacy, then it deserves greater scrutiny.

This PhD builds on approaches to conceptualising dementia literacy based on foundational work on health and mental health literacy research and on the limited existing dementia literacy evidence. It seeks to better understand what (and why) knowledge gaps identified in current dementia literacy research exist. It focuses on how older adults within the general population acquire their understandings of dementia and how their social networks impact on these understandings. Attempts at addressing gaps in dementia literacy are likely to be more effective if they are

grounded in an awareness of what people currently understand and believe about dementia. This may aid efforts to address these identified information and other needs. Thus the overall objective for this research was to understand the dementia literacy of older adults in Wales and its influencing factors. It is situated within a broader understanding of the population's health literacy.

Thesis structure

The thesis is structured in four main parts

- Part 1 includes this introduction to the thesis and chapters 2 and 3 which set out, respectively, the framing of dementia and a review of the state of knowledge of dementia literacy as it has emerged from the broader construct of health and other disease specific literacies. It highlights the importance of social contexts.
- Part 2 includes chapters 4 and 5 and covers the overarching methodology and then specific methods employed in this thesis.
- Part 3 includes chapters 6 and 7 which present the integrated results of the empirical analysis.
- Part 4 cover chapters 8, 9 and 10 which are the discussion, recommendations and concluding comments.

2 THE FRAMING OF DEMENTIA LITERACY

Dementia is a contested concept. The conceptualisation of dementia to frame this research will influence assessment of participant's knowledge about dementia. This is an epistemological and ontological issue about what knowledge about which social phenomena is valued. I conducted literature searches on dementia knowledge and dementia literacy as a fundamental part of this study. During this process I identified my 'taken for granted assumptions' about dementia. As part of my reflexive practice as a researcher (Ritchie & Lewis, 2003) I aimed to arrive at a conceptualisation of dementia in which to frame understandings of dementia. In the following section, I review these conceptualisations and articulate how they have informed the approach taken throughout this research.

Conceptualising dementia

Broad models conceptualising dementia include: biomedical, psycho-social and social-gerontological. The latter approach is a relative newcomer to conceptualising dementia which has traditionally (over the last approximately 100 years) been defined in terms of medical and cognitive factors. Evidence that neuropathology alone cannot explain the experience of dementia has encouraged the development of other non-medical perspectives of dementia. More recently disciplinary perspectives such as social psychology and social gerontology have emerged to frame dementia within wider social contexts (Cuijpers & van Lente, 2015; Innes & Manthorpe, 2013). The brief review of these conceptualisations that follows provides a backdrop and rationale for the approach taken in this research.

Medical models

According to the biomedical model, dementia is a condition affecting an individual and is caused by diseases of the brain. Hence it has been considered that the best way to manage the condition is by medical responses (Cuijpers & van Lente, 2015). The World Health Organisation (2017b) definition is illustrative of this model:

'Dementia is a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing. It affects memory, thinking, orientation, comprehension,

calculation, learning capacity, language, and judgment. Consciousness is not affected. The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. Dementia is caused by a variety of diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke.' (WHO, 2017b key facts)

Among the most common forms of dementia are Alzheimer's Disease (AD), vascular dementia, frontotemporal dementia and dementia with Lewy bodies. Numerous subtypes of dementia exist and there are frequently mixed types with unknown aetiologies (Alzheimer's Association, 2016). Dementia has been classified as a 'major neurocognitive disorder' within the Diagnostic and Statistical Manual (DSM-5) (Sachdev et al., 2014). This reclassification has been considered in part as an attempt to help reduce the stigma associated with both the word dementia and the conditions that it refers to (Cations et al., 2018). The syndrome covers a range of difficulties in memory, language and behaviours and leads to progressive impairments causing interference with activities of daily living (ADL) and independence (American Psychiatric Association, 2013). The emphasis on cognitive deficits attributed to underlying neurological pathology appears to threaten individual identity and agency and led to some earlier writers describing this as "loss of their essential personhood" (Sweeting & Gilhooly, 1997, p. 95). The biomedical or medical models have for a considerable time influenced care policy and practice and underpin many dementia strategies (Fortinsky & Downs, 2014).

A feature of biomedical models has been an emphasis on the process of diagnosis and the categorisation of symptoms, an approach that has been criticized for its tendency to reduce individuals to their symptoms or diagnosis (Bosco, Schneider, Coleston-Shields, Higgs, & Orrell, 2019). Even within this medical process, the diagnosis of dementia can be problematic due to its frequently subtle onset and symptoms resembling 'normal ageing' (Brayne, 2007; Robinson, Tang, & Taylor, 2015). As Brayne (2007) notes:

'In every study the same problem occurs, namely deciding where normal ageing stops and dementia starts. Clinical judgement is an empirical case by case phenomenon' (Brayne, 2007, p. 235).

Disputes still exist as to whether different types of dementia are the natural consequence of biological decline or whether they can be framed as terminal diseases, chronic conditions or indeed mental health issues (Bosco et al., 2019). Some have argued that the very process of ageing itself may indeed appear to be pathological as degenerative changes in many organs and systems are common in older age (D.H.J. Davis, 2004). Post mortems have revealed that some older people diagnosed with dementia show no associated neuropathology and conversely some without dementia symptoms show an underlying pathology (Spector & Orrell, 2010), 2010). Common views of dementia, particularly within the general public are that it is a normal part of the ageing process (Cahill et al., 2015).

Such observations highlight the need to consider how symptoms and indeed dementia as a whole is perceived and treated. There are advantages and disadvantages of describing dementia in terms of brain disease. From a clinicians perspective labeling of dementia and its symptoms can provide an efficient way of understanding and conveying large amounts of information related to the aetiology, progression and prognosis of the disease (Garand, Lingler, Conner, & Dew, 2009). Some affected by dementia may also prefer to use the dementia label in order to dismiss fairly widely held views that dementia may, in some way, be related to character flaws (Low & Anstey, 2009). Having an identified disease may also enable individuals and carers make sense of symptoms and to access support and seek treatment (if required). In contrast, a dementia diagnosis is often associated with views of people living with dementia as ‘sufferers’ or as ‘victims’, which can strip people of their dignity and self-esteem and reinforce stereotypes (Shakespeare, Zeilig, & Mittler, 2017; Swaffer, 2014). As such people with dementia are frequently advised to relinquish their “pre-diagnosis life” and consider putting end of life issues in place in what has been termed “prescribed disengagement” (Swaffer, 2015, p. 3). This approach has been described as reductionist. The focus on irrevocable decline due to neurodegenerative changes ignores the impact of social context and interactions with others on one’s sense of self in the maintenance of quality of life (Bartlett & O’Connor, 2007).

A sole focus on the medicalisation of dementia has placed the onus on health services to be responsible for its care (Bosco et al., 2019). The bio medical model of

dementia frames the condition as treatable and even preventable (in the future) given further development in understanding of its aetiology (Manthorpe & Iliffe, 2016). But lack of available and effective disease-modifying options has been cited as one of the reasons clinicians are reluctant to diagnose (Dubois, Padovani, Scheltens, Rossi, & Dell’Agnello, 2015). Positioning dementia as a preventable disease can also place the onus onto a number of parties to take action to reduce risks. In recent years, the UK has seen a shift in responsibility from governments towards individuals via policy documents and public health campaigns (Peel, 2014).

Social-psychological models

Social and cultural contexts influence the way individuals experience dementia and the way the condition is socially constructed in societies (Bosco et al., 2019). Social models focus attention on the experience of those affected by dementia (including care givers) and on strategies for care and support that aid coping with the condition (Innes & Manthorpe, 2013; Spector & Orrell, 2010). Within these models, individuals with dementia are seen as socially integrated and their self-esteem and personhood are emphasised (Dewing, 2008; Gerritsen, Oyebode, & Gove, 2018). A central tenet of many social models is “person-centred dementia care” (PCC), a philosophy pioneered by Kitwood and Bredin (1992). At its core PCC assumes that individuals with dementia have moral worth regardless of the degree of cognitive impairment. Person-centred care is relational, assuming that how others act towards those with dementia “will enhance or diminish that individual’s personhood or standing as an individual” (Downs & Lord, 2017, p. 12). Those who adhere to such models, argue that it is possible to live well with dementia in a community and society with sufficient understanding of the condition that respects differences and attempts to lessen the impact of dementia in everyday life (Bartlett & O’Connor, 2010; Downs & Lord, 2017). An issue with such perspectives is their emphasis on the individual and care at the expense of consideration of the exclusionary physical and social barriers that restrict opportunities for meaningful societal engagement (Beard, Knauss, & Moyer, 2009). Staunch opposition to apparent biomedical reductionism can also mean that any potential benefits of therapeutic medical interventions are overlooked.

In acknowledging some of the strengths of other models (including the medical model), bio-psychosocial models of dementia amalgamating existing models have been proposed (Keady et al., 2013; Spector & Orrell, 2010). An underlying assumption of such models is that biological, psychological, and social factors and their interactions are taken into account in understanding health, illness, and health care delivery. Strengths of the medical model such as prediction of stages of progression are incorporated into a theoretical framework that works to identify ways to improve quality of life and reduce excess disability (Spector & Orrell, 2010).

'Bio-psycho-social perceptions of dementia and disability emphasise the importance of the person without rendering the person individually responsible for his/her condition. Bio-psycho-social perceptions may have an impact on the way that people with dementia are treated, as they acknowledge individuality and personhood' (Gerritsen et al., 2018, p. 3).

Psychosocial models centrally locate the person living with dementia and focus attention on their experiences and achieving their wellbeing, not primarily or solely in terms of their dementia diagnosis (Cuijpers & van Lente, 2015). An example is the growing emphasis on upholding the rights of people living with dementia to citizenship and participation to the extent they wish in community life and in their care (Bartlett & O'Connor, 2007; Shakespeare et al., 2017). Social models have facilitated the direct involvement of people with dementia, their carers and dementia activists in processes around some UK dementia strategies (Innes & Manthorpe, 2013). Dementia statements (Dementia Action Alliance, 2017) developed by people living with dementia and reflecting what is needed to be put in place to ensure quality of life for people with dementia and their carers were used to inform the implementation of the Prime Minister's Challenge on Dementia 2020 and the Dementia Action Plan for Wales (Department of Health, 2015; Welsh Government, 2018). Such perspectives offer insights into the interventions and support that can be offered to people with dementia and their support networks.

Social gerontological models

Social gerontology brings to this conversation the significance of ageing in understanding dementia (Higgs & Gilleard, 2017). Social gerontology has highlighted the place and status of older people in society and in particular structural

inequalities and power imbalances faced by older people in general (C. Phillipson & Baars, 2007) without the potential further disadvantage of having dementia. In the development of gerontological theories, we see a shift from ageing as a period of decline and loss and a problem to be solved (Baltes & Carstensen, 1996), to a “new gerontology” where this decline and loss paradigm is replaced with one that emphasises the possibility for a healthy, engaged older age (Holstein & Minkler, 2003). Yet themes of both conceptual traditions persist. For example, Rowe and Kahn's (1997) successful aging model has been much debated, especially around assumptions that individuals are responsible for their later life success or lack thereof (Hillman & Latimer, 2017; Katz & Calasanti, 2015; McParland, Kelly, & Innes, 2017). Recent articles have brought debate into dementia discourses to the fore, arguing that there are new threats to those with dementia, not merely that they have the condition but they failed to prevent it and were unable to postpone frailty by not managing themselves and their risk better (Latimer, 2018; Peel, 2014). The “double jeopardy” of ageing in combination with dementia has been described as especially stigmatising by Greengross (2014) who considers: “we still have much to understand about why dementia remains outside the realm of acceptable everyday conversation even as the profile of dementia rises” (Foreword. Bamford, Holley-Moore, & Watson, 2014, p.6). Her statement highlights an argument that the lack of open discussion may prevent knowledge diffusion and opportunities for greater understanding of dementia and how it is more broadly viewed.

My framing of dementia

The process of reviewing these conceptualisations of dementia has helped me to clarify my own beliefs. The complexity of dementia ensures that it is not adequately answered by any one model. Dementia is understood differently in alternative social and cultural contexts and over time. There are aspects to each model that I believe can add to our understanding and yet each model appears in opposition to the others, in the attempt to argue their own benefits. ‘Cure’ and ‘care’ have been considered almost as two conflicting strategies with different overarching discourses. Cure defined as medical treatment (aimed at curing), and care as ‘alternative strategies’ providing physical, practical, emotional and spiritual needs (Cuijpers & van Lente, 2015) are not mutually exclusive. Models which incorporate

all the relevant factors need to be explored and indeed the amalgamation of different models has been suggested (Downs, Clare, & Mackenzie, 2006).

The different ways we view dementia frames how we look for responses or solutions to it. Negative and pervasive perceptions that can lead to stigmatizing attitudes and lack of hope are prevalent (Peel, 2014; Zeilig, 2015). I believe more positive conceptualisations and additional representations of dementia are needed to challenge this and need to be at the core of any new models.

Yet these are my views. I realise that if I am to really understand the views of others, I must not truncate the conversations with them. The interviews conducted as part of this research allowed these conversations to expand. Dementia literacy as currently defined and measured includes a scientific knowledge of dementia including that of causes, consequences, risks, symptoms, treatments and prognosis (Low & Anstey, 2009). Analysis of participants' dementia literacy based purely on such criteria (of the biomedical model) could misrepresent what is actually 'known' or understood about dementia. This research therefore reflects the consideration of different possible models and conceptualisations - and combinations (such as those presented above) which can allow alternative views to co-exist.

I think different models will resonate in different circumstances and at different times dependent on status (for example if one has or does not have dementia). Consideration of alternative frameworks can allow an exploration of more complex understandings of dementia, consequences and outcomes than one model could explain. A combination of models, taking into account the context and needs seems a pragmatic approach.

Although I consider dementia a syndrome, as detailed previously, for simplicity the term dementia is used throughout this thesis as an umbrella term that represents a number of diseases affecting the brain. Alzheimer's disease (AD) is by far the most common form of dementia (contributing to 60-70% of all cases) (Alzheimer's Society, 2019). As this appears to be a relatively familiar term both to participants involved in this study and which is represented heavily in the body of literature reviewed the terms Alzheimer's disease and dementia are at times used interchangeably within this document.

3 LITERATURE REVIEW

Introduction

Improving public knowledge and understanding of dementia is considered a precursor to taking action to reduce risk, optimise care and improve the quality of life of those with dementia and their caregivers (World Health Organisation, 2017). Increased population levels of dementia knowledge are seen as a route to counter negative social representations of dementia and stigmatising attitudes (Department of Health, 2015, Welsh Government, 2018). Dementia literacy is a term that encapsulates these goals. Yet despite beliefs about its importance the construct is not well developed. The purpose of this chapter is to review the state of knowledge of broader health and disease specific literacies as a basis for the examination of domains of dementia literacy among the older population in Wales.

Conceptualising health literacy

Health literacy is the term used to broadly convey the skills, abilities and motivation to find, understand, communicate and use information in ways which can promote and maintain good health. Contemporary conceptualisations of health literacy stem from two traditions (Nutbeam, 2008; Sørensen et al., 2012). The first arises from a medical perspective, that considers health literacy as the skills and abilities of a patient to comply with medical advice and care directions to improve health outcomes – to ‘function’ in a health care setting (Baker, 2006; Sudore et al., 2006). The second comes from a social or public health perspective and arises initially from educational research into literacy and concepts of health promotion (Nutbeam, 2008) It includes the motivation and skills to keep well in everyday life and is viewed as an asset allowing greater control over health in its broadest sense (Kickbusch, 2008; Peerson & Saunders, 2009). Both conceptualisations contribute to understanding health literacy in different settings and contexts (Guzys, Kenny, Dickson-Swift, & Threlkeld, 2015).

Within early medical conceptualisation the focus was frequently on an individual’s skills, and their low health literacy was considered a risk factor for poor health (Baker et al., 2002; Sudore et al., 2006). The importance of functional health literacy was cemented by observations that low health literacy was consistently

associated with numerous poor health outcomes (Baker et al., 2007; N.D. Berkman et al., 2004) with up to triple the rates of hospitalisation and emergency care and associated health care costs (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004). Patients with low health literacy have been identified as being less able to understand their disease and symptoms (Gazmararian, Williams, Peel, & Baker, 2003; Williams, Baker, Parker, & Nurss, 1998) and display poorer condition management (Bains & Egede, 2011; Dennison et al., 2011; Heide et al., 2014). A number of studies have demonstrated that lower health literacy is associated with less knowledge about and poorer uptake of preventative and screening opportunities (Bennett, Chen, Soroui, & White, 2009; Cho, Lee, Arozullah, & Crittenden, 2008; Kobayashi & Smith, 2016). This may indicate less understanding of the benefits and potential risk reduction opportunities that these activities allow. An emphasis on the ability to function in health care settings has remained a considerable focus of health literacy research (Baker et al., 2007; Nurss, 2001; Parker, Baker, Williams, & Nurss, 1995).

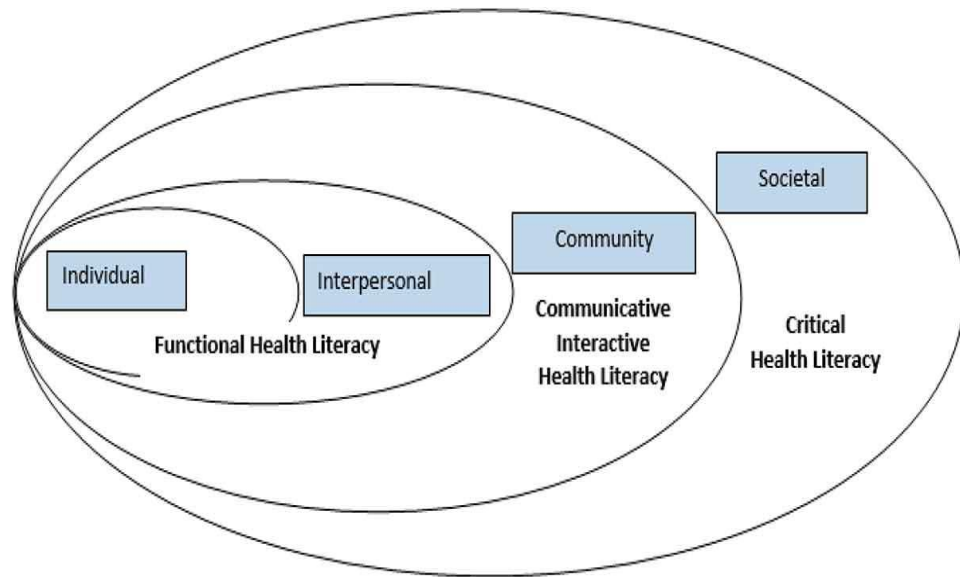
Population level health literacy extends the concept beyond individual capabilities. One of the earliest and an extensively utilised conceptualisations of health literacy is Nutbeam's (2000) tripartite model - comprising functional, interactive and critical health literacies operating essentially at the equivalent of: individual, social, and societal level. The model provides a structure to map on competencies beyond acquisition of basic health knowledge (Velardo, 2015) and offers a way of integrating the two health literacy perspectives. The term Functional health literacy is broadly comparable to 'medical' health literacy (as above) and refers to basic skills in numeracy and literacy to function in everyday health situations; Interactive or Communicative health literacy (IHL/CHL) involves the more advanced cognitive, social and literacy skills to extract, interpret and construct meaning from information gathered from a variety of sources to make personal sense of the information with regard to potential risk and relevant actions and finally; Critical health literacy (CHL) reflects increased cognitive and communicative skills supporting critical analysis of information used to exert greater control over life events individually and/or for population benefit (Chinn, 2011; Nutbeam, 2008; Sykes, Wills, Rowlands, & Popple, 2013).

The differentiation between these functional to higher levels of health literacy have been examined and refined in a number of studies (Heijmans, Waverijn, Rademakers, van der Vaart, & Rijken, 2015; Ishikawa, Takeuchi, & Yano, 2008; Sykes et al., 2013). The three types of health literacy have been found to be important for different aspects of influence over health. Communicative and critical health literacy (HL) skills have been demonstrated as important for chronic condition management for example in navigating with health professionals and support systems the often complex monitoring and maintenance required (Heijmans et al., 2015). Also communicative and critical HL are more closely associated with self-efficacy (Fernandez, Larson, & Zikmund-Fisher, 2016; Geboers et al., 2015; Inoue, Takahashi, & Kai, 2013; Osborn, Paasche-Orlow, Bailey, & Wolf, 2011) which has been suggested as improving health outcomes in some theoretical models (Sørensen et al., 2012). Self-efficacy (belief in the ability to achieve required changes) has been shown to explain a substantial part of associations between health literacy and the uptake of physical activity for instance in some studies (Geboers et al., 2015; Osborn, Paasche-Orlow, Bailey, & Wolf, 2011) but not all (A. M. H. Chen, et al., 2014). Osborn and colleagues' (2011) study examining physical activity uptake in those with hypertension demonstrated direct relationships between; 1) demographic factors (education, race, age) and health literacy; 2) health literacy and knowledge, self-efficacy and self-care behaviour (e.g. physical activity), and 3) self-care behaviour and health status (subjective health). Their findings suggested benefits to increasing disease specific knowledge, which could increase self-efficacy that in turn may encourage the uptake of health promoting behaviours. This mechanism was proposed in an earlier conceptual framework (Paasche-Orlow & Wolf, 2007). Differences between health literacy status and uptake of certain health behaviours and not others (for example uptake of recommended physical activity levels but not of fruit and vegetable consumption) found in other similar studies (A. M. H. Chen et al., 2014; Geboers, Winter, Luten, Jansen, & Reijneveld, 2014), points to a complexity of factors involved in the mechanism between the two. Attitudes and beliefs about the behaviours of interest as well as self-efficacy perceptions in individual social cognitive models of behaviour change (Armitage & Conner, 2000) may thus need to be examined more thoroughly alongside external influencing factors when measuring and planning for interventions based on such models. This is

particularly relevant when considering uptake of risk reduction behaviours with regard to dementia. There are increasing expectations for individuals to take action to reduce their dementia risk, with little or no research for example on attitudes and beliefs of older adults regarding the efficacy of specific behaviours. Current evidence on personal dementia risk reduction benefits remain inconclusive (Yaffe, 2018).

Others have endorsed and some have expanded Nutbeam's (2000) model and in particular the conceptualisation of critical health literacy (Chinn, 2011; Sykes et al., 2013; Zarcadoolas, Pleasant, & Greer, 2009). Zarcadoolas and colleagues (2009) include scientific literacy (an understanding of science and technology), civic literacy (knowledge of social processes such as social capital and social cohesion as well as media literacy skills), and cultural literacy (recognition of collective beliefs and practices which contribute to behaviours and decision making) which may better reflect the intricacies and expectations of critical health literacy in everyday life contexts (Guzys et al., 2015). This has salience in interpreting the multiple presentations of dementia from media and/or public health sources for example – when covering diverse issues from scientific advances in terms of dementia treatments to the causes and ramifications of abuse of older adults in care homes. A useful model for considering where specific health literacy levels (and targeted interventions) may come into play was proposed by Dawkins-Moultin and colleagues (2016). Nutbeam's (2000) model is superimposed onto a socio-ecological model (Fig 3-1). Consideration of relevant factors (from individual to community) at the intersections can ensure that health literacy is seen as critical and reformative, with the ultimate goal being both individual and communal agency (Dawkins-Moultin, McDonald, & McKyer, 2016). This more explicitly demonstrates health literacy alignment with the goals of public health and health promotion, via capacity building within individuals and communities and the potential to advocate for policy and legislative change (Chinn, 2011; Guzys et al., 2015)

Figure 3-1 Health literacy model superimposed on socio-ecological model (Dawkins-Moultin et al 2016 p32)



Health literacy: core components and models

The current expansive health literacy conceptualisations share many agreed components including: knowledge, skills, attitudes/motivation, social capital, empowerment and actions extending beyond the individual towards improved health. A number of theoretical models have attempted to capture components and pathways (Baker, 2006; Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012; von Wagner, Steptoe, Wolf, & Wardle, 2009). Such models have shed light on the factors that may influence health literacy such as skill development (Baker, 2006; Mancuso, 2008), or motivational factors progressing health literacy to outcomes (Paasche-Orlow & Wolf, 2007; von Wagner et al., 2009). Socio-ecological models that more explicitly focus on the impact of environments on factors that influence the development of health literacy skills as well as those that mediate the effects of health literacy on health outcomes have also been proposed (Dawkins-Moultin et al., 2016; Sørensen et al., 2012; Squiers, Peinado, Berkman, Boudewyns, & McCormack, 2012). Squiers et al.'s (2012) framework distinguishes itself from other models in ways that inform our understanding of disease-specific health literacy. An assumption is that a number of background factors including prior knowledge of health and previous illness experiences, influence the development and use of health literacy skills such as recognition and understanding of a new health concern (Zarcadoolas et al., 2009). In

addition mediating factors such as motivation, perceived norms and the relevance of messages to individuals will affect health related behaviours and outcomes (Squiers et al., 2012, p. 48). Using lung cancer as an example, they argue that an individual may understand from consistent and clear messages that smoking can cause lung cancer. However, they may lack the motivation, health or social support to act on these messages to stop smoking. Other mediators in this example could include fatalism (i.e. the outcome is pre-determined for example dementia is incurable, so there is little point in attempting to change things), or lack of trust in messages (citing other's experiences that discredits the messages) (Kobayashi & Smith, 2016). Theoretical models that can operate at a single health behaviour level (managing a specific condition such as dementia) or at a global/societal level (influencing health enhancing attitudes and behaviours) are required to understand the factors influencing outcomes in these complex situations (Richard, Gauvin, & Raine, 2011; Squiers et al., 2012). Recent thinking in behavioural theories support this in considering that people's attitudes are reflected in behaviours that are shaped in social situations and influenced by groups norms and societal expectations (Burke, Joseph, Pasick, & Barker, 2009). Individual based behavioural models do not always however adequately consider the wider social context, including social, historical, political, and cultural influences that impact on knowledge and behaviours and that influence people in their everyday lives (Pleasant, 2011; Sørensen et al., 2012).

Health knowledge is included as a core component of many health literacy definitions although its exact function varies across models and definitions. Health knowledge has been conceptualised in different models as an antecedent (von Wagner et al., 2009), as an integral dimension of health literacy (Freedman et al., 2009) or as a consequence of health literacy (Baker, 2006). Some process models refer to health knowledge as antecedents as well as consequence of health literacy (Baker, 2006; Nutbeam, 2008) with von Wagner et al. (2009) envisaging a causal chain from existing knowledge, via health literacy and additional specific acquired knowledge to beliefs and attitudes. Such conceptualisations indicate the relevance of understanding what prior knowledge or common understandings regarding specific health issues (such as dementia) exist when contemplating health literacy processes.

A further consideration is that the achievement of health literacy is impacted on by interactions related to the demands of health systems in addition to the skills of individuals and communities in navigating them (Nielsen-Bohlman, Panzer, & Kindig, 2004; Pleasant et al., 2016). Complexity of health texts or poor communication skills of providers may impede understanding (McCormack, Thomas, Lewis, & Rudd, 2017). Some have therefore called for the environments where health decisions are made to have similar requirements to be health literate (Batterham et al., 2014; Sykes et al., 2013). A wide range of interactive skills may be required within different social and cultural contexts and an individual's health literacy may fluctuate within novel situations dependent on content and context and its perceived relevance to them (Mårtensson & Hensing, 2012).

These components (and others) may also be considered when thinking about the specific elements related to dementia literacy that ensure it progresses alongside health literacy advancements but which remain contextually developed. In the absence of an established definition, components or indeed outcomes of health literacy, Pleasant and colleagues (2016) consider researchers should make clear their own focus of research and how it relates to current understandings. They also advocate further data gathering to illustrate how the pathways to informed health actions may be initiated and advanced (Pleasant et al., 2016).

Health literacy: towards an operational definition

Health literacy is a socially constructed concept within a constantly evolving field that is subject to social, political and cultural processes. There have been a number of attempts to combine or operationalise the multiple definitions in existence (N.D. Berkman, Davis, & McCormack, 2010; Peerson & Saunders, 2009; Sørensen et al., 2012) chiefly to serve as a basis for developing interventions and measurement tools. Sørensen and colleagues (2012) summarised and combined twelve existing definitions and models to produce a useful integrated model which brings together components from both medical and public perspectives:

“Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention

and health promotion to maintain or improve quality of life during the life course.” (Sørensen et al., 2012, p. 3)

This definition acknowledges the different contexts that may impact across the life course on the ability to access, understand, evaluate, communicate, and use health information and concepts to make informed choices, reduce health risks and improve quality of life. As such it is a useful starting point when considering dementia literacy and what that may entail. As is evident from this brief summary however such is the level of variance within existing conceptualisations that the definition of health (and dementia) literacy ultimately selected may depend further still on one’s specific goals (N.D. Berkman et al., 2010)

Measurement and prevalence of health literacy

Understanding levels of health literacy in a population is central to the consideration of targeting appropriate health care and health messages aimed at achieving health actions and improved health outcomes (Guzys et al., 2015). The struggles in achieving agreement on a definition of health literacy have also impeded the progress in the development of an all-encompassing tool to measure the construct (Baker, 2006; N.D. Berkman et al., 2010; Pleasant, 2014). Measures should demonstrate the complexity of the concept for analysis and be able to assess relative differences in various contexts (Guzys et al., 2015; Pleasant, 2014). Several well tested measures of functional health literacy exist assessing an understanding of medical situations such as the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995) or familiarity with medical vocabulary such as the as the Rapid Estimate of Adult Literacy in Medicine (REALM) (T. C. Davis et al., 1991). Other recently developed tools have attempted to measure different levels of health literacy in clinical populations (Bains & Egede, 2011; Ishikawa, Takeuchi, & Yano, 2008; van der Heide, Heijmans, Schuit, Uiters, & Rademakers, 2015) and across the general population (Sørensen et al., 2013). Some population approaches have attempted to move beyond assessing individuals and clinical settings and include several studies that have imputed measures of health literacy from socio-demographic data routinely collected in large scale population surveys (Laursen, Seed, Protheroe, Wolf, & Rowlands., 2015; Martin et al., 2009; Miller et al., 2007). Such predictive models includes the Demographic Assessment of Health Literacy

(DAHL) which was found to serve as a reasonable proxy for estimating limited health literacy against variables of interest (Hanchate, Ash, Gazmararian, Wolf, & Paasche-Orlow, 2008). Benefits of this approach are that health literacy estimations and factors impacting on health literacy can fairly easily and economically be ascertained across populations. Sub groups likely to be at increased risk of poorer health literacy may also be identified.

Prevalence of limited health literacy

Considering the recognised importance of health literacy to health outcomes there is little data on its prevalence. An ability to quantify the extent of limited health literacy (and associated likely disease specific knowledge for example) in a population provides opportunities to target interventions to reduce disparities. A recent European health literacy survey (HLS-EU-Q), found that nearly half (47%) of those aged fifteen and over in the eight European countries tested, had limited health literacy (Sørensen et al., 2015). Mean health literacy scores varied considerably between the countries and within countries, and displayed distinct social gradients, also identified in earlier studies (N.D. Berkman et al., 2011). A limited number of studies have assessed health literacy in the UK population. Von Wagner and colleagues (2007) reported lower prevalence (eleven per cent) of limited health literacy in their UK study although this significantly increased with age (6% in those aged 18-44 rising to 30% for aged 65 and over). A similar result (27% with limited health literacy skills) was observed in a population-based study of English adults aged 50 years (Kobayashi, Wardle, Wolf, & Wagner, 2014). There are currently no available assessments of health literacy in Wales. A scoping study to explore implications of health literacy, identification of a definition and possible measurement tools was conducted in 2010 at the instigation of the Welsh Assembly Government (Puntoni, 2010). The report emphasised that via: “measuring and tackling the health literacy level of our Welsh population we will be able to diminish the health inequities gap” (Puntoni, 2010 p 3). Subsequently health literacy was identified in the Welsh Government policy document Fairer Outcomes for All as one of seven action areas aimed to reduce health inequities (Welsh Government, 2011 p 22). However further published research action or extensive policy development does not appear to have progressed.

Contexts of health literacy

Health literacy, it has been noted, operates in a wide variety of settings and should be viewed as content and context specific. Different health contexts may require specific content knowledge (diabetes for example) and specialised skills (glucose monitoring) to manage them (Heide et al., 2014; Kickbusch, 2008; Nutbeam, 2008). An ability to use health literacy skills effectively in one environment (for one condition) does not necessarily imply an equal ability to manage in novel situations. Interdependencies between individuals and their environments too have been noted (Kickbusch, 2008; Nutbeam, 2008) and dynamic skills (aligned to critical health literacy) are required to navigate them (Chinn, 2014; McCormack et al., 2017). Yet individuals exist in networks of social and community settings that influence their health decisions. Communities and social networks of family members and friends can be valuable (or otherwise) in supporting the various aspects of health literacy (Edwards et al., 2015; Rowlands, Shaw, Jaswal, Smith, & Harpham, 2017).

The emphasis on health literacy outside health care settings proposes a greater potential (or necessity) for individual, social and community control over health promotion and the management of health. Public health models of health literacy urge individuals and their social networks to use their health literacy skills to address public health decisions benefitting their communities (Freedman et al., 2009; Guzys et al., 2015). Creating health literate populations with greater understanding of critical health messages (and dementia could be a pertinent example) that may affect themselves, their communities or wider society is considered an ethical imperative (Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005).

Health literacy, social networks and social support

The importance and roles of social support and social networks to health have been discussed in the gerontological literature for decades (Fiori, Antonucci, & Cortina, 2006; Golden, Conroy, & Lawlor, 2009; Heaney & Israel, 2008; Wenger, 1996). But it is only more recently that the role of families and social networks have been proposed as impacting on health literacy within theoretical models (Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012; Squiers et al., 2012). Empirical work has added to the conceptual understanding of how social networks may affect the

development and use of health literacy in every-day situations (Abreu, Nunes, Taylor, & Silva, 2018; Edwards et al., 2015). The terms social support, support networks and social networks are often interchangeably used and some clarity is required as their potential to impact on health literacy is increasingly suggested.

Social networks, social support and (social) support networks

Social networks refer to the web of social relationships surrounding individuals (Ashida & Heaney, 2008). Social support refers to the functional content of these relationships and has been described in terms of the provision of four main types of support, namely: emotional (provision of empathy, love and caring); instrumental (provision of tangible aid directly helping a person in need); informational (provision of advice and information) and appraisal (constructive feedback and affirmation) (Heaney & Israel, 2008; House, 1987). Support networks may thus function as providers of support: as a source of informational, physical and emotional support to individuals; as a stress-buffering mechanism; as a screening and referral agent to formal agencies; and as a context in which attitudes, values and norms can be transmitted (Wenger, 1994). Support networks have also been identified as having different configurations, including number of social contacts and relationships of contacts which can facilitate these functions (Litwin, 1997; Stephens, Alpass, Towers, & Stevenson, 2011; Wenger, 1991). An approach to capturing the effects of being embedded in multidimensional social networks is to identify different individuals with distinctive patterns of social networks which are associated with differences in health (Golden et al., 2009). Wenger's Support Network Typology (1991) and Litwin's Support Network Types (1997) are some of the most commonly used (Burholt & Dobbs, 2014). These typologies categorise social support, face-to-face interaction with family, friends and neighbours, and integration in community and religious groups. Knowing a person's support network type could help predict what type of support may be available or required from within networks (and what is not available) and therefore what interventions are likely to be more useful and effective (Wenger & Shahtahmasebi, 1990).

A number of research studies have demonstrated how health literacy may be developed and shared within networks (Abreu et al., 2018; Edwards et al., 2015; Ellis, Mullan, Worsley, & Pai, 2012; Papen, 2009). Exploratory qualitative research

within chronic condition management has demonstrated how those network members with more proficient skills (health literacy mediators) shared their skills and experiences over time to support others to become more health literate about their condition (Edwards et al., 2012; Ellis et al., 2012). These resources can also encourage uptake of health promoting activities, reduce risky behaviours and interact more successfully in environments that impact on health, thus some have urged increased focus of interventions including families in recognition of this (Beauchamp et al., 2017; Y.-C. Chen et al., 2018).

Social support may also buffer against the adverse effects of low health literacy by altering the perception of low health literacy (S.-Y. D. Lee, Gazmararian, & Arozullah, 2006). Help seeking behaviour may be constrained by a person's circumstances, for instance, embarrassment about poor health literacy, communication skills or condition, inhibiting them from fully discussing their health problems or requesting further explanations during a consultation (Nielsen-Bohlman et al., 2004). However, confidence to do this can be gained in the presence of additional support structures or by virtue of a sense of belonging to a social group. It is important to note that ineffective support (including from others with limited or inaccurate knowledge) may actually accentuate the poor health literacy skills of the individual and amplify adverse health outcomes (S.-Y. D. Lee, Arozullah, & Cho, 2004) and/or reinforce unhelpful attitudes. In addition social support is dependent on numerous personal (e.g. support network types), environmental and cultural factors and so cannot be assumed to permanently reside in social networks or necessarily be available when and exactly how it is required (Gottlieb & Bergen, 2010). Context is also of relevance here and the potential protective influence of some social network types over others and the various supportive roles they play may yet be outweighed by the broader social context such as socioeconomic deprivation, inadequate access to primary health care and discrimination (Stephens et al., 2011).

Different types of network have been found to facilitate access to and sharing of information and support within their network structures (Stephens et al., 2011). Those networks with weak ties and with greater heterogeneity and dispersion of membership offer a broader range of communication channels which are important in information seeking (Granovetter, 1983; Stephens et al., 2011; Wenger, 1991).

The swapping of health information and advice occurs routinely in our daily lives in passing conversations, within social networks as we talk about problems we have encountered or that have occurred in other's lives (Thoits, 2011). "Social networks spread information about their members' lives, especially details of tragedies and triumphs" (Thoits, 2011, p. 154). Even those on the periphery of networks can be brought in to share their experiences and make the management of an unfamiliar situation for one, less stressful and manageable for another. This is similar to Granovetter's (1973, p. 1360) earlier work highlighting the "strength of weak ties". His later elaboration however emphasizes that although weak ties may provide access to information and resources not always available within closer social circles, those networks with stronger ties generally have a greater motivation to provide support and assistance and are typically closer to hand to be in a position to do so (Granovetter, 1983). Such networks with more frequent interactions may offer greater opportunities to check or influence health behaviours, (Cornwell & Waite, 2012). Discussion in networks may be particularly effective with respect to disease recognition, diagnosis and management (Bevan & Pecchioni, 2008; Cornwell & Waite, 2012). However behaviours advised or modelled by family, peers, and wider society (social norms), are more frequently focused on and thus may impact more directly on social wellbeing and attitudes to keeping healthy, rather than on the necessity to prevent disease (Stephens, 2008).

Social norms (and perceived norms) are included in the complex relationship with knowledge and attitudes that impacts on health literacy (McCormack, Thomas, Lewis, & Rudd, 2017; Nutbeam, 2017). People acquire 'norms' much as they do other pieces of information. They are developed through comparison processes with similar others within their social networks for example around behaviours such as exercise and diet patterns, or as attitudes towards ageing and dementia or health promotion and risk reduction. Individuals assess the appropriateness of their own attitudes, beliefs, and behaviours against the standards as modelled by the "reference group members" and so social influence through this process may have protective or damaging consequences dependent on the reference group (Thoits, 2011, p. 147). People often affiliate themselves with others who are like them (homophily) and so those with low health literacy and who undertake risky health behaviours (such as smoking) may be normalised within the group thus reinforcing poor health practices

(McPherson et al., 2001). Similarly views on ageing or dementia that can encompass stereotypes and stigmatising attitudes towards others may also be shared and shaped in networks. Such ‘institutionalised’ norms may have a strong impact on expectations of how and where people should age and in particular when ageing with specific conditions such as dementia. Negative views on aging have been found to be a risk factor for a decrease in life satisfaction during old age and may consequently influence motivation to invest in one’s future including the adoptions of behaviours that may promote or support health (Rothermund & Kornadt, 2015) and this could include actions to promote positive cognitive health.

Disease specific literacy

A disease specific focus to health literacy is warranted, as has been emphasised, context counts when considering health literacy. A more comprehensive dimension of health literacy explicitly conceptualising the relationship between health literacy and particular conditions (such as cancer, mental health and dementia) can contribute to a deeper understanding of any associated condition-specific attitudes and behaviours. Disease specific health literacies and their uptake may be specific to particular diseases or conditions (Kobayashi & Smith, 2016; Morris et al., 2013). There is evidence, for example, that with diseases often considered to be fatal, such as cancer, people avoid seeking information or discussing the condition if they are not themselves affected by it (Balmer, Griffiths, & Dunn, 2014; Morris et al., 2013). In addition a recent qualitative systematic review of lay understandings of cancer by adults without the disease found evidence that fear prevented engagement in health behaviours such as self-examination or information seeking (Balmer et al., 2014).

Mental Health Literacy

Mental health literacy is a useful exemplar of a disease specific literacy because it holds some similarities to dementia. Although dementia is not considered to be a mental illness (Ticehurst, 2001), both dementia and mental health are traditionally viewed within a medical model (and dementia is often managed within psychiatric services). The wider environmental and social factors that contribute to and can ameliorate any symptoms are increasingly recognised for both (Dröes et al., 2017). There has been a shift to include both conditions within the broader disability

movement to protect human rights and in an attempt to reduce discrimination and stigma (Regan, 2016; Shakespeare et al., 2017). As the definition of dementia literacy has been directly extracted from that of mental health literacy (MHL), this review considers MHL in brief but separately to other condition specific literacies.

Conceptualising mental health literacy

The construct of mental health literacy (MHL) has evolved alongside advancing health literacy definitions and evidence from empirical research. Originally focused on increasing knowledge and skills surrounding mental health in the primary care sector and its workforce, its relevance and reach has extended to include the wider population (Jorm, 2015). The concept was introduced by Jorm and colleagues (1997b) as: “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (1997b, p. 182). Seven core attributes that constitute MHL were identified and grouped into; firstly recognition of mental health disorders, secondly attitudes that promote recognition and help seeking behaviours, and finally knowledge of specific factors relating to mental health (i.e. how to seek information, knowledge of risk factors, knowledge of causes, knowledge of self-treatment and knowledge of professional help available) (Jorm et al., 1997b; O’Connor, Casey, & Clough, 2014). Kutcher and colleagues (2016) extended the definition and explicitly include the concept of stigma, which although acknowledged as having a considerable interrelationship with mental health had previously been considered separately (Angermeyer & Dietrich, 2006; Link & Phelan, 2001; Reavley & Jorm, 2011a, 2011b). These attributes can provide a starting point from which to closely examine their relevance for dementia literacy.

There is a robust literature describing the interrelationship between mental health knowledge and various types of stigma (Kelly, Jorm, & Wright, 2007; Kutcher et al., 2016; Schomerus & Angermeyer, 2008). Stigma exists when the four interrelated components comprising it converge (Link & Phelan, 2001). The first component is where differences between people are distinguished and labelled. In the second, dominant cultural beliefs link labelled people to undesirable characteristics (negative stereotypes). Thirdly this categorisation allows a degree of separation of "us" from "them" and fourthly the labelled persons experience status loss and discrimination. The process of stigmatisation can occur contingent on the power

structures in place (for example politically and socially) that will allow it to do so (Link & Phelan, 2001, p. 367). Stigma, understood in this manner is likely to affect many people affected by mental health conditions (including dementia) and impact on their life chances and choices in various ways. Stigma can diminish self-esteem and limit social opportunities via discriminatory attitudes (Corrigan, Druss, & Perlick, 2014). It has prompted some to describe stigma and discrimination as having worse consequences than the condition itself (Thornicroft et al., 2016). The field of dementia literacy is still in its infancy regarding the role that dementia literacy may play in influencing stigma and vice versa. It is useful therefore to explore this within the context of MHL to see what lessons may be learned.

Measurement and prevalence of mental health literacy

In order to assess mental health literacy (MHL) Jorm and colleagues (1997b) used a vignette approach. The vignette described an individual with one of two mental health conditions (depression or schizophrenia), followed by a series of questions related to the condition. This same approach was adapted for dementia by Low and Anstey (2009) in their original dementia literacy study. This vignette interview has been extensively used but has faced criticisms as initially incorrectly identifying the disorder means that participant's answers may not accurately reflect their knowledge, also as with previous critiques of other health literacy measures - it incompletely measures the construct (Kutcher et al., 2016; O'Connor & Casey, 2015). Increasingly other condition specific health literacies (diabetes and cancer for example) are using disease specific knowledge assessments in addition to or incorporated within measurement tools that capture dimensions considered essential from the broader construct of health literacy (Bains & Egede, 2011; Diviani & Schulz, 2011; Ishikawa et al., 2008; Wei, McGrath, Hayden, & Kutcher, 2015).

Much of the mental health literacy research suggests that knowledge of mental illness within the general public is poor. Many people are unable to correctly identify mental disorders, do not understand common causes, treatments and self-management options, are frequently fearful of those perceived as mentally ill, reluctant to seek help for mental health problems and do not know how to help others with problems (Jorm, 2000; Jorm, Christensen, & Griffiths, 2005; Kutcher et al., 2016). In addition attitudes towards those with mental illness are often negative with

fear, stereotypes, stigma and prejudice fairly common and this is associated with a general reluctance to seek help (Clement et al., 2015; Kutcher et al., 2016; Reavley & Jorm, 2011b). Evidence to date suggests that this may be a similar case for dementia (Blay & Peluso, 2010; Werner, Mittelman, Goldstein, & Heinik, 2012).

Improved mental health knowledge can help with earlier identification of mental disorders and better awareness of how to seek help and treatment (Jorm, 2012; Rüsçh, Evans-Lacko, Henderson, Flach, & Thornicroft, 2011; Wei et al., 2015). Better mental health literacy and positive attitudes have also been demonstrated to improve individual's confidence to provide help to others (Jorm, 2012; Kelly et al., 2007; Kutcher et al., 2016). Factors implicated in influencing mental health help seeking include stigma (negatively associated) (Jorm, 2012; Wang & Lai, 2008) and social support (encouraging help-seeking) (Jung, Sternberg, & Davis, 2017; White & Casey, 2016). These factors are highly relevant to our understanding of dementia literacy.

It has been assumed that increasing mental health literacy will improve attitudes (reducing stigmatising attitudes) towards those with a mental illness, and thus counter one of the barriers to help-seeking and treatment access (Thornicroft et al., 2016). A complex relationship appears to exist between mental health literacy, stigma (including its different sub-types) and attitudes towards help seeking (Clement et al., 2015). Whereas someone with good mental health literacy may be able to use their knowledge and remain objective when interacting with someone with a mental illness, if they were affected personally by mental ill health, their knowledge and beliefs may not reduce their sense of shame and self-stigma sufficiently to seek help for themselves (Kutcher et al., 2016). Self-stigma is understood as the point where a person with a mental illness accepts and attaches to themselves the stereotypical or prejudicial notions against them (Corrigan, 2004).

While recognition of mental health disorders is an important precursor to help seeking, attitudes towards help seeking and beliefs about the helpfulness of treatments also impact on this behaviour (Balmer et al., 2014; Kobayashi & Smith, 2016). Help seeking intentions (HSI) is positively correlated with mental health literacy (MHL) and can influence decisions to access formal or informal help

(O'Connor et al., 2014; C.L. Smith & Shochet, 2011). A number of studies have indicated that the majority of respondents believe that a full recovery or recovery with possible recurrence is the likely outcome for most people with a mental illness receiving appropriate professional help (Jorm, Christensen, & Griffiths, 2006b; Picco et al., 2016). Those who believe that mental health treatment is beneficial and effective are more likely to hold positive attitudes towards the benefits of help seeking and use of mental health services (Jung et al., 2017). Such results highlight some stark differences between mental health and dementia outcomes, whereas full recovery is a distinct possibility with appropriate mental health treatments, this is not the case with dementia. The benefits of accessing help and support for dementia may therefore need a different focus with the advantages of early help seeking and diagnosis made more apparent.

Mental Health Literacy: Social Networks and Social Support

Supportive networks are important in mental health help-seeking behaviours (Kelly et al., 2007; Picco et al., 2016) and may be even more relevant with respect to mental health conditions compared to physical illnesses. Possibly due to a combination of perceived public stigma and poor mental health literacy many people do not directly seek out help from mental health professionals, and prefer to receive help initially from family, friends and other informal resources (Jung et al., 2017). Both increased mental health literacy (MHL) and social support for mental health care are more likely to increase favourable attitudes towards mental health help seeking and thus access to treatments (Jorm, 2012; Jung et al., 2017; White & Casey, 2016). This is however dependent on the knowledge and beliefs about mental illness of those supporting the individual. Friends and family are unlikely to encourage older adults to seek advice from mental health professionals for example, if they attribute signs and symptoms to normal ageing as opposed to depression (Wuthrich & Frei, 2015). A study by White and Casey (2016) found that family members with greater mental health literacy were more likely to say that they would provide a supportive role to those with a mental health condition. As before within the general health literacy field, such findings reinforce calls to extend mental health education to a community level - including not just those at risk of mental illness but those who may be in a position of supporting them i.e. everybody (Jorm, 2012).

Positive impacts of mental health education have been reported on increased knowledge, attainment of more positive attitudes - including towards help seeking behaviours, reduced stigma and helping others with mental illness (Jorm & Kitchener, 2011; Kelly et al., 2007; Kitchener & Jorm, 2006). An Australian national campaign “Beyond Blue” designed to increase public mental health knowledge was credited as having some influence in changes to MHL levels including condition recognition, knowledge and beliefs about mental disorders and their treatments (Jorm, Christensen, & Griffiths, 2006b and 2006c; Jorm et al., 2005). There was also an increase in willingness post campaign to declare a personal mental health problem and in identifying the presence of discriminatory attitudes towards those with mental illness (Jorm et al., 2006b). A similar German study however showed only minor changes in public attitudes towards those with mental illness (Angermeyer, Holzinger, & Matschinger, 2009). It has been suggested that while changing mental health knowledge in principle is not difficult, changing deep seated emotional reactions to mental disorders may be more problematic (Jorm et al., 2006a). Research with clinicians has indicated that although scoring high on mental health literacy they were not necessarily low on stigmatising attitudes (Jorm et al., 2006a, p. 4). A similar concern with regard to dementia literacy exists and a hesitancy and delay around dementia recognition and diagnosis has been found to be prominent in many EU states with stigmatising attitudes held by health professional implicated as a powerful factor behind this (Vernooij-Dassen et al., 2005). Angermeyer et al’s (2009) trend analysis has suggested that the mental health literacy of the public has increased over time, however the desire to distance oneself (a component of stigma) from people with major depression and schizophrenia has remained unchanged or has even increased. Those less likely to exhibit this desire were those with a personal or family experience of current or past psychiatric treatment (Angermeyer et al., 2009). Other studies have supported this and in addition identified other factors as influencing stigma including beliefs about the causes of mental illness and education level (Jorm & Oh, 2009; Jung et al., 2017). Such studies indicate a complex interplay of factors related to the specific conditions in influencing mental health literacy and its outcomes. A more complete understanding of conditions (and public understanding of them) is similarly required when contemplating dementia.

Dementia Literacy

Background

Dementia literacy (DL) shares many common issues with mental health literacy, when considering the general lack of knowledge, misconceptions and stigmatising attitudes within the broader population towards both dementia and mental illness. Critically, and differently from mental health conditions, dementia is a progressive and terminal illness, that predominantly affects older adults. In the absence of cure the population may need to be convinced of the merits of early diagnosis and successful intervention options (elements of the DL definition) in order to shift the dominant view that nothing can be done about dementia or for those living with dementia (McParland, Kelly, & Innes, 2017; Reed, Carson, & Gibb, 2017). The concept of dementia literacy has enormous potential when considering impacts on policy and practice of health and mental health literacies (N.D. Berkman et al., 2011; Jorm, 2015). Health literacy and to some degree mental health literacy have been the topic of scrutiny and conceptual and theoretical discussions, yet despite the increasing acknowledgement of dementia literacy as a separate concept, or specific aspect of health literacy (Haralambous, Mackell, Lin, Fearn, & Dow, 2017; Loi & Lautenschlager, 2015; H. Zhang et al., 2017) - the construct as yet appears underexplored.

Conceptualising Dementia Literacy

Dementia is commonly understood as a multifaceted spectrum of diseases “with diverse underlying pathologies” (Annear et al., 2015, p. 2) and with various physical, psychological and social manifestations (Livingston et al., 2017; Vernooij-Dassen & Jeon, 2016). There has been an increase in empirical research on aspects of the general public’s knowledge of dementia, particularly over the last ten years (Cahill et al., 2015; Cations et al., 2018). Also, but often separately, attitudes towards dementia have been examined (Aihara, Kato, Sugiyama, Ishi, & Goto, 2016; Cheston, Hancock, & White, 2016; Jones, Mackell, Berthet, & Knox, 2010). There is however a more limited body of literature specifically that captures the entirety of the construct of dementia literacy.

A criticism of mental health literacy has been its overt acceptance of the dominant psychiatric framework providing the backdrop for ‘gold standard’

knowledge and treatments without taking into account the broader perspective of how mental illness is characterised and understood (Holman, 2015). This is a potential problem for dementia literacy definitions (Cuijpers & van Lente, 2015). Although Low and Anstey (2009) base their definition firmly at the population level with the understanding being that good public knowledge of dementia will “aid recognition, management, or prevention” (2009, p. 43) – it retains a predominantly biomedical perspective (Annear et al., 2015; Cahill et al., 2015). Alternative conceptual frameworks of dementia understanding were presented in chapter two. It is within this context that the approach to examining dementia literacy and potential expansion of the current definition should be considered. Framing an understanding of dementia purely within a biomedical model of risk, treatment and (medical) management may exclude alternative definitions acknowledging the potential impacts of social components. However pitting one conceptualisation of dementia against another could be counterproductive. A greater awareness of what is and is not understood about dementia and how this may translate to attitudes and actions does however seem relevant in order to address dementia concerns for individuals and populations (Y. Zhang, 2018).

The backdrop to population understanding of dementia

What the essential ‘facts’ are about dementia for knowledge assessment purposes (and how they are decided) are relevant to our understanding of dementia literacy. There are a number of parties with a vested interest (and frequently power) in defining dementia literacy including: governments; medical infrastructure; Alzheimer Associations; and the pharmaceutical or other industries involved in pharmacological interventions or marketing the maintenance of cognitive health (Innes & Manthorpe, 2013). Michel Foucault introduced the concept of ‘biopolitics’, the set of mechanisms through which the biological features of individuals become the object of a political strategy. The process of medicalising dementia, and what was formerly called senile dementia (and attributed to normal ageing), in particular has been described as a bio-political process (Y. Zhang, 2018). Increasing dementia knowledge within the general population has been singled out as a key area of public policy (Dua et al., 2017). Broadening awareness of the impacts of dementia and potential accompanying investment in research appears to be positive news. But it

may to an extent depend on the definition (who is involved in the defining) and what outcomes and for who are expected of it.

How dementia is defined is not necessarily how it is more generally perceived. Dementia is ubiquitously portrayed in terms of catastrophic imagery including as a “tidal wave” (Sabat, 2009, p. 1805), “epidemic”, and a “time bomb” in academic journals as well as mainstream media (Larson, Yaffe, & Langa, 2013, p. 2275; Peel, 2014, p. 890). The economic and the social “burden” of dementia are widely discussed and these predominantly negative and pervasive views are further distributed throughout the general population (Alary, Goldberg, & Joannette, 2017; Shah et al., 2016; Werner et al., 2012). Prevailing public opinions are thus in terms of disease, tragedy and passivity and language such as ‘loss’, ‘suffering’, ‘victims’ and ‘burden’ serve to pathologise individuals with dementia (McParland et al., 2017; Peel, 2014). People living with dementia are frequently subject to the fear, ignorance and negativity of wider society. The psychologist Sabat calls this “malignant positioning” (Sabat, Napolitano, & Fath, 2004, p. 177). Such imageries, proliferated throughout the media can serve to reinforce dementia as one of the most dreaded and stigmatised diseases in western society (Van Gorp & Vercruyse, 2012) resulting in a wide range of negative impacts such as aversion and exclusion (Lüdecke, Knesebeck, & Kofahl, 2016). Our understandings of dementia literacy must be considered acknowledging these overarching socially constructed representations of dementia. Peel (2014) suggests that how dementia is currently represented in our society may have different impacts on different individuals and group.

Empirical Research on Dementia Literacy

There is a limited body of research on dementia literacy. If one considers learnings from health and mental health literacy definitions and models, dementia literacy would include as core concepts; dementia related knowledge, motivation and other competencies required to access and apply the knowledge on an individual level and/or on a wider community level (Jorm et al., 1997b; Kutcher et al., 2016). The following research evidence therefore has been categorised as far as possible according to these main components. There are also apparent confusions in this nascent body of studies. A number of studies purporting to be about dementia literacy are in fact merely establishing levels of dementia knowledge as in studies by

Diamond and Woo (2014) and J.P. Lee and Woo (2015). Conversely the concept exists in other studies when considering these core elements (Cahill et al., 2015; Rimmer, Stave, Sganga, & O'Connell, 2005). Dementia 'knowledge' as indicated earlier is contested.

Dementia literacy measures

Low and Anstey's (2009) original dementia literacy study gathered responses regarding recognition of the character in a hypothetical vignette as having dementia/AD, with further questions to elucidate knowledge and attitudes around the subject of the vignette (as per Jorm's (1997b) mental health literacy measurement). The vignettes were developed with the help of clinical dementia experts (Low & Anstey, 2009, p. 44). Others have also used this approach (Blay et al., 2008; Cheng et al., 2011; Werner, 2003; Werner & Davidson, 2004). Alternative approaches to measurements include the use of extensive survey tools (Bond et al., 2005; McParland et al., 2012; Rimmer et al., 2005; Roberts, McLaughlin, & Connell, 2014) and in-depth qualitative examinations (Corner & Bond, 2004; Kim, Sargent-Cox, & Anstey, 2015). There is a more extensive body of literature examining dementia knowledge (Arai, Arai, & Zarit, 2008; Glynn, Shelley, & Lawlor, 2017; Lüdecke et al., 2016; Riva et al., 2012) and/or dementia attitudes (Aihara et al., 2016; Cheston et al., 2016; McParland et al., 2012) using a range of validated or purposefully designed (and some un-validated) measures. However dementia literacy like mental health literacy is: "not simply a matter of having knowledge [...] Rather it is knowledge that is linked to the possibility of action to benefits one's own mental health or that of others" (Jorm, 2012, p. 231). Nevertheless knowledge of dementia is a core component of dementia literacy and so relevant studies are also included in the review.

Recent systematic reviews of dementia literacy or dementia knowledge have found a lack of consistency across studies, regarding fundamental constructs and how knowledge was operationalized and measured (Cahill et al., 2015; Spector, Orrell, Schepers, & Shanahan, 2012). Reviews of dementia knowledge measures have found limitations, including weaknesses in psychometric properties, having limited scope and crucially not reflecting current best knowledge and evidence about dementia (Annear et al., 2016; Spector, Orrell, Schepers, & Shanahan, 2012). Most

studies measured dementia knowledge from a biomedical perspective and have been acknowledged as not necessarily reflecting broader and widely held views (Annear et al., 2015). Also some measures are considered to be more suitable for use within specific population groups, for example carers, health professionals or the lay public (Spector et al., 2012). This may be germane as there is an appreciation of a possible need for different levels or focus of knowledge for alternative groups, however there appears little consideration of any problems that may arise from these multiple knowledge bases. Another key issue highlighted was that even within the expert dementia research community there are differences in opinion as to the ‘right’ answer regarding particular knowledge or attitude items included in some survey studies (Annear et al., 2015; Connell, Scott Roberts, McLaughlin, & Akinleye, 2009). Few qualitative studies have explored these “complexities and contradictions” but have been recommended to aid in resolving some of these issues (Cahill et al., 2015, p. 274). When understanding (and measuring) dementia knowledge the separation of knowledge from beliefs or at least recognition that there are differences, is a pertinent concern (O’Connor & McFadden, 2010).

Dementia literacy and factors influencing it

Recent reviews examining dementia knowledge have consistently found that the general public has only a fair to moderate understanding of dementia and that misconceptions are widespread across the vast majority of studies (Cahill et al., 2015; Cations et al., 2018). Factors influencing dementia literacy observed in a number of studies (though sometimes found in opposing directions of influence) include: age, sex, education/socioeconomic status and ethnicity (Cations et al., 2018). There is a consistently reported social gradient regarding dementia knowledge with those having higher level educational attainments and higher social status tending to have greater dementia knowledge (Kim et al., 2015; Lüdecke et al., 2016; Roberts et al., 2014) which mirrors some of the key socio-demographic factors influencing health literacy. Knowing or caring for someone with dementia is commonly associated with increased dementia knowledge (Cahill et al., 2015; Low & Anstey, 2009; Tan, Hong, Luo, Lo, & Yap, 2012). The results regarding the effects of age and sex on dementia knowledge are somewhat inconsistent, although in general more studies demonstrate that women have better knowledge than men (Arai et al., 2008; Roberts et al., 2014; B.J. Smith, Ali, & Quach, 2014; Werner,

Goldberg, Mandel, & Korczyn, 2013). These reported differences have been frequently attributed to the higher likelihood of women providing care for people living with dementia and thus gaining knowledge via experience. Older adults were found in several studies to be less knowledgeable about dementia than younger adults (L.N. Anderson, McCaul, & Langley, 2011; Werner, 2003). Others found no significant difference between age and dementia knowledge (Ayalon & Areán, 2004) or a split result with the youngest and oldest age groups demonstrating greater risk factor knowledge (Low & Anstey, 2007). Poorer dementia knowledge was found among ethnic and racial minorities in a number of studies (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011; Connell, Scott Roberts, McLaughlin, & Akinleye, 2009; Low et al., 2011; Roberts et al., 2014). Education level and proficiency in English were implicated rather than ethnicity per se in some (Ayalon & Areán, 2004; Low et al., 2011). More diverse results have been observed where different models of lay knowledge have been considered. Where distinct cultural views regarding fate or karma are linked to attitudes towards dementia and views on the inevitability of its course, these may for example, influence uptake (or not) of risk avoidance behaviours in particular (Low et al., 2011; Tan et al., 2012). Lack of consistency in study populations, measurement tools, approaches to sampling and which aspects of dementia knowledge were included in the study make it more difficult to draw firm conclusions across studies reviewed about many influencing factors. The variations across studies also indicate a complexity of factors and interrelationships between them that may influence dementia knowledge, that to date have been little explored.

Ability to recognise dementia

Better recognition of the signs and symptoms of dementia have been indicated as an important gateway to presenting for diagnosis and access to treatment opportunities (Leung et al., 2011; Welsh Government, 2018). A number of studies have demonstrated that the general public has a good recognition of the symptoms of dementia when presented with a vignette describing someone with cognitive impairment (Loi & Lautenschlager, 2015; Low & Anstey, 2009; Low et al., 2011; Werner, 2003). However Low and Anstey (2009) acknowledge that their developed vignette (where 82% correctly identified the diagnosis) may have too clearly summarised and presented cognitive and functional changes for typical Alzheimer's disease, whereas recognition of atypical symptoms or even usual symptoms but

which develop over time in real life, may not be so easy to detect. Early signs and symptoms of dementia have been identified as more problematic to recognise (Bunn et al., 2012; Laditka et al., 2009; Werner & Davidson, 2004). Lengthy delays averaging 47 weeks from first noticing symptoms of cognitive impairments to consulting doctors were observed in one European study (Bond et al., 2005). These were attributed to factors including fear, stigma and attribution of symptoms to normal ageing or other conditions. Differences in diagnoses rates vary considerably across the UK with the lowest in Wales (53%) and there is little understanding of why this variation exists. Although financial incentives for GPs via the Directed Enhanced Service for GPs on dementia in England did see a marked increase in diagnosis rates (Alzheimer's Society, 2015). Combinations of factors are likely to be involved in the decision when to seek professional help and for delays in diagnosis and some of these are considered below.

Knowledge of dementia risk and protective factors

A key focus of dementia literacy, in particular from a public policy perspective, is that improved knowledge of dementia risk and protective factors will lead to action to reduce one's own risk or facilitate this (by sharing knowledge) for others. Achieving reduction in dementia could have both social and economic benefits and so has been the focus of much research. Reviews of large scale international epidemiological studies suggest that between a third and up to half of all dementia cases may be attributable to modifiable risk factors (for example smoking, hypertension, obesity, cognitive inactivity, physical inactivity, hearing loss, smoking, social isolation and education) (Barnes & Yaffe, 2011; Livingston et al., 2017; Matthews et al., 2016; Norton, Matthews, Barnes, Yaffe, & Brayne, 2014; Yaffe, 2018). This relatively new evidence provides a strong rationale for focusing on risk factor reduction for dementia, and it is at the core of recent UK dementia strategies as well as Global responses (WHO, 2017). However two recent systematic reviews aimed at summarising best evidence from such research have produced differing recommendations. The Agency for Healthcare Research and Quality (US) suggested there was moderate evidence that some cognitive training and physical activity was effective for example, but that there was insufficient strength of evidence to justify large-scale investing in public health interventions aimed at preventing dementia (Kane et al., 2017). The Lancet International Commission on

Dementia Prevention and Care review published the same year made recommendations that included being “ambitious about prevention” (Livingston et al., 2017, p. 5). It suggested pursuing those interventions most likely to be beneficial such as increasing physical activity and social engagement, reducing smoking and treating hypertension, diabetes and hearing impairment – essentially as such activities will likely do no harm and offer other potential health benefits. It is apparent that the seemingly conflicting derived evidence and advice, sometimes arising from reviews of the same evidence by experts (Yaffe, 2018) could be a source of confusion for those attempting to extract the key ‘facts’ of the situation and act on them.

There are considerable differences in the general public’s knowledge of dementia risk and prevention as observed across a number of studies (L.N. Anderson et al., 2011; Corner & Bond, 2004; Hudson, Pollux, Mistry, & Hobson, 2012). Substantial proportions of participants across studies considered that there was nothing that can be done to reduce their dementia risk (NatCen Social Research, 2015; B.J. Smith et al., 2014) including a recent national Welsh dementia awareness survey of those aged 16 and over where over half believed this to be true (Cox, 2017). Other studies have reported relatively high levels of agreement that dementia risk can be reduced but often with less certainty on the specific factors that can facilitate this (Low & Anstey, 2009; Roberts et al., 2014). In Low and Anstey’s (2009) study, 72% of the population thought that dementia risk could be reduced by carrying out activities such as keeping mentally active, reducing alcohol and drug consumption, improving nutrition and diet, exercising more and keeping socially active, but also included risk factors with less scientific evidence to support them such as exposure to aluminium and personal characteristics such as laziness and weakness of character. Recognition of a genetic component to dementia risk was widespread throughout the 34 studies reviewed in a recent systematic review but its significance was often overestimated (where this could be determined in the study design), and non-genetic factors, such as cardiovascular risk factors, high blood pressure, high cholesterol and smoking were in contrast underestimated (Cations et al., 2018). Almost half of those surveyed in a recent UK social attitudes survey failed to identify any of the key risk factors in a prompted list that could increase a person’s risk of developing dementia (Alzheimer’s Research UK, 2018). Similar to risk

factors, studies examining knowledge of protective factors which may help lower the chances of developing Alzheimer's disease (AD), have also endorsed a wide range of factors. These include keeping mentally active, eating a healthy diet, keeping physically active, and taking vitamins or supplements, with stronger research evidence base for some more than others, such as keeping mentally and physically active (Cations et al., 2018; Friedman et al., 2015; Roberts et al., 2014). Low & Anstey (2007) have suggested that public perceptions of what might increase or lower dementia risk may be influenced more by general beliefs about health and keeping fit rather than by scientific evidence about dementia. There also seems to be less conviction in undertaking activities that are not specifically or so obviously related to brain function for example stopping smoking and increasing physical activity as compared to cognitively stimulating activities such as socialising or puzzle books (L.A. Anderson, Day, Beard, Reed, & Wu, 2009; Low & Anstey, 2007; Roberts et al., 2014). It is possible that enduring perceptions and long established beliefs about dementia are contributing to poorer recognition or understanding of more recent physical, mental and social contributing factors to dementia. The diversity of risk or protective factors identified in previously mentioned studies does however suggest that there may be openness to public health messages that could encourage risk prevention or cognitive health promoting actions. There does appear to be difficulty in assessing best evidence – potentially indicting a lack of critical health literacy skills and/or insufficiently clear presentation of 'facts'.

Knowledge of risk factors alone is insufficient to initiate health behavioural responses (Kelder, Hoelscher, & Perry, 2015; Nutbeam, 2000). The extent to which the public not only consider that risk reduction is possible, but believe that they can successfully apply this within their own lives varies. For example 41.5% in B.J. Smith et al's (2014) study believed that the risk of dementia could be reduced, but this number shrinks to just over one-quarter (27%) who felt very confident that they could act to lower their own personal dementia risk. Belief in the preventability of AD was indicative of uptake (or intent to) of preventative activities in some studies (L.N. Anderson et al., 2011; Kim, Sargent-Cox, Cherbuin, & Anstey, 2014). Such pathways from health literacy to health action have been suggested within some health literacy (HL) models (Paasche-Orlow & Wolf, 2007; von Wagner et al., 2009) and social cognitive theories can offer an explanation for choices and resultant

actions (von Wagner et al., 2009). There is therefore a need to consider what might affect people's motivation to adopt dementia risk reducing behaviours. Perception of one's own perceived risk is one such factor. People may be more likely to change their behaviour if they perceive themselves to be personally vulnerable to developing dementia and if they believe that there is some effective practice that will reduce that risk (Riva et al., 2012).

Knowledge of treatment and management of dementia

Knowledge and misconceptions around the treatment and management of dementia also varied across studies reviewed. The majority of respondents across a number of studies in a recent systematic review correctly responded that there are no available treatments to prevent dementia (Cations et al., 2018). However a number of studies found high percentages (between 44, 43% and 61% respectively) who considered dementia to be treatable (L.A. Anderson et al., 2009; Arai et al., 2008; Riva et al., 2012). It is possible that there may have been confusion of terminology regarding treatments leading to cure or those that can moderate symptoms; as survey questions such as "some types of dementia are treatable" could be misinterpreted, as one author pointed out (Arai et al., 2008, p. 436). Such results highlight not only the variations in knowledge but also in use of and interpreting of terminology.

Few studies have specifically examined knowledge of psychosocial approaches to dementia management or alternatives to pharmacological options. There is a general perception that treatments function solely to support wellbeing as opposed to slowing the progression of the disease (Cations et al., 2018). There is evidence to suggest that both pharmacological and non-pharmacological treatments can delay functional and cognitive decline (Laver, Dyer, Whitehead, Clemson, & Crotty, 2016). There is an increasing evidence base of the benefits of psychosocial interventions (including life story work, cognitive stimulation therapy, reminiscence therapy and music therapy) for people living with dementia and carers, albeit with reported cautionary comments on interventions that the studies have been of limited duration with issues around sustainability (B. Johnston & Narayanasamy, 2016; Oyeboode & Parveen, 2016). There has also been an increased emphasis on the efficacy and value of a number and variety of treatment and management options (Aguirre, Woods, Spector, & Orrell, 2013; McDermott et al., 2018). A greater

awareness of the options available to support better management of the condition and improved quality of life could reduce fatalistic views that result in people not even attempting to access help (Rahja, Laver, Comans, & Crotty, 2018). It is uncertain why there is limited interest or awareness of this more positive news.

Knowledge, beliefs and misconceptions

Gaps in dementia knowledge and commonly held misconceptions have been consistently identified in studies assessing dementia literacy or dementia knowledge (Cahill et al., 2015; Cations et al., Hudson et al., 2012; Loi & Lautenschlager, 2015; Low & Anstey, 2009). The belief that dementia is a normal part of aging is probably the most common misconception (Cahill et al., 2015; Kim et al., 2015; McParland et al., 2012; Tan et al., 2012) and one that has been documented for decades even among health professionals who diagnose and treat dementia (Dubois et al., 2015). There are misconceptions throughout knowledge areas identified as required for dementia literacy; from causes, risk and protective factors to treatment and management (Lowe, Balsis, Hughes, Shine, & Carpenter, 2015). For example using reminder notes for people with AD (a tool considered useful in the management of memory problems) was considered to be “a crutch” which could contribute to decline in some studies, although considerable differences were observed even using the same measures; with 68% of participants in one large US study believing this to be the case (Lowe et al., 2015) whereas only 21% agreed in a smaller UK study (Hudson et al., 2012). Other differences in study designs could perhaps account for this variance but it may also indicate contrasting successes in the dissemination of key messages.

Misconceptions and illness perceptions that perpetuate and do not coincide with current predominant scientific best evidence may obstruct attempts to reduce risk and improve early diagnosis efforts (Lowe et al., 2015; Roberts et al., 2014). Misconceptions that nothing can be done to treat and support those with dementia (including by individuals with symptoms, their support networks and health professionals) have been noted to contribute to diagnostic delay (Bunn et al., 2012; Vernooij-Dassen et al., 2005). Greater understandings of where and why misconceptions exist could lead to more effective educational interventions and have been suggested in previous research (Cahill et al., 2015; Corner & Bond, 2004).

However as Cations and colleagues (2018) note, without accompanying infrastructure to facilitate risk reduction and help seeking, the benefits of improving public awareness will be limited.

Attitudes and beliefs that promote (or prevent) recognition and help seeking

A final critical element of dementia literacy (as suggested from the core mental health literacy definition) is that of attitudes towards dementia that may promote recognition and help seeking. There is a large body of evidence linking attitudes to behaviours (Fishbein & Ajzen, 2011). Such attitudes include those that promote help seeking behaviours for oneself or others when faced with symptoms suspicious of dementia (L. Phillipson, Magee, Jones, Reis, & Skaldzien, 2015), but also behaviours such as avoidance of people living with dementia (Blay & Peluso, 2010). Beliefs including that dementia is a normal part of ageing, can impact on the likelihood of seeking help if the outcome (dementia as you age) is considered inevitable (Clare, Goater, & Woods, 2006; Vernooij-Dassen et al., 2005; Werner, Goldstein, Karpas, Chan, & Lai, 2014). Likewise, perceptions of genetics and brain disease as causes of dementia may promote views suggesting that these factors are unavoidable or beyond our control, leading to beliefs that there are no or limited options to prevent dementia or reduce risk (Low & Anstey, 2007; B. J. Smith et al., 2014).

Attitudes towards dementia as captured in some population surveys may however be open to interpretation and can appear value laden. For example a British social attitude survey reported that a substantial majority of those surveyed held relatively negative views about caring for someone with dementia as 71% agreed that “caring for someone with dementia often means that your own health suffers” (NatCen Social Research, 2015). Older people, those with a higher self-assessed knowledge and carers (thus more likely to come into contact with someone with dementia), were more likely to agree with this statement than not, suggesting that respondents were answering on a ‘factual’ basis as opposed to demonstrating underlying negative attitudes. This highlights the difficulty in assessing attitudes if it is uncertain whether the responses reflect positive or negative attitudes and also appears to perpetuate assumptions of the inevitability of “suffering” as a result of caring for someone with dementia.

Stigmatising attitudes have been found in a number of studies examining public attitudes towards dementia (Aihara et al., 2016; Bond et al., 2005; Kim et al., 2015; McParland et al., 2012). Stigma has been implicated as a factor that delays presentation for help or diagnosis (Vernooij-Dassen et al., 2005; Werner et al., 2014). One way this manifests is via fear of being labelled by the disease with the prospect of being discriminated against resulting in a general reluctance to seek help (L. Phillipson et al., 2015). A number of studies have found that participants would feel ashamed if either they or a family member developed Alzheimer's Disease (AD) (Aihara et al., 2016; Cheng et al., 2011; Jang, Kim, & Chiriboga, 2010; Tan et al., 2012). Desires to keep dementia 'hidden' have been suggested as relatively common in Asian Societies (Aihara et al., 2016).

Stigmatising attitudes can profoundly undermine well-being and quality of life for those with dementia and those who care for them (A. Milne, 2010). They are widely attributed to a lack of understanding of the disease (Devlin, MacAskill, & Stead, 2007; Jolley & Benbow, 2000; A. Milne, 2010; Vernooij-Dassen et al., 2005) and thus increasing dementia literacy is a core focus of recent UK dementia strategies. Having a good knowledge of dementia is however, not always associated with holding either positive or negative attitudes towards someone with dementia as was found in several studies and so it is likely that there are other, more complex factors at play (McParland et al., 2012; NatCen Social Research, 2015; Tan et al., 2012). McParland and colleagues (2012) found that older people were more likely to hold stigmatising views than younger people and, for example, subscribe to the view that newly diagnosed people with dementia were not able to lead independent lives. This has implications for both those with dementia whose autonomy and abilities are instantly put into question at the point of diagnosis as well as potential carers who consider that responsibilities become likewise, immediate. Such findings indicate the significance of culture and context in understanding the development and sharing of attitudes.

Fear of dementia is also widely reported on in this body of literature (Cahill et al., 2015; Corner & Bond, 2004) and can act as both a barrier and a motivator to behaviours related to dementia (Low & Anstey, 2009; Tan et al., 2012). Riva and colleagues (2012) considered that participants in their study were "sufficiently

informed and they are afraid of AD” and this perceived vulnerability was considered a crucial prerequisite to help-seeking (Riva et al., 2012, p. 514). Fear of developing dementia was considered to be greater than the pleasure of doing something that might increase their risk of dementia (e.g. smoking) and was observed as a potential motivating factor to stop certain behaviours in Kim et al’s (2015) study. Another qualitative study revealed that older people experienced difficulties in confronting their fears about developing dementia and its possible outcomes, consequently they were reluctant to even discuss dementia and were also less likely to visit people within their networks affected by dementia (Corner & Bond, 2004). Evidence from a variety of studies suggests considerable diversity in older people’s views on the matter. Whereas several studies have revealed that older adults fear developing dementia (Cantegreil-Kallen & Pin, 2012; Corner & Bond, 2004), yet others suggest that the majority of older adults are not particularly worried about developing dementia (Low & Anstey, 2009; Roberts et al., 2014; L.H.J. Yeo, Horan, Jones, & Pendleton, 2007). It is possible that misconceptions (dementia is a normal part of ageing) or established beliefs (that nothing can be done), as identified earlier may contribute towards influencing this seeming lack of concern. However there has been little investigation exploring this in more detail.

Dementia literacy, social networks and social support

It has been suggested that public opinion and social networks can influence dementia knowledge and help seeking behaviours within network members (Blay et al., 2008; Friedman et al., 2009). Blay and colleagues (2008) study demonstrated that belief systems prevalent in communities and in particular in people’s social networks have an important role in where help for treatment and support is sourced. Help seeking, they observed, focused initially on people’s most intimate circles and then moved outwards, with those having a broader web of communications accessing these opportunities for information and support, before then turning to professionals (Blay et al., 2008). Kim and colleagues (2015) focus group approach to examining attitudes towards dementia and risk reduction highlighted a mechanism of dissemination of knowledge. Although some individual participants lacked dementia knowledge, group interactions enabled a few more knowledgeable participants to share their understandings. Media stories or indirect experiences from family and friends with dementia experience were the main sources attributed to their acquired

knowledge (Kim et al., 2015) as has been found in other studies (Devlin et al., 2007; Friedman et al., 2009). A study that asked older adults for recommendations on most appropriate disseminating of brain health promotion messages included spreading messages via their own social networks with some suggesting inviting medical specialists to their existing group meetings to “broaden our knowledge” (Friedman et al., 2009, p. S57). Participants in the study also identified social comparison as a motivating factor by comparing themselves with similar others who were achieving the recommended healthy diet and active lifestyles for example and thus considered peer educators as another potentially useful mechanism (Friedman et al., 2009). In spite of this limited exploration of social networks role in the dissemination of dementia literacy, it is possible to glean some information about such activities from other studies reviewed and theoretical knowledge. Pleasant and Kuruvilla (2008) have argued that “The diffusion and use of knowledge in society is arguably one of the most important factors in improving health outcomes” (2008, p. 158). However if the knowledge is inaccurate or shared beliefs regarding appropriate health behaviours do not coincide with best evidence and practice, this can be problematic. Similarly continued dissemination of the predominantly negative discourse surrounding dementia throughout the general population, can cause perpetuation of bleak and unchanging outlooks (McParland et al., 2017; Reed et al., 2017). In order to address some of these concerns (and also in response to the WHO action plan requirements (World Health Organisation, 2017) a number of media campaigns have been developed.

The role of the media and broader societal perspectives on dementia literacy

What people know about dementia has had a greater focus than how people know about dementia including their sources of information. However this appears to be a key factor in understanding where misconceptions and attitudes towards dementia arise and persist. Understandings of the impact of cultural literacy (collective beliefs and practices) and civic literacies (knowledge of social processes including media roles) from Zarcadoolas and colleagues (2009) elaboration of critical health literacy warrants consideration regarding widely held public beliefs about dementia. As indicated in the introduction to this thesis, predominant views of dementia are negative and frequently evoke fear with stigmatising attitudes towards those with the condition widespread (McParland et al., 2012; A. Milne, 2010) and

such representations then form part of a “shared narrative” (Van Gorp & Vercruyssen, 2012, p. 1275). A qualitative study aimed at understanding the construction of such representations analysed print media and conversations with carers of people living with dementia (Peel, 2014). It found two main discourses - “panic and blame”; one related to the notions of dementia on an “epidemic” scale and its impact as a public health “crisis” (underpinned by a biomedical ideology); and the second associated with the prevention of dementia made possible from individual health and lifestyle factors (Peel, 2014, p. 885). Such dichotomised portrayals of dementias as preventable through lifestyle and behavioural modifications (framed by the catastrophic potential outcomes resulting from inaction) may, the author suggests, signal “victim-blaming” for those afflicted who have failed to age successfully (Peel, 2014, p. 886). As the focus on preventative behaviours is a fairly recent phenomenon, this may indeed impact more in the future. The role of the media in distributing not only health information, but influencing attitudes (key components of dementia literacy) is apparent. This may be beneficial if accurate and balanced pictures of dementia and people living with the condition are portrayed. However these have to date been almost exclusively framed from a negative perspective (Van Gorp & Vercruyssen, 2012).

A number of recent multimedia campaigns have attempted to raise awareness of dementia aimed in particular at improving public attitudes and reducing stigma (Aihara et al., 2016; Werner & Kermel Schiffman, 2017). Aihara and colleagues (2016) found that those who accessed multiple information sources or had conversations about dementia more frequently had more positive responses following the campaigns. Werner et al (2017) found a similar result but also suggested that those who accessed more sources were likely to be more receptive or motivated to do so as they tended to be older, were more familiar with dementia and were more worried about developing the condition. Although positive emotional responses were elicited in Werner and colleagues study, stigmatising attitudes were unaltered - as was also observed in some mental health literacy campaigns (Clement et al., 2013). The fundamental approach, breadth and focus of campaigns may impact differently and be more or less effective dependent on this (Corrigan, 2015; Stuart, Sartorius, & Thornicroft, 2019). Corrigan (2015) details two distinct approaches to addressing mental health stigma: a rights based approach involving those with lived

experiences challenging discrimination; and a service based approach framing mental illnesses as treatable disorders aiming to influence a broad population's views of services using health communication channels. The two approaches may impact on different populations and may not always complement each other. Addressing the different types of stigma has been acknowledged as particularly problematic (Griffiths, Christensen, & Jorm, 2008).

Similar dementia literacy campaigns are emerging in the UK (albeit with differing objectives) including; #STILLME in Northern Ireland aimed at raising awareness of the signs of dementia and reducing stigma and fear about the condition, and ACT NOW in Wales urging everyone to adopt a healthier lifestyle to reduce their risk of developing dementia (#STILLME dementia campaign launch | HSC Public Health Agency, 2016; "Welsh Government|Healthier living NOW can reduce dementia risk", 2017). Both campaigns were launched in 2016 and as yet there are no published peer reviewed reports of their impact. The Welsh Government communications campaign (ACT NOW) is ongoing. It aims to help people understand about dementia and to inform the public "that adopting a healthier lifestyle now can reduce the risk of developing dementia later in life by up to 60%" ("Welsh Government|Healthier living NOW can reduce dementia risk", 2017, opening paragraph). The campaign was largely informed from the findings of a longitudinal cohort study over 30 years in Caerphilly, Wales that indicated that addressing specific lifestyle factors (maintaining physical and social engagement, reducing obesity, avoiding excessive drinking of alcohol and smoking) as advocated in the campaign, could reduce the risk of cognitive impairment (Elwood et al., 2013). Overall public knowledge of risk factors for dementia in Wales was low (reducing from 8.5% answering all seven statements correctly to 5.9% post survey). Over one in five surveyed (24% W1 and 22% W2) agreed that "There is nothing anyone can do to reduce their risk of getting dementia". There has as yet though been limited awareness of the campaign with 15% pre (W1) and 16 % post (W2) survey awareness of the ACT NOW campaign launch (Cox, 2017).

The successes of media campaigns are likely to be dependent on numerous factors and a number of recommendations based on past learning has been suggested (Devlin et al., 2007; Randolph & Viswanath, 2004). Campaigns may for example be

competing with factors such as powerful social norms, pervasive alternative perspectives to the views proposed and suggest behaviours that audiences lack the resources to change (Wakefield, Loken, & Hornik, 2010). Planned messages may also have unintended negative consequences; for example if heightened awareness increases fears of dementia it may actually result in reduced dementia literacy due to avoidance of the topic. As identified in the previous studies potential anxieties and fears raised as a result of messages would need to be countered (Devlin et al., 2007; Peel, 2014). Such is the focus on measuring what is intended (i.e. raised awareness), unintended consequences may however be ignored (Randolph & Viswanath, 2004). The crowded media landscape where mixed messages are relayed by other media sources can confuse messages (Gerritsen et al., 2018; Peel, 2014). In particular few campaigns appear to take account of media reporting separate to the intervention despite evidence that such coverage can generate exposure to conflicting health messages and influence behaviours (Randolph & Viswanath, 2004). Alongside campaigns, concurrent availability of relevant information, services and support for those motivated and acting on campaign messages should also be in place (Wakefield, Loken, & Hornik, 2010).

Chapter Summary

This chapter has reviewed the literature relevant to a more complete understanding of dementia literacy. It has examined the development and components of health and mental health literacies to do so. Good health literacy may underpin the core foundations of successful understanding, prevention and management of chronic diseases, including dementia. An awareness of levels of health literacy within a population could provide an indication of expectations regarding dementia literacy. It may also allow identification of subgroups that are vulnerable to limited health (and dementia) literacy and associated behaviours and outcomes. However there are no currently available Welsh health or dementia literacy assessments and this is an area that this study aims to address in part.

A number of key issues pertinent to further understanding of dementia literacy have been identified in this review. Recent scientific improvements in dementia knowledge and campaigns aimed at increasing awareness of dementia do not appear to have improved public understanding of dementia (Cahill et al., 2015;

Cations et al., 2018). Although there have been a number of studies assessing dementia knowledge (a core component of dementia literacy), few have taken into account how people obtain this knowledge or considered what is known or believed as opposed to what is not known. Most studies have based their assessment of dementia knowledge on biomedical understandings despite the availability of alternatives. Most studies fail to examine why alternative views exist, and how or why they are reinforced and disseminated and what impact this may have. Understanding what is commonly understood (and misunderstood) about dementia is critical to identifying individuals' underlying thoughts, misconceptions and often firmly held beliefs about what is normal or not and what can be achieved or not as this can impact on their motivations (another core component of dementia literacy) to behave in a particular way (L.N. Anderson et al., 2011). Whereas there is evidence to suggest that health literacy can be developed and shared within social networks to better manage health conditions, facilitate sharing of information, resources, skills (and attitudes) there is little if any equivalent research for dementia literacy. Some studies have suggested that families and friends would be a key source of information and persons first consulted for concerns about cognitive health (Blay, Furtado, & Peluso, 2008; Bunn et al., 2012; Werner, 2003). It is also a topic that many people prefer not to discuss or think about (Corner & Bond, 2004; Langdon, Eagle, & Warner, 2007) as dementia is widely portrayed and perceived negatively and remains a stigmatised condition (A. Milne, 2010). Such conflicting perspectives deserve greater investigation.

Research Questions

This research was therefore designed to address the following overarching research question: What do we know about the dementia literacy of older adults in Wales and the social factors that may influence it? In order to address this, a number of steps were taken in the form of a subset of research questions that could illuminate the main question. i) What do we know about the health literacy of older adults in Wales both across the broader population and within individual's social and support networks; ii) Can health literacy help us to understand dementia literacy within the population? iii) What can we understand about older adult's dementia literacy - how do older people describe their understanding and display attitudes towards dementia?

iv) What are their motivations for knowing (or not) about dementia and what influence do their social networks and social interactions have on this?

4 Methodology

Introduction

This chapter outlines the methodology and overarching theoretical framework used in this thesis. It briefly discusses the complexities in defining some of the study's key concepts: dementia and dementia literacy which impacts on the methodological approaches used in the study's research. An overview of the research paradigm informs the rationale behind this pragmatic convergent mixed methods approach. Finally ethical issues and research reflexivity are discussed. A more detailed explanation of the specific research methods for the separate stages of the research will continue in the following chapter.

The overarching aim of the study was to obtain a deeper understanding of dementia literacy in the older Welsh population (aged 65 and over) and the social factors that may influence this. Health literacy as a more widely established and researched concept can help illuminate and provide a backdrop to this understanding of dementia literacy. This study therefore firstly provides a picture of this population's level of health literacy giving an indication of the potential to act on health information and manage health and disease related demands. To understand the health and dementia literacy within this population we need to first conceptualise the world around them and its potential impacts with respect to these phenomena and begin to explore relationships, patterns or behaviour within the world and over time. As Alasuutari and colleagues explain:

In short methodology constitutes a whole range of strategies and procedures that include: developing a picture of an empirical world; asking questions about that world and turning these into researchable problems; finding the best means of doing so – that involve choices about the methods and data to be sought the development and use of concepts and the interpretation of findings. (Alasuutari, Bickman, & Brannen, 2008, p. 1)

Adopting a mixed methods approach for this study

The decision to adopt a mixed methods approach for this study was dictated largely by the research questions identified in the last chapter and an understanding of the complexity of the phenomena of interest. The purpose of conducting mixed

methods research is to provide a more complete understanding of a phenomenon than would otherwise have been possible using a singular approach (Bazeley, 2018; Creswell & Clark, 2007). Qualitative and quantitative approaches can come together in a complementary way that builds on and combines their individual strengths (Morgan, 2007) and this was the intent with this study's research.

Cognitive Functioning and Ageing Study (CFAS) Wales

In order to establish an understanding of the health and dementia literacy within the Welsh population, use was made of the available CFAS Wales, nationally representative study of community dwelling adults aged 65 years and over. The CFAS Wales study was funded by the Economic and Social Research Council (ESRC) and the Higher Education Funding Council for Wales (HEfCW) and builds on the design and infrastructure of the successful Cognitive Function and Ageing Study collaboration (MRC CFAS, 1998). The study was originally designed to investigate physical and cognitive health and the interactions between health, social networks, activity (physical and social) and participation (Clare et al., 2017). Specifically, the five core research areas are: incidence and prevalence of dementia, social networks, resilience, cognitive reserve and nutrition. The thesis draws on data from the CFAS Wales survey sample to answer research questions about the health literacy of the population. This study also involved the collection of new data (via qualitative interviews), specifically for the purpose of this study and were taken from the same CFAS Wales cohort.

Quantitative data

Although the CFAS Wales data set did not itself contain a measure of health literacy, an approach described in more detail in the next chapter was used to establish one. This survey data, gathered in an objective manner (utilising a positivist approach) has thus enabled generalisations about this population's health literacy to be made. Secondary analysis of existing data, as in this case by making use of the CFAS Wales data, allowed me to analyse a large data set that it would have been very unlikely for me to have been able to collect myself (Dale, Wathan, & Higgins, 2008). The benefits of the use of secondary data are apparent, but are not without issues. As CFAS Wales data was collected for a purpose separate to that intended for this study it was initially investigated to determine if it was suitable to address this

study's research questions. The provenance of the data (why it was collected, its trustworthiness and currency) were established (M.P. Johnston, 2017). A common concern regarding secondary data use is that not all the questions that the researcher would have liked to have asked have been. This is certainly the case in this study as ideally a measure of health or dementia literacy would have been included in the CFAS data set used. Another issue with accessing secondary data is that often researchers using the data have not generally participated in its data collection design or process and thus do not have an insight into response rates or potential (mis)understandings of survey questions. This concern can generally be overcome by accessing study documentation and technical reports (Goodwin, 2012). In this case however, although I was not involved in the study design, I did take part in a second wave of the CFAS Wales data collection and so this was not an issue.

Qualitative data

There are a variety of approaches to qualitative data gathering and analysis dependent partly on the ontological and epistemological viewpoint of the researcher that reflects the purpose of the data collection, the approach to data collection, and intentions of its end use (Creswell, 2013; Lewis, 2015; Miles, Huberman, & Saldana, 2013). The primary focus of my analysis was to capture and interpret the substantive meanings in the data. I wanted to better understand older adult's knowledge, attitudes and motivations about dementia; what they know and believe about it, including risk reduction possibilities, treatment, care and its impact on others - in other words their dementia literacy. In order to better comprehend what dementia literacy meant for participants I aimed to explore under what circumstances they accessed information, from what sources and how information was understood and shared within their social networks. In depth qualitative interviews were considered the most appropriate choice to ascertain these perspectives.

Qualitative interviews are a powerful mechanism of capturing the voices and the ways in which people make sense or understand their experience of a particular phenomenon of interest (Rabionet, 2011). The theoretical background to the approach is the reconstruction of subjective views. Therefore in using this method I concentrated on the content of subjective theories for example around subjective dementia knowledge and attitudes and how this may be applied. There are debates

about how far knowledge is constructed during the interview process or whether it is an existing phenomenon that is extracted and what the interviewer's role then is within the interaction (A.Yeo, Legard, Keegan, Ward, McNaughton Nicholls & Lewis, 2013, p.179). A pragmatic view is that interviews allow access to the meanings that individuals attribute to their experiences and social worlds. The interview, although an interaction which could influence the data generated, does not discount the possibility that it does provide an account of the interviewee's experiences, views and interpretations of the phenomenon of interest (Ritchie et al., 2013). A social constructivist approach is one where 'realities' are continuously created/re-created and based on participants' social and experiential interactions with social phenomena. Meanings are therefore not fixed but evolving, dependent for example on prevailing historical or cultural views (Alasuutari et al., 2008), and this was evidenced during the interviews where participants referenced how dementia used to be considered in their past. It is therefore important within this research paradigm to explore how these social constructions occur. This perspective better reflects the complex set of circumstances that have informed and continue to inform people's knowledge and understanding of dementia and of the evolving concepts of health and dementia literacies. For this study it is not only important how health or dementia literate people are, but what meaning or relevance this has for them and what or who may influence its relevance.

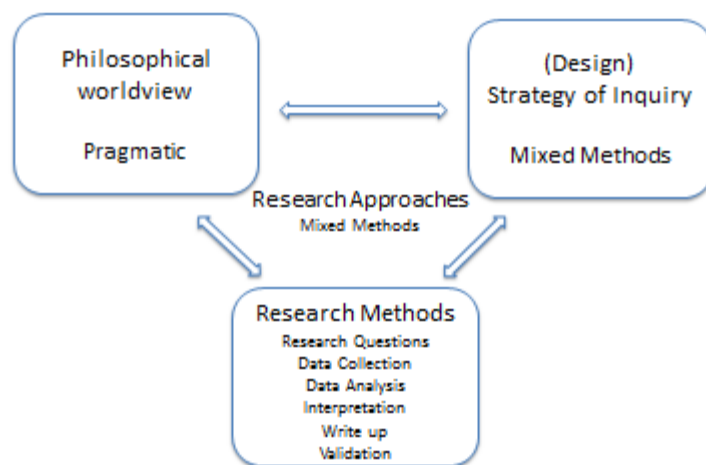
Integrating methods: a pragmatic philosophical framework

Qualitative and quantitative approaches to undertaking research have previously been considered as mutually exclusive approaches to understanding the world, and the ongoing debates were termed by Gage (1989) as the "paradigm wars" (p4). These were essentially debates about the underlying philosophical ideas rather than debates about the technical merits of particular methods (Onwuegbuzie & Leech, 2005). Pragmatists can provide a philosophy that supports paradigm integration and thus the complete integration of methods (mixed methods) within a single study (Johnson, Onwuegbuzie, & Turner, 2007).

Pragmatism, has gained traction as it capitalises on the strengths (and associated methodologies) of both positivism and constructivism (Johnson & Onwuegbuzie, 2004; Tashakkori & Creswell, 2007). Epistemologically, pragmatism

does not conform to any one philosophy but instead focuses on what needs to be done to answer the research problem (Creswell, 2014). It uses diverse approaches and, by giving primacy to the importance of the research problem and associated questions, as opposed to the method, it values both objective and subjective knowledge. Pragmatism accepts philosophically that there are singular and multiple realities available and aims to provide practical solutions to ‘real world’ problems (Feilzer, 2010). It is frequently viewed as the most appropriate paradigm when conducting mixed-methods research as it provides the underlying philosophical framework (B.C. Evans, Coon, & Ume, 2011; Johnson et al., 2007; Tashakkori & Teddlie, 2010). The interconnection of this mixed methods approach including the philosophical worldview, research design and research methods is depicted in Figure 4-1.

Figure 4-1: The interconnection of worldview and strategies of inquiry (adapted from Creswell, 2014 p5)



Defining concepts

When applied to concepts of health and illness, pragmatism can suggest that people give illness its meaning by enacting it (for those with a specific condition) and responding to it (for those who do not) (Conrad & Barker, 2010). How illness is understood and experienced should be considered within the context of people’s everyday lives. This thesis acknowledges that different conceptualisations of dementia exist within our society (and this has been more fully considered within Chapter 2; the framing of dementia). These different conceptualisations impact on

how dementia is more widely understood, affecting not only policy, practice, treatment and management but how people react to the condition and behave towards those who live with it (Gerritsen et al., 2018). There are differing opinions of the causes and nature of dementia, not only among lay people but also health care professionals, scientists and theorists (Frankish & Horton, 2017; Livingston et al., 2017; Norton et al., 2014). This can cause confusion when attempting to ascertain ‘knowledge’ of the condition.

Our knowledge of dementia has changed considerably over centuries. Dementia had acquired a medical connotation by the early 18th century, but was considered an inevitable aspect of ageing until the 19th century (Cipriani, Dolciotti, Picchi, & Bonuccelli, 2011). Up until the early 1970s symptoms of dementia were linked and categorised by age so that Alzheimer's disease was considered exclusively as pre-senile dementia as opposed to the already existing senile dementia (McParland et al., 2017). Research and scientific understandings of dementia have proliferated, particularly over the last 50 years. Advances in biomedical research have identified possibilities of understanding complex genetic risk factors and potential for interventions. Similarly pharmacological advances have seen the emergence of some medicines with the potential to limit cognitive decline (at least temporarily), however promised cures and wide scale benefits remain elusive (Bond & Corner, 2001). The biomedical perspective of dementia continues to dominate our understanding, with an emphasis on loss of function and decline until death - the “tragedy discourse” which is often presented in media stories in particular (McParland et al., 2017). But there is an increasing body of evidence (including decades of social research) that demonstrates the influence that social relationships, engagement and support can have on the capabilities of people living with dementia (Vernooij-Dassen & Jeon, 2016). This understanding challenges the negative perceptions that the effects of dementia cannot be ameliorated and offers an opposing discourse of “living well” with dementia (Banerjee, 2010; Department of Health, 2009). McParland and colleagues (2017) suggest incorporating an approach that recognises more than a dichotomised discourse (either living well or of tragedy) at either end of a “successful ageing” paradigm and that the complex nature of dementia should thus be considered along a continuum of the condition reflecting the “multiple and complex realities of dementia” (McParland et al., p. 8; Rowe & Kahn, 1997).

Dementia literacy, (which has been examined in some detail in Chapter 3), must equally account for this changing dementia knowledge and the alternative perspectives that are available. This should occur within the developing construct of its overarching framework - health literacy; which has over time shifted its focus from an ability to function in medical settings (functional health literacy) to acknowledge that other factors influence health at a societal level in everyday lives (Freedman et al., 2009). Dominant frameworks such as biomedical models of health and illness are subject to social forces such as public and lay beliefs that are long established (and medically concurred e.g. senile dementia) (Holman, 2015). Dementia literacy, it is anticipated, will be influenced at all levels by the structures surrounding individuals and policies of the time as well as those that have gone before and remain of relevance to individuals and their networks. Many factors that influence dementia literacy occur over time and context and are impacted on within people's social relationships and wider society. A life course perspective is useful when considering skills, experiences and knowledge gathered over a lifetime (Alwin, 2012; Squiers et al., 2012). Access and expectations of social support (including informational) and social capital is often embedded within broader social and historical process and occur throughout the life course (Antonucci, Ajrouch, & Birditt, 2013; McDonald & Mair, 2010) and will need to be considered when appreciating long established understandings of and attitudes and behaviours towards dementia.

A fuller conceptualisation of dementia literacy, with greater clarity on its attributes or core components would be helpful, but does not appear to have been explored in any detail to date. The relevance of the context of dementia literacy and its significance at an individual level (for example considering one's own possible risk and actions) and population level (recognising the factors that influence current health inequities surrounding dementia) would align it more closely to the current concepts of health literacy (Dua et al., 2017; Wortmann, 2012).

A convergent mixed methods approach

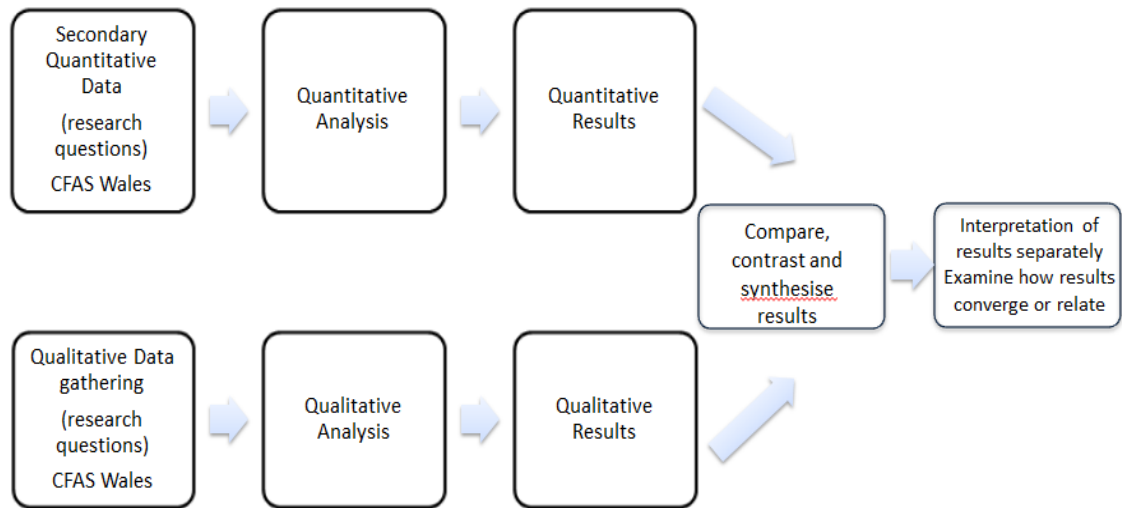
The approach used in this thesis is best described as a convergent mixed methods approach (depicted in Fig 4-2), where different, but complementary data is collected separately but around the same topic area. The different approaches taken

allow distinct aspects of the overarching research question to be explored (Pluye & Hong, 2014). As Bazeley explains:

To deeply understand human experience and human behaviour at any level, whether that be individual, group, or societal, it is beneficial, if not essential, to employ a variety of approaches, components, data, and/or strategies for data collection and analysis. (Bazeley, 2018, p. xi).

It is commonly agreed that mixed methods studies should in some way combine qualitative and quantitative research in viewpoints, research design, data collection and/or analysis (Johnson et al., 2007; Shannon-Baker, 2016). One method, within a pragmatic approach, is to use inductive and deductive reasoning from the different approaches to theory and data and synthesise the results to present the different perspectives of ‘reality’ (Creswell & Clark, 2007). This process, referred to as abduction has been proposed as most useful in arriving at the best explanations and understanding of the data (Feilzer, 2010; Johnson & Onwuegbuzie, 2004). The health literacy levels estimated for the older Welsh population contributes to an understanding explored more deeply within the qualitative dementia literacy interviews. These interviews have helped to suggest relationships discovered in the quantitative data. This was particularly exemplified in regard to the possible social nature of the distribution of information within different social support network types and those with higher levels of social participation. The qualitative interviews explored phenomena from a natural setting (the relevance or not of dementia to participants personally) and may be interpreted in terms of the meanings that people bring to that setting. Both sets of data were collected and analysed separately, and then finally synthesised and interpreted together (within chapters six and seven). The goal of mixing methods is not always to search for corroboration but rather to expand one's understanding (Onwuegbuzie & Leech, 2005), and this is the case in this research study. The research strategy used the most appropriate available data (CFAS Wales) to address the research questions, and the results from the different data sources were juxtaposed to develop complementary insights in order to create the bigger picture (Brannen, 2005). Thus the convergence of the approaches add to and complement each other, enabling a more complete picture of the overarching understanding of dementia literacy within older adults in Wales to be viewed.

Figure 4-2 Convergence Model (adapted from Creswell & Clark, 2007, p. 63)



Ethical Considerations

There are ethical issues to consider throughout research endeavours; from the research questions posed, the development of the research proposal and design, conducting the research through to the analysis and the final reporting (Creswell, 2014). The following overarching statement encompasses a core value that was adhered to throughout this research: “The principal ethics consideration should be to ensure the maximum benefit of the research whilst minimising the risk of actual or potential harm” (ESRC, 2015 p 2).

A number of key guidelines and texts were consulted with regard to ethical considerations throughout the research study; in particular the British Society of Gerontology (BSG) guidelines on ethical research with human participants (British Society of Gerontology, 2012) and the Statement of Ethical Practice for the British Sociological Association (BSA, 2017). Other relevant resources were consulted at specific stages of the research to ensure attention was given to the design and planned conduct of the research and the maintenance of sound ethical standards throughout (Bryman, 2015; Creswell, 2014). As the research population studied for this research fell under the auspices of the Cognitive Functioning and Ageing Studies (CFAS) Wales it was considered prudent to consult ethical research bodies funding the overarching study (i.e. the ESRC) and to follow their principles and expectations

in addition to drawing from others' experience within the CFAS Wales research team. Creswell (2014) presents a table and checklist detailing the ethical issues and how to address them, throughout the different stages of the research process (from preparing for ethics submissions, design of information and consent forms, conduct of interviews, thoughtful analysis and honest reporting) and these were usefully referred to and reflected on at these stages (Creswell, 2014, pp. 93–94).

The welfare of all participants demands careful attention throughout the design and implementation of any research project. This was particularly salient for this research study which is actively concerned with what may be considered as sensitive topics; including ageing issues, cognitive functioning and health literacy. Therefore attempts were made to minimise any risk of causing distress within the questionnaire design and by conducting interviews sensitively and participants were, for example, reminded that they could terminate the interview at any point should they wish to stop. Many people enjoy participating in research projects which gives them an opportunity to contribute to a topic they are interested in and to have their voice heard on the matter (Mcmurdo et al., 2011). Consideration was given to individual's specific needs related to their general health, cognitive ability/disability, physical frailty, literacy, background and culture whenever arranging and conducting interviews. As far as possible, attempts were made to ensure that all participants had as positive an experience of the research activities as practicable (BSG, 2012).

From the inception of the research project, its value, merit and relevance were considered and how best to do this from both a methodological and ethical perspective. A clear aim was to conduct a worthwhile research project that would benefit those involved in the study, or failing that, would certainly aim to contribute to the knowledge that would benefit others in similar circumstances in the near future.

Reflective practice

Throughout the study, I aimed to demonstrate reflexive research practice. I acknowledge the importance of recognising my social position and my own values, assumptions and theories of health (Feilzer, 2010). This particularly came to light when assessing what was known about dementia within the qualitative interviews. I

realised that I was initially making my assumptions of dementia knowledge as per the biomedical model that currently frames dementia literacy. Although this is typical of studies of dementia literacy and dementia knowledge to date, it does not acknowledge the availability of alternative perspectives. I have therefore included the additional framing of dementia chapter to present these alternative views. Although I aimed to avoid asserting influence in any specific direction within the qualitative interviews in particular, but also throughout the research process, inevitably my world view impacts on this process. My reflective practice therefore incorporates two fundamental characteristics; careful interpretation and reflection when presenting reviewed literature or interpreted analyses for example. All references to empirical data are the result of interpretation. This requires constant awareness of theoretical assumptions, pre-understanding of phenomena and the importance of language throughout reporting (Alvesson & Sköldbberg, 2017). Reflection within empirical research can be understood as the “interpretation of interpretation” and therefore I have critically explored my own interpretation of data and taken for granted assumptions throughout (Alvesson & Sköldbberg, 2017, p. 11). The research process involves (re)construction of the social reality of the researcher and the researched, and interpretation of data with the aim to illuminate a particular phenomenon, which if not carefully performed may inadvertently suppress alternative meanings (Silverman, 2015). I have aimed to make all methods, actions and my interpretations as transparent as possible throughout this thesis. The following reflections provide a tangible example of this practice and provided an opportunity to share my reflections with other researchers involved in the qualitative interviews.

Reflections on the qualitative interviews

During a debrief session held after the completion of the qualitative interviews the three interviewers discussed and reflected on their perceptions of the conversations. A shared view was that talking about dementia was not something that many participants were fully at ease with. The subject matter, we concurred, was either not something that participants usually discussed, was something that they had not given a lot of thought to (confirmed by several of the participants in their interviews) or that they were otherwise hesitant to express expansive views on the matter. All participants at this stage would have taken part in at least three CFAS

interviews (two computer assisted survey interviews and one previous qualitative interview) between 2011 and 2016. In addition participant information sheets and at least one newsletter promoting the project's progress would have been received by all participants. However it was apparent by the reactions of some, for example appearing slightly taken aback as the dementia section was introduced, or by the brevity of responses that this topic of conversation caused them a degree of uncertainty or discomfort. All three experienced interviewers found in some instances, that careful probing still did not elicit further elaboration to questions asked. A shared concern was that for those with a cognitive impairment, intensive probing on aspects of dementia knowledge could have been misinterpreted as interrogating them on their own condition, meaning that we may have been slightly overcautious for this group. This and the possible genuine lack of participant interest or knowledge of the topic meant that responses to specific questions on areas of dementia knowledge in general were often quite brief. Although interviewers were aware of a participant's MCI classification as determined in their first CFAS Wales interview, the extent of participant's acknowledgement of their own condition appeared to vary. One participant readily referred to her memory problems as dementia in spite of her lack of a diagnosis (she was waiting for an appointment with a psycho-geriatrician, following tests including a brain scan) and appeared to be relatively at ease with this term when initially asked about her condition. However she exhibited strong self-stigmatising attitudes (for example referring to herself as "stupid" or "wonky") throughout the interview when she was uncertain how to respond to some questions or was recounting events that appeared to draw attention to her condition and perceived limitations. Others seemed reluctant to consider their conditions as either dementia or potentially a precursor to dementia. Instead there appeared to be a degree of self-denial of this possibility or perhaps as in the case of one participant, had been informed that "it hasn't got to that stage". The duration of the interviews (as a second part of a longer interview) and possibly that there was only a single interview held with each participant conducted, did not perhaps allow sufficient time to gain greater confidence or rapport. Doing so may have allowed fuller exploration of some of these more complex issues. On a similar point another observation made by all interviewers was that the use of humour in several accounts was often seemingly used as a device to deflect from something potentially

upsetting, or from continuing along a conversational pathway that they were reluctant to pursue. This we all noted was a successful ploy.

Summary of study rationale and my mixed methods approach

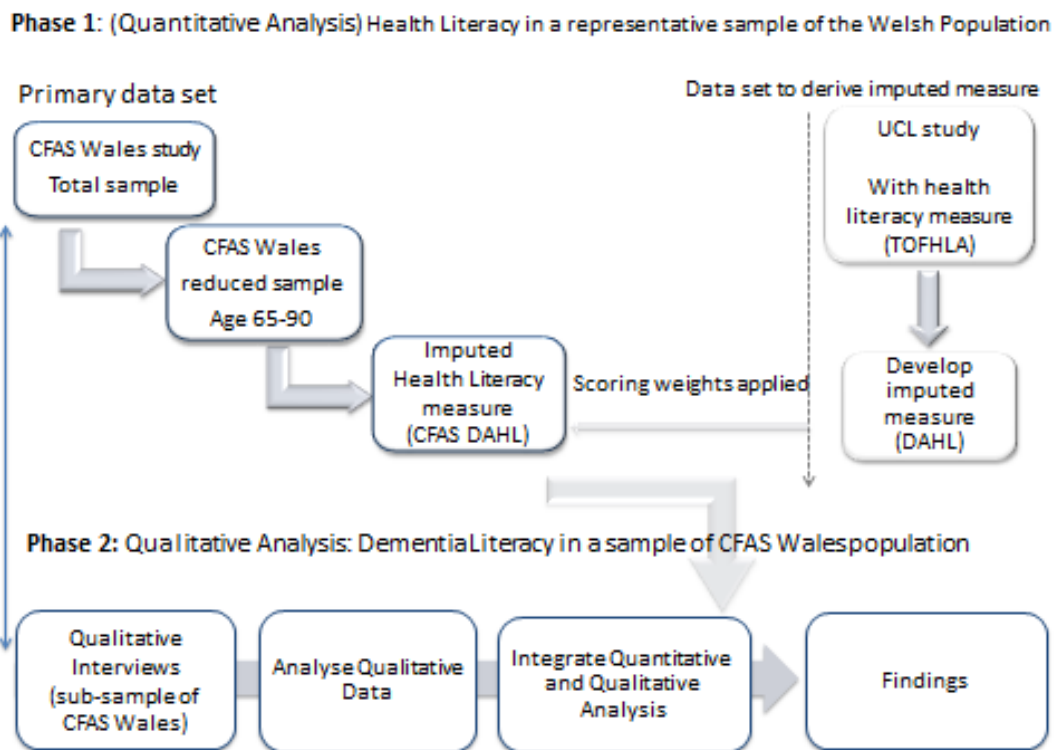
I considered an overarching pragmatic theoretical framework to be most appropriate to reflect my own world-view and within which to fully address the research questions. I aimed to select the most appropriate approach to address the research questions while taking into consideration the importance of sound theoretical underpinnings. The reasons for adopting a convergent mixed methods approach in this thesis are: a) there is relatively little research on dementia literacy and an exploratory approach facilitates greater understanding of the complex concept and what factors (such as social networks) might influence it, b) dementia literacy is an aspect of health literacy a topic on which we know more. Investigating levels of population health literacy and its influencing factors in the cohort studied may provide a useful mechanism for gaining a more complete understanding of the related concept of dementia literacy.

5 METHODS: RESEARCH DESIGN AND PROCESS

Introduction

This chapter details the methods involved in the two separate phases of this mixed methods study to explore the dementia and health literacy of older adults in Wales and explains the steps involved in addressing the research questions that together can support the main thesis aim. The previous chapter gave a rationale for this overall research methodology. An overview of this convergent mixed method process and the core Cognitive Functioning and Ageing Study (CFAS Wales) and supplementary data set involved is depicted in Figure 5-1. The phases are detailed below for simplicity, in the order they were conducted and not in order of primacy of methodological approach.

Figure 5-1 Overview of the study process



The chapter initially describes the study populations used in each phase of the research as well as relevant recruitment and training process involved, before detailing the key measures, variables and sampling strategies used within the

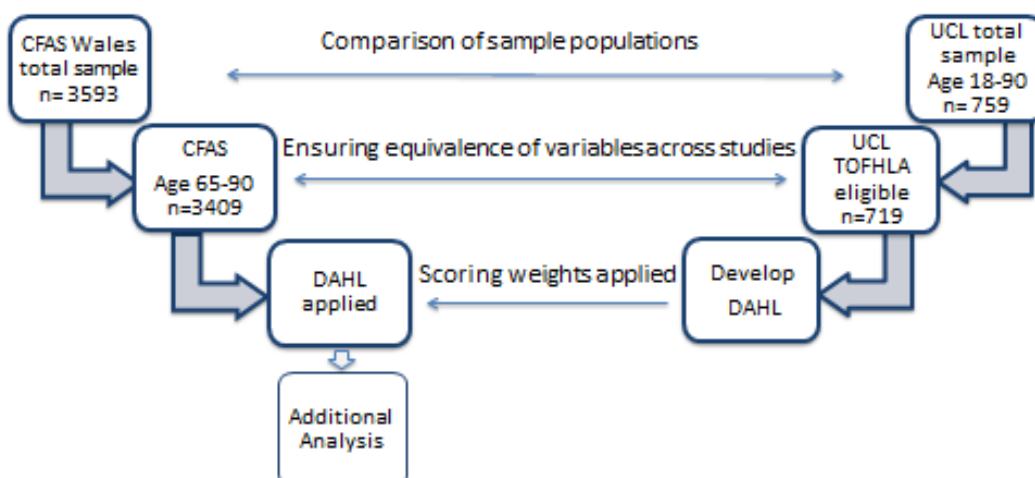
analysis. It describes the quantitative and qualitative methods of the research separately before explaining the process of integrating the results.

PHASE 1: HEALTH LITERACY STUDY OVERVIEW

QUANTITATIVE STUDY

The aim of this part of the analysis was to arrive at an estimation of health literacy within the CFAS Wales study population. It used an established methodology to derive an imputed or proxy measure of health literacy, from predictor variables available in the study population sample (Hanchate et al., 2008). This required the use of two data sets, the primary data set being the CFAS Wales data and the second data set containing both a validated health literacy measure, and equivalent predictor variables to those available in the core data set. In brief, this study firstly identified a comparable UK dataset with a validated health literacy measure, secondly it derived weights based on regression analyses from this comparable dataset and finally applied these weights to impute a synthetic health literacy measure - the CFAS Demographic Assessment of Health Literacy (CFAS DAHL) within the primary CFAS Wales data set (see Fig 5-2). An overview of the study populations used in this process is included below. A detailed description of the steps involved in the CFAS Wales data collection is initially presented prior to a brief description of the second data set - The University College of London (UCL) Study before continuing to present the regression model used to estimate health literacy in the CFAS Wales population.

Figure 5-2 Creating the health literacy measure in CFAS Wales



Core study population – Cognitive Functioning and Ageing Study Wales

Sites of data collection

The CFAS Wales study was conducted in two main areas of Wales; representing a largely rural area in North Wales (Gwynedd and Ynys Môn) and a contrasting relatively densely populated, urban area of South Wales (Neath and Port Talbot). Neath and Port Talbot represents one of the most deprived Unitary Authorities in Wales (13.2% of its 91 Lower Super Output Areas (LSOA) are in the top 10% most deprived compared to 2.3% of Ynys Mon's 44 LSOA's and 4.1% of Gwynedd's 73 LSOA's) (Welsh Government, Knowledge and Analytical Services, 2018). The overarching health profiles of the two study areas also differed with older people in Neath Port Talbot (NPT) having poorer overall health status and reporting more limiting long-term illnesses (33% in NPT compared to 24 % (G) and 27% Ynys Môn) than their counterparts in Gwynedd (G) and Ynys Môn (YM) (Welsh Government, Knowledge and Analytical Services, 2018)

Methods of data collection

The sampling and conduct of CFAS Wales interviewing followed the established methodology developed in the Medical Research Council Cognitive Function and Ageing Study (MRC-CFAS) run from the Institute of Public Health, Cambridge. Recruiting the sample for the CFAS Wales study involved cooperation of the General Practitioners (GP) in the region where the study took place, with the NHS Wales Business Services Centre initially identifying information drawn from GP lists (Clare et al., 2017). GPs screened the age eligible sample to exclude those people that spoke neither English nor Welsh, were diagnosed with a terminal illness or were considered to be too violent or aggressive to participate. Following approval from the GP, the Cambridge team administered and compiled batches of potential participant details (generally 20 at a time, preferably in similar postcode areas) to the trained interviewers. The response rate, in terms of the proportion of those eligible and contactable who participated, was 44% with a further 13% who were unable to participate because of ill health (Clare et al., 2017).

Interviewer Training

Prior to commencing any data collection, interviewers received an intensive three day training to deliver the standardised computer-assisted personal interviews

(CAPI). The training covered all aspects of the interviewing process such as data management, informed consent process, the Mental Capacity Act (Department of Health., 2005) and how to conduct the necessary physical tests such as a timed gait and balance tests, hearing and vision tests. The possible interview types such as full interview, abbreviated version and those completed by an informant were explained and supplementary materials were also provided to ensure consolidation of information after the formal instruction. Following a period of post training practice, all interviewers were required to send in a taped version of a practice interview to the Cambridge Administration Centre for quality assurance prior to going into the field. Regular liaison and rating mechanisms with the Cambridge team ensured ongoing quality control and progress.

The data used in this study's analysis was from CFAS Wales wave 1 conducted between 2011 and 2013. Participants were then followed up two years later (wave 2). I was involved in conducting wave 2 interviews, which took place from September 2015 to March 2016. As it was not critical to this study which wave of data collected was used, it was considered preferable to perform my analysis on wave 1 as it did not then rely on the wave 2 data being cleaned or accessible within the time frame of this study. I will describe the training and data collection that I underwent which was identical to the first wave of data collection.

Training as per wave 1 was conducted at the Institute of Public Health, Cambridge University. I participated fully as a CFAS Wales interviewer conducting all the necessary activities required to recruit, interview and report back to the central team over a six-month period. Thus although I did not collect the data used in this study's analysis, I was involved in an identical process of data gathering and administration. This opportunity provided me with greater insights into the data gathering and handling process than merely accessing the data from a repository would have allowed. The process that I was involved in for conducting the computer assisted personal interviews (CAPI) is detailed below.

Quantitative Survey: Participant Recruitment and Interview

Potential participants were sent a letter inviting them to participate in the study. This initial letter also contained an information sheet about the study and a

photograph of the interviewer who would be conducting their interview. The interviewers made initial contact with the participant in order to introduce themselves, explain the study in more detail and answer any questions, prior to scheduling a convenient interview time. Repeated attempts were made to contact the participant if they were not initially contactable.

Participants were interviewed in their own homes by the trained interviewers (including myself) in their preferred language (English or Welsh) using Computer Assisted Personal Interviews (CAPI), although I conducted interviews in English as I do not speak Welsh. Informed consent was obtained prior to commencement of the interview and involved ensuring that the participants had read and understood the information sheet and had the opportunity to have any questions answered. Capacity to consent was established during this process and the full interview continued if possible. If it became apparent during the course of the interview that the participant was losing concentration, becoming distressed or appeared to have lost the ability to understand what was taking place, the interview could be cut short and continued in an abbreviated form or terminated as required. In these circumstances, where possible an informant interview was carried out with the participant's consultee as per the agreed protocol. In addition proxy interviews with a relative or carer were conducted with 20% of all full interviews at random.

The interview used a combined interview and assessment schedule that had been specifically designed for the CFAS-1 study (MRC-CFAS, 1998) with additional selected questions to cover the core research areas of interest for CFAS Wales, as indicated previously. Questions included in the interviews were established and standardised techniques to enable the investigation of cognitive impairment, physical disability and healthy active life expectancy for the whole group and within groups. Of particular relevance to this research, within the questions is the presence of Wenger's (1991) social support network assessment instrument in addition to many standard socio-demographic questions. The assessment interview also included a measure of cognition - the extended Mini-Mental State Exam (MMSE).

The CFAS Wales Sample for Analysis

CFAS Wales wave 1 data (version 2) was used in this analysis. The baseline sample consisted of 3,593 individuals (Matthews et al., 2013). Those who had proxy interviews (conducted by a participant's consultee) and therefore had missing data in the key areas of interest for this study were excluded from the analysis. The age range for this analysis was also limited to those aged between 65 and 90 years to match the maximum age of a secondary data set – the University College of London (UCL) Study on Functional Health Literacy in the British Population which was used to derive the health literacy measure for this study's analysis (see below) (von Wagner et al., 2007). Therefore a reduced sample of 3,409 CFAS Wales participants was used in the final analysis.

Applicability of supplementary data set (UCL)

The CFAS Wales sample does not contain a measure of health or dementia literacy, and indeed there are no studies in Wales that contain either measure. It was therefore necessary to establish an imputed measure of health literacy (which will be referred to as the CFAS Demographic Assessment of Health Literacy (CFAS DAHL)). This was carried out using data, acquired with permission from a second study (The University College of London (UCL) Study on Functional Health Literacy in the British Population) as detailed in the ethical approval Appendix A. The UCL study contains a measure of health literacy and based on the significant predictability of certain variables (such as education levels, age and sex) can be used to model and predict health literacy when the same models are applied to the primary data set of interest (CFAS Wales). As models were to be created in one data set and transposed to another, comparability, compatibility and uniformity in data and its collection in both studies was assessed for transparency and replicability (Winters & Netscher, 2016). Such checks help to demonstrate the validity of the approach taken in this research. Thus the following section explains the supplementary data set and its design and purpose in more detail.

The University College of London (UCL) Study

The University College of London (UCL) Study on Functional Health Literacy in the British Population is one of the few studies in the UK that contains a measure of health literacy and as far as can be determined, the only one that is

appropriate for the purposes of deriving an imputed measure according to Hanchate and colleagues' methodology (2008). An alternative measure of health literacy within the English Longitudinal Study of Ageing was also explored using the methodology, but provided insufficient detail with an appropriate scale to be viable for this study's purpose. A summary of this research activity is covered in Appendix B.

The original UCL study was designed to measure the prevalence of limited functional health literacy (FHL) in the UK using the Test of Functional Health Literacy in Adults (TOFHLA) (von Wagner et al., 2007). It examined associations of FHL with health behaviours and self-rated health. The population sample included adults aged from 18-90 years from areas covering most of the UK (excluding Northern Ireland and the Scottish Isles). The UCL sample was reasonably representative of the UK population with regard to age and ethnicity but displayed differences in education and gender. There were more participants without a formal qualification (29%) and more women (58%) than representative of the UK population (at 21% and 51% respectively) (von Wagner et al., 2007, p. 1087). Due to the fundamental purpose of the UCL study there were also only a limited number of variables that were not directly related to the TOFHLA measure and its outcome measures; namely self-rated health, physical activity, smoking behaviour and fruit and vegetable consumption.

Test of Functional Health Literacy in Adults (TOFHLA)

The UCL study used the Test of Functional Health Literacy in Adults (TOFHLA) as its measure of health literacy which is one of the most widely used measures and has previously been considered as a gold standard health literacy measurement tool (Haun, Valerio, McCormack, & Paasche-Orlow, 2014). A fuller explanation of the data management and gathering process of the assessment of Test of Functional Health Literacy in Adults (TOFHLA) in the population are available in von Wagner and colleagues' (2007) paper but are included in brief below. The assessment was carried out on those participants correctly answering three out of four questions screening for visual acuity and basic reading ability. All participants in the UCL study answered basic questions on demographic characteristics, self-rated health and specific health behaviours (von Wagner et al., 2007). The TOFHLA

simulates some of the materials that someone may encounter in a health care setting and incorporates both numeracy and literacy skills. Scoring of the TOFHLA was interpreted as 0-59 inadequate health literacy (HL); 60-74, marginal HL; and 75-100 adequate HL as per the original study (Nurss, 2001). The UCL study used a modified version of the TOFHLA to make it more relevant for a UK population (von Wagner et al., 2007). The final adapted version of the TOFHLA modified in both the numeracy and the literacy sections, was sent to the developers of the original TOFHLA (Nurss, 2001) for approval before being re-piloted in door to door interviews.

UCL Sample for analysis

The UCL study, in contrast to the CFAS Wales study, included participants with an age range from 18 to 90 years. The UCL baseline sample consisted of 759 participants, 40 of whom did not pass the preliminary visual acuity test and so were ineligible for the health literacy assessment reducing the sample size for analysis to 719. Matching the two studies in age range (65-90) reduced the UCL sample size further to 159, severely limiting the TOFHLA distribution. The balance between conducting analysis on a vastly reduced data set to maintain integrity with same age samples, and retaining sufficient data for the development of the imputed measure was difficult and so analysis was performed on both initially. The wider distribution of TOFHLA scores and stronger correlation between the CFAS DAHL and the TOFHLA was obtained using the full study sample (n= 719). Therefore reporting continues only for the full UCL sample.

Deriving the measure of health literacy (CFAS DAHL)

The process of establishing the CFAS DAHL as depicted previously in Figure 5-2, gives an overarching view of the data sets involved and the necessary steps taken throughout. Initially the two studies were compared with respect to their sample population and purpose, secondly variables collected in each study were compared ensuring equivalence of these variables between the studies and finally scoring weights derived from the regression model equation from the UCL study (with the original health literacy measure) were applied to the equivalent variables in the CFAS Wales study data. The following section describes this process in more detail.

Variables for developing the health literacy measure (CFAS DAHL)

Prior to developing the predictive models of health literacy the relevant variables were prepared for analysis. In order to facilitate the application of scoring weights from one study to another, variables to be used in any analysis were made equivalent (harmonized) - if required, in other words they were recoded and/or modified to ensure equivalence across both the research studies (Chan, Kasper, Brandt, & Pezzin, 2012; Gatz et al., 2015). The decision criteria for selecting and recoding the data are intended to be as explicit as possible. This process is described in more detail below. All variables selected for inclusion in the predictive models had either a strong empirical or theoretical association to health literacy.

Age

Age was used as a continuous variable in the core analysis for the linear regression for the development of the predictive CFAS DAHL model. Age was matched to cover the same maximum age across both studies i.e. up to and including age 90. It is possible that there are larger differences within this 90+ year age group as previous research has indicated that heterogeneity in health status increases with age and that this is particularly evident in nonagenarians (Santoni et al., 2015).

Sex

Sex (male, female) was measured identically across the data sets used in this study and therefore there was no need for any recoding. Sex has been found to be associated with health literacy in a number of studies (Miller et al., 2007; Protheroe et al., 2017).

Education

Education has been determined to be one of the strongest predictors of health literacy in a number of studies (Hanchate et al., 2008; Miller et al., 2007; van der Heide et al., 2016). The differences in comparing educational levels across studies and age groups can however be problematic. In Britain, as in many other European countries, many of today's older population left school at the minimum age with no formal academic qualifications (Grundy, 2001), as can be seen in the data samples used in this analysis (CFAS Wales 47.3%, UCL 52.3% (in the age 65-90 age range)).

Therefore when recoding was carried out particular attention to achieve equivalence was undertaken.

Recoding the educational level variables

Qualifications that covered a range of different educational levels and skills were recoded and matched between the studies to capture vocational and trade as well as more formal academic qualifications, thus eventually covering five educational qualification options: none (no qualifications); school leaving equivalent and trade qualifications; ‘A’ level, their equivalent and vocational; Higher education-not degree and equivalents; Higher education - degree and equivalents; and foreign or other qualifications. This is displayed in Table 5-3 below.

The education variable was measured as a categorical variable in this study’s analysis and to an extent assumes that certain educational achievements may have a greater impact on health literacy (Grundy, 2001).

Table 5-1 Recoding the educational variables

CFAS → recoded to →	Recoded variable	←recoded to ←UCL
None	None	no qualifications
School leaving certificate	School leaving and trade	trade apprenticeships
Technical college	School leaving and trade	GCSE/O Level grade (<5 A-C)
Secretarial college	School leaving and trade	GCSE/O Level grade A* C (≥ 5)
Trade qualifications	School leaving and trade	-
Completed apprenticeship	‘A’ level and vocational	A levels, vocational level 3 and equivalents
Higher professional qualifications < degree	Higher education < degree	Other higher education below degree level
University degree	Higher education equivalent to degree	Higher education & professional/vocational equivalents
Other	foreign/other	other qualifications

Employment/retirement variable

A number of demographic and social factors have been identified as influential in impacting on a person's level of health literacy such as socioeconomic status, occupation, employment and income (Beauchamp et al., 2015; Protheroe et al., 2017). A variable that reflected current employment/retirement status that could be adapted from the two separate studies was considered to be an appropriate potentially predictive variable and was developed for this analysis. It included categories: retired, not retired (i.e. employed) and those who have never worked to align with the CFAS Wales data.

Recoding the employment/retirement variable

The UCL variable for employment status was matched to the CFAS Wales employment/retirement three possible options: retired, employed or never worked. Working in a paid job (30+hrs), working in a paid job (8-29hrs), working in a paid job, self-employed and unemployed were all coded as employed/not retired; and retired from paid employment and disabled/long term sick were coded to retired; Not in paid employment/looking after house or home was coded as never worked. This is displayed in Table 5-2 below.

The decision to code these last two categories as specified was informed in some part by The National Statistics Socio-economic Classification (NSSEC) guidance (Rose, Pevalin & O'Reilly, 2005). This recognises the difficulty in assigning status particularly with respect to unemployed categories, those who have never worked and those looking after house and home. I therefore coded those participants who specifically selected 'unemployed' rather than any other category as employed/not retired and those who selected 'not in paid employment/looking after house and home' as never worked although it is recognised that these individuals may be either looking for employment or have recently come out of the labour force to take on a caring responsibility for instance (Rose, Pevalin & O'Reilly, 2005). All other responses were coded as missing (n=3)

Table 5-2 Recoding the employment/retirement variables

CFAS Wales	←recoded to ← UCL variable
Retired	retired from paid employment
Retired	disabled/long term sick
Not retired (employed)	working in a paid job (30+hrs)
Not retired (employed)	working in a paid job (8-29hrs)
Not retired (employed)	working in a paid job(<8hrs)
Not retired (employed)	self-employed
Not retired (employed)	unemployed
Never worked	not in paid employment/looking after house or home

Other variables considered and tested in models

Self-reported health

Health literacy has been found to be associated with self-rated health and smoking status (von Wagner et al., 2007). These additional variables were therefore included in the testing of predictive models to ascertain any improvement in predictability on the basic four-factor model.

Due to the differences in responses available in the self-reported health question between UCL and CFAS Wales where UCL responses had included an additional level - ‘very good’ in their scale (excellent, *very good*, good, fair or poor), the variable was therefore recoded. The UCL variable was recoded, with excellent and very good combined and the other options, good fair and poor remaining the same. The variable was used as either this reduced scale or as dichotomised variable for different analysis. The dichotomised version was coded as ‘excellent/good health’ versus ‘fair/poor health’ to minimise any potential recoding imprecisions (Grundy, 2001).

Smoking status

A variable reflecting current smoking status was available in both studies, and which were measured identically.

The CFAS Demographic Assessment of Health Literacy

The CFAS DAHL: A measure of health literacy

Using the UCL data, multiple linear regressions were used to derive equations (scoring weights) for predicting the Test of Functional Health Literacy in Adults (TOFHLA). The continuous variable containing the raw TOFHLA score was used as the dependent variable with the predictor variables being combinations of age, sex, education, retired/employment status, self-rated health status and smoking status. A number of models were tested ranging from a single education model to the six-factor model containing all the relevant and available variables. The models were created to establish the best combination of predictive ability and parsimony for the final CFAS DAHL (imputed health literacy measure). Models with interactions among the variables were not explored in this analysis. Collinearity diagnostics was selected as an option during the multiple linear regression to give additional output that allowed further assessment of any potential collinearity problems (ie ensuring that strong correlations among predictor variables did not occur as these can lead to potentially unreliable estimates of regression coefficients). There were no significantly strong correlations shown in the variables used for the CFAS DAHL.

Selection of the CFAS DAHL model

The purpose of this aspect of my research was to develop an imputed measure of health literacy (the CFAS DAHL) that could serve as a useful proxy measure of health literacy in the CFAS Wales population. Using the UCL data and multiple linear regression, significant models for the six factor predictor model ($F_{6,690}=31.361, p < .0005$), five factor (age, sex, retired, education, self-rated health ($F_{5,691}=37.128, p < .0005$)); and the four factor model (age, sex, retired, education ($F_{4,692}=40.469, p < .005$)) were obtained (see Table 5-3). The five-factor model was selected as the final CFAS DAHL as it retained parsimony, used variables that are commonly available in most demographic and large scale surveys and other than sex, all demonstrated a significant contribution to the model. Although the adjusted R square of 0.21, 0.21 and 0.19 respectively represents a relatively small percentage of the model accounted for by the variables available (21% and 19%), it nevertheless enables a reasonable imputed measure to be developed. An education only model produced an adjusted R square of .095 and although this model too was significant it was not considered to be worthwhile to pursue this single item option.

Significant variables that added to the model are as detailed below (Table 5-3) identified with an asterisk (*); sex and smoking status were not significant predictors in the models. The sex variable, was retained as its removal from the model reduced the overall adjusted R square and additional analysis sorted by sex was planned. Predictive strength of the models, coefficients and R squared were therefore compared across models to obtain the highest R squared value while considering the statistical significance of the predictor variables.

Table 5-3 Descriptive statistics and regression coefficients UCL CFAS-DAHL

Predictor variables	Beta (6 factor model)	<i>p</i> significance	Beta (5 factor)	<i>p</i>	Beta (4 factor)	<i>p</i>
Educational qualifications	.241	.000*	.245	.000*	.261	.000*
Age	-.234	.000*	-.218	.000*	-.248	.000*
Retired or not	-.085	.023*	-.086	.022*	-.108	.004*
Sex	.054	.122	.058	.099	.065	.065
Smoke or not	.053	.138				
Self-rated health	-.147	.000*	-.157	.000*		

Applying the scoring weights to create the CFAS DAHL

The model with the best combination of simplicity and predictability, i.e. the five factor model which included age, sex, education, retired/employment status and self-rated health status, was selected as the CFAS DAHL. The scoring weights of this model were then applied to the selected predictor variables to derive an imputed health literacy score, initially within the UCL data set which enabled comparison of this imputed measure (to be the CFAS DAHL) against the actual TOFHLA measure. Applying the scoring weights within the CFAS Wales data set produced an imputed health literacy score for each of the studies participants. This health literacy measure within the CFAS Wales data set, then allowed additional analyses against other variables of interest.

The regression equation derived from the *B* coefficient constant and the standardised coefficients for the selected variables is detailed below.

$$\text{CFAS DAHL} = 90.381(\text{constant}) + (\text{edqual}*.245) + (\text{qage}*.218) + (\text{qsex}*.058) + (\text{retired}*.086) + (\text{SRhealthUCL}*.157).$$

Testing the relationship between the TOFHLA and the CFAS DAHL

Within the UCL data set, there was a significant positive correlation between the CFAS DAHL and the raw TOFHLA scores ($r = .456$, $n = 697$, $p = < .005$, two tailed). This positive correlation supported the use of the CFAS DAHL as a useful health literacy measure in the absence of a test based measure in a population sample (CFAS Wales in this instance). If the UCL sample was reduced to only those aged 65 and over ($n = 153$) the positive correlation remained ($r = .411$, $n = 153$, $p = < .005$, two tailed) and as stated previously this gives confidence in the use of the full UCL sample for the final CFAS DAHL.

When comparing the distribution range of the CFAS DAHL scores to the original TOFHLA scores in the UCL study, it was shown to have a more compact distribution as the imputed measure is derived from only a few factors.

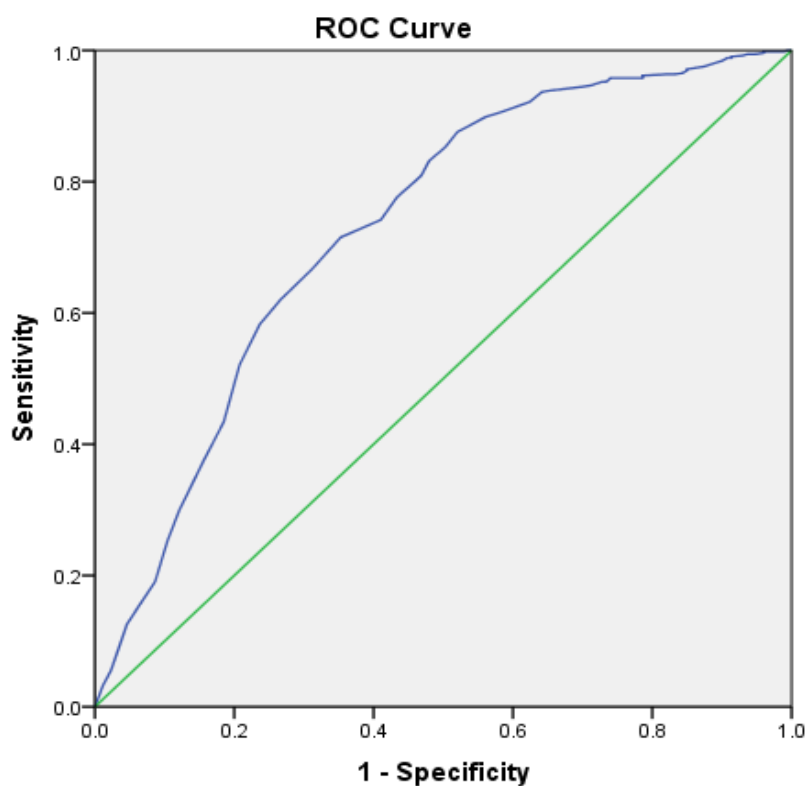
Testing the predictability of the imputed measure

Following the development of the imputed CFAS DAHL models, a Receiver Operator Characteristic curve (ROC curve) was also used as an additional measure of accuracy using a dichotomised version of the CFAS DAHL (limited or adequate health literacy). The overall indication of the CFAS DAHL model's predictive accuracy was assessed using the Area Under the Receiver Operating Characteristic (AUROC) otherwise known as the *c* statistic (or area under the curve). An AUROC value closer to one represents the measure's greater reliability in distinguishing the outcome of interest i.e. the ability of the dichotomised measure to correctly classify those with limited and those with adequate health literacy.

For this accuracy test, the lowest quartile of the CFAS DAHL scores were selected to represent limited health literacy and the other 75% determined to represent adequate health literacy (as per Hanchate et al (2008)). In terms of the ability of the CFAS DAHL to discriminate relative differences in the dichotomous

outcome, this model does fairly well, that is, the Area Under the Receiver Operating Characteristic (AUROC) curve is 73% (CI 0.68, 0.78) which is categorised as a fair model (see Fig 5-3)

Figure 5-3 ROC curve characteristic for the five-factor CFAS DAHL model



Variables used in analysing health literacy in the Welsh population

The development of the CFAS DAHL presented an approximation of the distribution of health literacy in the Welsh population, which enabled additional analysis of associations of health literacy with variables of interest. Variables of interest and the analysis undertaken are detailed below.

Social Support Network type

Wenger's (1991) network typology was used to identify the informal social support networks (SSN) available to older people. It classifies networks into five types: family dependent (FD), locally integrated (LI), locally self-contained (LSC), wider community focused (WCF) and private restricted (PR) (Wenger, 1991). The network type is captured by the responses to eight questions within the battery of CFAS Wales questions, which cover the respondent's accessibility to local family,

frequency of their face to face interactions with family, friends and neighbours and their community integration (Wenger, 1994). The calculated network type is then incorporated into one variable which gives rise to six options, five being the network types and the sixth an inconclusive result (i.e. an inability to classify into one of the five network types). Wenger's (1991) support network typology was developed as part of a longitudinal study of ageing in rural communities in Wales and this makes use of this typology particularly relevant in this study. A summary of the network types and their key characteristics is displayed in Box 5-1.

Figure 5-1 Network typology summary Wenger (1994b) p 4-6

Network Typology (Wenger, 1994 p 4-6)
<p>The wider community focused support network is typified by active relationships with distant relatives, usually children, and high salience of friends and neighbours. Absence of local kin is typical. The distinction between friends and neighbours is maintained. This type of network is frequently associated with retirement migration and is commonly a middle class or skilled working class adaptation. Older people with this network type are generally involved in community and/or voluntary organisations. Networks are larger than average. An older person with this type of network would probably tell you: <i>“Although all my family live away, I’ve got good friends nearby and they’d help me if I needed anything.”</i></p>
<p>The locally integrated support network includes close relationships with local family, friends and neighbours. Many neighbours are also friends. These networks tend to be larger on average than others, are usually based on long-term residence and active community involvement in church and voluntary organisations in the present or recent past and to have frequent contact with relatives. A person with this network type would tell you: <i>“We all know each other round here and look out for each other. There’s always someone popping in to see how I am.”</i></p>
<p>The local self-contained support network typically has arms-length relationship or infrequent contact with at least one relative living in the same or adjacent community or neighbourhood, often a sibling, niece or nephew. Reliance is focused on neighbours but older people with this type of network tend to adopt a household focused lifestyle and community involvement, if any, tends to be very low-key. Networks tend to be smaller than average. Childlessness is common as is having no living siblings. Older people with this type of network are likely to say: <i>“I like to keep myself to myself, but I know the neighbours are there if I want them.”</i></p>
<p>The family dependent support network has a primary focus on close local family relationships (ties) and few peripheral friends and neighbours. It is often based on a household shared with, or in close proximity to, an adult child or children (usually a daughter) or siblings. Networks are more likely to be small. People with this network type are more likely to be widowed, to be over 80 and in poorer health when</p>

compared to those in other network types. Their support needs are generally met by relatives. Community involvement is generally low. An older person with this network type would be inclined to say: ***“I’m very lucky to have my family around me. They’ll take care of me if necessary.”***

The private restricted support network is typically associated with absence of local kin, other than in some cases a spouse. Contact with neighbours is minimal, and they have few nearby friends and a low level of community contacts or involvement. The network type subsumes two sub-types: independent married couples, and dependent older people who have withdrawn or become isolated from local involvement. Networks are smaller than average. People with this type of network would be likely to say: ***“I don’t really have much to do with the people round here but then I’ve always been independent/a bit of a loner.”***

Recoding the Social Support Network type variable

The social support network type was recoded to exclude the inconclusive network type (and was entered as system missing). The variable therefore included only the five defined network types.

Social participation

Social participation which can be defined as engagement or participation in a range of both formal and informal social events, was measured by the response to a single question “Do you attend meetings or any community or social groups?” The responses were captured in three categories: 1) No, 2) Yes occasionally, and 3) Yes, regularly.

Marital status

Marital status included five responses where one and two (married and cohabiting) were combined due to small numbers in the cohabiting category and recoded thus collapsing the responses into four categories: 1) married or cohabiting, 2) single, 3) widowed and 4) divorced or separated.

Welsh Index of Multiple Deprivation

The Welsh Index of Multiple Deprivation (WIMD) is the Welsh Government’s measure designed to identify the areas where the highest concentrations of several different types of relative deprivation exist (Welsh Government, 2015). Eight types of deprivation are included in the index and these are: income, employment, health, education, access to services, community safety,

physical environment and housing. The WIMD ranks all small areas in Wales from 1 (most deprived) to 1,896 (least deprived). The small areas are defined as lower layer super output areas (LSOA) which are similar in size in terms of population numbers, but not necessarily geographical size, which may vary quite widely. For the purpose of this analysis WIMD was divided into three groups; most deprived (ranked 1-632), average deprivation (633-1265) and least deprived (1266-1896). The WIMD rankings are a relative system of measurement and so we are only able to determine which areas are more or less deprived than other, but not by how much. The WIMD also cannot tell us about multiple deprivations on an individual basis (Noble, Wright, Smith, & Dibben, 2006; Welsh Government, 2015).

Social Class

Social class was coded using computer assisted standard occupational classification (CASOC) (Elias, Halstead & Prandy, 1993). It identified the following six categories: I = Professional occupations, II = Managerial and Technical occupations, III = Skilled occupations (non-manual), IIIM = Skilled occupations (manual), IV = Partly-skilled occupations, V = Unskilled occupations.

Statistical tests measuring health literacy with variables of interest

Applying the scoring weights from the regression equation produced an imputed health literacy score for each of the study's participants. It is important to recognise however that the CAFS DAHL is not designed for individual assessment of health literacy (Hanchate et al., 2008). The main analysis possible with this imputed measure was determining associations between this derived health literacy measure and the variables identified above. Basic descriptive analyses were obtained using the explore procedure which produces univariate descriptive statistics, as well as confidence intervals for the mean, normality tests, and plots. Listwise exclusion was selected to exclude cases with missing values for any of the selected variables in the analysis. Comparison of means, variance and standard deviations were observed as well as any skewness or kurtosis of the distributions. Box plots were produced to obtain a visual display for comparative purposes.

One-way between subjects ANOVA

One way between subjects analysis of variance (ANOVAs) were conducted to compare the effect of the previously described independent variables on the distribution of health literacy. An ANOVA is a statistical method used to test differences between two or more means. As current evidence (outlined in chapter 2) suggests that people's social worlds impact on their health literacy, analyses were performed on participant's social support networks, marital status, social participation, overall level of deprivation of participant's locale (WIMD terciles) and social class to determine if similar associations may also be observed in this population. Performing this statistical test allows comparison between the means (and the effects) of the selected independent variable for example if an individual's support network type influences health literacy (CFAS DAHL) - the dependent variable. The Scheffe test was used in all post-hoc analysis following any significant F-statistic. The F statistic is a value obtained from the ANOVA test to determine whether the variability between group means is larger than the variability of the observations within the groups. The Scheffe test is used when the sample sizes are unequal as in several of the cases above. It is a flexible test, but it also has one of the lowest statistical powers. It was necessary to use this in order to compare all possible simple and complex pairs of means.

PHASE 2: DEMENTIA LITERACY STUDY OVERVIEW

QUALITATIVE STUDY

This next section details the steps taken to investigate the phenomenon of dementia literacy within a small subgroup of the overall CFAS Wales population. There have been no dementia literacy studies carried out in Wales (as far as can be determined) and there are no currently available measures that adequately assess the entire concept of dementia literacy as previously identified in this study's literature review. Qualitative in-depth semi-structured interviews were conducted to allow detailed exploration of this phenomenon within the population studied, including how social relationships and interactions in participant's daily lives may influence this. The semi-structured nature of the questions supported the maintenance of a focus on the overarching topics while allowing flexibility to enable the introduction of new areas of interest and inquiry to be pursued. The Framework Method for the

analysis of qualitative data was used to facilitate an inductive and deductive (thematic-style) analysis of the data generated (Ritchie, Lewis, Lewis, Nicholls, & Ormston, 2013). The interconnected stages of this approach allows the researcher to move across and within the data (including within and between cases) to explore and refine themes, moving from descriptive to possible explanatory accounts of the phenomena observed (Gale, Heath, Cameron, Rashid, & Redwood, 2013; Ritchie et al., 2013).

Ethical approval

This study's research was arranged to coincide with and be included within a planned second wave of CFAS Wales qualitative interviews returning to an earlier social network study conducted. This PhD's research objectives are separate and distinct from the main CFAS Wales qualitative study. However the planned semi-structured interview for this thesis was sufficiently similar in design to a subset of these earlier interviews also focusing on an aspect of health literacy, that it was incorporated as before, as an extension of the main interview. The methodology was successfully used before and therefore it was considered achievable and appropriate. This PhD study was covered by a favourably viewed substantial amendment of the original study by the Wales Research Ethics Committee as per Appendix C.

The qualitative sample

As the aim of this aspect of the study was to explore the phenomenon of dementia literacy in the context of participant's social lives and networks, the study needed to include participants with a range of support network types (Family Dependent, Locally Integrated, Locally Self-contained, Wider Community Focused and Private Restricted, as identified previously - Box 5-1). The main inclusion criterion for this study was to ensure that this complete range of social support networks were included in the sample selected. In the original Wave 1 qualitative interviews, a subset of the sample had an additional section of their interviews focused on aspects of health literacy and therefore it was deemed appropriate to remove these from the Wave 2 sample to avoid the risk that their prior involvement on a similar topic may affect their responses (i.e. they may be better informed than the rest of the population). There was no requirement to select participants according to any diagnosis or knowledge of someone with dementia, or of having a diagnosis

of mild cognitive impairment, and if they did so it was a result of the random sampling beyond the initial requirements as detailed below. Therefore the remainder of the inclusion/exclusion criteria was based on the requirements of the main qualitative study to which this PhD was aligned. The main qualitative study was particularly interested in those participants whose networks had changed over the last two years (and so this too formed part of the sampling strategy). The sampling strategy then adopted methods used for CFAS Wave 1 qualitative interviews and taking account of the previously mentioned inclusion/exclusion criteria, then used SPSS to randomly select participants from North and South Wales in turn (see Appendix D).

Generally, qualitative samples are small as their purpose is often, as is the case in this research, to explore the area of focus deeply and serve to illustrate themes and issues rather than attempt any representation of a larger population (Bazeley, 2018). Twenty six people (seventeen women and nine men) agreed to take part in the interviews. Two people, who were invited, did not wish to participate and were substituted on resampling. A summary of participants detailing their network types and study region is displayed in Table 5-4 (additional details of participants are included later in this chapter (Table 5-5). Participants ranged in age from 66 years to 90 years (as at wave one interview). All support network types were represented (ten Family Dependent (FD), five Locally Self-contained (LSC), one Private Restricted (PR), six Locally Integrated (LI) and four Wider-Community Focused (WCF). There was a fairly even representation between the two regions with fourteen participants from South Wales (Neath and Port Talbot) and twelve from North Wales (Gwynedd and Ynys Môn). Five of the participants were described as having mild cognitive impairment (MCI) as calculated by their scores (between 24-27 on the MMSE = mild MCI) at CFAS Wales wave 1 interview. (MMSE scores range from 0 to 30 with higher scores representing greater cognitive capacity. The MMSE scores were grouped according to Sachdev and colleagues' (2015) criteria: <23 (moderate to severe), 24–27 (mild), and 28–30 (intact or no significant impairment).

Table 5-4 Summary of participants by study area, network type and sex

Study Area	North Wales		South Wales		total
Sex	Male	Female	Male	Female	
Network Type					
Family Dependent	1	3	1	5	10
Locally Integrated	1	2	2	1	6
Locally Self-contained	1	1	2	1	5
Wider Community Focused	1	1		2	4
Private Restricted		1			1
Total	4	8	5	9	26

Developing the interview schedule

The aim of in-depth interviewing is to achieve both breadth and depth across the phenomenon of interest (Ritchie et al., 2013). The semi structured interview schedule was developed in order to explore aspects of dementia literacy and what may influence it, in particular the role of social networks and information sharing behaviours. The schedule was primarily informed by the relevant dementia literacy and mental health literacy literature as reviewed and detailed in Chapter 3. The schedule aimed to facilitate an understanding of participant's current experience and understanding of dementia. Specific questions were loosely based around what have been considered as core attributes of dementia or mental health literacy including; knowledge of risk factors, sources of help and support, how to seek information (and the motivation to do so), the ability to recognise dementia and attitudes towards it (Jorm, 2000; Jorm et al., 1997b; Low & Anstey, 2009; O'Connor & Casey, 2015). Questions and possible probes were introduced to explore how dementia was talked about within participant's social networks and how knowledge was shared within networks. As a final part of the interview, five potential methods of sharing health information were detailed in the form of mini vignettes. Each vignette represented how a specific network type may typically share health information within that network. An understanding and (in the case of the primary supervisor) experience of using Wenger's (1994) Network Typology facilitated the development of these vignettes. There were two main reasons for including these vignettes at the end of the interview: firstly to establish the participant preferred mechanism for sharing health

information (and if it did indeed match their defined network type) and secondly it provided an opportunity to move away from the dementia questions to a general health focus and thus to end the interview on a lighter note. All questions were designed to be open-ended, unambiguous and sensitive.

The full interview schedule was comprised of three sections; the first section related to the main CFAS study interview schedule (i.e. not part of this study's analysis). The full interview schedule was developed with members of the CFAS Wales team, including myself. This first section focused on the provision and receipt of support from friends and family and if it had changed over the two years since the last interview. The latter two sections were specifically focused on dementia literacy and were designed by me in consultation with the team (Appendix E). All participants had taken part in a similar qualitative interview (minus the dementia literacy section) two years ago and so the structure was kept in a comparable format to this earlier interview. The premise was to quickly put participants at ease, build up rapport and progress through the interview in a manner that was most likely to generate rich data.

Piloting the interview schedule

The entire interview schedule was piloted in order to avoid any potential misinterpretations of questions and to test timings (Arthur, Mitchell, Lewis, & McNaughton Nicholls, 2014). The aim was to limit the duration of the entire interview to around one hour taking into consideration any potential physical or cognitive issues participants may have. Piloting was undertaken initially with one individual and following amendments in response to this, was re-piloted with a further two older adults, all fitting the criteria of the sample population. Section three (the vignettes) was adapted the most as in its first iteration each vignette was considerably longer in order to achieve a more nuanced view of how network members may share health information. These detailed versions were considered to be too long at the end of an interview taking up to an hour and so a shorter version was devised that still exemplified the salient features of the different network types. I also concluded as a result of piloting, that it would be preferable to have the vignettes typed out and allow the participants to read and digest them in addition to reading the options to them.

Preparing and training for the qualitative interviews

There was an imperative to complete all CFAS Wales wave 2 interviews (qualitative and quantitative) by the end of February 2016 as a result of the overarching project constraints. This was quite a difficult target to achieve due to the numbers of quantitative interviews that were required to be completed within this time frame. Prerequisites of the Cambridge CFAS team meant that only those who had successfully completed training and quality control were able to conduct the quantitative interviews, therefore one researcher whose expertise lay in qualitative interviewing conducted the majority of the qualitative interviews (13), while I conducted both qualitative and quantitative interviews. I was able to conduct eight qualitative interviews in both North and South Wales. Another bilingual interviewer conducted the remaining five qualitative interviews with participants whose preferred language was Welsh.

In order to ensure consistency between interviewers and a thorough understanding of the research objectives, a qualitative training programme was devised and held on October 19th 2015 (Appendix F). The training covered sampling logic, ethical protocols, data management and the background of the study with a particular focus on this research's key areas of interests and aims and was delivered by myself and the Swansea Principal Investigator of the CFAS Wales study. Both the other interviewers had been involved in the first wave of qualitative interviews and therefore were familiar with its philosophy and format. The interview schedule format was similar to the original version with the new dementia literacy section replacing those about health literacy and managing chronic conditions that formed a subset of the first interviews. The main focus of the session however was practising the interview schedule with two of the senior CFAS investigators, discussing any questions arising and contributing to any additional prompts that the interviewers considered may stimulate responses to ensure key aspects of the study were covered.

Recruiting and interviewing

The qualitative interviews were conducted from September 2015 up to the end of February 2016. Following the sampling procedure, participants were identified and invited to take part as per the quantitative part of the study. Prospective participants were sent an invitation letter to take part in the interview, an

information sheet (PIS) about the study (Appendix G and H) and a photograph of the interviewer. The letter and Participant Information Sheet (PIS) contained the study details and gave assurances about ethical principles, such as confidentiality and anonymity. These allowed respondents to make a decision on whether or not to participate based on this information and formed an initial part of the consent process.

Participants were interviewed in their own homes and prior to commencing the interview were given an opportunity to ask any questions about the contents of the information sheet or any other aspect of the study before signing the consent form (Appendix I). Participants were reminded that they could take a break or stop the interview at any time if they wanted to or were at all uncomfortable with any aspect of the interview. The participants were informed that the interview was in three sections.

The first section of the interview, was as previously detailed, a follow on to an earlier qualitative interview that all the participants had taken part in two years previously. It is important to note that although this study's aim was separate and distinct to the overarching study and formed a discrete part of the interview schedule it would be imprudent to suggest that the format and style of the first part did not set the tone for the next sections.

The pace of the first section of the interview was different to the latter two as there was more of a structured focus on any changes in circumstances for participants since their last interview and what may have influenced these. The second dementia literacy section and third health information sharing sections were intended to be much more open and explorative. This concern had been identified at the piloting stage and was managed by the interviewers at the time. The intersection between the first and second parts of the interview was delineated by the following introduction:

I'd now like to move on from talking about support within your network of family and friends to exchanges of information. We are particularly interested in people's knowledge of dementia. The word dementia describes a set of problems of symptoms that may include memory loss, difficulties with thinking and problem solving or

language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease, Lewy Bodies or a series of strokes (referred to as vascular dementia). (Interview schedule - Appendix E)

When designing the interview schedule the decision was made to explain briefly what dementia is (or as it is more commonly accepted to be) using information adapted from the Alzheimer's Society website (Alzheimer's Society "What is dementia?", 2019). Although this could be seen as potentially influencing responses that are ostensibly related to someone's knowledge of dementia, it was decided it was preferable to be explicit about the subject under discussion. The intent was to then explore this in much greater detail and therefore presenting this brief introduction would not detract or cause particular concern with respect to guiding the rest of the interview in a particular direction. However, in retrospect, this introduction immediately frames dementia within a medical model. It alludes to the set of assumptions about dementia knowledge that I had intended to use as a backdrop to my analysis, but reveals some preconceived notions, that could have influenced the direction of responses. In reality this did not seem to have this effect, and participants appeared to respond illustrating their own understanding regardless of this introduction.

Knowledge of the interview schedule via piloting and practicing made the interview 'more like a conversation'. This enabled the interviewer to listen carefully to the respondent allowing them the time to think about and answer the question; drawing them back into the topic if they had diverged or probing gently for more details where either clarity or more detailed information on a response was desired. The format allowed both the interviewer and interviewee to pursue an idea or topic in more detail. As the intent was to draw out participants' experiences, knowledge of and attitudes to dementia and discussions around it – prompts such as "Can you tell me a bit more about that?" were added to encourage more detail or the extending of the conversation in that direction.

On completion of the interview participants were asked if they wanted to add any additional comments or ask us about anything that was raised during the interview. Several participants took advantage of this and clarified or came back to

points discussed in the interview. These dialogues formed part of the field notes but verbatim comments were not used from these conversations as we had noted that the interview had come to an end.

Post interview

Short interview field notes were made immediately after the interview relating to any key issues, concerns or general observations about the interview that were considered important to include as part of the research analysis. As I was unable to conduct all the interviews any comments were fed back to me during the course of the data collection in order for any amendments to be made. No specific amendments were made to the interview schedule, as the researchers involved were confident that via prompts they were able to gather the data required. Data familiarisation commenced as it was gathered and early thoughts and ideas were detailed in a writing journal as they arose.

The interviews were all digitally recorded and transcribed verbatim afterwards (in the case of the Welsh interviews they underwent transcription and then translation). This provides an accurate record of exactly what was and was not said during the interview (Silverman, 2013). The total interview duration varied in length from 33 minutes to 134 minutes, with the dementia literacy sections ranging from eight minutes to 43 minutes, with the majority lasting between 20-40 minutes. There were four interviews that had dementia literacy sections in the region of eight to ten minutes; two of these participants had been identified as having mild cognitive impairment (MCI) following wave 1 quantitative interviewing, and did not appear to be very comfortable talking about dementia. Another participant appeared to consider that the questions were irrelevant to her (she was aged in her nineties) and was beginning to get impatient and thus the interviewer did not pursue these questions at length. One further participant was unforthcoming in her responses throughout the entire interview (all three sections), and although she did not appear to be particularly reluctant to answer could not be encouraged to give more in depth responses despite careful attempts to do so.

Debrief with interviewers

Post completion of all the interviews, a debrief session with the three interviewers was held, giving all an opportunity to discuss aspects of the data gathering and any particular thoughts or comments that had arisen. I prepared questions as a result of my own experience and thoughts in the field and started the discussion. As in the participant interviews, I asked for permission to record the conversation. The notes made were added to the field notes used alongside the transcripts in informing the analysis. As well as general feedback on how the interviews went, I was particularly interested in how comfortable participants and interviewers were talking about dementia. A general view was that it was a topic that many of the participants were not fully at ease with and also something that they had not given a lot of thought to. It was not always easy or comfortable for the interviewers either, in particular in conversations with participants with a cognitive impairment. Attempts to probe or ask more detailed questions about what they knew about or their experiences of dementia may have been misinterpreted as interrogating them on their own condition and so interviewers were possibly overcautious. I was also able to sound out some of my early thoughts and analysis at this session, which was particularly useful.

Qualitative Analysis

The qualitative data obtained from these interviews gives depth and richness to this study and most importantly gives participants a voice. I aimed to interpret and reflect these voices thoughtfully and honestly throughout this thesis. The approach used to undertake the thematic qualitative analysis was via a framework approach. Framework is an analytical tool that helps manage the data via a series of thematic matrices. The steps in the process and the developing matrices allow the “analyst to move back and forth between different levels of abstraction without losing sight of the raw data” (Ritchie et al., 2013, p. 283).

The framework analysis approach

All transcripts and additional post interview and debrief notes were uploaded into QSR Nvivo (QSR, 2012) to form the data set for research. The framework analysis approach was facilitated by the use of the Nvivo software which also

effectively stores and supports the management of the raw data arising from the interviews.

The framework approach comprises six key stages: familiarisation, identification of the thematic framework, indexing (coding), charting, mapping, and interpretation (Ritchie & Spencer, 1994). The framework approach uses a conceptual framework that takes into account pre-identified themes for investigation, in this case knowledge, attitudes and beliefs about dementia and informational support for example (deductive). It also incorporates a flexibility allowing for the identification of new emergent themes generated from the data through open coding techniques (inductive) (Gale et al., 2013; Ritchie et al, 2013). The process worked well for me as it kept me close to and grounded in the data and provided a structure that facilitated emergent ideas, concepts and patterns to be drawn out and revisited easily via the linked data.

(i) familiarisation

All 22 interviews conducted in English were listened to and compared to the transcripts to ensure their accuracy. This process also gave me an overall ‘feel’ of how the interviews went, as I had not conducted all the interviews personally. The Welsh interviews were reviewed by the Welsh speaker for accuracy. All 26 interviews were uploaded into Nvivo and read through repeatedly to ensure familiarisation, which facilitated the coding process. Over the course of the data analysis I returned to the audio-interviews on several occasions to confirm how things were said as well as what was said, particularly where humour was used in responses. When reading transcripts it was sometimes difficult to ascertain the tone of the interview, unless it was also listened to simultaneously. For example one participant was describing how she may forget what she had gone upstairs for, when describing occasional memory lapses and said “But I wouldn't tell <son> that I was halfway down the stairs [laughs], he'd have me certified”. Although transcripts were annotated to include where laughter or if somebody appeared to get upset – it was nevertheless very useful to hear the way things were said and what came prior to the comments and if that also changed emphasis of the conversation afterwards. It was identified during the course of the analysis that humour was seemingly (consciously

or unconsciously) used to deflect or change tack after referring to upsetting events. Initial impressions, reflective notes and emerging themes and concepts were recorded during this process. Abstraction and conceptualisation began at this stage although was developed throughout the following steps, which were more fluid and overlapped more than their distinction as outlined below suggests.

(ii) identification of the thematic framework

The thematic framework was constructed from a combination of; the a priori themes arising from the Low and Anstey's (2009) definition of health literacy and the emergent themes from the coding developed during the familiarisation stage. The thematic framework developed over a period of weeks during the early stages of familiarisation as data was considered and interpretations and connections were explored. This framework was tested, developed and refined further by each additional transcript, which ensured that the framework was capturing and appropriately filtering the data (Ritchie & Spencer, 1994). The thematic framework remained tentative at this stage and was further refined at later stages of the analysis. The main themes and subthemes use within the matrices prior to in depth analysis are included in Appendix J.

(iii) Indexing

The transcripts were then read through carefully and a label or code that described my interpretation of the particular section was systematically coded (indexed) using the thematic framework. The term 'indexing' rather than 'coding' is used by Ritchie and Spencer as the aim is to classify all of the data so that it can be compared systematically with other parts of the data set (Ritchie & Spencer, 1994). The process involves making judgements as to the meaning and significance of the data, which can also relate to multiple themes and necessitate referencing to multiple indexes or codes (Ritchie & Spencer, 1994). Codes referred in some instances to substantive things such as participants' reported knowledge of aspects of dementia; incidents and how they were described by participants, such as a relative 'escaping' from a care home; beliefs about dementia such as genetic links or intelligence; emotional responses such as fear or humour and also to capture less tangible aspects - such as noting when a participant appeared to change their tack part way through a

point as if rethinking a response or when the interviewer may have felt uncomfortable pursuing a point.

(iv) charting,

Charting, the next step within the framework process involved summarising the data from each transcript by category/code and building up a picture of the data as a whole across themes and cases. A balance between summarising the data on one hand and retaining the original meanings and 'feel' of the participant's words on the other was required (Gale et al., 2013, p. 5). Charts or matrices were developed using the headings and subheadings drawn from the index and were displayed in a way that made the most sense and aided the interpretation, identification (or confirmation) of key concepts and presentation of the findings. To remain close to the data I frequently used the language of the participants, including relevant quotes that were included verbatim within the chart. The Nvivo software retained a data link to the original transcript. Additional comments that captured developing thoughts and ideas were also included at this stage to chart the ongoing progress of the analysis. When additional concepts emerged during synthesis that did not fit to the existing themes, thematic synthesis was repeated to enhance the existing framework incorporating the additionally identified concepts.

As a thematic approach was adopted, matrices were drawn up for each of the six key themes. Within each matrix, each participant is assigned a row and each sub theme is allocated a separate column. A screen shot of a developing matrix reflecting attitudes to dementia is displayed in Fig 5-4. A key feature of framework analysis is the summarisation of the data to reduce it to a more manageable amount. This process enabled increasing familiarisation of the data and facilitated commencement of more detailed conceptual analysis during data reduction and summarisation.

(v) mapping, and (vi) interpretation

The final stages of mapping and interpretation, involved the systematic analysis of the key characteristics and themes as abstracted and summarised according to the matrices. Reviewing the charted data and analytical notes while comparing and contrasting participants' accounts allowed the identification of

patterns and connections and also differences in the data and possible explanations for these (Gale et al., 2013; Ritchie, & Spencer, 1994). The structured steps taken throughout the framework process, and constant revision and focus actually facilitated the creative task of understanding the meaning and substance of the data leading to identification of connections and associations within the data (Fereday & Muir-Cochrane, 2006). Mapping connections between categories helped in the exploration of relationships and possible causality (knowledge and attitudes and behaviours for example) leading to the possible emergence of phenomena and the potential to predict how some individuals may respond to a particular situation. Conceptual similarities between cases around particular themes pointed to emerging typologies (for example those more emotionally and/or physically close to someone with dementia influencing their increased dementia literacy).

It was envisaged that knowing the participant's network types may present opportunities to discern if particular patterns of information seeking or other health behaviours may be attributable to their specific network types. However this was not apparent in these interviews. Some network types were not well represented (only one private restricted and three wider community-focused for example) and it is possible that other more significant factors (such as past experience of dementia or not) would exert a greater influence over any patterns instead.

Figure 5-4 Example of a developing framework matrix

	A: ageing and memory or dementia	B: changing attitudes	C: describing dementia and terms used	D: describing someone with dementia	E: don't think or want to know about it	F: end it all
1: 14100483 anonymised. SSN type (final) = FD Age = 70-74 Condition = Unassigned Gender = Male	He jokes with a GP friend of his says we're getting old and GP replies 'Who are you?' Talks about his wife's private caring - mainly ladies as they live longer - an elderly community so its prob more obvious (describing how common dementia is)		lady his wife visits 'didn't know what planet she was on this morning'	Second hand information when talking to his wife who works with the elderly and she'll refer to people who 'didn't know what planet she was on this morning' and how difficult it was to get through - He also says his wife has had no formal training Over 8-9 years his cousin in N American country 'wasn't responding very well to anything we might say ' now has daily care coming in		
2: 14202510 (1) anonymis... SSN type (final) = FD Age = 70-74 Condition = Unassigned Gender = Female	she describes her memory and is quite fearful that she is going the same way as her mum 'You don't think that it's just old age? My mind deteriorating? Because you're getting on and you get fearful of what's going to...'	they didn't used to talk about things like this before 'has lost her mind' - people didn't call it the same thing	when interviewer is introducing dementia qs she says 'Yes, they lose their hold.' Then goes on to recount her mother and dr diagnosing her mum 'Such and such has lost their mind' she also describes her concerns of 'losing it' They used to describe it in the past as 'lost their mind'	describes her mum's progression with dementia. friend called to say she'd been out on the road in her nightie at 3am, and how it got worse	when asked about specifically looking for info she says 'I don't want to think about it...Just want to throw it over my shoulder.' and ignore it	she goes into quite some how and why she won't end it all - she doesn't want to go into a home for the elderly (used to manage one); planning her funeral (satisfied if she lives an years) Has done a letter - after the death of her and sons - funeral costs brothers in hospital an niece don't put me in a room - not in a mixed ward asked for bottle of wi

Inter-rater reliability

The relevance of inter-rater reliability for qualitative research has been debated (Braun & Clarke, 2013; Ritchie et al., 2013). The concept is taken from quantitative research, and the assumption is that if the research question is designed and presented clearly, two different researchers would code the same data similarly. However for qualitative data, labelling and coding is conducted as an approach to manage the data in order to produce a meaningful account of the phenomenon. This also requires transparency of process - but is less about a right or a wrong way of coding (Ritchie et al., 2013). In order to gain confidence that others reading the same transcripts would have a similar understanding of the same data and to ensure that one particular perspective does not blind one to alternatives, some (inter-rater) checks were carried out, but this was to an extent more about confidence in analysis than searching for 'accuracy'. Initially I coded a transcript and shared the key or primary codes and a clean transcript with my (then) second supervisor, which she also coded. There was considerable agreement of the coding when comparing

transcripts, and some areas of differences with new coding suggestions discussed between us. This process was extremely useful as it alerted me to a slight tendency to posit ideas slightly beyond that which the data may suggest and it also supported improvements to my coding framework (which was also discussed). (Unfortunately this supervisor soon afterwards moved to another university, forcing a change in my supervisory team). In addition another PhD student was also seeking affirmation on her analytical thoughts and coding structure, consequently we conducted a similar process to support each other's analysis. Two anonymised transcripts each from our own research were swapped. One transcript was hand coded and the other was coded within Nvivo making use of a coding comparison query using Kappa's coefficient, which measured inter-rater reliability. Both researchers coded the same transcript under separate user names in NVivo. A visual display of the similarity and level of agreements was checked between the two coders using coding stripes. This stage did not measure agreement but gave a very useful display of what text was coded to which nodes as well as the amount of data coded and was more helpful for assessing where the coders agreed or disagreed in relation to the source content coded. The Kappa coefficient is a statistical measure and takes into account the amount of agreement that may be expected by chance. The majority of scores were near to or over 0.75 indicating good to excellent agreement between researchers. Where data was uncoded or disagreements were highlighted, this was discussed and again was used to illuminate additional, alternative codes or meanings. The most useful aspect of this process was found to be the discussion around the differences in coding as displayed by the coding stripes. Additional suggested codes and general thoughts on ongoing thematic interpretation were usefully debated. It allowed greater reflexivity in rethinking observations and becoming alerted to alternative perspectives. Challenging the developing analysis forces a greater consideration of any anomalies in the data. It allows greater clarification of thought processes to explain the interpretation, which serves to strengthen the analysis.

Key characteristics of the participants and their experience of dementia

Table 5-5 gives an overview of the key characteristics of the study participants including; their pseudonym, age, support network type (Wenger, 1991), region of residence and if they had been diagnosed with mild cognitive impairment (MCI). The age range of this sub-group reflected that of the total CFAS population

as used in the quantitative analysis (ages 66-90). All Wenger's (1994b) social support network types were represented within this group and the shading in the table denotes blocks of the separate network types. Within the group there were five people who had mild cognitive impairment (MCI) according to the criteria previously described (Sachdev et al., 2015). The table presents a brief summary of participants' experience of dementia (i.e. who and how they know someone living with dementia). It includes if they have mentioned that the person or people known are considered as being within their close networks, as this has been indicated in previous research as impacting on dementia literacy (Kim et al., 2015; Low & Anstey, 2009).

Table 5-5 Key characteristics and experience of dementia (Qualitative sample)

Participant Pseudonym	Experience of dementia
Harry (70) North Wales Family Dependent	Harry's cousin (he feels close to, lives with dementia (LWD) but in N. American country). He used to visit regularly, but not now. Contact is via other cousins on phone/skype. His wife works as a carer -several clients LWD
Audrey (75), MCI North Wales Family Dependent	Audrey attends a memory clinic. She was often confused during the interview. She thinks her parents (deceased) visit. She feels lucky to have her family around her (lives with her husband & sons visit regularly). She would not like to ask others with dementia about it
Sylvia (76) North Wales Family Dependent	Knows of several people LWD. A close relative, now in a home, was in and out of several that his family was not happy with. Helped a neighbour as her husband LWD. Raised concerns regarding a friends husband's symptoms
Vera (74) North Wales Family Dependent	Her mum had dementia (died some time ago), but talks vividly of her experiences. She used to run a care home. She is concerned about her own memory and that she may be "going like mam" and "would want to end it all" if affected
Susan (73) South Wales Family Dependent	A close friend's mum LWD at home (where she died) – they used to sit with her, while they were chatting. Susan's daughter's father in law has Parkinson's and dementia and is in a care home
Mair (72) South Wales Family Dependent	Mair's mum had cancer and it "made her mind go". Her brother in law is now in a home too. She was worried about her own memory and asked her daughter to look up her

	symptoms on line.
Heather (90) South Wales Family Dependent	Heather was agitated with some of the questions. She says she has not got it - she can remember way back. She does not want to talk about it really. She does not get out much now, as is reliant on her daughter to do so.
Cissie (78), MCI South Wales Family Dependent	Cissie has memory problems and was waiting for an psychogeriatrician appointment. She described her condition as dementia. She talked negatively about the effects of her memory problems. She previously worked in a care home.
George (72) South Wales Family Dependent	George's wife (deceased) had a rare form of genetic dementia (It caused multiple TIAs). One of his children has the same condition. A few acquaintances he knows LWD (though no one close). He cared for his wife at home.
Edith (70), MCI South Wales Family Dependent	Edith has learning difficulties, knows nothing about dementia; says she does not have it. Maybe her sister in law has it – her brother attended the interview and prompted her.
Veronica (69) North Wales Locally Integrated	Veronica's husband (died of dementia 2 years ago). She cared for him at home. She used a number of support services throughout his illness. She has campaigned for services since.
Elizabeth (71) North Wales Locally Integrated	Elizabeth was very socially active but did not know anyone with dementia. Her friends discussed experiences of it. She does not want to be someone who just talks about ailments.
Mike (68) South Wales Locally Integrated	Mike knows no one close (friends of friends and neighbours). Thinks it better to be open about having dementia. He talked about the role of celebrities in raising awareness of dementia.
Matthew (66) North Wales Locally Integrated	Matthew was involved in the church. A number of the congregation have dementia, including a close friend's sister His sister in law LWD. He finds this more difficult to cope with, as she has lost her capacity to converse coherently.
Fred (72) South Wales Locally Integrated	Fred is very active socially but does not know anyone with dementia or anything about it –“just what's on the news”. He describes it as sad.
Gillian (71) South Wales Locally Integrated	Gillian's friend's husband LWD. Friends who attend exercise classes and social events -they discuss this in their group. She mentions about three others LWD – but no one very close - no one in the family.
Mavis (74) North Wales	Does not know anyone with it – no one in her circles, and she was reluctant to talk about dementia (and gave limited

Locally self-contained	responses throughout the whole interview).
Burt (78) South Wales Locally self-contained	Burt's close friend (lives downstairs) was recently diagnosed. He helps her on a daily basis, taking her to appointments and social activities - she has been stopped from driving. He communicates with her daughter to keep her updated.
Frank (70), MCI South Wales Locally self-contained	Knows no one with it (just picks things up from the news) but thinks it's a dreadful disease "feels sorry for them". He would prefer to have "a pillow over my head" if he had it.
Alf (82) North Wales Locally self-contained	Alf's brother's wife (now in a home) has dementia – she is not included in his described network now as she is in a home and does not recognise anyone including her children.
Eileen (67) South Wales Locally self-contained	Her aunt LWD but a very long time ago – she was involved in her care and describes the experiences in detail. Her brother in law had Parkinson's disease, and developed dementia.
Reg (75) North Wales Wider community - focused	Reg, a chaplain visits a nursing home regularly to give communion to residents there, many have dementia. A friend (church warden), her husband LWD, but no one very close. He keeps his mind active.
Jane (67) South Wales Wider community - focused	Jane's ex-husband (since died) had dementia, her daughter kept her informed. She has heard about a close friend she had lost touch with, who developed dementia and talked to her daughter about it.
Eleanor (87) South Wales Wider Community - focused	Elinor used to visit a friend LWD in a care home regularly but had poor health herself, which made it difficult. The lady who used to help her when she was rehabilitating at home developed dementia and deteriorated very rapidly.
Mary (68) North Wales Wider Community - focused	Mary (ex-nurse) was very sociable with many contacts. A close friend died last year of dementia (she raised concerns about her symptoms with the family. Her sister died from dementia. She talks of causes and possible treatments.
Dolly (82), MCI North Wales Private Restricted	Dolly attends a memory clinic but it "has not got to that stage" (dementia). A friend who lived opposite – "you couldn't talk to her" due to her dementia. She thinks you can lose friends over it (dementia). She accesses a befriender.
Total 26 (12N/14S)	

Chapter summary

This chapter has provided an overview of the processes involved in answering the research questions via the two main approaches. The data gathering mechanisms and population samples have been described in some detail alongside the justifications for employing the methods used. The aim throughout this chapter was to give a transparent account of data collection, management and analysis. The remainder of the thesis will present the integrated results from these approaches. Using quantitative methodological tools alongside qualitative approaches that explore sociocultural dimensions of dementia literacy may offer some potential toward achieving a comprehensive approach capturing different dimensions of dementia literacy in different contexts (Velardo, 2015). The findings will be synthesised and discussed in Chapter eight as will the strengths and limitations of the study.

6 HEALTH AND DEMENTIA LITERACY

Introduction

There are powerful assumptions in the body of health literacy literature that good health literacy can lead to better disease specific knowledge which can influence attitudes and behaviours such as taking action to reduce disease risk and to promote or maintain better health. An awareness of levels of health literacy in the general population therefore gives us a starting point for potential expectations of knowledge of dementia. Better knowledge and understanding of dementia therefore, could be anticipated to encourage people to act on recommendations to maintain and support cognitive health. It may facilitate the ability to recognise symptoms in oneself or others thus eliciting earlier action to seek and take advice on the best treatment and management options available. Increased awareness of dementia is similarly expected to improve understanding and attitudes towards dementia and people living with dementia.

This research was designed to obtain a better understanding of the dementia literacy of older adults in Wales and the social factors that may influence it. The following two chapters present findings from both the qualitative and quantitative research strands of this study which may challenge some of these assumptions. As previously indicated, these research strands were designed to address the broad questions: 1) What do we know about the health literacy of older adults in Wales both across the broader population and within individual's support and social networks; and what can we infer from this that may contribute to our understanding of dementia literacy? 2) What do we know about older adults' dementia literacy, and the factors that influence this? The integration of quantitative and qualitative data within these chapters allows a greater opportunity to explore similarities and differences in health and dementia literacy and what this may mean for this population and beyond.

This chapter initially presents a description of the study populations and key variables used in the separate analyses. This is followed by the quantitative findings regarding the overall health literacy of over 65 year olds (n= 3409) in Wales. The health literacy measure used provides a heuristic device to begin to consider the phenomena of dementia literacy in this population. The qualitative findings related to the in-depth exploration of dementia literacy in a sub sample (n = 26) of this population provide the rich data from the personal

narratives and lived experiences enabling us to understand what dementia literacy means to those ‘on the ground’.

Characteristics of the CFAS Wales sample

The core study sample used to provide an estimation of the population health literacy was detailed in the previous chapter. The main characteristics of the CFAS Wales sample (i.e. variables used in the predictive model equations) and marital status are described below and are summarised in Table 6.1. The participants were predominantly female (n= 1843, 54.1%). This slightly higher ratio of females to males is as expected due to the lower mortality rates of older women and is comparable to that of the general population of Wales in the age range 65 and over (55%) (Office for National Statistics, 2018). The age range of the participants was from 65 to 90 with a mean age of 74.4 years (standard deviation \pm 6.5). Nearly half of the study sample (47.4%) had no formal qualifications. The majority had retired (89.4%). Most were married (63%) with just over a quarter widowed (25.7%). The majority (67.7%) rated their health as either excellent or good. A small percentage (7.5%) rated their health as poor.

Table 6-1 Key socio-demographic characteristics CFAS Wales

CFAS Wales Sample (n= 3409)	% of population
Variables	
Sex (F)	54.1
Age (Mean \pm Standard deviation (SD))	74.4 \pm 6.5
Highest Qualification %	
none	47.4
School leaving & trade	14.3
‘A’ level & vocational	11
Higher education<degree	10.6
Higher education/degree equiv.	8.6
Foreign and other qualifications	8.2
Retired or not %	
No (employed)	8.3
Yes (retired)	89.1
never worked	2.5
Self-rated health %	

Excellent	21.5
Good	46.2
Fair	24.9
Poor	7.5
Marital status %	
Married/cohabiting	63
Single	4.1
Widowed	25.7
Divorced/separated	7.2

Analysis indicating social context

Socioeconomic characteristics such as social class (or status) and financial deprivation were identified in the earlier literature review as impacting on health literacy levels (Paasche-Orlow & Wolf, 2007; Sørensen et al., 2015; Zarcadoolas, 2005). Investigating relationships between health literacy and certain individual and broader social factors, including measures of social class and area deprivation, can give some indication of additional impacts of social context on health literacy and of any potential social gradient (potentially reinforcing existing health inequalities). Examining the different relationships and factors (such as socio-economic status and deprivation) that can impact on health literacy can provide a greater understanding of the diverse range of factors that affect our capacity to achieve desired health outcomes as well as where these disparities may exist (Protheroe et al., 2017; Rikard, Thompson, McKinney, & Beauchamp, 2016). Basic measures of social class and area deprivation are therefore used alongside the participant profiles to give additional context to the study population. Associations between these variables and health literacy indicating similar patterns and social gradients to those previously observed (Protheroe et al., 2017; Sørensen et al., 2015) can additionally strengthen support and confidence in this study's measure.

Social Class

The distribution of the population according to an occupational based socio-economic classification as determined by Computer Assisted Standard Occupational Coding (CASOC) (Elias, Halstead & Prandy, 1993) is displayed in Table 6-2. Most of the study population were fairly evenly divided between II - Managerial and Technical occupations (27.1%), IIIM - Skilled (manual) occupations (28.6%), IIIN Skilled (non-manual) occupations (21.5%) with

smaller percentages in IV - Partly-skilled occupations (12.2%), (I) - Professional (5.7%) and the fifth (V) - Unskilled occupations (5%).

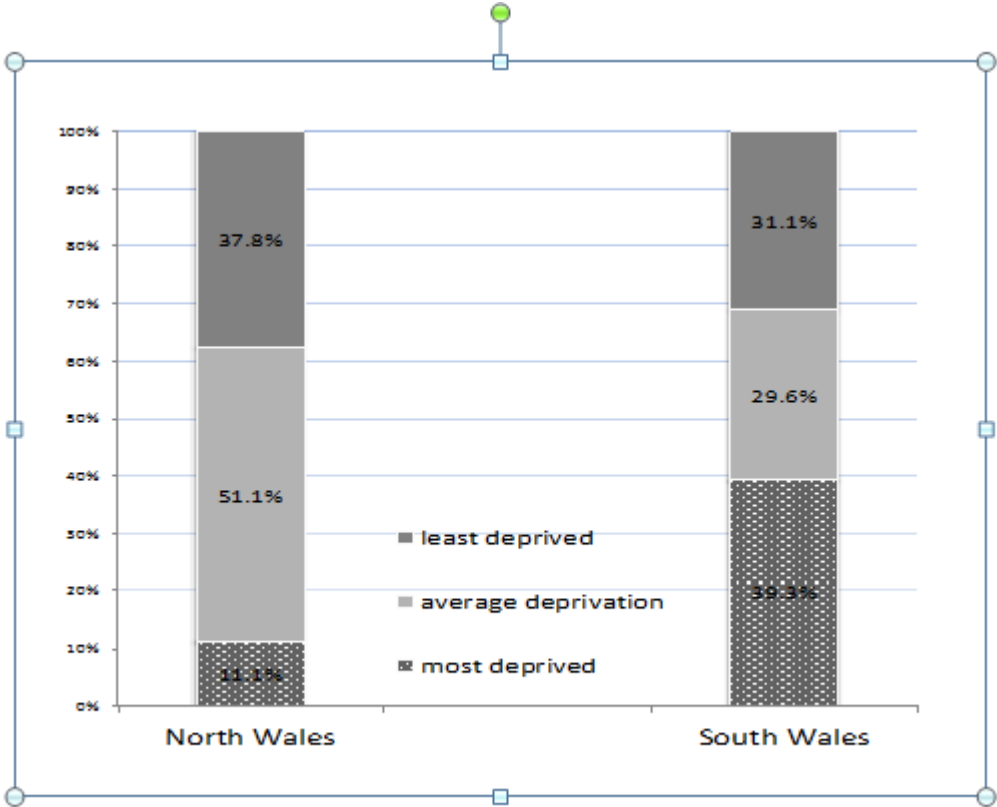
Table 6-2 Distribution by occupational based socio-economic classification

Social Class		Total%
I	Professional	5.7
II	Managerial and Technical	27.1
IIIM	Skilled (manual)	28.6
IIIN	Skilled (non-manual)	21.5
IV	Partly-skilled	12.2
V	Unskilled	5

Welsh Index of Multiple Deprivation (WIMD)

Those living in higher areas of deprivation have previously been found to have significantly lower health literacy compared to those living in the least deprived areas (Protheroe et al., 2017). Identifying levels of health literacy in populations and subgroups within them and possible factors that may impact on it can deepen our understanding of health literacy. The Welsh Index of Multiple Deprivation (WIMD) is designed to identify the small areas of Wales that are the most deprived (Welsh Government, 2015). The levels of deprivation according to the Welsh Index of Multiple Deprivation (WIMD) terciles, split by the North and South Wales study regions are displayed in Figure 6-2. This gives an indication of the differences between the two regions, in terms of the percentage of small areas, known as Lower Super Output Areas (LSOAs), that are most deprived according to WIMD rankings. There were similar percentages of Lower Super Output Areas (LSOAs) within the least deprived rankings in both areas (37.8% in North and 31.1% in the South). However there were over three times as many LSOAs in the most deprived ranking in the South Wales study region (39.3%) compared to the North Wales region (11.1%).

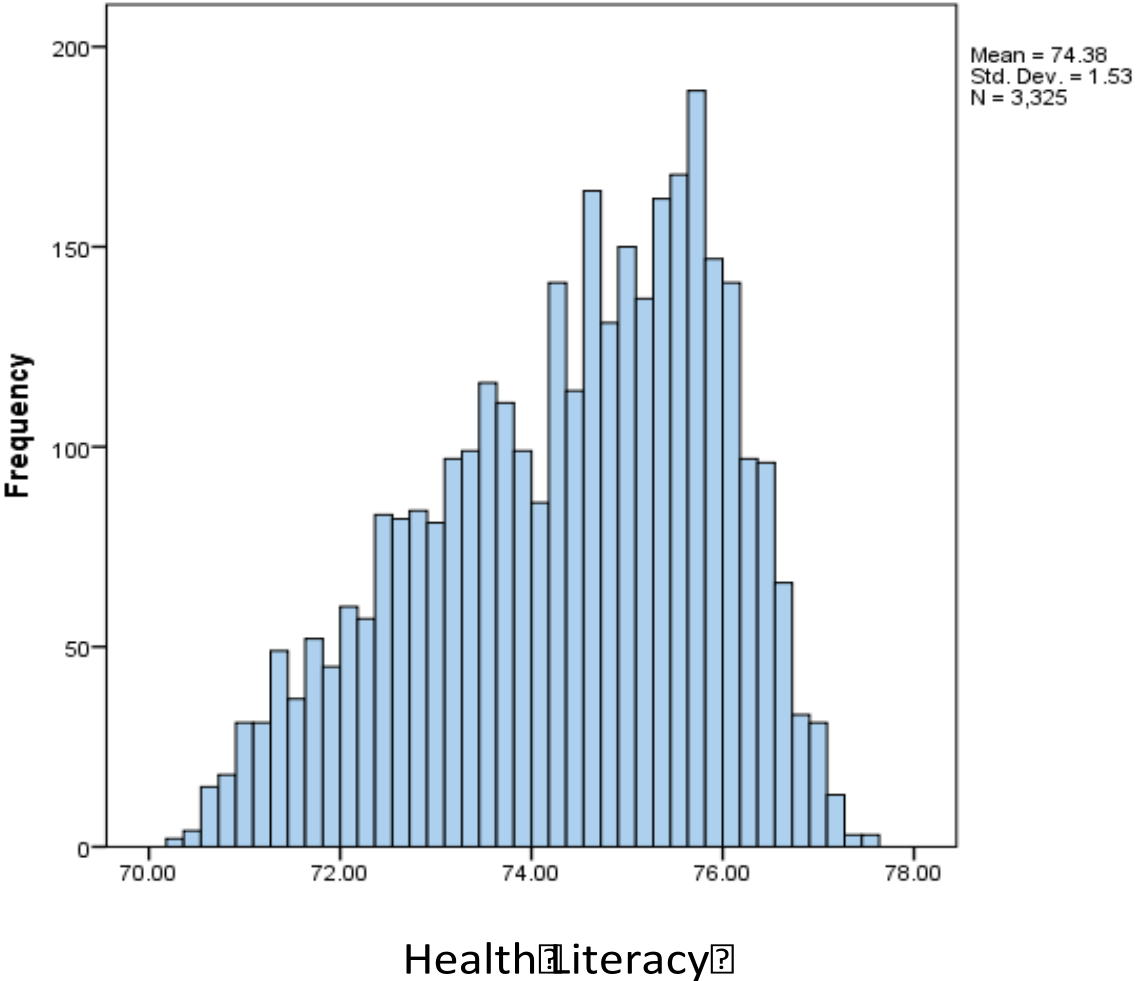
Figure 6-2 Level of area deprivation according to WIMD terciles



Health literacy in the Welsh population

As detailed in the previous chapter an imputed measure of health literacy (CFAS DAHL) was developed from a five factor predictive model and applied within the CFAS Wales population. Using this predictive formula the estimated distribution of health literacy within the Welsh population is displayed in Fig 6-3. The range of predicted health literacy scores within the Welsh population was calculated to be from 70.26 to 77.49 with a mean of 74.38 and a standard deviation of 1.53. It has a narrow range of scores when compared to the measured TOFHLA (range from 15-100) in the UCL study from which the measure is derived (von Wagner et al., 2007), which is to be expected due to the limited number of factors defining the derived measure. Also the large difference between the measured TOFHLA scores in the UCL study versus the imputed measure is likely to be influenced by the measured TOFHLA’s ability to capture and allow for ‘outliers’ that will identify low HL scores (possibly due to decline in cognitive skills). The imputed measure however (by design) predicts scores based on the model factors only, and does not allow for the outliers. The distribution of health literacy shows a slightly negative (left) skewed distribution.

Figure 6-3: Distribution of health literacy in the Welsh population age ≥ 65



The literature review demonstrated that specific groups in society, for example older adults, are at greater risk of limited health literacy and of associated poorer health outcomes (Kobayashi et al., 2014). The derived health literacy measure (CFAS DAHL) was applied in the following analysis to produce and compare estimates of mean health literacy and identify specific subsections of the population that may be more vulnerable to low health literacy and who may benefit from targeted health literacy interventions for example (Martin et al., 2009). The CFAS DAHL was initially used to observe associations between health literacy and social class and the effects of living within different areas of relative deprivation using the Welsh Index of Multiple Deprivation (WIMD).

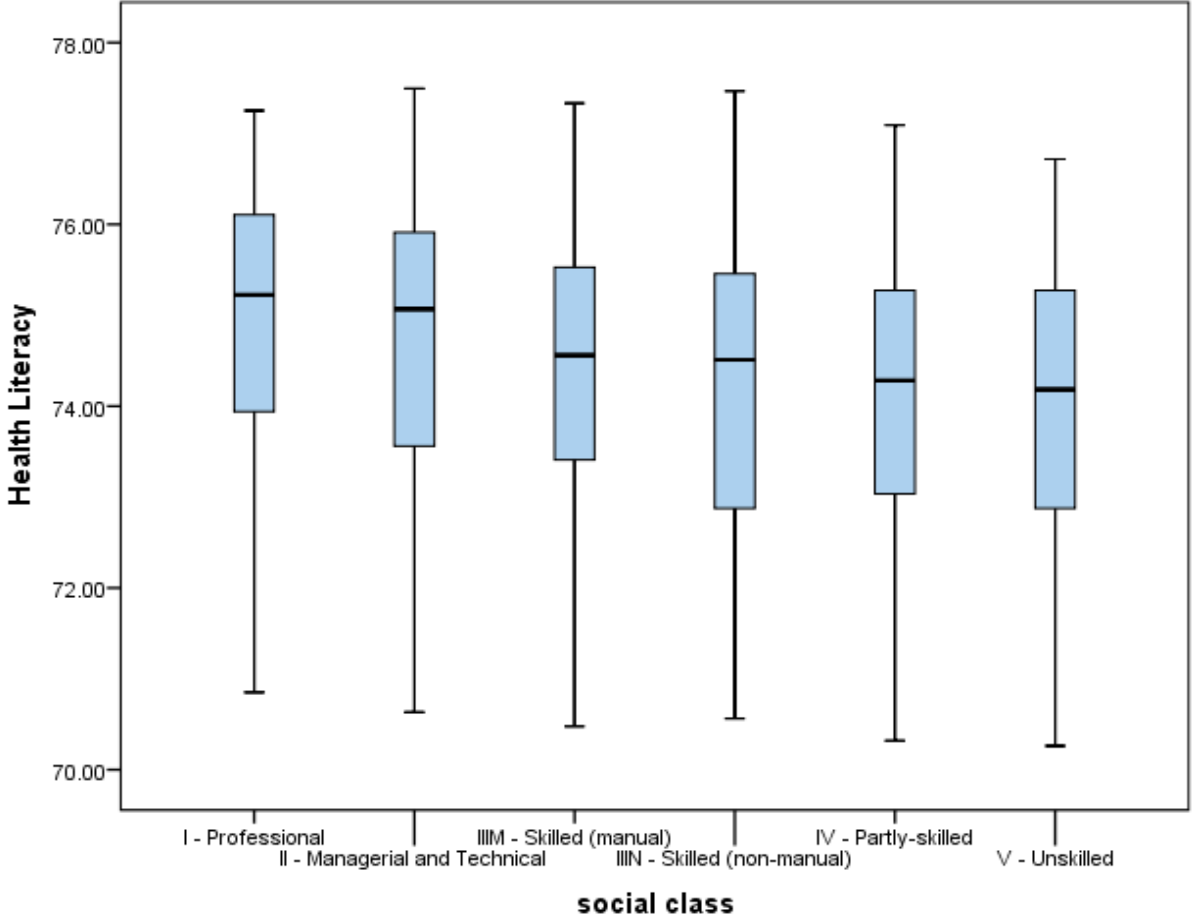
Distribution of health literacy by social class (SC)

The notion that health literacy is a social construct has been increasingly evidenced and previously described. Social factors such as social class have previously been suggested

to impact both on individual and population level health literacy (Holman, 2015; Rikard et al., 2016). Identifying which factors (possibly within specific populations) that can contribute to disparities in health literacy can contribute to our overall understanding of health literacy.

The relationship between an individual’s social class and their health literacy was compared using a one-way between subjects ANOVA and is displayed using a box plot (Fig 6-4). There was a significant relationship at the $p < 0.05$ level across the six groups [$F(5, 3152) = 20.98, p = <.005 \eta p = .03$]. The Levene’s test of homogeneity of variance was not significant ($p = 0.075$), thus indicating that the homogeneity of variances assumption was met.

Figure 6-4 Box plot – Comparison of mean health literacy by social class



Post hoc analysis using the Scheffe test indicated that the mean score for health literacy was significantly higher in social class I – professional ($M = 74.87, SD = 1.46$) than all the other social classes (SC); SC IIIM – skilled manual ($M = 74.37, SD = 1.47$), SC IIIN –

skilled non-manual (M =74.18, SD = 1.57), SC IV – partly skilled (M = 74.09, SD =1.44), SC V - unskilled (M= 73.92, SD = 1.55) except SC II managerial and technical (M=74.73, SD = 1.49). The results between the other social classes, was slightly more complex (see Table 6-3).

Table 6-3: Comparisons of significant mean differences between social classes

Social Class (SC)	Mean HL	SC-I (sig.)	II(sig.)	IIIM(sig.)	IIIN(sig.)	IV(sig.)	v(sig.)
I	74.87	-	.942	.006	.000	.000	.000
II	74.73	.942	-	.000	.000	.000	.000
IIIM	74.37	.006	.000	-	.294	.101	.036
IIIN	74.18	.000	.000	.294	-	.971	.568
IV	74.09	.000	.000	.101	.971	-	.918
V	73.92	.000	.000	.036	.568	.918	-

SC II was significantly different to all other classes other than SC I; SC IIIM was significantly different to SC I, II and V but not IIIN or IV; SC IIIN was significantly different to I and II but not the other social classes; SC IV was significantly different to I and II but not the other SCs and finally SC V was significantly different to classes I, II and IIIM but not SC IIIN and IV, making a somewhat more complex relationship between the classes. In addition the partial-eta squared demonstrated the effect to be weak $\eta^2 = 0.032$ (accounting for only approximately 3% of the variance of the dependent variable).

Taken together and as inferred by observing the box plot (Fig 6-4), these results suggest that as one moves from the lowest social class to the highest social class, then health literacy improves, significantly so, for all classes apart from between SC I and II. The results could possibly indicate that there is more of a binary division in social class and health literacy, rather than the health literacy gradient, as classes IIIM, IIIN, IV and V are different from I and II but not each other.

Distribution of health literacy by Welsh Index of Multiple deprivation (WIMD)

The Welsh Index of Multiple deprivation is a measure of relative deprivation for small areas in Wales. Areas of higher multiple deprivation may indicate lack of opportunities and resources such as access to services, education, community safety, safe environments and good housing, which we might expect to have access to in our society. Characteristics of an area, including deprivation levels, can additionally contribute to the availability of social resources in the area (Tampubolon, Subramanian, & Kawachi, 2013). The impact of living in areas of multiple deprivation can negatively impact on individuals above and beyond their own personal circumstances and impact on inequalities (but people who are multiply disadvantaged do not necessarily live in multiply deprived areas) (Platt, 2017).

To compare the effect of residency within an area of greater or lower levels of multiple deprivation (i.e. most, average, least deprived WIMD tercile) on health literacy, a one-way ANOVA was conducted (Fig 6-5). The results demonstrated that there was a significant effect of WIMD grouping on health literacy at the $p < 0.05$ level across the three groups [$F(2, 3322) = 9.213, p = <.005 \eta^2 = .006$]. The Levene test of homogeneity of variance was not significant ($p = 0.805$), indicating that again the homogeneity of variances assumption was met.

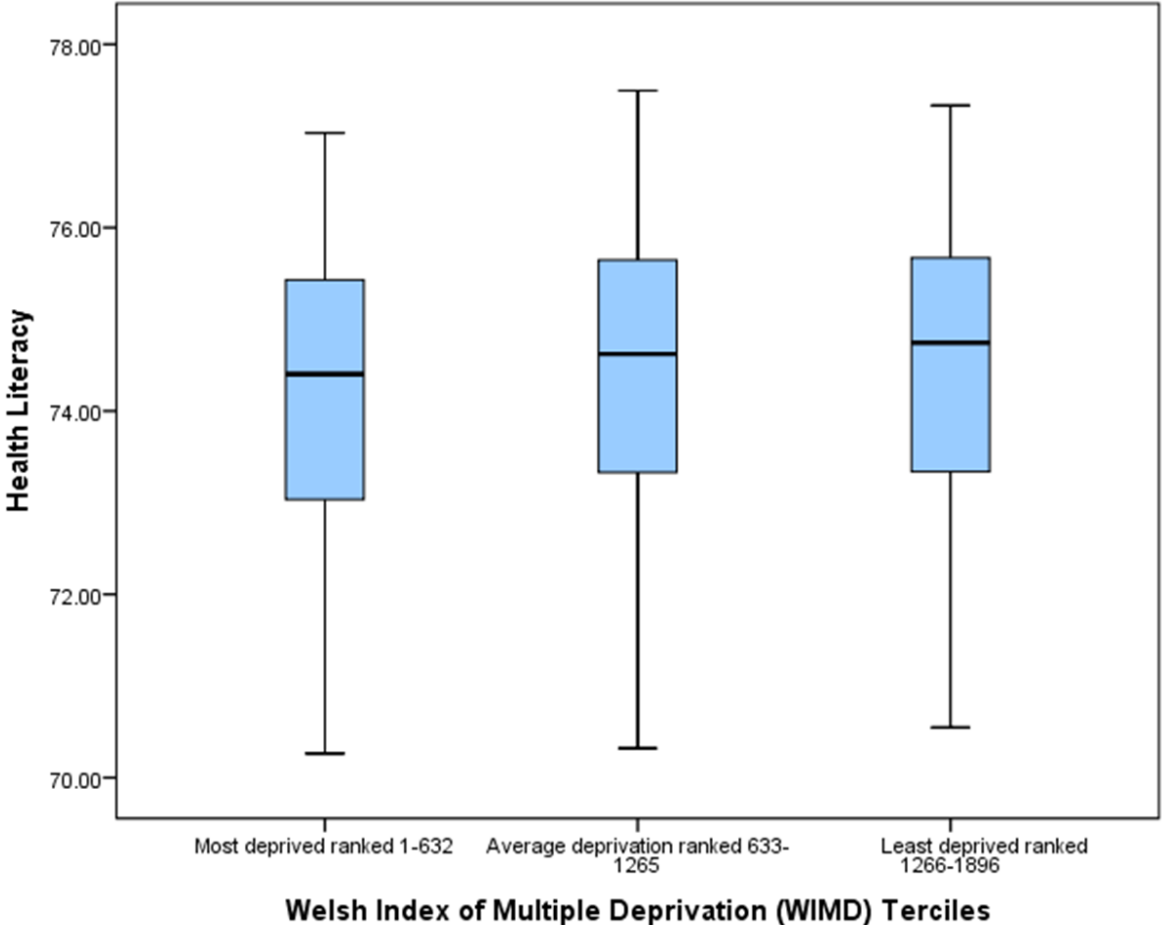
The Scheffe post hoc test indicated that the mean scores for health literacy within the most deprived ranked group ($M = 74.18, SD = 1.52$) was significantly lower than the average deprivation ranked group ($M = 74.42, SD = 1.53$) and the least deprived ranked group ($M = 74.47, SD = 1.53$). The average ranked deprived group was significantly higher than the most deprived group but the difference between the average and the least deprived group was not significant [$F(2, 3322) = 9.213, p = <.005$].

Therefore the results suggest that as one moves from most deprived to least deprived areas as determined by the WIMD terciles, then health literacy improves, but the effect does not appear to be as great in moving between the average and least deprived. The partial-eta squared again demonstrated that this was a weak effect $\eta^2 = .006$.

These findings indicate a complex interrelationship between social and environmental factors that may impact on both individual and population health literacy. There are key factors and resources required in gathering, assessing and using information for health and specific health issues such as dementia (including availability and access to local resources).

A better awareness of such factors within specific populations and locations can further aid our understanding as to what additional requirements may be needed for different health contexts.

Figure 6-5 Box plot - Comparison of mean health literacy by WIMD



Section Summary

This general assessment of the population health literacy could allow inferences to be drawn about some core health literacy skills and competencies of the older Welsh population. Findings suggest, according to previous research, that this population may have better disease specific knowledge (Gazmararian et al., 2003; Ishikawa et al., 2008) leading to expectations of 1) relatively high levels of dementia literacy in the Welsh population and 2) differences in dementia literacy according to certain socioeconomic factors. Those with higher health literacy may be more likely to engage in risk reduction or health promoting behaviours, as suggested in previous research identified in this study’s review (Diviani & Schulz, 2014; Taggart et al., 2012). The predictive model developed also provides information on the

distribution and mean health literacy of the population and is therefore a mechanism of determining which groups within that population may benefit from targeted health literacy interventions and improve desired outcomes. This will be covered in the next chapter as it has a more specific focus on which groups and social factors may influence health and dementia literacy. The results of the analysis conducted have revealed statistically significant associations for health literacy with selected characteristics of neighbourhood and personal social circumstances. Findings are indicative of a social gradient for factors related to social class and living in areas of ranked levels of deprivation. Higher health literacy was associated with belonging to a higher social class and living in less deprived areas. The predictive measure of health literacy (CFAS-DAHL) may be a useful starting point from which to generate hypotheses about dementia literacy in the Welsh population.

Exploring Dementia Literacy

The population health literacy estimated for this study gives an indication of the extent to which some sections of the population are likely to manage the complex demands of health in modern society better than others. The literature reviewed also suggests that a different or additional skill set may be required to capture health literacy in different contexts as in the case of specific conditions such as dementia. The need for disease specific literacies to better explain particular knowledge and response requirements requires a much deeper understanding of the concept (as identified in the case of mental health literacy for example). The following section presents such an exploration of the rich data gathered from interviews within a subset of the CFAS Wales participants.

The following section and chapter seven present the empirical findings on dementia literacy. It begins with a summary profile of the 26 respondents, sampled from the overarching CFAS Wales population (as detailed in the previous chapter). The characteristics of the 26 older adults interviewed were described in the previous chapter (in Table 5-5). A descriptive overview of the interviews is then presented. The interviews yielded rich data relating to participants' experiences and their (complex) understandings of dementia, which do not always appear to sit easily within the dominant biomedical understanding. Barriers and motivators to becoming more dementia literate were revealed. In combination such factors provide a more detailed understanding of what factors could contribute to a more nuanced definition of dementia literacy. The next chapter will include further details of how dementia literacy may be further developed or impacted upon within social networks.

Dementia Literacy - thematic overview

While the health literacy measure has provided an indication of what may be expected regarding a general ability and motivation to acquire, understand and use information about health, the qualitative interviews have explored the sociocultural dimensions of dementia literacy in everyday contexts within this population of interest. Based on familiarisation of the gathered qualitative data and the prior engagement with the literature on health, mental health and dementia literacies, six thematic matrices were initially produced. These covered the core elements of dementia literacy within this population, derived from the combined framework approach of inductive and deductive analysis and comprised; i) dementia knowledge and beliefs ii) attitudes towards dementia and PLWD iii) information (accessing and sources – including barriers and motivators) iv) sharing information v) experience of dementia and vi) developing dementia literacy skills. The initial key themes and sub themes from the framework matrices are displayed in Appendix J.

Detailed analysis, reflection on and interpretation of the data gathered, facilitated by these framework matrices, found mixed evidence supporting components or attributes of current conceptualisations of dementia literacy (that broadly include knowledge, skills, motivation/attitudes and actions) . It led to the development of four overarching themes which also shed light onto new areas of interest: 1) the many ways of knowing (or not) about dementia 2) perceptions and portrayal of dementia; 3) actively seeking, passively finding and 4) incidental sharing of dementia understandings. The sub theme ‘titles’ detailed below reflect the balance between encapsulating the content of the theme while capturing participants’ words. The first two themes are detailed in this chapter. The third and fourth theme; actively seeking and passively finding and incidental sharing of dementia understandings, are covered in the following chapter alongside additional health literacy findings that contribute to a better understanding of participants’ health and dementia literacy in relation to social interactions.

Interview findings are presented below under major themes and subthemes and are illustrated with verbatim quotes from the participants’ narratives. All names used in the reporting are pseudonyms. Participants’ ages and if they had a cognitive impairment or not (indicated by MCI after their name) are included alongside the quotes.

Theme 1: The many ways of knowing (or not) about dementia

There was little evidence of broad or detailed knowledge about dementia throughout the interviews or indeed the desire to know about it. There were variations in what facets of dementia were known about, including causes, risks and disease course, and how these came to be known. There was much uncertainty about dementia expressed.

Subthemes

a. Not knowing “a lot” about dementia

A striking finding about dementia knowledge was the assertion that many participants knew little or nothing at all about it. Some explained how they might have heard about dementia, which was generally not actively sought and apparently did not provide sufficient information for them to declare themselves knowledgeable.

I don't know anything at all, only what's just discussed, I don't read anything about it, just what's discussed on TV. Elizabeth 71

*I: ...so do you know anything about dementia at all?
R: No. Only what I've heard on the news. Fred 72*

Lack of knowledge was sometimes linked to limited personal experience.

*I: How much do you know about dementia?
R: Not a lot, no one in my family has ever had dementia. Gillian 71*

Similar responses were given by participants with cognitive impairments, suggesting that their own memory difficulties had not prompted a desire to know more about conditions associated with such symptoms.

I don't know nothing, I only pick bits up what they ... on the news and things you know, what they're trying to do and different cures but 'bout as far as I know about it. Frank 70 MCI

I don't actually know a lot, apart from, you know yourself if you're not the full shilling, don't you?" And I know I sit and think, oh you should remember that. Cissie 78 MCI

*I: How much do you know about dementia?
R: Mm, nothing, it's not very, only it's not very nice you know. Dolly 82 MCI*

There appeared to be uncertainty of the distinction between dementia (the common umbrella term for the group of diseases) and specific dementias such as Alzheimer's disease.

It could have been Alzheimer's and not dementia, I don't know, you know? I mix the two up, but it could have been Alzheimer's, forgetting, more than dementia I think. Mike 68

but I mean it's so variable and Alzheimer's is a bit of a blanket term a bit like saying rheumatism or cancer it all covers such a wide range of anything. Mary 68

There was also a seeming reluctance in many interviews to use the terms Alzheimer's disease or refer to any of the other specific dementias by name, even when specifically discussing someone identified as having dementia.

Well at the moment the lady downstairs, we are friends but I do a lot for her, you know, I take her here, I take her there. And at the moment she's forgetting, she's losing out on herself. [...] Her memory is terrible. Burt 78

[...] but their mother or their father has gone down with it Mike 68

These results indicate an overall limited knowledge of dementia. This was corroborated by self- assessment. There was a preference throughout the interviews to use terms such as memory problems, forgetting or equivalents – making it difficult to know if there was a lack of knowledge and confusion of the terminology or if there was a reluctance to use the terms dementia or Alzheimer's disease.

b. Avoiding knowing: "I don't really want to know" - "What do I want to know about it for?"

There was a sense of avoiding knowing about dementia amongst interviewees. A number of reasons were given for this. Some expressed a conscious decision to avoid thinking about or talking about dementia.

I'm inclined to brush it under the carpet ... I don't really want to know. Susan 73

I don't want to think about it ... Just want to throw it over my shoulder ... ignore it. Vera 74

One participant, in his response, compared his reluctance to know about dementia to other potentially terminal or unpleasant conditions he would similarly wish to avoid knowing about.

I no more want to know about dementia than I want to know details of either cancer or ... the anal fish and the effects it might have on you if you go swimming in the Amazon, you know. [...] It is honestly one of those things I'd rather ... not know much about. Matthew 66

Fear of or anxiety about the condition was another reason given for this avoidance, with some seemingly preferring to ignore its possibility until such times as perhaps they may have to confront it.

but until it actually affects yourself, then it's 'ah well, you know ...I don't want to look at that, it's frightening like. Mike 68

No I don't really want to know... Cause I wouldn't want to find ... if I went for a test, and then I found out, then I would fester more and think why did I go that way. [...] but it to me, I don't like to go down ... long as I feel my faculties are alright at the moment, I'd rather keep it that way. Frank 70 MCI

Moreover this reaction was thought to be an expected response, perhaps due to what was known about the condition: absence of a cure - and that "it's bloody scary".

If you thought that you were starting to have dementia, then obviously you would be scared, I think, wouldn't you? Perhaps you wouldn't really want to know the outcome. Jane 67

Do I know much about it (dementia)? I know it's bloody scary. And a lot of people must be worried about it [...] and there isn't a cure as such, that there's very limited treatment. Matthew 66

In some instances, even being asked about dementia appeared to be somewhat threatening, eliciting a defensive response.

R: Well there's certain versions of it, somebody said you can't remember anything that's happened to you in your lifetime, but I can remember a lot of things through my lifetime

And when the interviewer probed a little further

I: So how much do you know about it. You've explained that...

R: Well I haven't got it that's all I know![...] What do I want to know about it for? Heather 90

I: As I say we're particularly interested in dementia [...] caused by disease of the brain, such as Alzheimer's or ...

R: No, no. I haven't got that.

I: No I'm not saying you have <participant>

R: No but they said I haven't got that, hasn't got to that stage.

Dolly 82 MCI

One participant described his friend's reluctance to accept her recent diagnosis.

I: And (friend) knows about the diagnosis?

R: Well in a sense yes, but I don't think she will accept it, you know

I: Why do you say that?

R: I don't know, er, I can talk to her now like I'm talking to you and perhaps five minutes later she don't remember what I've said

I: Does she understand

R: [...] I don't think she wants to know really Burt 78

Active avoidance of the topic and a response that typified one of 'ignorance is bliss' appeared to be common responses in not wanting to know about dementia. This suggests it was due to what participants did 'know' or believe about the condition, including the perceived lack of effective dementia prevention, treatment or management. As this latter aspect was not always verbalised in connection with lack of dementia knowledge, it appeared to be generally assumed that such was the nature of dementia that not wanting to know was a 'normal' response. There was an air of defensiveness or reluctance for some to consider themselves or to be considered by others as at risk of or having dementia, thus potentially distancing themselves from something they did not wish to consider as a possibility.

c. Uncertain knowledge: "I don't know if it's true but..."

When encouraged to talk about specific areas of their dementia knowledge, there were some expansions on previous comments but there was often uncertainty voiced when describing what was 'known' with several participants questioning their own responses. The greatest areas of confusion and widely held misconceptions throughout the interviews were around memory loss, ageing and dementia.

Memory loss was commonly expected (and conflated) with age.

He's got a bit of dementia. He's 87. He's in a nursing home now – well a lot of it is old age related isn't it? Susan 73

There were similar quotes from two participants; one without any measured cognitive impairment and another with mild cognitive impairment (MCI) and regularly attending a memory clinic.

I can't do much. It's just there, and it's not as though, if I was a lot younger maybe it would be easier but you expect it when you get to our, my age, you expect your memory's not so good anyway. Dolly 82 MCI

Yes, I mean it's what affects us all, I can tell you what happened 60 years ago but ask me what I had for lunch yesterday and I don't know, your short-term memory and names of course, people you see time and time again all of a sudden you think what's their name! And I think that happens to most people, the short-term memory goes first. Alf 82

Although it was mainly recognised that dementia was not an inevitable part of ageing, one participant in particular exemplified her lack of conviction when, within a few sentences, she expressed somewhat contradictory views on this matter.

But not everyone suffers with it, do they? Her sister (mother's sister), lived on a farm ... she was nearly a hundred and one, and she didn't get it.

A few minutes later when referring to her own memory concerns, she questioned the interviewer:

You don't think that it's just old age? My mind deteriorating? Because you're getting on and you get fearful of what's going to ... you think that ... there are huge mountains in front of you and quite often they don't exist. Vera 74

A conversation with one participant's general practitioner (GP) demonstrates that in fact the association between ageing and memory decline is reinforced by the GP.

[...] quite often my GP, I've known him for years, he's a mate of mine actually and I quite often go and say "Christ (Dr) we're getting old here aren't we!" And he'll say "Yes (participant) who are you?" Harry 70 FD

Uncertainties were apparent, particularly when discussing causal, preventative or risk reducing factors. In addition to misconceptions (misunderstood information) there was evidence of having taken on board myths or misinformation.

The latest thing I found that, you probably know about is, coconut oil which I didn't know but I've been speaking to a guy, and his wife's just been diagnosed with Alzheimer's and she's a nurse and also into alternative medicine... so they're trying to eat lots and lots of coconut oil because it's supposed to actually reverse the symptoms (of dementia) as well – I don't know if it's true but I bought some and I'm putting it on my breakfast. Mary 68

Misconceptions about preventative measures and interventions or a possible confusion with treatments more commonly attributable to other conditions were also revealed.

I don't know if there is a prevention is there? unless you smoke wacky backy ... is that Alzheimer's or dementia I can't remember? Mike 68

Mary, who was asked specifically about dementia, appeared to respond with ideas about other conditions (such as delirium or dehydration) that presented in a similar way but were more easily treatable.

if you realise what circumstances are causing somebody to become confused you can sort it out quite easily [...] a lot of people are getting confused from a perfectly presentable reason Mary 68

Certain personal characteristics were thought by some to increase susceptibility to dementia.

It seems to strike...like, with (friend), it seems to strike people that seem to be more intelligent ... I know that sounds a bit of a silly thing to say. Jane 67

She was a mathematician and she found she couldn't tell the time on an analogue watch and she couldn't count out her change so it's funny the way it attacks you in your strong point [...] I think maybe it often hits you in your strongest point. Mary 68

Overall, these results indicate that memory loss was conceptually linked with ageing and with dementia. This has been widely reported in the literature over several decades of research (Corner & Bond, 2004; Scodellaro & Pin, 2013). The point at which memory loss attributed to 'normal' ageing became severe enough to indicate possible dementia was a source of much confusion, which was seemingly reinforced through conversations with others. Areas of doubt and misconceptions were expressed across most areas of dementia knowledge (eg risk, causes, treatment and management of the condition) indicating that these may be areas where attention of future educational campaigns could be focused. The benefits

of coconut oil, for example, were assumed to be well known to the researcher and probably more widely; and regardless of absolute conviction as to its veracity, the participant was following the advice that she had heard. Attempts to understand or explain what may be risk or causal factors, such as dementia affecting more intelligent people, as also observed in other studies (Corner & Bond, 2004), seemed to be based on participant's observations rather than on scientific knowledge accessed, and in this instance the evidence runs counter to this (Sharp & Gatz, 2011).

d. Changing knowledge in context - over time and circumstances: "When we were children, nobody knew what it was"

Another reported theme was that what was known and discussed about dementia had changed (and was still doing so) over the lifetimes of participants. Some noted that in the past dementia was commonly considered as a part of the normal ageing process (and as identified in previous quotes, this remains a common misconception).

When we were children like, nobody knew what it was, just that it was ... old age ... people said it was old age. Reg 75

What did they used to call it years ago, going back to the second childhood, oh senile decay, they're old? Gillian 71

The perceived lack of a complete understanding of the condition still, with no likely imminent change to this situation, was also observed.

Yes. I mean I don't think we will really find out those things will we. It's so scary though, isn't it? If you think on it too much. Susan 73

Different types of dementia information and knowledge were wanted dependent on context, and this too changed over time as did need (disease specific or service availability in these instances).

I mean they knew very little about it, very little. They know an awful lot more now [...]. We actually, yeah, we actually had a meeting, children and myself, we... when (wife) was diagnosed by (professor), following on from that, because there was this possibility that you know, it could be passed down. George 72

To tell you the truth, when it (the dementia) started five years ago, there wasn't anything available anywhere. Veronica 69

The sense of constant flux regarding scientific knowledge and information available in general (also brought up in other parts of the interviews), and dementia knowledge in particular, quite possibly contributed to an air of confusion as to causal factors and the nature of the disease. Indeed the attributing of dementia to ageing has taken place over hundreds of years and it is only comparatively recently that pathological causes were implicated and confirmed (Ryan, Rossor, & Fox, 2015). The debate continues as to whether normal ageing and Alzheimer's Disease (AD) exist at extremes of the same continuum (Spaan & Dolan, 2010). It appeared that advancing dementia knowledge in the public domain, changing personal needs and changes in and availability of appropriate services, represented a constantly fluctuating set of circumstances to navigate.

e. *Knowing through experience: "So I've actually been through that with her"*

Much of the knowledge acquired by participants, it appeared, was drawn from direct personal experience or 'second hand' stories described by others in their social networks.

Those with a closer, personal connection to someone living with dementia identified a broader range of symptoms over the course of the disease. Often they identified early behaviour changes that were out of character.

Well it started off when she became quite aggressive to her daughter [...] which was not normal. [...] well then of course she was, she started wandering [...] it just progressed slowly in the beginning. Susan 73

She came in and started to talk to me in Welsh. Now I've never ever spoken Welsh, she hadn't spoken Welsh for 20-odd years. [...] it was small TIAs continually killing off the brain and she got to the stage where she couldn't remember names, she couldn't remember... and eventually, I mean it gradually got worse and worse and she couldn't feed herself and it was really, really bad in the end. So I've actually been through that with her. George 75

For some, understanding came gradually with changes in behaviours over time. For certain participants this was particularly due to infrequent meetings with the person living with dementia. It appeared that either unfamiliarity with early symptoms, or the combination of a number of small changes that were out of character, eventually indicated that something was not right.

Well we didn't see her very much [...] She said 'I'll make a meal for you', but she took ages to do something and then it wasn't a meal really you know, we'd get a bowl of soup and that would be it [...] and you know at the time we thought oh she seems not quite with it. Alf 82

... and I realised after two or three visits that she wasn't really responding very well to anything we might say or she'd avoid giving you an answer, just laugh perhaps,... and it's reached the stage now where she's got daily care coming in [...] but it's obviously progressing. Harry 70

...but they could see with her when she went to meetings that she was starting to forget things. And, and ...stumble over, and then I've seen her coming with her slippers on like, you know what I mean? I know she lives over there but she's all dressed up and she's still got her slippers on and she's going down the road you know? Mike 68

One participant, who stated that she knew “*nothing*” about dementia prior to her husband’s diagnosis had, over the duration of his illness become more knowledgeable. This extended to the point that when reflecting back she now recognised that dementia could almost certainly explain the behaviours of another local woman: “*I didn't realise at that time that it was dementia. Did I? [...] She'd walk everywhere*”. Her assertion that there would be no general interest in acquiring information unless you knew someone with dementia was confirmed in some other interviews.

Yes, I've learnt a lot. Things have improved here. [...] There's the memory café, that's come along now, it didn't exist before, and (information booth). But they were telling me things that I already knew. You know... you don't go to there unless you know somebody who's got dementia do you? Veronica 69

Knowledge had been acquired by some participants as a requirement of a position or role in a paid or voluntary capacity, which involved the support or care of people living with dementia.

I mean I'd know a fair bit about it sort of having trained as a nurse and from having known other people who have had it. Mary 68

The lecturer talked a lot then. And for me really, that time I did learn ... know what it is, it's starting to get forgetful, starting to get frustrated... because of the forgetting. Vera 74

My sister-in-law has dementia... and two or three people that we know through church have dementia. [...]. We're reasonably well-informed [...] I

mean, it's obvious, church congregations getting older... every congregation has got at least two people with some form of dementia at least. Matthew 66

The results suggest a greater confidence in recognition of dementia (even if retrospectively) and knowledge of symptoms and the progressive nature of the disease than other areas of dementia knowledge. Also participants appeared to be more easily able to recount these experiences than recalling other areas of dementia knowledge (such as causes or risks). What was known about dementia was generally drawn from personal experiences or those of close others and frequently accompanied by vivid descriptions of people affected by dementia. In the cases where someone very close, such as a spouse was affected, there was an apparent greater motivation to find out more or information of a specific nature.

f. *Knowing what can be done/risks and remedies: "if that happens, you're buggered."*

It was generally considered that there was little or nothing that could be done about dementia in terms of prevention, cure and treatment. Differing opinions on what might be available were in evidence to some degree, but again there was much uncertainty expressed.

Well I think they're a long way of it, at the moment. What I listen on the news, but I don't know. Harry 70

They used to say you could have tablets to check it, but I don't think there's a lot they can do about it. Burt 78

... it's one of those things you think, well, if that happens, you're buggered really ... so there's not a lot of point in spending too much time in worrying about it. Matthew 66

The lack of treatment and management options was also identified by some experiencing memory problems. Possible therapeutic interventions regarding their own diagnosis or ongoing management did not appear to have been discussed with health professionals or were not recalled.

[...] well to me it's sort of something that's packing up and you can't do anything about it. Cissie 78 MCI

"I don't think you really can be treated, so, if it's [memory] gone it's gone" Dolly 82 MCI.

The possibility of improved treatment options with seeking early professional help was sometimes explicitly linked.

Well... they're saying that they've got things that you can take and that you should go and see the doctor if you feel that it's starting to come on. Eileen 67

There were in addition several references in the interviews to items on the topic of dementia seen or heard about, but often the detail could not be accurately recalled.

Well, there is some treatment but I think it's if they catch it soon enough that they can do something ... but I think they've still got a long way to go, haven't they, before they actually find proper treatments? They were talking about one the other day on the radio that they're quite pleased about ... I can't remember what that was, but they were saying in the next couple of years, that might be helpful. Jane 67

One participant considered that his regular attendance of a local branch of a national organisation and the learning of 'parts' kept his mind active, which he considered may play a role in preventing dementia.

That's the only thing I'd say. That we all act in a play. Learn our part. Over the year. And I've realised that the brothers, most of them who've been taking part, their minds are very active. And they do tend to live a bit longer [...] The reason being that they use their minds. I do some of it in Welsh [...] it keeps the mind active. Reg 75

Several participants stated that they attempted to keep themselves cognitively active but without suggesting that this was something they considered could act as a protective factor against dementia.

I do try to do the crossword now and again. I try and use my brain. {laughs}. Eileen 67

[...] keep trying to keep mentally active ...and physically active and so on. Matthew 66

When asked about potential treatments, participants it appeared, tended to interpret this in terms of curative treatments only, as opposed to possible day-to-day management, therapies and interventions that may improve conditions for those living with dementia. In spite of probing questions that aimed to explore a broader awareness of alternative

interventions and condition management, participants' responses were limited. Possibly participants were unaware of psychosocial interventions or other support options, or they did not consider them treatments or of therapeutic benefit. Those that did posit suggestions around prevention generally suggested the maintenance of active minds (and perhaps a clearer cognitive link), with several seemingly adhering to the 'if you don't use it you lose it' aphorism as has also been previously observed (Low & Anstey, 2007). Some of the more recently produced strategies are making recommendations for risk reduction actions based around evidence of improved cardiovascular and diabetes control or increased physical activity and maintenance of a healthy weight for example (Baumgart et al., 2015; Livingston et al., 2017).

In summary, overall dementia knowledge was limited, in particular around risk reduction and treatment options. Participants were most knowledgeable of dementia symptoms, but many seemed to recognise these only retrospectively after an assessment of the 'clues' and looking back at the gradual changes that had happened over a period of time. Uncertainties or misconceptions were frequent across a range of knowledge areas. The lack of general interest in knowing anything or more about dementia, it appeared, was due in large part to the perception that little could be done about dementia in terms of prevention, treatment, management or cure. Some participants' fear of dementia and its trajectory apparently caused further avoidance of the topic. For some this emotional response was inextricably linked to what was 'known' about dementia. Although dementia appeared to be recognised to some extent as not an inevitable part of ageing, the association between ageing, memory loss and dementia was also one of the greatest areas of confusion within the group, as also previously observed in other studies (Corner & Bond, 2004; Glynn, Shelley, & Lawlor, 2017; Langdon, Eagle, & Warner, 2007).

What was known about dementia was to a large extent driven by who was known with dementia (and their closeness to the participant), suggesting an association between the two. This appeared to motivate a desire to understand more about the condition in some. Thus increased knowledge was possibly in order to or as a result of navigating care and services. Knowledge acquisition tended to be based on specific needs and at particular times. There was an appreciation that knowledge was not static.

Theme 2: Dementia perceived and portrayed

Almost all participants knew of someone with dementia or had direct personal understanding and therefore had experiences to draw on. Overwhelmingly these experiences, perceptions and descriptions of dementia were negative. Attitudes towards dementia and those living with the condition are reflected in participants' descriptions and imageries and in the language used to illustrate their accounts.

a) Experiences and perceptions of living with dementia: "It's a terrible disease"

The disease, and its effects on individuals and carers, was almost universally described in negative terms and in terms of loss. There were often attempts to gain confirmatory responses from the interviewer with regard to the 'awful' nature of the disease and its effects.

It's not a very nice subject, really is it? I think it's a dreadful thing to happen to anybody, isn't it? And I think for the carers as well ... I know a friend of mine whose mother had it, but they went to see her often and she didn't recognise them and things ... it is hard, isn't it? Jane 67

To be quite honest it's a terrible disease. Burt 78

Common themes expressed towards those living with dementia were in terms of loss, pity or aversion.

But I do feel sorry for them, I seen people with it and it's not a nice disease [...] they have a conversation, then they drift to a different... and you see some then, shaking, you know. I've ...it's pitiful to ... Frank 70 MCI

... (she'd) been a secretary for years, and the poor thing had a committee meeting [...] she brought the [...] notes from the time before. Pity, pity you know. And the poor thing went downhill afterwards. Shame, shame to see her, you know, so active. Reg 75

A recurrent theme in the interviews were that increasing confusion, dependence and accompanying safety concerns as the disease progressed, placed increasing demands, both emotionally and practically on those involved in caring for someone with dementia.

it was just continuous confusion. Total confusion and ...it was pointless trying to... you just had to handle things. If she said something one minute and said it again the next, you just had to pretend, just carry on. Eileen 67

she was, started wandering ... You know she'd be knocking people's doors late at night and all that. So it meant she couldn't be left on her own at all.
Susan 73

... but then she started walking off and she'd be found, like, five or six miles away, not knowing where she was. I think, on one occasion, she'd taken some of her clothes off, or something, and then when it got to be ... people started getting really anxious. Matthew 66

Some made comparisons with physical conditions. The perceived inability to communicate or reciprocate in relationships, attributed to dementia, was considered by some to be worse than physical ailments, with the inference that this was harder for carers than the person living with dementia.

R: There are those I know who've got MS you know... that's an awful affliction.

I: but it doesn't affect the brain quite as much does it?

R: No no it doesn't. That's the only ...you can take [...] some kind of comfort that you can connect with them Reg 75

One participant, drawing on her friend's description of the anticipatory loss of her husband due to his dementia, compared it to her own experience of caring for and losing her husband.

She said 'The man I met and married is gone' [...].My husband was physically ill but I think this is [...] far, far worse especially when somebody you love and care for and you've gone through ... celebrated your golden wedding and they've no clue who you are. I think that's very, very sad.
Gillian 71

Another view expressed was that the nature of the disease and the resultant circumstances (in these instances, living in a care home) for those affected by dementia were such that their lack of insight into their condition (anosognosia) would be preferable to them fully understanding their situations.

She's happy there (nursing home). [...] Quite content ... which is just as well because she'd be horrified to see the situation she's in. Eleanor 87

To tell you the truth, it's a good thing they've got dementia...I hope that I get dementia so that I don't know where I am. Vera 74

For some with a closer emotional relationship with someone living with dementia (spousal in these instances), such perceptions appeared to be tempered to an extent.

It was part of the stroke family really, but it was small TIAs (transient ischemic attacks) continually and it was killing off the brain [...]. Yeah, it's a type of dementia insomuch as you... especially in the early stages, you start to forget things and well [...]. You lose the ability to be able to do simple things, you know, very simple things. And then it just gradually gets worse from there and then you lose your speech and I mean [...] And it was just progression along those eight years. George 72

R: Yes, but by the end he couldn't walk, move or eat anything. And he had phlegm. He caught pneumonia, yes.

I: Yes, that's it, so that's what happens in the end?

R: Most of them get pneumonia, yes. [...] his brain wasn't telling him what to do, was it? Veronica 69

But for two participants, the prospect of living with dementia in circumstances that they considered unacceptable was untenable for them and they expressed a preference to end their lives rather than do so.

You know, it must be horrible thing. You know, you got... and then you've got people then 'cause they got it [...] They want to go to Switzerland and that and have all this done, isn't it. Like I always said, if I thought that way, I'd have someone [...] put a pillow over my head. I know it's the wrong way to think but perhaps that's what my way of... 'cause you've been pretty active then land up stuck in a chair and you're a burden, to me I rather put a pillow.

Frank 70 MCI

I'd kill myself [...] Maybe two bottles of whiskey and I would have gone by morning. [...] I don't want to go to a home for the elderly. I don't want to go to hospital. [...] I've been writing my funeral day, and chosen hymns. And there's a letter for (niece) to do with money. Vera 74

For some living with memory loss, divergent discourses emerged. The comments below illustrate how their condition had impacted on them. An inability to communicate or manage as effectively as they wished had at times caused some to feel awkward or embarrassed in social situations.

But I can't always remember, silly things, sort of, like when I'm talking to you er it just goes [...] a bit awkward on times. Dolly MCI

Memory loss, yeah. It's stupid, it's you feel sometimes that you could kick your other leg when you should remember that [...] you feel so silly. You know, you try to remember things and, it's hard work to try and remember it. [...] but I know my blooming memory ain't what it used to be. But ... It's embarrassing [...] it's embarrassing when you try to work it out yourself. Cissie 78 MCI

In one case, a participant described how communication difficulties had contributed to the end of a relationship with a close friend who had dementia.

I used to be friends with her, but in the end you couldn't talk, couldn't talk to her. [...] they couldn't really make conversations with her. Well I can't explain it really. Well she, well she was just awkward to talk to, you know, because of her loss of memory and that. [...] Dolly 82 MCI

When reflecting on the possible impacts of dementia later in the interview, loss of friends was the first point that Dolly expressed.

I: How much do you know about dementia?

R: you lose, could lose a lot of friends over it [...]

I: Why would you lose friends with that, rather than any other health issues?

R: if you couldn't conver, conversation. Dolly 82 MCI

Conversely another participant appeared able to communicate as needed with those around her and felt supported by family and friends and was thus able to manage.

My mother and my father. They'll come. And I've got brothers and sisters haven't I. I'm very lucky eh. At least I consider myself lucky you know. Yeah, and it's a small village so you get to know people and (husband's) family's from here so that helps a lot doesn't it; (husband's) always with me, always [laughs].[...] No I think I can talk to people now and explain 'cause there is a little nurse in town, fantastic.[...] 'How's <participant> today?' [...] and I think I'm okay. Audrey 75 MCI

Dementia was almost universally considered a “terrible” disease with those affected by it perceived as having little awareness of the people or the world around them. There was an assumed shared discourse, as was exemplified by those seeking agreement from the interviewers. For some it was perceived as a fate worse than death; and the two who talked of ending their lives rather than live with dementia seemed to have given it more than a passing thought or a hasty response to possibly unexpected questions. The negative impact on social and close caring relationships was prominent in most accounts, but were seemingly described almost in the form of reportage and using less emotive language when described in very close

relationships (in this case spousal). They tended to use medical terms (Alzheimer's disease as opposed to colloquial language such as "losing it") to describe both the disease and often the symptoms (e.g. transient ischemic attacks - TIA's). This possibly reflects an increased awareness and familiarity of the terminology due to more frequent medical encounters or a reluctance to use alternative 'labels' that could be considered as potentially stigmatising terms. The picture for those with personal experience of memory loss or dementia was more complicated to assess and compare. In particular, Audrey articulated clearly how "lucky" she was to have her supportive network around her, some of whom (her parents) were actually no longer alive. Nevertheless her conviction that she was okay and had people to talk to and whose company she enjoyed appeared no less valid.

b) Expectations of disease progression and care – who cares?

There was an apparent general understanding that dementia was progressive. The disease was frequently described throughout the interviews in terms of "deterioration," "stage" or "progression". The consequences of the changing abilities and needs of the person living with dementia were highlighted as well as implications for carers.

These views surfaced mainly in relation to who would provide the anticipated ongoing support and care needs as well as how this may affect all concerned, financially and practically.

I mean fortunately she had one son who had never left home. So, um, otherwise she would have had to have gone into a home I think. Susan 73

[...] and they've gone into a home because they can't be taken care of in the house through their children working. You know, they're working full time and they can't spend the time or can't afford to not work, so the parent has had to go into a home. Mike 68

Expectations of who cares and what care is provided appeared to an extent to be contingent on how the disease progressed and how symptoms were manifested and may have been conditional on family or friendship relationship.

And it was because she was just walking out ... she was living on her own, with one or two friends around her, helping out and things ... [...] I think people tried for a while, but ... and then when she started losing the ability to feed ... er ... look after herself ... it became difficult. Matthew 66

This caused one participant to reflect on what would happen if he was in a similar situation to his friend who he had been increasingly supporting as her physical and cognitive health were deteriorating.

R: So she can't walk. So wherever she goes, whatever it is, I take her and fetch her. [...] Now if I'm in that position, I've got nobody to do that. Because my family's living away. If I wasn't here her family would do it, and they'd probably take her down there to live. Burt 78

The themes of burden and sacrifice were evoked in several of these descriptions (and throughout narratives), with the strain on carers leading to the point where there seemed to be no alternative available to them but for the person with dementia to be moved into a care home.

she got taken away and put in a home 'cause the kids had been going in ... they'd do a rota that they'd stay in her house to make sure she was alright every night, and then it just got too much for them to manage, I mean they were sacrificing their family life and she was getting beyond them to look after so she went into a home. Mary 68

(niece) took her in for a while but she started to roam, so I'd say – well it was the doctor who said, mam's doctor from (place) I can't remember his name, 'you've got to choose now between niece and your mother.' Vera 74

This sense of being a burden or placing (perceived) excessive demands on others, seemingly extended to a reluctance to ask others, including close family, for help with daily caring responsibilities.

She wasn't going to come to this Christmas lunch [...] she doesn't like to ask (for someone to help care for her spouse). She's got one boy, living locally and one daughter living away and she said, I can't ... they've got family of their own, they're working they can't give help [...] the carers come in to help me get him out of bed and they come in to help me get him into bed but she said, I can't leave him down there if we're going about half 11 and not back till five o'clock. Gillian 71

This and having no one to ask were identified as barriers for carers in maintaining friendships and participation in social events and maintenance of quality of life.

Well she just used to say that she... well it became a very lonely life because I think with the effort of everything they get tired don't they and they want to go

to bed every night early and then she said ... she was then saying there wasn't much pleasure in life. And I was thinking, no there isn't. Sylvia 76

A common expectation among participants was that someone living with dementia would sooner or later live in a care home. There were mixed views of care homes expressed but on the whole perceptions of these were negative, even where there appeared to be little direct experience of them.

A view expressed by one participant was around the lack of attention to how the person with dementia had presented themselves previously and the current failure to attend to this along with a lack of expected basic care.

Before he didn't have a beard but he'd got this untidy beard with all his food was in there, and food on his jumper, and he was such a meticulous chap and he was obviously not cared for [...] He's been to various homes [...] And then he went to a superb place where they kept him clean. He had his own trousers on and they were so thrilled he'd got to this place. Sylvia 76

For others it seemed to be viewed as the beginning of the end for the person and the final destination before death.

And then to me, I don't say this all the time, but that seems to be the downward step. Once they go into a home, they seem to go into a shell or sommit I don't know. Mike 68

And me daughter keeps on about, you should go into a sheltered place. I say, I ain't going in one of them. You die in there. Cissie 78 MCI

One participant however expressed the view that this would be her preferred option, with the implication being that the impact of dementia was often (as also described previously) more keenly felt by those providing the caring role.

'If I ever get to that just put me in a home'...because I should hate to be a burden on them. Susan 73

Expectations of who could or would provide care seemed to shift away from friends and neighbours, that had sometimes provided support functions at earlier stages of the condition, towards increased involvement of family and/or the engagement of statutory services and, in particular, care homes. The language used to describe this move appeared to

be that it is a last resort, when other options were used up. The impact of dementia on a variety of relationships was a significant area of discussion throughout the interviews and in particular spousal and close family relationships.

c) Experience and perceptions of support and services: “there wasn’t anything available anywhere”

There was very little awareness expressed of support services available to people affected by dementia in the community or at home unless participants had cause to access them. Some participants described supportive roles played in enabling someone living with dementia to carry out their usual activities, or making it easier for them to remain in their own home.

So I make a list of things, I write them down, for me to remember because I've got my own to remember and I've got things for her to remember. Burt 78

Oh this morning I got to take her (friend with dementia) to (location) [...] she goes to the town hall to do exercises. Tuesday she goes to (church). Wednesday she goes to Wednesday club, right, and Thursday I take her shopping, so I take her down, they've stopped her driving. Burt 78

And he (neighbour) said if it's just moving her (wife with dementia) in between the nurses' visits, just give me a ring [...] if it's a bit more personal, (neighbours wife) will come round [...]. And you can't really ask for more than that can you? George 72

A number of perspectives were expressed regarding availability and suitability of formal services. Some described services of uncertain purpose, not consistently available to them, or not entirely suitable to their needs.

My memory's terrible. But I go occasionally; I go, there, about every four or five months to have the memory clinic. They don't help much, they just talk and do a lot of funny things, but I suppose they know what they're doing. Dolly 82 MCI

She (participant's friend) takes him down there (to a specialised unit in a hospital) she's driving, she doesn't want to drive she's very nervous driving but it's the only way she can get him down here she said otherwise you're waiting forever for these ambulances. [...] she's delighted to come with us and come out to lunch with us and then she's got to be back by ... to pick him up by a certain hour. Gillian 71

One participant detailed a series of groups and services attended to support her and her husband (now deceased) that included travelling some distance to access them - “*I’ve been everywhere*”. Initially the couple’s views appeared to be divergent, as the quote below implies, her husband didn’t necessarily see the need for support whereas the participant may well have. Several of these groups attended were short lived, and other services didn’t match their needs well.

When it first started five years ago, there wasn’t anything available anywhere. There wasn’t anything, well it was terrible. And then, well in that first year it didn’t matter. According to him, he was quite good. And then we started going to [...] (details several groups over the years, and in a variety of locations)

And later [...]

They were pushing for me to have a carer come to the house, for me to go out. What was the point, they knew he was fine, what was the point of having them sit there? I’d tell them there’s no point you sitting here when he wants to go out is there? Veronica 71

There were some positive comments, in particular with regard to end of life care. The two participants who talked of these experiences spoke highly of those who supported them during this stage of their spouse’s illness.

I mean the help we had was unbelievable [...] it gradually increased as she got progressively worse [...] These were actually medically trained carers, I don’t think they were full nurses or anything but they had medical training and they used to call well, four times a day in the end. And then the district nurse used to come every other day. We had Crossroads that used to come and sit so that I could have a few hours and then, as she gradually got worse, Marie Curie were called and they used to come. George 72

The ability to access services seemed to be reliant (certainly in these latter two instances) on having a key and knowledgeable contact that could connect the seemingly disparate options available. In George’s case above it was via his GP, for Veronica it was via social services “*they’ve got a good one in social services*” (Veronica 71).

Family, friends and neighbours were described in some interviews as providing informal support for someone with dementia; at least in the early stages of the disease and some did so throughout the illness. A range of support from a variety of providers, including the voluntary and statutory sectors, had been accessed by some to support their role as carers. Individual needs and specific requirements changed during the course of the illness, and there

was often a mismatch between the two reported in interviews. Service provision not matching need led to a general dissatisfaction with what was available.

d) *The language of dementia: “Away with the fairies”*

The dementia literacy interview was introduced using terms such as Alzheimer’s disease and vascular dementia, however there was a general tendency not to use these same terms in the narratives. Instead synonyms, euphemistic or occasionally pejorative terms were used to refer to dementias and those living with them.

Negative and potentially stigmatizing language was evident in a number of accounts.

R: And I see people there of course. Most of them are in some sort of ...damaged I’d say. Mentally damaged.

I: ...some sort of dementia?

R: Yes they’ve got some kind of dement. [...] And you see over a period of time the deterioration in them like. Reg 75

One participant described her own condition, in a self-stigmatising manner, demonstrating the possible combined impacts of ageism and sexism in addition to the negative stereotypes associated with those affected by dementia (A. Milne, 2010).

I: So you’re using the word dementia. Is that something you’ve decided yourself is what causes the memory loss?

R: Well, it’s what it is isn’t it? I’m just getting old and past it. [...] you know yourself if you’re not the full shilling, don’t you?

Later in the interview she asks the interviewer about an appointment that she is due to attend: *I mean, is it? Is it just for wonky women? Cissie 81 MCI*

A variety of terms were used throughout the interviews, indicating changes in cognitive functioning or abilities. These, it seemed, were broadly intended to convey someone with dementia not being fully aware of their surroundings and suggesting, that although physically present, their minds were focused elsewhere.

she was fine, and when she got to 100, I think, you know, she started losing it, now, she’s in cloud cuckoo land really. Matthew 66

My wife is working with the elderly, so she’ll come home and say for instance “(resident) didn’t know what planet she was on this morning, I’ve had terrible trouble getting her to ... you know” Harry 70

I'm not quite as bright as I was two years ago –but I think I've still got my marbles to a great extent Eleanor 87

Especially with the responsibility that I've got of looking after my grandchildren, you know. It's no good being doolally is it? Eileen 67

[...] she didn't say "has got dementia", or anything. "She's away with the fairies" or something, which was about right really. Matthew 66

Alternative terms were also used in a number of narratives when describing behaviours or symptoms, such as “talking gibberish” when referring to problems with communicating and “escaping” with reference to walking out of home or a care home when experiencing the confusion inherent within more advanced stage dementias.

Another common term when describing aspects of dementia was that of absence or “loss”, not only for the individual with dementia, due to their inability to function and manage as expected; “*they lose their hold*” (Vera),

And she had to be fed and everything you know. [...] Which was so sad. [...] They lose all their dignity ...

And in a later comment

I could never believe there was nothing there. Susan 7

but also for those close to them. Several spoke in terms of ‘loss of the person’ to dementia, prior to their actual physical demise.

Well I think it's rather sad if they don't know you, [...] as (friend) says, he ain't got a clue who she is [...]. Oh yes he doesn't know her now or the children. She said 'The man I met and married is gone' Gillian 71

There was an apparent reluctance or discomfort in using the terms Alzheimer's or dementia possibly, in part, due to the confusion for some between these terms as indicated previously. It is also possible that widely held negative attitudes or associations with the ‘labels’ Alzheimer's disease or dementia as a whole, might mean that these terms were actively avoided and alternatives were used (A. Milne, 2010). Whereas use of some terms (demented) are now widely considered as pejorative others considered demeaning (away with the fairies) may have been used in an attempt to convey a normalising description (Swaffer,

2014). Such phrases, for example being doolally or losing one's marbles seemed intended to present situations that we may all experience at some point. The intent also being perhaps to lessen the impact of using terms such as dementia and Alzheimer's, that are considered more threatening or worrying.

e) *More awareness, more sympathy?*

There was a general perception expressed of an increased awareness of dementia now, compared to in participant's youth. Greater awareness was linked to the increasing numbers of people with dementia and publicity reflecting this.

Well you hear so many stories, don't you? I mean I know it's on the increase and you get some people who say that no, there is no cure. George 72

There's more people lately that seem to be diagnosed with it [...] I think it's getting far more. Gillian 71

One participant questioned if it merely appeared that more people were affected by the disease, or if it was just the heightened publicity that caused people to think that it was more prevalent. Another linked this increasing prevalence to increased longevity.

Well it seems to be getting more common, I don't know, you never know with these things, the more news we get I mean there may have always been a lot of dementia but we hear about it more and more now. Alf 82

Oh its (dementia) certainly increasing...yeah... but partly as a result of the fact that people are living longer. Matthew 66

With increased awareness, some thought that there was a greater readiness to talk about dementia and potentially, more positive (or less negative) societal attitudes towards it and towards people living with the condition.

More people get dementia [...] people aren't scared of talking about it now, are they? Veronica 69

There's more publicity for it now isn't there, in the olden days people would act strange [...] "God he's a funny character" I'd say "in the village" [...] (now). More awareness, more sympathy now. Reg 75

That it was now more readily recognised as another illness also contributed to this ease for some.

It's only another illness isn't it? It's not as it used to be, some looked on as something to be ashamed of [...] it's talked about on television whereas at one time, it just wasn't talked about. Mair 72

In spite of the suggested improvements to attitudes, these views did not on the whole reflect the reality for how many spoke of dementia during the interviews or how those living with the condition experienced it (as reflected throughout the interviews and discussed previously in this section). Although several participants had linked dementia to ageing, nobody in this cohort specifically stated they saw themselves as belonging to a population (or being personally) at increased risk of developing dementia.

Chapter Summary

This chapter has set out some of the key findings relating to participants' dementia literacy. The quantitative analysis demonstrated a reasonably high level of health literacy within this population. Higher levels of health literacy have previously been associated with better specific disease knowledge (Baker et al., 2007; Cho et al., 2008; Jorm, 2012), however this does not appear to be the case with respect to dementia knowledge in this sample. The qualitative interviews demonstrated that biomedical dementia knowledge was in general limited, particularly with regard to causes and risks, potential protective factors and management of the condition. Other understandings (and misunderstandings) of dementia were however apparent. Perceptions of dementia and those living with the condition tended to reflect personal experiences, sometimes experienced closely (as a carer for example) but more frequently as a result of interpretation of shared or observed experiences from a greater distance.

Crucially, these findings offer an insight into why people are reluctant to know about dementia; including fear and anxiety of the condition often resulting from what people understand or believe about the disease and its management. The negative connotations (and fear) associated with dementia appeared to cause participants to distance themselves from their own cognitive impairments if they had one – and for those without, to if at all possible avoid thinking about it.

Many participants were aware of the increase in age related dementia prevalence, the progressive nature of the disease, the lack of cure and limited treatment options with a trajectory of worsening symptoms and severity over time. This, alongside a lack of awareness of potential risk reduction opportunities, the perception that there is little available support for people living with dementia or their carers and the perceived loss of independence and self, contributes to what could be considered a bleak outlook. Misconceptions and perceptions contribute to this picture. Knowing someone with dementia however did appear to impact on dementia literacy, with those with a closer personal experience having a broader knowledge of dementia and generally a more positive attitude. This increased dementia literacy was possibly in order to or as a result of navigating care and services. Attitudes of those with more direct experience of dementia also appeared to be less discriminatory as evidenced by the use of language and descriptions when referring to dementia or people living with dementia. It may also influence their information seeking and knowledge sharing behaviours.

7 THE ROLE OF SOCIAL FACTORS IN HEALTH AND DEMENTIA LITERACY

Introduction

This chapter addresses the research question: What can we understand about the role that social support networks and other social factors play in older adult's health and dementia literacy? Although it is increasingly evidenced that health literacy may be distributed within individuals' social networks, how this may occur within specific network types or within particular contexts or disease conditions (such as dementia) has been little researched. This study's findings offer some insight into these issues. It provides a focus on some of the motivations and difficulties in accessing information and on the preferred (or actual) sources of dementia materials. It demonstrates how distribution of dementia literacy can occur and as such can inform our understanding of it with a view to more effectively addressing any identified gaps.

The importance of health literacy in relation to improved health knowledge, behaviours and outcomes is well established (N.D. Berkman et al., 2011). The literature has suggested that positive resources and support from within individuals social networks can impact on health literacy by improving the desire and ability to acquire, understand, navigate systems and act on health information that impact on health in a range of settings (Edwards et al., 2012; S.-Y. D. Lee et al., 2004). An understanding of current health literacy levels and where such resources may reside or be required from (within different social support networks) is a useful starting point to consider where potential dementia literacy gaps may also exist. Specific network types may not only have different preferred mechanisms of accessing and sharing information, but also sources of that information. The context of the health situation may also impact on motivations to engage in the particular health context – as appears to be the case with dementia. Findings so far suggest that the distribution of dementia literacy may operate in a different way to that of general health literacy.

Health literacy and social support networks

Initially findings are presented that demonstrate the distribution of health literacy between the different social support network types as described by Wenger (1991) within the entire CFAS Wales study population. This identifies those network types and groups within this population that are more likely to have limited health literacy and, potentially, correspondingly limited dementia specific knowledge.

Participants support networks

Participant's support network type as defined using Wenger's (1991) network typology were included in this analysis in order to determine if health literacy was distributed differently within these networks (i.e. is health literacy typically higher in some network types than others?). Combining understandings of where health literacy skills exist throughout network types, and how networks typically interact to spread specific health related information, attitudes and behaviours can inform us where any gaps exist.

The majority of CFAS Wales participants had either a locally integrated (35.9%) or family dependent network type (21.7%) with the remainder split fairly evenly between the other three network types - wider community focused (16.4%), private restricted (15.1%) and locally self-contained (10.9%) as per Table 7-1. This is consistent with Wenger's (1994) original findings of the distribution of different network types, where locally integrated and family dependent networks made up more than half of the network types in most communities.

Table 7-1 Distribution of Social Support Network type in CFAS Wales

Social Support Network Type (SSN)	% SSN type in CFAS Wales
Family dependent	21.7
Locally integrated	35.9
Locally self-contained	10.9
Wider community focused	16.4
Private restricted	15.1

The distribution of health literacy by support network type

Previous research has demonstrated that individuals exist within different social support networks (Antonucci, Ajrouch, & Birditt, 2013; Litwin, 1997; Wenger, 1996). A number of studies have further demonstrated how health literacy may be developed and shared within networks (Abreu et al., 2018; Edwards et al., Ellis et al., 2012; Papen, 2009).

How specific network types may impact on health literacy has not been investigated. Even under similar health circumstances different network types may react differently and a better understanding of where poorer health literacy resides can offer opportunities for targeted interventions that are likely to be more useful and effective for particular network types.

The five different network types involved in this research have been described previously. They are associated with different patterns of membership (made up of family, friends and neighbours) and different type of relationship, reliance on, or contact with these people (Wenger, 1991, 1994b). Whereas more homogenous network types comprised of mainly family members with stronger ties (eg family dependent) may be a useful network for practically supporting the central individual with their daily needs, they may be less helpful in accessing diverse information, experiences and views. Access to more extensive information and views may be more important in developing health literacy skills and for encouraging health promotion and risk reduction for example (Stephens et al., 2011). Wider community focused and, to a slightly lesser extent, locally integrated networks are more likely to offer such opportunities.

Comparison of mean health literacy by support network type

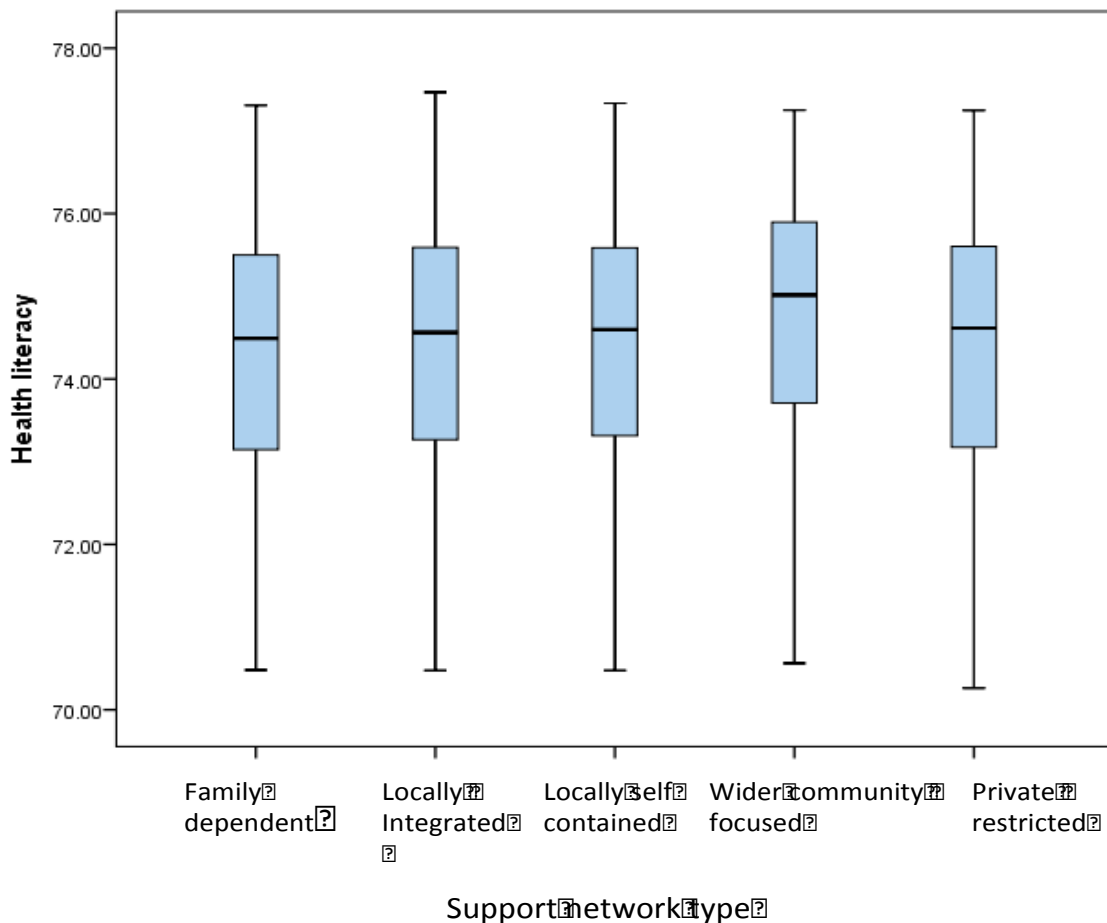
A one-way ANOVA was conducted to compare the effect of individual's social support network types on health literacy (Fig 7-1). The results demonstrated that there was a significant effect of social network types on health literacy at the $p < 0.05$ level across the five network types [$F(4, 3184) = 7.207, p = <.005$]. The Levene test of homogeneity of variance was not significant (i.e $p = 0.119$), thus indicating that the homogeneity of variances assumption was met.

A post hoc test was conducted to determine between which network types the significance could be found. The Scheffe post hoc criterion for significance indicated that the mean scores for health literacy within the wider community focused network was significantly higher ($M = 74.71, SD = 1.51$) than the mean scores for all the other network types [FD ($M = 74.27, SD = 1.47$); LI ($M = 74.35, SD = 1.51$); PR ($M = 74.33, SD = 1.62$) except the locally self-contained network ($M = 74.43, SD = 1.50$), [$F(4, 3184) = 7.207, p = <0.005 \eta^2 .009$].

These results indicate that someone with a wider-community focused network is statistically more likely to have a higher level of health literacy than those who have family

dependent, locally integrated or private restricted network types. The trend also looks (by eye) to be the same for the locally self-contained network type within the box plots (Fig 7-1), however this was not shown to be significantly different. The partial-eta squared or effect size was demonstrated to show a weak effect ($\eta^2 = .009$).

Figure 7-1 Comparison of mean health literacy by support network type



Those with wider community focused network types tend to be more socially active and involved in their communities according to previous research on support networks (Stephens et al., 2011; Wenger, 1994b). Statistically they are more likely to belong to voluntary groups, have larger than average network types with a tendency for self-care when required and be married (living with their spouse only) (Wenger, 1991, 1993, 1996). These features could point to more extensive opportunities to come into contact with diverse people, wider views and experiences and with the potential to acquire the additional skills required for good health literacy.

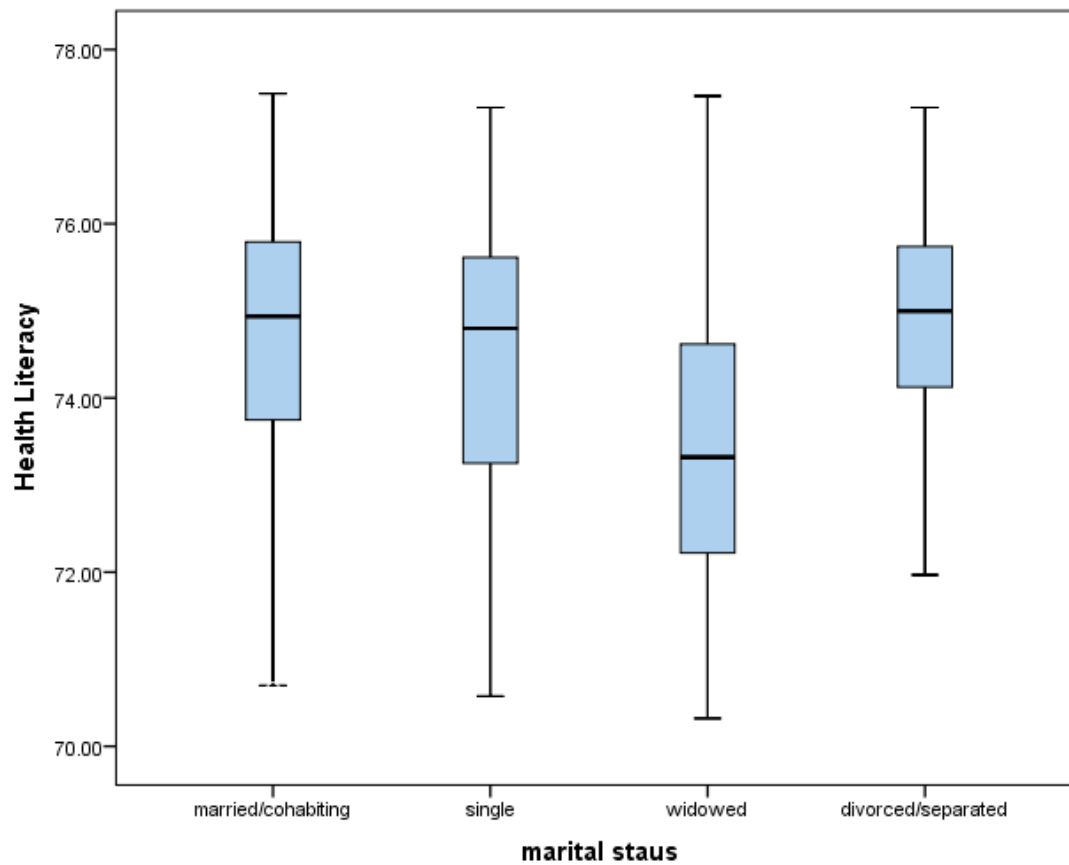
Comparing the distribution of health literacy by marital status

The effect of marital status on health literacy has not been thoroughly investigated, although it was found to be a significant predictor of health literacy in one study developing a predictive measure of health literacy (Martin et al., 2009). A longitudinal qualitative study examining the distribution of health literacy skills within social networks, demonstrated that spouses frequently acted as health literacy mediators i.e. they supported their spouse in becoming more health literate about their medical condition (Edwards et al., 2015). Spouses were involved in seeking, understanding, evaluating, discussing and supporting decision making with regard to long term condition management. It is possible that the loss of a spouse and therefore someone to perform this role could impact negatively on health literacy status. It is impossible however to draw any inferred causal relationships from the following results.

The effect of individual's marital status on health literacy was compared within this study sample using a one-way ANOVA (see Fig 7–2). There was a significant effect of marital status on health literacy at the $p < 0.05$ level across the four defined marital types [$F(3, 3319) = 165.91, p = <.005$]. The Levene's was significant in this instance and so we may conclude that there is insufficient evidence to claim that the variances are not equal. However the Levene's test for homogeneity of variance works better when the samples are approximately equal which they are not in this case (eg married/cohabiting 63% compared to 4.1% single). Also the total population sample is large and any hypothesis test is more likely to be significant using a large sample size. As long as $n > 30$ then the original ANOVA test is robust to violations of homogeneity of variance. I therefore elected to continue with the post hoc test. Post hoc analyses again using the Scheffé post hoc criterion indicated that the mean scores for health literacy within the widowed group was significantly lower ($M = 73.43, SD = 1.54$) than the mean scores for all the other marital status groups, [married/cohabiting ($M = 74.70, SD = 1.39$); single ($M = 74.45, 1.53$); divorced/separated ($M = 74.80, SD = 1.32$)], [$F(3, 3319) = 165.91, p = <.005, \eta p.13$].

The results suggest that being widowed has a significant negative effect on health literacy. The partial-eta size ($\eta p .13$) again demonstrated that this was only a weak effect.

Figure 7-2 Comparing mean health literacy by marital status



Comparing the distribution of health literacy by social participation

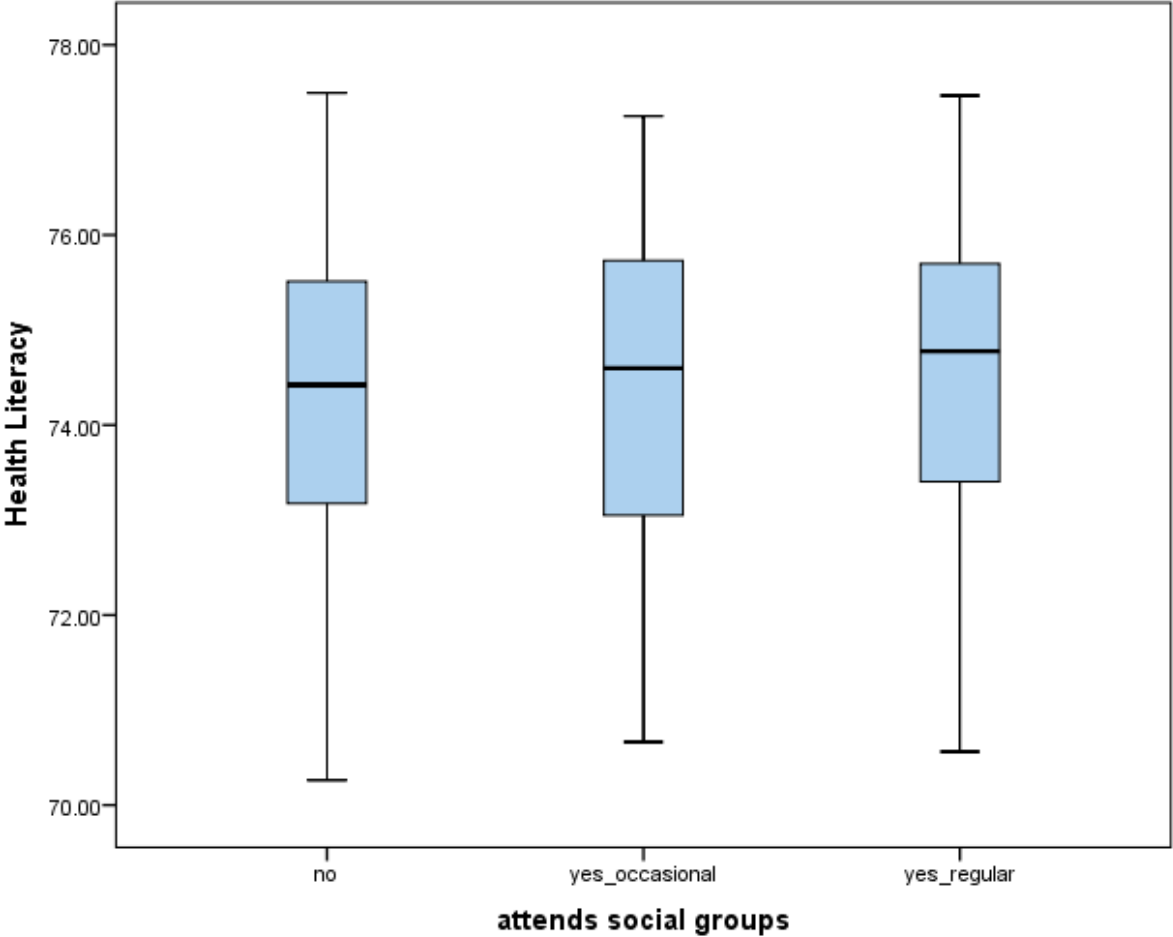
Previous research has demonstrated that people with fewer social contacts and lower engagement in social activities have lower health literacy (Geboers, Reijneveld, Jansen, & Winter, 2016). The following analysis examines if similar results are found within this study.

The effect of an individual's social participation on their health literacy was examined using a one-way ANOVA, as previously detailed (see Fig 7-3). Social participation was measured by attendance of social or church groups. There was a significant effect of social participation on health literacy at the $p < 0.05$ level across the three groups (don't attend ($n = 1634$), yes- occasional attendance ($n = 188$) and yes- regular attendance ($n = 1499$) [$F(3, 3319) = 165.91, p = <.005$]. The Levene's test of homogeneity of variance was not significant (i.e $p = 0.119$), thus indicating that the homogeneity of variances assumption was met. The post hoc analyses indicated that the mean scores for health literacy within the group that did not attend social groups ($M = 74.25, SD = 1.53$) was significantly lower compared to those who regularly attended social groups ($M = 74.51, SD = 1.51$) but there was no significant difference between

non-attenders and occasional attenders (M= 74.44, SD = 1.60), and occasional attenders and regular attenders [F(2, 3318) = 11.39, p = <.005 η p =.007].

Therefore the results indicate that regular attendance of social groups has a significant positive effect on health literacy. The partial-eta squared again demonstrated that this was only a weak effect η p .007.

Figure 7-3 Comparing mean health literacy by social participation



Section Summary

Significantly higher health literacy was observed in wider community focused networks and for those who regularly attended social groups (greater social participation). Conversely being widowed had a significant negative effect on health literacy compared to being married/cohabiting, being single or divorced/separated. This suggests that those with

more diverse networks having a greater number and range of contacts or opportunities to connect with others via participation in groups may have more occasions to share and compare health information and experiences and thus improve their health literacy. This research indicates that there may be features of specific networks (structure and/or function) that could better support the development of health literacy skills. Common features of wider community focused networks were the greater tendency to be involved in the community (social participation), and increased likelihood of being married, both of which appear to impact positively on health literacy in these findings. It is likely that there are associations between all three of these measures (social participation, network type and marital status), however I did not control for this via any multivariate analyses.

This study's literature review demonstrated that being health literate assumes not just that generic literacy skills are applied in health situations, but that individuals (and groups) may also need condition-specific (e.g. dementia) literacy competencies and/or the critical skills to transfer knowledge from one situation to another (i.e. critical health literacy). As observed in the participant interviews in the last chapter, context influences how relevant it is for people to seek to develop or use health literacy skills. In the context of dementia where dominant illness perceptions in this and prior studies indicate that there is little that can be done about dementia (Cuijpers & van Lente, 2015), motivation, self-efficacy and other factors (including influential others) will likely be contributing factors in whether individuals wish to be informed and are willing to seek the advice and care available (Paasche-Orlow & Wolf, 2010).

As identified in the previous chapter, the presence of relatively high population levels of adequate health literacy did not appear to translate to high levels of dementia literacy within the cohort interviewed. Hypothesised associations between the two may be more complex than anticipated or indeed absent. The bulk of this chapter therefore covers the thematic analysis of the qualitative interviews, exploring the complexities surrounding dementia literacy and its influencers further. It continues the examination of dementia literacy within this cohort within the themes identified that relate to participants' seeking and sharing of dementia information. This is important not just for condition management but, as indicated throughout the literature review, in order to reduce negative and stigmatising attitudes which are more generally prevalent. Improved dementia literacy may support interventions that encourage behaviours to support cognitively healthy lifestyles and risk

reduction behaviours (aligned to best evidence as and when it becomes available). There may also be specific interventions that are more likely to be successful dependent on individual's social support network type and this requires a deeper understanding of the complexity of interactions within networks.

Active seeking, passive finding and sharing dementia knowledge

Overview

The remainder of the chapter continues the examination of aspects of dementia literacy within this cohort. The following section presents the overarching themes and subthemes extracted from the qualitative data relating to 3) active seeking and passive finding of dementia information and 4) the incidental and purposeful sharing of dementia information and knowledge. The other two major themes (the many ways of knowing (or not) about dementia and the perceptions and portrayal of dementia), were covered in the previous chapter.

Theme 3: Active seeking and passive finding of dementia information

It was apparent throughout the interviews that there was little appetite for general dementia enquiry. Most participants stated that they had not actively sought out information on dementia. *"I haven't gone looking for it, no"* (Vera 74); *"No. It's not as if I've studied it like"* (Reg 75). Yet news and views about dementia were present from other sources, notably the media and presented diverse aspects of dementia which, alongside personal or shared experiences, informed participants.

Subthemes

a) Barriers to active seeking: "What's the point?" / "they should tell you shouldn't they?"

A key barrier to accessing dementia information was attitudinal. There was a general sense from participants' comments that they perceived little benefit or relevance for them in accessing information to improve their dementia knowledge. Even as in the case below where the participant had some degree of cognitive impairment.

Interviewer: It doesn't help? Having information?

Respondent: No. No. It don't help, so what's the point [...] Dolly 82 MCI

Availability of information did not necessarily encourage engagement with the information.

*I have seen things, but it's not something that I particularly seek out.
Matthew 66*

*I haven't thought, there's a leaflet, I'll pick it up and read up on that.
Elizabeth 71*

In the event that they did want to find out about dementia, a reported barrier for some was the fundamental matter of not knowing where to look for it.

I wouldn't know where to look. Mair 72

*I wouldn't have any idea, pamphlets and that. [...] From the surgery perhaps?
Gillian 71*

Difficulty in accessing their local surgery, an often suggested first port of call to meet information needs related to cognitive concerns, was another frequently reported problem. Past negative experiences of the often complex or just time-consuming process required in navigating the doctor's appointment systems were identified as barriers to future visits for this purpose.

To get a medical professional, to start with I've got to fuff about with making an appointment, then I've got to go and see them, then I'm not going to be entirely sure which one of five doctors I'm going to see, three of them I wouldn't want to! Harry 70

*I can't be unique in thinking that for the amount of money that doctors get paid, the fact that getting to see them now is harder than getting to see the Emperor of flipping India ... or something...it's just ... I think it's appalling.
Matthew 66*

One participant reported that changes to her local surgery had altered her inclination to attend there now for a non-urgent or non-specific medical issue. Whereas previously drop in sessions had been welcomed, her perception of the environment now was far removed from this view.

Years ago our surgery used to have different clinics, well woman clinic, you could just pop in [...]. They've stopped all that [...]. I try and stay away from that, its not somewhere where I want to go, and they had behind the reception desk there were big cork boards all around and there was nothing but notices there don't do this, don't do that, don't ring us ring NHS direct. [...] I find it intimidating, 'we don't want to help you go away', you know. Gillian 71

For others who had wanted to receive information about their cognitive health and were seemingly assuming its provision in some instances, there were also barriers.

One described her somewhat negative experience while discussing who helped manage her memory concerns and health information needs between memory clinic visits.

R: Well I won't say the doctors because they don't want, seem to want to know [...] they just don't want to know. Dolly 82 MCI

Similar responses in terms of expectations or satisfaction in addressing information needs were expressed by two other participants, one from the perspective of a carer and one still navigating the process of diagnosis.

I: So you'd see the consultant. In terms of getting information about it (husband's dementia), how things would progress and so on, [...] Was that from the consultant?

R: I didn't get much information from them. Veronica 69

I: Would you ask somebody else to look for information for you? [...] if you wanted more information?

R: Well I thought naturally when you do see these doctors, they should tell you, shouldn't they? But, I mean some of them are, sort of, when you walk in or sit down, you can see their brain working over. 'She ain't quite the thing'. You know. It's as bad as if you're hearing them saying it. ... I know they're not doing it, but. I think that's why I end up laughing. Cissie 78 MCI

Cissie, in the previous quote, while acknowledging that this may not be what the doctors are actually thinking, it is what she imagines them doing. This appeared to add to her previously stated feelings of embarrassment about her condition, and potentially a further reluctance to pursue her enquiry.

For some, such negative experiences with general health concerns and anticipated difficulties in access to doctors caused them to rethink what might have been their preferred option for obtaining dementia related information and consider alternative sources.

Well it'd be the internet at the moment because it's so difficult to get a doctor's appointment these days Mair 72

Yeah, I'd go online health-wise first before making the effort to make a doctor's appointment. [...] well, its easy and its straightforward isn't it?
Eileen 67

Yet lack of access to a computer or confidence with the technology was another reported problem for others.

Too old for things like that (computer). Too technical and yeah [...] I haven't even got a phone, a mobile phone. Frank 70 MCI

A number of barriers or reasons for not accessing information or finding out more (or anything) about dementia were raised. This primarily appeared to be related to the attitude that participants saw little reason to look for information. There was still, for some, uncertainty about the best place to be able to get general information or advice although most participants suggested their general practitioner for concerns they may have if displaying dementia symptoms. However previous experiences and perceptions following visits to their doctor's surgeries had left some viewing the overall experience negatively and not conducive to broaching either general enquiries or dementia specific health concerns. Cissie and Dolly's experiences, for example, suggest that they did not always receive the information they wanted. Reluctance (including stigmatising attitudes) or other difficulties (lack of knowledge or availability of support services to refer on to) experienced by their doctors in comprehensively addressing or managing concerns and requirements have been previously identified (Ahmad, Orrell, Iliffe, & Gracie, 2010; Moore & Cahill, 2013).

b) Sources of information and their credibility: "never believe everything it tells you"?

A number and combination of sources were suggested by participants when considering potential information sources for dementia.

Several participants for example mentioned online sources and using search engines to find information.

I'd just google dementia or Alzheimer's, or whatever [...] That's my first port of call for most things. Matthew 66

I'd just go into Google and put up whatever it is, dementia or Alzheimer's or Parkinson's or whatever, see what the symptoms were and then see if they applied to her (his wife) or to me because as long as I had this (computer) I'd do it myself. Mike 68

Although some expressed that they had little idea of how to access the specific online information they may be looking for (or may not have easy access to a computer), they had been convinced by social contacts that this was the place to find it.

I: So you're looking on the internet, would you know, how would you go about looking?

*R : I have no idea because I've not looked anything up. But you know, people say, 'Go on the internet' you know, 'you'll get the answer'
Elizabeth 71*

R: Something I don't like using. The internet more than likely [...] More than likely, I could ask family [...] I'll tell you who'd do it for me. It's (rugby club friend). He loves the computer.

I: So you think that would be a good source of information then?

R: Well he tells me it does. It tells you everything, so... Fred 72

There were differences in opinion expressed with regard to the reliability of information and various mechanisms of assessing information on which to base their decisions. This was particularly highlighted with respect to online information, but not exclusively so.

I: Is there any reason that you'd prefer to look at that online than speaking to somebody?

R: Well you should get the right advice, you should get the truth [...] So far as I can gather, they wouldn't be allowed to print stuff on Google if it wasn't true, or would they? [...]. See I wouldn't ask family or friends for health information because how do you know it's going to be the right information? I'd want it from somewhere more believable. Sylvia76

Others were not so convinced of the trustworthiness of online information and so were taking that into consideration, if not actually attempting to mediate for that possibility.

I: So you'd go straight to the computer? Is that reliable information?

R: No not really! Just reading Bill Bryson's book, [...] and he says never believe everything it tells you. [...] That would be my first place to go. Alf 82

I: don't believe everything that I read. [...] And I don't ... go for the worst scenario... I try lots of sites and then work out which is [...] if you have sort of like, three different views on something, you can usually find which is the middle bit, which would probably make the most sense. Eileen 67

In spite of the problems many mentioned in accessing their general practitioners, most considered that doctors would be the experts in this area and therefore more likely to give the best information.

*I'd say 'Right come on kid we're up to the doctors, because you're doing things and I can't find anything on line, so we'll go and speak to the experts'.
Mike 68*

Well my initial reaction is well, surely it's the likes of the doctors would be likely to give me the best information Susan 73

There was also recognition by some participants that there were limitations to this source of information too, particularly in regard to less common conditions.

This lady doctor who is only just [...] didn't know anything about polymyalgia and she admitted it, you know what I mean. So I knew more about it than she did. So you can't always guarantee that health professionals are going to know. Sylvia 76

*I: So you saw the professor in (place) and got information from him about the condition?
R: Yeah, yeah. I mean they knew very little about it, very little George 72*

These results suggest that there were conflicting opinions on what participants considered were the most credible (and accessible) sources of information. Information found on the internet was suggested by several as a reliable source, or perhaps more so than from other sources that were easily available to them. However one participant in particular was under the impression that there was some form of policing of the information available online. Doctors were commonly (but not always) considered to be 'experts' but access to them was often problematic as indicated in the earlier accounts. It was observed that doctors and others providing health information did not always have all the answers as medical advances and understanding changes over time and require constantly updating knowledge.

c) Motivating factors: "If it affected me..."

In spite of the prevailing sense that most participants did not see the point or want to obtain more information about dementia, there were circumstances that some suggested would cause them to overcome this reluctance.

The main motivation expressed for improving their dementia literacy was knowing someone with dementia.

It would have to be something that I am interested in or concerned about. If, as you said, a member of my family had it, or suffering from it then if it came on television or there was a programme about dementia or Alzheimer's I'd think, right I have to have a look at this just to see so that I can find out things and maybe help in some way or other, that's when I would look. If it affected me, I've got to be honest, we're all insular, - I don't care what anybody says, I mean we all look after one another if we can, but until it actually affects yourself, then it's 'ah well', you know. Mike 68

And this appeared to be the case for one participant who had asked her daughter to help with her concerns.

*R: I was worrying at one point because my memory's got terrible and I've always ... all my life I've been obsessed with words and using the language properly and I find I can't remember words and that really, really annoys me.
I: So you've been concerned, so rather than you looking, you asked <daughterI>, yeah?
R: Well she said it's just age, from what she can see.*

This was also borne out in the interviews with the spouses of those who had lived with dementia (now deceased). Both had searched fairly extensively for information, although with a different focus.

Because there was this possibility that you know it could be passed down, we decided to have a meeting with one of the doctors [...] we went through the whole thing with this doctor and it was left with the children really as to whether they wanted to know or not. George 72

I'd get information (about support services) [...] when I went to hospital with (friend), I'd pick up a leaflet there. [...] well I'd pick up every leaflet I could get. Veronica 69

Other circumstances under which some envisaged that they may take more of an interest in dementia were if new knowledge or prophylactic treatments became available.

If they announced there was actually a tablet that if you took it every day you would not... it was guaranteed that you wouldn't get dementia, I'd say wow, give me the information, I'll take the tablet. Matthew 66

This appeared to be the case for one participant who was going to check up on a potential cure that she had heard of.

I think when I next go back online I should look up this coconut oil thing cause I think that's extremely interesting having just discovered that Mary 68

The closer (emotionally) the participant was to someone living with dementia or if they were involved in their care and support, the more likely the participants were to have sought information. Information needs were varied and were context and content specific. For the spouses of someone with dementia, information needs were dependent both on their own needs and those of their spouses (and extended families) at the time and over time. It ranged for example from detailed specific genetic information to the availability of support groups and carers that could provide relevant support to match the specific needs at the time. It was sought from specialists to somewhat indiscriminate access to leaflets. There was also evidence of a more general interest in scientific breakthroughs regarding dementia treatments.

d) Passively received information: "So soap operas do have a use"

A commonly observed theme was that dementia information was generally passively acquired as opposed to actively sought. A frequently mentioned source of dementia information in participant narratives were the media including; television, newspapers and radio.

Some participants described that the appeal of a personality had been an incentive to engage with a particular story. The absence of a real or fictional character of interest may not otherwise have caught or held their attention.

...there was the programme on, that Terry Pratchett [...]. Perhaps interesting is the wrong word because it was just so sad, but I was sort of interested in his life then if you like. I mean perhaps if it had been anybody else, somebody that I had never heard of... perhaps I wouldn't have watched it. Susan 73

Some who had become engaged in a particular story and the issues raised suggested the potential utility of such programmes for awareness raising and making it known that dementia can happen to anyone.

And now it's come out in the paper, his wife... his second wife has written a book, 'My Gentleman Jim' (regarding Jimmy Hill former footballer and commentator). And the two children are complaining now that she shouldn't

have done it until he's dead. They feel that they've highlighted his Alzheimer's to other people and they didn't want it known like.[...] But I think if you've got a personality like that who, who's got it, it might help other people to come out and say, 'well yeah, my mother or my father's got it ...' Mike 68

One participant also added that portraying potentially less well known and possibly shocking symptoms could perhaps reduce some of the fear surrounding it.

[...] Iris Murdoch. They did a film didn't they? And I think okay perhaps some of it was a bit ... you know, but some of these things actually did happen and I think it's good for people to know that these things do happen, and if it comes to you, it doesn't frighten you so much does it?

I: So is it about knowing the signs and symptoms and what can happen?

R: Yes they can turn violent and you know... because it's a shock when somebody you love can turn on you. But it happens. Sylvia 76

Soap operas too were considered useful in this respect.

R: They're trying to deal with it in Emmerdale at the moment [...] One of the characters is sort, of is in the beginning. It's how he's reacting to it.

I: Oh right okay, so is it showing ... has he got a diagnosis or anything like that?

R: he's got a partial diagnosis at the moment but he won't tell his wife or anybody 'cause he's scared you know [...]. So soap operas do have a use (laughing) Mair 72

Mair, in this next quote, however suggests that raising awareness does not necessarily furnish people with the practical information to do anything about what they have learnt.

It just gets mentioned every so often in different sorts of programmes but nothing that... I haven't seen anything that I could say "Oh yes I'll do that" Mair 72

Whereas most were able to recount details of the story lines and arguments involved in relation to personalities, participants generally seemed less able to recall 'factual' data and specific information from news items.

Well you hear so many stories don't you [...] there is no cure but there is a method of slowing it down, slowing down the onset of dementia George 72

I think it maybe just on the news where they've given numbers or that so much money is going, or more care, or more research into it. Or they may say that someone's charity this year is dementia. Elizabeth 71

[...] something on the TV where they were saying about ... that they've .. they think they've found some ... well what are they talking now? About my poor cat ... they can give you the same thing as they do for ... you know like, you have a patch [...] it's like an insert and they think it's going to help. Eileen 67

A view frequently aired was that there was little cause to actively look for information about dementia. Those who had looked declared a specific reason for doing so - as someone close to them was affected. Where there were expectations of being informed by health professionals these had not always been effective or well fulfilled encounters. In general there appeared to be little consideration of how to discern the veracity of available information, although some questioned 'expertise' and acknowledged that there were still gaps in knowledge and that research was ongoing. The media was accredited as a primary source of participants' dementia information. Personalities in particular had impacted on people's engagement with information and possibly influenced attitudes towards dementia. It was noted however that improvements to specific areas of knowledge that could support better cognitive health or reduced risk for example appeared unlikely to occur as a result of such engagement.

Theme 4: Incidental and purposeful sharing of dementia understandings

A commonly expressed view was that dementia was not something that was talked about routinely within participants' networks. It was apparent though, that exchanges had occurred in some shape or form, as many were able to recount wishes or statements about dementia that had at some point been articulated. For others some conversations needed to happen to manage everyday life with dementia or memory issues.

a) "those sort of things were never talked about"

Some suggested that dementia was considered a 'taboo' topic in the past with the implication being that this had now changed.

The older generation, I mean older than me even. You don't... those sort of things were never talked about. They were put to one side. Mair 72

What happened before was, we didn't talk about it [...] people didn't call it the same thing. Vera 74

Matthew's comment below seemed to capture one key element of this general reluctance to avoid conversations about dementia - the lack of cure.

if there was a cure for ... dementia, dementia, then ... probably we'd talk about it a bit more often. Matthew 66

The subject it appears is still one that most would generally still prefer to avoid discussing. Talking about dementia was not a particularly easy or comfortable topic of conversation for some during the interview (and possibly in everyday life). There were a couple of interviews in particular where it proved almost impossible to draw the participants into providing fuller responses. A more positive outlook for dementia in terms of available cure or treatment options would perhaps, as indeed one participant suspected, more readily promote discussions on the topic.

b) Reluctantly discussing: "we were very delicate about it"

Although as indicated previously there was a reluctance to talk about dementia, participants suggested reasons as to why they had or may have to broach the topic within their social networks.

In the following examples participants had attempted to initiate a conversation with friends, as they were concerned that a relative of theirs may have dementia.

We were very delicate about it around (friend), because we weren't quite sure how she would take any comments we might make. Matthew 66

So I said to her (close friend), I wonder if they've ruled out Parkinson's (referring to friend's husband) but I didn't want to frighten her you see [...] about three weeks later she phoned me up and she said [...] it was vascular. Sylvia 76

For Sylvia (above), the matter was complicated further, as during a subsequent conversation with her friend she had the impression that there may have been additional collusion within her friend's family in an attempt to reduce her friend's potential distress.

R: It could be that (friend's husband) and son ... perhaps I interfered. They perhaps probably didn't want her to know, trying to keep her ...

I: So you think he may have known himself?

R: I think so Sylvia 76

For some discussing dementia was considered a “personal” matter which should not be talked about widely, beyond the immediate family and close friends; as may have been the case in the previous example.

I probably wouldn't want to (talk about dementia), but might have to. [...] It's a personal thing isn't it you know? [...] I don't really discuss medical problems with anyone or anything like that; it is a medical problem isn't it?
Harry 70

I: I was asking you whether you know anybody who's been told they have dementia and you said you wouldn't want to ask.

R: Oh no, I don't want to ask anybody if they've got it. I don't think I should do that

I: Why is that?

R: I don't know

I: Is it different to asking somebody about any other sort of health problem?

R: I don't know people all that well Audrey 75 MCI

These quotes highlight complexities within family and network situations where discussions around dementia diagnosis, even where the condition is suspected, may be avoided to reduce the risk of upsetting or frightening someone. The latter quotes indicate both the reluctance to intrude on what are thought to be personal matters, but also the uncertainty in the first instance as to what dementia actually is – is it a medical problem?

c) Sharing (out of necessity): “I'd have to ... in case I started acting funny”

Several suggested that discussing dementia and its possible consequences was something that would need to be done within the family and perhaps the wider network in order to support the management of the condition.

I would have enough sense if I thought I was going down that lane to tell (son - a nurse) about it and he'd soon find out everything. [...] and he would take charge no problemo. Gillian 71

Some considered practical concerns and responsibilities,

I: If you had a problem with your memory or dementia, who would you talk to? [...] Would it be your daughters?

R: Yes, oh yes. And I mean, if I, I would go and do something about it straight away. Especially with the responsibility that I've got of looking after my grandchildren, you know? It's no good being doolally is it? Eileen 67

in addition to preparing others for anticipated behavioural changes.

Oh hell aye I'd have to. I'd have to tell my daughters and my son...and with friends in case I started acting funny. [...] If I've got signs of it, it's best to let people know in case I do something that might embarrass. Mike 68

One participant noted during his response that intentions did not necessarily match the actual actions taken. He gave the example of his friend's reluctance to discuss concerns, with her doctor in this instance. The decision was eventually taken out of her hands by her daughter.

I: Would you talk to anybody about it if you were concerned about it?

R: If I was concerned I would probably talk, ... I mean, there again (friend) wouldn't go to the doctor's about her memory would she? [...] no definitely not and in the end she was forced to go because her daughter made the appointment for her to go. So it's difficult to answer that, unless you're in that position. Burt 78

For some participants, dementia care, support and management were part of their everyday life and sometimes to do that, conversations had to be had and decisions made.

For one participant the implications of genetic testing within the family needed to be discussed.

Its... a genetic thing, a genetic problem and therefore can be passed down through the family. [...] She (daughter) said she wasn't having it done (genetic testing) because she was frightened. But she's coming around now [...] but son his attitude to life is what will be will be. And he's absolutely in denial [...] he just doesn't want to know. He doesn't even want to talk about it. George 72

Another who was supporting a friend with dementia was in almost daily communication with her daughter (who lived some distance away) to keep her informed of progress.

I go down in the morning, see if she's okay. [...] And during the day I call in and see if she's ok [...] I go down every evening about nine o'clock [...] we watch the telly or we're talking or whatever [...] ... her daughter phones (him) twice a day, she phones first thing in the morning and round about tea-time. I mean they appreciate what I'm doing for her. Burt 78

Not all family members either wanted to or were included in the family discussions involving decisions that needed to be made around ongoing dementia care.

R: When she went to the home? Um ... I don't ... I'm not absolutely certain how that decision came about, to be honest.

I: So it wasn't necessarily ... you wouldn't have been part of discussions ...

R: I wasn't. I assume <wife> was at some stage, but I wasn't. Matthew 66

Compared to expectations of how those not affected by dementia may conduct their conversations in the future, there were mixed responses from those who were currently experiencing memory problems about their routine communications.

Some had shared their diagnosis or issues associated with their memory loss with selected support network members.

*I know I've got it, and I know my friends and the family know I've got it [...]
Well, mostly we don't sit and have a conversation about it, but they know. ...
yeah and they allow for it. Dolly 82 MCI*

For others there was a preference not to share their diagnosis or memory issues with particular family members or friends, potentially so as not to add to others concerns or worries.

I: Do you talk to your kids about the memory clinic, do they know about that?

R: I can't think I have but I don't think it's necessary at the moment. If it comes necessary I would do it, oh yes, but I don't think it is at the moment.

Audrey 75 MCI

I think I've told (grandson), but I don't think I've told my son, ... wouldn't want to know, and ... But, you know, they've got their own problems. I don't want to push some of mine on them. Cissie 78 MCI

There were some discrepancies in these latter accounts as it was apparent from earlier comments in their narratives that their children were aware of their condition. Their comments were made in direct response to questions relating to whom they may discuss their memory problems with, and so I considered this represented their views on the matter at that moment. Expectations of how participants without dementia may handle future conversations were sometimes at variance to those who were living with memory issues. For those living with cognitive problems, in general it appeared that where conversations were had, these were

not regular or perhaps in depth. In most instances discussing dementia appeared to be on ‘a needs to know basis’, around the necessity of keeping people informed in order to better plan and manage particular concerns at the time. Although some seemed to prefer to remain on the periphery of these and perhaps considered there were specific people that should be making the decisions (perhaps closer family members). On the whole actual or envisaged discussions seemed to be purposeful. These may include difficult but necessary conversations around genetic testing for instance, or making sure that others were privy to decisions that were made around care choices and otherwise, it appeared, was best avoided.

d) Ongoing conversations and support

Another emergent theme was regarding the type of conversations that elicited or provided the dementia support that participants required or provided. Support came in a variety of forms from practical assistance to advice and emotional support.

Some participants provided support via advice, offering a different perspective on a matter of concern or just a listening ear to others in their network who were caring for someone with dementia.

She said, ‘I can’t leave him down there if we’re going about half eleven and not home until five o’clock – that’s outers’. So I said, ‘well why don’t you have a word to your son’, I said to her, ‘him and his wife are lovely people aren’t they?’ [...] I said ‘just ask him, you’re having a Christmas lunch you’d like to go but you know its impossible and he might say well why is it impossible mum?’ Gillian 71

She used to write me these little notes every now and again saying, ‘(husband with dementia)’s getting worse. [...] he (husband) wanted to go out everyday. It didn’t matter where she took him [...] But he, I think felt that he’d had a trip, he’d been out. And so she was worrying about him losing out [...] So I think to myself these things are important aren’t they? Sylvia 76

Some participants requested to be accompanied to their memory related or other health care appointments by family members ostensibly to better understand what was communicated. Implied (although not corroborated) was that there would be a post consultation conversation between those attending appointments to confirm and clarify what was discussed.

Oh he (grandson) won’t let me go on my own [...] But I’d rather have him there anyway. He’s got a better memory than I’ve ever had. [...] Well, when

you go to see these people, you hear it but you don't know what they're saying. [...] He's better edified than what I am, or ever were. And he would know, probably more than were being said than I would understand. Cissie78 MCI

R: About a month ago I went up there (memory clinic). (Son1) takes me, and he always comes in with me and that.

I: Have you had any sort of diagnosis?

R: No, no, not really [...]. They just talk to me like you do, you know, and ask me one or two things [...] with the memory and that [...] Dolly 82 MCI

Not everyone desired or thought it appropriate to have company at appointments. One participant had seemingly overstepped the balance between support and interference when accompanying his friend to her appointment.

I have been to the doctor's with her, you know and er because I speak up for her and she's said, "Right, you're not coming in" (laughs) right, I leave that to her now. Burt 78

One participant had been involved in ongoing conversations with her local MP and raising awareness about dementia and lack of support for carers and people living with dementia. This followed her own experience of the limited services that she considered were available to her and her spouse (now deceased) during his illness.

Well, there wasn't anything going on and I felt with social services and things like that, [...]. But if I didn't tell somebody like (local MP) they wouldn't know, would they? If you don't tell people, they won't know. Veronica 69

Although she did not find the response very useful ("two sheets of A4 saying exactly – I knew everything in it! – Veronica 69) she still considered it important to have been involved.

Having somebody to talk to for confirmation of understanding, reassurance or advice appeared to be needed and valued, as was the opportunity to share everyday concerns. The presence of their support network members at appointments was generally described as a mechanism to ensure that nothing was missed from the interaction although it did not always appear to serve the purpose of ensuring clarity. Cissie for example remained unclear as to what had been discussed during the appointments she had attended with her grandson and Dolly was uncertain about her diagnosis and what this meant for her. This was perhaps due to either: their acknowledged memory problems and forgotten discussions; the possibility that the presumed discussions and clarifications after the appointment did not actually take place;

or that the appointments held had failed (for a variety of reasons) to adequately answer or provide the relevant information in the first place. It is also possible that participants or their supportive other had not asked ‘the right’ questions and so further explanations or information were not given. General practitioners attitudes and possible reluctance to convey bad news or speak overtly to their patients without using euphemistic terms has been observed in previous research (Ahmad et al., 2010; Moore & Cahill, 2013).

e) Talking (or not) about dementia? “there’s one thing I always said...”

Although most participants claimed not to talk about dementia, the following quotes depict a variety of recalled conversations within their networks.

Some participants referenced conversations with family members expressing their explicit future preferences if affected by dementia.

If I get to be like one of them (niece’s name) I said, don’t put me in here will you? ‘What do you mean’ she said, I’m not going to a mixed ward like that, I don’t want to end up in one of them. ‘Right, What am I supposed to do then?’ Bring me a bottle of whiskey and some tablets from somewhere, for me to go to bed, ‘I can’t do that, the law will be after me’ she said. Stuff the law I said, they’ll be none the wiser, I’ll be gone. Vera 74 FD

There’s one thing that I always said, or do say to my children: ‘If I ever get to that just put me in a home’ Susan 73 FD

Of note in these last quotes, and also as evidenced throughout the interviews, are the words used when referring (unthinkingly perhaps ?) to people living with dementia in a way that could be seen to diminish the person, such as “*like one of them*” or the state of being “*if I ever get to that*” (Sabat, Johnson, Swarbrick, & Keady, 2018; Sabat, Napolitano, & Fath, 2004).

It was apparent in many narratives that anecdotes and descriptions had been derived (second-hand) from conversations with their social networks.

R: I’ve not had any contact (with someone with dementia) – but I have heard people talk about someone who they’ll just keep going for long walks, you know, they just keep going off ... They don’t know where.

I: And so that would perhaps be discussed to a certain extent within your groups then would it?

R: Yes, yes, well they would say, it's a shame and, you know, and you know what people have to put up with... cope with it, yeah. [...] And that's how you start to pick up little... You know, through chitchat. Elizabeth 71

Its parents or parent or someone I know and been associated with over the years like you know what I mean? I don't say I'm very friendly with them and that, but their mother or their father has gone down with it and they've gone into a home because they can't be taken care of in the house through their children working. Mike 68

The initial declaration by most participants that dementia was not talked about within their networks was often seemingly contradicted, with opinions expressed and shared with others. These may not register as conversations about dementia as they were perhaps seen more generically as expressed wishes in the event of losing capacity or perhaps as throwaway remarks that were not engaged with in depth. Second hand conversations (and perhaps such throwaway remarks) had allowed some to develop perceptions about dementia and those with the condition. In the latter quotes participants were either privy to ongoing discussions on, for example, the decisions made regarding nursing home placement, or the difficulties coping with someone with dementia or perhaps assumptions were made from their interpretation of the situations.

f) Humour in discussions: “that’s why I always end up laughing”

Humour was used extensively throughout the interviews. It was used when participants pretended to have forgotten what they were saying or had actually lost their train of thought. They then joked; “*one of the first symptoms*” (‘of dementia’ – implicit, but not stated) and laughed at themselves - with the interviewer, often as a welcome relief.

A common theme in the interviews was referring to memory lapses when they had forgotten what they had gone upstairs to get for example. Several described how they joked with friends about this.

We all talk about it in the rugby club every time we're having a chat. [...] I've gone upstairs and half way up (wife) have shouted something and I've answered her and I've got up the stairs and I think now what did I come up here for? Mike 68

I know we joke about it [...] You know, if you go upstairs for something and then you have to go back downstairs again to think what you'd gone for. Elizabeth 71

One participant in particular used humour throughout her interview and seemingly in interactions with others, as she explained that the nurses had told her not to lose her sense of humour. She stated that she seemed to “*be able to turn things round so that we could all have a laugh*”

I've had x, not x scans, x-rays of the brain and ... flogging a dead horse, there's no brain there, otherwise I'd be better than I am.
Cissie 78 MCI

As well as reducing the discomfort for others it could be used as a coping mechanism for themselves.

R: I think that's why I always end up laughing
I: That's your way of coping with it?
R: Yeah I think so Cissie 78 MCI

I feel sometimes that I'm losing it, like I was saying. Then you laugh and it's gone. Vera 74

Humour was used within family environments in a similar way.

Just read this on the internet, I think that's me! {laughs} [...] They'd say, "Mam we were expecting that?" {laughs} Eileen 67

R: Oh I often tell them to tell the truth. 'I'm sure I've got something, you know.' I'll say, if I can't find my purse. 'What are you like, it's there' she'll say'.
I: Is that something that's more of a joke between you now than it used to be?
R: It is. Vera 74

When talking about events that were apparently quite upsetting for them, some participants were able to quickly turn to humour to express a view or recount a humorous story in response to a question. An example here is where one participant had described several worrying episodes and unusual behaviour displayed by her mother, then recounted her mother's encounter during cognitive testing.

And I was over there that afternoon, (brother) and me. And one question he asked was 'can you tell me what the Queen's name is?' ... And mam pulled a very funny face and said, 'If you don't know that, a man in your position, then

I'm not going to tell you.' [Respondent laughs]. I'm telling you. And (brother) and I rolled around laughing. Vera 74

Humour was a device used frequently throughout the interviews and, it seemed, when bringing up the subject of dementia or memory loss in their conversations within their social networks, in a seemingly more 'acceptable' way. It was perhaps used to try and assess the 'normality' of an experience (forgetting what they had gone upstairs for example). However it could also serve to disrupt the flow of conversation and provide an escape route from engaging in a more serious conversation. This appeared to be the case in a couple of included instances above, where participants appeared to be attempting to broach conversations about their memory concerns with others in their support networks that were then 'laughed away'. These concerns may have been dismissed as they were considered to be not problematic or possibly that the issue was not something that either party particularly wished to acknowledge or pursue.

Chapter Summary

In summary, this chapter has presented findings indicating the presence of higher health literacy levels in wider community focused support network types and for those who regularly attended social groups. This suggests that those with a greater number and range of contacts or opportunities to interact with others may be better placed to share health information and experiences and thus improve their health literacy. However, in general seeking out and discussing information about dementia, if not actively avoided, was certainly not a priority for those without close contacts affected by the condition.

Overall, across the latter two chapters a perspective of the dementia literacy of this population emerges. What is known, perceived, sought and shared about dementia and what may motivate any interest is beginning to be exposed. But much confusion is apparent, and conflicting views in the narratives, even within individual's stories, are observed. Among the participants there is little known about what are considered to be the important facts about dementia (as previously detailed and as incorporated into measures of dementia literacy). Critically there is generally no desire to know and find out more about dementia and reasons suggested for this include; fear, stigma, fatalism and a lack of perceived relevance for them. Participants' narratives reveal their understandings or what they do know about dementia which almost without exception is a negative and nihilistic portrayal. Their personal experiences and those gleaned from others during their network interactions seem to confirm

this shared bleak outlook. Recent media representations of dementia have seemingly encouraged more interest and some debate and to an extent included if not more positive than slightly less negative portrayals than are generally conceived. The next chapter explores some of these issues in greater depth and discusses what this may mean for dementia literacy.

8 DISCUSSION

This mixed methods study has explored the dementia literacy of older adults in Wales and the factors that influence it. Current conceptualisations of health and disease specific literacies, in particular mental health literacy, have formed the backdrop to this exploration of dementia literacy. Existing studies within the somewhat limited body of research on dementia literacy have tended to focus on the biomedical knowledge of dementia and recognition of its symptoms. There has been less emphasis on how pre-existing beliefs, attitudes and social factors may impact uptake of knowledge about dementia. This study examined participants' experiences and knowledge of dementia - what was known and how it was known and shared. It explored what factors may motivate or deter people from becoming more dementia literate and examined some of the underlying assumptions about dementia that could inform an enhanced definition. It suggests that a more expansive definition (and understanding of additional influencing factors) would align it more closely to current health literacy models and could prove beneficial in terms of future outcomes.

There are three key findings from this study. The first is that knowledge of dementia is imbalanced, fragmentary and distorted. The second is that attitudes toward dementia knowledge acquisition are negative. The third is that social contexts (including social networks) do not facilitate knowing more about dementia. Findings are discussed in light of the gap between relatively high health literacy among the population of older people in Wales and low dementia literacy. The chapter concludes with a discussion of the advisability of pursuing any further development of models of Dementia Literacy.

1. Knowledge is fragmentary and distorted.

Participants' lack of knowledge and misconceptions about dementia were evident from this research. Participants freely expressed the limitations of their knowledge. Where they did 'know', their knowing was imbalanced. Yet there was dissonance in their understandings. On the one hand, uncertainties about boundaries between age-related changes in memory and the onset of dementia fed into pre-existing beliefs and expectations with ageing. On the other hand when asked about knowledge of the disease, their illustrations were freely and often vividly expressed.

Participants expected a decline in cognitive abilities with age. Symptoms such as forgetfulness were sometimes (perhaps wishfully) associated with 'normal ageing'.

Uncertainties about the point at which forgetfulness became indicative of cognitive decline created anxiety. Whereas earlier in life, memory lapses were dismissed (it happens to us all), as they were getting older, questions about whether such changes indicated the start of dementia became both personal and worrisome. Ageing, memory-failings and dementia were conflated.

In contrast, when framed in terms of knowledge of the disease, dementia was referred to in terms of a process. Yet it was most often presented based on symptoms associated with late stages of the illness. The main focus was thus on the most dramatic elements of the condition (e.g. severe memory problems, inability to communicate, loss of capacity to exert control over one's life and a lack of recognition of loved ones). It appears that for participants in this study, these late-stage symptoms represented the entire disease.

There is a kind of logic of self-protection in this discourse that memory decline with age is normal and does not indicate a disease which has a dramatically different outcome. However, participants' conversations suggest that holding these two perspectives was difficult. An uneasy shifting between normal versus disease perspectives was observed within the same conversation as participants attempted to explain concerns with their own cognitive health. This was particularly exemplified by one participant who had cited an example of her aunt living to beyond 100 years of age with no signs of memory impairments but had then attempted to engage the interviewer in assuaging her current anxieties by attributing her troubling memory concerns to "*just old age*". Her mother however had developed the condition and so her fears were intensified as she was concerned she may be going down the same route. Reconciling these two accounts with no other apparent reasons or causal factors to help explain either situation was causing apparent anxiety.

This idea of dissonance might help us better understand the persistent finding of confusion about the point at which normal became pathological (Cahill et al., 2015; Corner & Bond, 2004). Findings from this study suggest that this may not just be an issue of confusion but a deep reluctance to entertain the idea that the differences are not comfortingly distinct but worryingly blurred. This is an unsurprising finding as normal ageing versus disease remains a contested area beyond the lay public (Cahill et al., 2008; Vernooij-Dassen et al., 2005). Some forgetfulness or other aspects of cognitive decline are accepted as a normal part of

aging and are unlikely to be pathologised in many clinical consultations (Brayne, 2007; Turner et al., 2004).

Knowledge of dementia risk also was similarly fragmented and uneven. Increased risk of dementia with age (Prince et al., 2016) was seemingly acknowledged – although there was little reference to participants’ own increased risk (due to their age), possibly due to the anxiety this engendered. Other evidence, some well-supported and some more equivocal was offered without a critical filter. These included the increased risk of dementia with stroke (which research supports (Livingstone et al., (2017); with higher intelligence (where the evidence runs counter to this when considering concepts of cognitive reserve (Clare et al., 2017)); and lack of mental stimulation where the evidence is more mixed (Fratiglioni, Paillard-Borg, & Winblad, 2004), but is a relatively common perception (Friedman et al., 2015). Incidental information gathering (passively acquired) and thus knowledge acquisition was from diverse sources that were personal and idiosyncratic. Sources ranged from storylines in soap operas, medical pages of newspapers not necessarily renowned for their evidence base (e.g. *“I’d recommend that anyone bought the Daily Mail, just for medical and social information”*) to some without personal experience themselves but who had acquired an understanding of the condition and its impacts via general *“chit chat”* with friends (*“but I have heard people talk [...], it’s a shame [...] what people have to put up with... cope with it”*); and *“I don’t say I’m very friendly with them and that, but their mother or their father has gone down with it”*).

Ideas about possible treatments and interventions followed similar haphazard styles of knowledge acquisition. Treatments or cures such as *“wacky baccy”* or *“coconut oil”* were presented (hopefully) from often unremembered sources that were not always entirely believed. Understandings seemed, in many instances, to stem from a combination of long established broader health beliefs, personal observations and interpretation as opposed to acquired and accepted from what may be considered as reputable external sources (such as an NHS website or Alzheimer’s Society information for example). Similar findings were observed in Low and Anstey’s (2007) research, where even those with experience of caring for someone with dementia or working as a health professional held views more consistent with general health beliefs as opposed to specialist dementia knowledge.

This evidence of a disjointed, unexamined and often dubious knowledge base about causes, risk or protective factors is not surprising. Previous researchers have reported similar findings (Cations et al., 2018; Robinson et al., 2018; B.J. Smith et al., 2014). The overwhelming message was that dementia was a dreadful disease and that nothing could be done about it. Perhaps then it is not so much that lack of knowledge is a barrier to the uptake of behavioural/lifestyle changes (Kim et al., 2015; Low & Anstey, 2009), but that there is little reason to acquire knowledge about a disease that is terrible and efforts to intervene considered futile.

2. Attitudes preclude knowledge acquisition

An underlying assumption in much of the research on health literacies is that knowledge must be accompanied by beliefs that action is possible towards the achievement of better health outcomes (Diviani & Schulz, 2011; Jorm et al., 2000). However, findings from this study suggest that when thinking about dementia, participants had little sense of the possible. There was evidence of fatalism about the disease process and outcome. There was fatalism and fear around what was viewed as an inevitable trajectory of loss. There were active attempts to create distance between oneself and all of this (bleak and frightening prospect).

a) Fatalism about processes and outcomes. “If you get it you’re buggered”.

A sense of fatalism was evident throughout the narratives of participants. Participants believed that there was no cure, limited treatment or therapies and nothing that could be done to prevent or better manage dementia. ‘Getting it’ was the beginning of an inevitable process of decline and hopelessness. Findings show that thoughts of cure were “*a long way off it, at the moment*”. References to past news items that had suggested potential optimism for cures or treatments that had not as yet materialised seemed to accentuate the current absence of hope in this direction. Few seemed to be expecting changes to this outlook imminently (“*I don’t think we will really find out those things will we?*”). The sense that “*If you get it you’re buggered*” was also reflected in the responses of those experiencing memory problems “*something that’s packing up and you can’t do anything about it*” and “*if it’s [memory] gone it’s gone*”. The almost universal and enduring sense of fatalism – that nothing can be done to prevent or intervene led to avoidance of the issue and perhaps in the latter cases an acceptance of that fate. That these latter statements were voiced following at least some appointments regarding their memory issues suggests that despite the increasing

evidence of the benefits of psychosocial interventions aimed at improving quality of life (Logsdon, McCurry, & Teri, 2007) these were apparently not offered or discussed, not locally available or were in some other way not accepted or believed.

This sense of fatalism about dementia resonates strongly with similar themes from research on attitudes toward cancer. An example comes from a probability sample of adults in the United States who were surveyed about their cancer knowledge and attitudes (Kobayashi & Smith, 2016). The authors used the term “cancer fatalism” to reflect “deterministic thoughts about the external causes of the disease, the inability to prevent it, and the inevitability of death at diagnosis” (p. 461). Fatalism was presented as a factor that reduced willingness to take actions such as screening or efforts to engage in preventative behaviours. In a study of dementia literacy in Singapore, Tan et al (2012) came to similar conclusions. They found that fatalism left people reluctant to seek or undergo diagnostic screening or to follow up after screening had occurred

b) Fear of loss. *“I could never believe there was nothing there”*

The dementia story was one of loss: lost communication skills, lost control over decisions, lost dignity. The ultimate loss was not death but personhood. Despite the assertion from one participant that *“I could never believe there was nothing there”*, a common sentiment was that though still alive, the person was gone (*“The man I met and married is gone”*). Boss (2007) named this experience “ambiguous loss” (p. 105). She described two types of losses: those in which there was physical absence with psychological presence, and those in which there was psychological absence with physical presence. Dementia represents the second type of loss. A main finding from Boss’ research is that such ambiguity “freezes the grief process and prevents cognition, thus blocking coping and decision-making processes (2007, p. 105). Only spouses, it appeared held firm to the belief that the essence of their partner was still there. Perhaps for them, this was a way of dealing with what Boss calls “the paradox of absence and presence” (p. 111).

For the most part, participants were fearful of this spectre of loss. Phrases such as *“it’s scary if you think on it too much”* and *“it’s frightening”* were evidence of this fear of dementia. Previous research has shown similar themes both with dementia and with other diseases such as cancer and discussion tends to be around how fear prevents engagement in information seeking (Balmer et al, 2014; Morris et al, 2013). Conversely this fear has been

seen by others as an essential precursor to behaviours to reduce risk (Kim et al, 2014). This study's research supports the findings of Corner & Bond (2004) that fear and fatalism can lead to avoidance of the topic and any attempts to plan for its possibility or its prevention. In addition fear associated with dementia can aid in the stigmatisation of the illness, leading those without the illness to distance themselves from people with it (Devlin et al., 2007).

c) Strategies to create distance (from) "*one of those*"

Participants used several strategies to distance themselves from the disease. These ranged from the fundamental avoidance of the whole topic if at all possible ("*I no more want to know about dementia than I want to know details of either cancer or ... the anal fish*"), to distancing themselves from "those" with the condition ("*But I do feel sorry for them*" (people living with dementia)). This was possible too for those with cognitive impairments, one participant clearly wished to differentiate whatever her condition was, as being a different condition to Alzheimer's disease ("*No, no haven't got that [...] but they said I haven't got that, hasn't got to that stage*"). Sometimes the act or process of distancing appeared to be less apparent and purposeful, and involved just losing touch over time - just drifting away ("*I used to be friends with her, but in the end you couldn't talk, couldn't talk to her*"). Friends, gradually it seemed disappeared as communication, in particular during social occasions, may have become more awkward for them to manage (Lapierre & Keating, 2013). The effects of reduced social contacts have been previously observed with detrimental consequences including increasing social isolation (Singleton, Mukadam, Livingston, & Sommerlad, 2017). Reduced participation in everyday activities for people living with dementia and carers can also result in limiting the opportunities for others to observe alternative possibilities to despair associated only with later symptoms.

Some participants in this study separated themselves from others with dementia by dismissing or diminishing their own symptoms and accentuating differences between what they were experiencing and what they saw in others. If the disease could happen to anyone (and knowledge or lack of it led to this conclusion) then it could happen to them and thus avoidance of those 'reminders' was preferable (Kitwood, 1997). The selective and somewhat haphazard approach to knowledge acquisition, discussed in the previous section, might be understood as a process of 'othering'. The notion of 'othering' has a long tradition in philosophy where it is understood as the construction of self or the group to which one belongs as separate from or in opposition to an inferior other or out-group (Brons, 2015). "*It*

hasn't got to that stage", or I am different from "*them*" and will therefore not succumb, are ways of keeping the 'other' at a distance. The idea of 'othering' – that those with dementia are different from those without it, increases the social distance between "them" and "us" during the process of stigmatisation (Link & Phelan, 2001). The negative effects of stigma can it seems only be avoided by attempting to pass oneself as 'normal', by changing the people one interacts with or withdrawing (Link & Phelan, 2001). Similar research on othering within mental illness has observed there are specific areas of difference that have been identified and developed into stereotypical behaviours or features associated with some mental illnesses which form the basis for this othering. For example beliefs around the danger and unpredictability or blame (person with the illness is at least partially responsible for it) of those affected are more commonly associated with perceptions of those with mental illness (Schomerus & Angermeyer, 2008; Yeh, Jewell, & Thomas, 2017). Thoughts about the individual's likelihood of recovery and if they may be considered as "a lost cause" are also linked to such stereotypical images with an associated desire to distance and in this situation could be seen to apply to dementia also (Yeh et al., 2017, p. 101).

Friends and relatives colluded with this othering. Some participants were reassured by people within their support networks that they were not 'as one of those – others', where for example a daughter told her mother that her cognitive concerns looked like "*just normal ageing*". Yet at least one participant observed herself 'becoming the other', using terms such as "*not the full shilling*" and "*wonky women*", that set her apart in the eyes of people around her – including her doctors. Such acceptance of others' stereotypical portrayals of those with dementia (self-stigma), have been observed to result in negative emotional reactions, especially low self-esteem and self-efficacy (Corrigan, 2015). This appeared to be the case here and although this was not entirely explicit in the interviews could result in a reduced desire to engage in health services or diminished ability to participate in encounters, as has been indicated in previous research (Corrigan, 2015; Rüsçh, Angermeyer, & Corrigan, 2005), which in turn can impact on an individual's health literacy and sense of self.

Dementia was seen as such a difficult and demeaning condition that physical removal to a care home or even suicide were seen by some as preferable alternatives. The 'burden of caring' was a common theme in interviews and is a term frequently used in the dementia literature. Rather than subject others (or themselves) to this "*pitiful*" state ("*stuck in a chair and you're a burden*") the preference was to distance/remove themselves (suicide) or to be

“put (me) in a home” to avoid this. “Caregiver burden” is a commonly used research outcome measure assessing impacts on caregiver’s quality of life by taking care of someone with dementia (Chiao, Wu, & Hsiao, 2015, p. 341). This terminology has made its way into everyday parlance. While acknowledging that there is reason and utility in the use of such terms, this stereotypical framing of dementia care has been charged with limiting any alternative perspective such as providing the *“opportunity to return kindness and warmth to parents, relatives, or friends”* (George, 2010, p. 587). Such physical removal (to a care home) is not usually discussed in relation to othering/stigma when thinking of dementia, but brings to mind those removed to prisons or historically to leper colonies (Combessie, 2002; Rafferty, 2005).

Othering and distancing, beginning with lack of insight (into an alternative more empathetic or positive perspective) and the acceptance of those with dementia as being less than “us”, can lead to tolerance of situations or circumstances that we would not accept for ourselves (*she’d be horrified to see the situation she’s in*). That this is accepted for others in this “situation”, and moreover that this is the expectation of the dementia trajectory, can only lead to the assumption that this will be permitted for us all. And this may contribute to the feeling of dread about the condition. These findings have added to our understanding of ‘othering’ that comes from the avoidance of this stigmatized condition.

Distance may be maintained by the use of evocative language, as in descriptions such as *“in cloud cuckoo land”* or *“away with the fairies”* which support the perspective that persons with dementia are seen as occupying a different world to the rest of us (Doyle & Rubinstein, 2014). Others have noted that such metaphors influence not only how those with dementia are seen (Zeilig, 2014) but also how those with the illness view themselves (Campbell & Deacon, 2006; Werner et al., 2012). The dramatic portrayal of symptoms, the focus on loss and emotive metaphorical language evident in this research has also been interpreted by other researchers as part of a broader societal portrayal of dementias that is both negative and alarmist (George, 2010; Peel, 2014; Zeilig, 2014). The expression of this same vision and narrative among participants in this research is then unsurprising as it merely reflects back what is consistently portrayed (Reed, Carson, & Gibb, 2017; Van Gorp & Vercruyse, 2012).

Yet what occurs at the personal level may not simply be a mirror of the societal perspective. The study's findings revealed that personal contexts made a difference too. The 'common view', prevailed until such a time, it appeared, as something caused that view to be questioned. That only seemed to happen when it directly impacted on participant's lives (*"until it actually affects yourself"*). So a carer who originally knew "nothing" prior to her spouse's diagnosis, subsequently over the years achieved a level of critical dementia literacy - culminating in campaigning to ensure that others may be better able to access the support and services that she had struggled to do. Her impetus to achieve such social justice for others might not have occurred had she not experienced these difficulties herself. In a different vein, another spousal carer gave the impression that he managed his circumstances facilitated by his support network. This included supportive neighbours whose attitudes did not conform to those previously described and who were willing to help out with a range of care needs (*"if it's just moving her [...] just give me a ring [...] if it's a bit more personal, (wife) will come round"*).

Attitudes towards dementia (fear, fatalism, and stigma) were such that there was little desire to know about dementia resulting frequently in attempts to distance oneself from all things related to dementia. Attempting to raise awareness of dementia with this backdrop requires considerable understanding of the complexity of issues involved, some of which are beginning to emerge from this study. Concerns have been raised regarding the ethical nature of positioning 'healthy people' (those without a particular condition) as at-risk of that condition due to a range of modifiable and non-modifiable risk factors considering the current lack of a cure or of effective treatments (Lawless & Augoustinos, 2017; R. Milne et al., 2018). This may exacerbate fear at the same time as positioning individuals as potentially accountable for either existing or anticipated cognitive health conditions (Lawless, Augoustinos, & LeCouteur, 2018).

3. The association of social contexts and support networks with health literacy and dementia literacy.

One of the premises on which this study was based is that social networks are important in influencing health literacy. As discussed in Chapter three, health literacy conceptualisations have emerged from two different roots: the first has a focus on low health literacy as a risk factor for poor health outcomes in health care situations – and is mainly viewed from a biomedical perspective (Baker et al., 2002). The second has its roots in other

forms of literacy and concepts of adult learning and health promotion which considers health literacy as an asset to be developed as an outcome of health education and improved knowledge and communication skills (Nutbeam, 2008). Later theoretical arguments added the importance of context and skills in determining approaches to gain specific health-related knowledge alongside self-efficacy necessary to put that knowledge into practice, while taking into account the broader societal influences (e.g. culture, community, and media) that impact on decision making (Chinn, 2014; Nutbeam, 2000; Squiers et al., 2012). Further, a number of models have suggested that “the positive resources and support in individuals’ social networks” can also improve the ability for individuals to acquire, understand and use health information (S.-Y. D. Lee et al., 2004, p. 1314).

Support network type impacts on health literacy

A key finding from this study’s research of the population of older people in Wales was the association between an individual’s support network type and health literacy. Those with more diverse networks (i.e. wider community focused networks) demonstrated higher levels of health literacy. Similarly, the results demonstrated that those with higher levels of social participation (i.e. those who more regularly attended social groups) also had higher health literacy. This suggests that larger and more diverse networks can facilitate increased opportunities for connecting with others via these networks offering greater occasions (and differing perspectives) to share and discuss any health information and experiences, thereby improving their health literacy.

Results of this study show that broader community networks were associated with higher health literacy. This finding augments previous research that has demonstrated health literacy as a social network resource (Abreu et al., 2018; Edwards et al., 2015; Papen, 2009), adding knowledge of how social capital functions in networks of older people. These findings resonate with past research on social capital as the “active ingredient” of social support networks (Golden et al., 2009, p. 280). For example, in research using Wenger’s network typology, Golden and colleagues (2009) found that better health came from higher levels of social engagement such as participation in social events and contact with friends and neighbours.

Social capital is a well-established concept - thought of as collective social resources available between members of a community including shared values and understandings

(Putnam, 2000). This study's findings align with this previous research, showing that the type of loose ties associated with the connections in wider community networks provide the best opportunities for linking people to health knowledge. Waverijn and colleagues (2016) investigation of the relationship between social capital and the health of people with a chronic condition found a positive effect of neighbourhood social capital on the health of people with chronic conditions which furthermore was stronger for those with better health literacy. To be able to tap into these neighbourhood resources may require better health literacy skills to access and understand information (Waverijn et al., 2016) or perhaps members of an individual's networks may be able to do so on their behalf. In contrast, bonding social capital which is typical of close relationships (as found in family dependent network types for example) is important in providing psychological and other support in day to day management and activities (N. Keating & Dosman, 2009). Thus closer knit networks can help with supporting older people in making them feel valued and cared for but who might not necessarily have the broader connections required to assist with gaining new health knowledge and acting on it.

Limitations with the imputed health literacy measure developed in this study (described in more detail in a later section of the chapter) restricted its use in the analysis. Findings of network differences in health literacy will require further testing with more robust health literacy measures.

Social networks did not appear to facilitate the development of dementia literacy.

In contrast to findings of the relationship between network type and health literacy, social support networks did not appear to facilitate the development of dementia literacy. Insights gained from the in-depth interviews suggested that if anything, support network members reinforced the attitudes that were expressed by most participants – that there is little point in knowing or doing anything about dementia. Although perceptions of dementia had, according to some, changed and that it was now considered “*only another illness*” the fact that most readily admitted to avoiding the topic (“*not a very nice subject*” and “*it's not a nice disease*”) implies that this was not always the case. Comparisons were made with other physical illnesses to highlight the distinctions (“*MS ... that's an awful affliction [...] you can take some kind of comfort that you can connect with them*”). Previous research on homophily – in which people associate with others similar to themselves, may give some indications as to

why people are only receiving limited perspectives from within their own networks (McPherson, Smith-Lovin, & Cook, 2001). But that there seems to be no difference between networks may support the view that current public framings of dementia are pervasive and widespread, and lead to general avoidance of the topic (Peel, 2014; Van Gorp & Vercruyse, 2012; Zeilig, 2014, 2015). Further, there is evidence that networks become smaller with increased age and disability (Wenger & Keating, 2008). The typical pattern where this occurs is to move to a smaller and more private network type - associated with less community involvement (Wenger, 1994b; Wenger & Keating, 2008) which has the same implications for reduced access to information and the support infrastructure to use it.

There are limitations with the interview sample that mean that the conclusions drawn may need to be taken with some caution. The sample size for the qualitative interviews was relatively small (26 participants), with limited representation of some network types – for example, there was only one participant with a private restricted network type and four with a wider community focused network type. The aim of ensuring representation of all the different networks was to observe any potential patterns between social support network types and dementia literacy. However even where there were larger numbers of participants within the specific support networks (as in family dependent and locally integrated support networks), no discernable patterns emerged that appeared to be attributable to their network types.

The main motivating factor influencing dementia literacy in this study population was close personal experience of dementia. Those participants with greater knowledge had acquired knowledge based on their experience and according to personal situations. Similar processes of knowledge acquisition have been observed with the development of health literacy skills over time (Edwards et al., 2012). Further understanding of the role of support networks in dementia literacy may best be developed through research on the management of the conditions over time as has been previously conducted with respect to health literacy (Edwards et al., 2015; Ellis et al., 2012).

Raising concerns about and rationalising dementia

Findings revealed that there were some attempts made by participants to raise the topic of dementia with others within their support networks when broaching concerns about their forgetfulness or persistently losing items (“*I often tell them to tell the truth. I’m sure I’ve got something, you know*” and for another “*I was worrying at one point because my memory’s got terrible. I asked <daughter1> to look*”). Though some efforts were more overt than

others and some were couched in humour, it was nevertheless apparent that there were genuine concerns and attempts to draw upon the experiences and knowledge of others to gain insights into possible explanations for their problems. We see collusion between the players and attempts to support and reassure by dismissing symptoms or assigning them to “*just age*”.

Close network members may be better able to provide the bonding/psychological support (N. Keating & Dosman, 2009) more suited to preserving well-being in the face of the (apparent) shared belief that nothing that can be done about the condition and ‘knowing’ may be seen merely as prolonging the agony. However such restricted views may then exclude the possibility of further linkages to wider resources within the networks with different advice and possible benefits attributed to earlier diagnosis. It is also possible that fears were only raised within more intimate relationships as participants really did not want to hear anything different (“*I don’t want to think about it*”). Attempts to minimise or normalise any apparent difficulties has been previously observed as a type of self-maintenance strategy with those in early stages of dementia thus preserving a sense of self (Clare, 2003). Others have identified that signs of cognitive deterioration can provoke a number and combination of reactions from denial to fear to action (such as information seeking) (Bunn et al., 2012; Juárez-Cedillo, Jarillo-Soto, & Rosas-Carrasco, 2014). It appears that older people may draw on the experiences of individuals within their networks via tentative approaches and by shared stories. But as observed - this does not necessarily lead to new or accurate information, precluding confronting, dispelling myths or learning more as nobody really had any desire to pursue the topic.

Previous research and findings from this study indicate that support networks can influence health literacy and health behaviours such as changing lifestyles and actions (e.g. help seeking) (Edwards et al., 2015; Ellis et al., 2012). Evidence of influence of support networks in these and other studies have focused on the management of chronic health conditions that are more openly talked about such as arthritis or diabetes and for which there is frequently a stronger evidence base that uptake of specific health related behaviours may improve condition outcomes. There has been less research evidence that indicates the relevance of social networks for conditions that are more stigmatised. Social support has been identified as particularly important with regard to mental health literacy as family and friends are often the first persons turned to for help prior to any health professionals (Kelly, Jorm, & Wright, 2007). Jung and colleagues (2017) found in their study, that improving mental health

literacy and strengthening social support could promote positive attitudes toward mental health help seeking. However an observation made by N.L. Keating et al (2011) following their study demonstrating only minimal influence of social networks on cancer screening behaviours, was that some behaviours may be less “contagious” than other as they are not so easily observed (undergoing a mammogram versus smoking for example) (N. L. Keating et al., 2011, p. 3050). Further, behaviours are easier to adopt when connections between cause and effect are more apparent and the health condition may be more or less easily discussed. The findings of this research show that dementia is not readily discussed. There was no evidence of dementia risk avoidance activities nor was it observed among peers or recognised within broader societal normative modeling behaviours.

Participants understood dementia according to their broader social contexts and from their own experiences and the limited shared experiences of others, about a topic little discussed. Information, it seemed, was on a need to know basis and most believed that they did not need to know.

Limitations

There are a number of limitations to this study. A methodological approach was used to derive a population assessment of the health literacy (HL) of the Welsh population that has not been used in the UK to date. Development of an imputed HL measure was based on the advantages of using large existing population based surveys containing a relevant measure of health literacy. Issues that arose in this study are explained here in some detail as a basis for informing future work in this area.

Neither of the only two UK population surveys identified (ELSA and UCL) that contained a measure of health literacy proved to be ideal for this study’s purpose. After repeated testing, using alternative variables, models and statistical analysis between the two data sets, the UCL study had the only viable combination of study population and measure that could be used (see Appendix B). However, the UCL study population was limited within the age range of interest and it appeared that the model worked differently by age (18 - 64 and 65+). There were also a limited number of additional variables available within the UCL survey from which to arrive at the best possible model and to provide additional checks as to the efficacy of the derived health literacy measure (see Appendix K for additional detail).

Despite these limitations, additional analysis provided sufficient confidence to serve this study's purpose. The inherent complexity in measuring the complete construct of health literacy, including test based measures, has been noted as have shortcomings associated with all current measures (Haun et al., 2014).

As noted previously, the interview sample was relatively small and had limited representation of specific social support network types. Additionally the questions for this sub study's qualitative interviews followed on from those of the main study. This possibly impacted on participant's responses in some way. The first part of the interview, although still aiming to allow detailed responses, was more structured than the latter part which was designed to allow conversations to develop and flow. The focus of this study which was more explorative and possibly more thought provoking occurred at the same time as participants' attention may have been waning; although this was not particularly noted in a post interview debrief session.

Strengths

The quantitative analysis provided a heuristic device that gave indications of where differences in health literacy exist and where for example interventions to improve health literacy could then be targeted. It indicated the relevance of certain social factors to health literacy. Those with wider community focused support networks are more likely to be engaged in diverse ways in their communities and tended to have higher health literacy for example and this has provided additional context to the in-depth exploration of dementia literacy.

A strength of the study was the range of experiences within the interview participants ; including those experiencing mild cognitive impairment, carers (and former carers) of people living with dementia and those who stated they knew no one and had no experience of dementia. The interviews provided a useful insight into how such different circumstances impacted on dementia literacy. Participant's stories enabled a greater understanding of what may prevent people from wanting to know about dementia, what may encourage them to know and how participants may come to their understandings. Despite the exploratory nature and small scale design of the interviews, a number of important findings have emerged from the research which could be examined further in other contexts or settings.

What this study contributes to the body of knowledge

This study sought to examine relationships between health and dementia literacy and the role that social support networks may have in influencing this. This research adds to the general picture of dementia literacy. It provided evidence of some of the reasons behind the reluctance to seek dementia information including fatalism, fear and elements of stigma. The general lack of desire to know about or discuss dementia kept conversations closed and restricted opportunities to see alternative perspectives or question the implications of dementia much beyond individuals own experiences. Existing beliefs were embedded in societal norms which are almost exclusively negative and are to an extent reflected back and shared almost unconsciously with others.

The findings have implications for future research and practice and this will be explored in more detail below. Increased dementia literacy could improve attitudes towards dementia in general, truncating the vicious circle of not wanting to know about dementia, due largely to what is known or believed about dementia. Alternative perspectives need to be available – to demonstrate what is or may be possible for dementia and those living with the condition.

Reflections: Dementia literacy – where to now?

The finding that dementia literacy among older people in Wales, does not map well onto health literacy (HL) suggests that there is something different about dementia literacy. Despite relatively high levels of HL in the wider population, dementia literacy was low within the interview sample. Jorm (1997) identified something similar with regards to recognition and awareness of mental health conditions as compared to physical health and hence developed the concept of mental health literacy. A key difference observed regarding mental illnesses related to the issue of stigma (Jung et al., 2017; Kutcher et al., 2016a; Reavley & Jorm, 2011a, 2011b). How do we understand this gap with regards to dementia literacy?

The health literacy findings are not surprising. Decades of research and related public health campaigns on positive health outcomes resulting from lifestyle behaviours are well known and promoted (Gillis & Gray, 2010; Glanz & Bishop, 2010; Protheroe et al., 2017). Scientific advances, improved treatments and supportive services (for example stop smoking services and exercise referral schemes) for various conditions and diseases such as cancer and cardiovascular disease have seen enormous changes to the outcomes of what were once

frequently fatal conditions. There are strong and (fairly) consistent public health messages about the benefits of lifestyle changes. Our public health campaigns have convinced us that based on increased knowledge of risk factors and appropriate actions we can influence at least some elements of certain disease processes and outcomes. There are also increasingly expectations of living well with chronic conditions for extended periods of time in a manageable way even if the disease is considered terminal. A recent example of a health promotion campaign to encourage healthier living in Wales (Health Check Wales) included a multimedia initiative comprising a 35 page supplement in several Welsh national newspapers. The supplement (and online equivalents) displayed positive and attractive messages about strategies to transform our lifestyles and improve our health. Personal interest (and success) stories from those achieving the changes were incorporated in the extended article, advocating a range of lifestyle and dietary changes (South Wales Evening Post, 2019).

The question arises - is now the time to connect these broad public health messages to dementia risks? While there are recent reviews that suggest some potential for dementia risk reduction (Livingston et al., 2017; Yaffe, 2018) - do we treat these with any caution or suggest such promotions are a good strategy? With a back drop of increasing deaths due to dementia that have steadily increased over time and have now taken over from cardiovascular disease as the leading cause of death in England and Wales (Office for National Statistics, 2018), it is difficult not to act. However in spite of evidence that something should be done, there is less evidence regarding what should be done or how it should be done (Carter et al., 2011).

Recent data demonstrating reductions in incidence and prevalence of dementia internationally (Matthews et al., 2016; Prince et al., 2016) have directed research interest into the potential for risk reduction at the population and individual level (Frankish & Horton, 2017; Livingston et al., 2017; Yaffe, 2018). This evidence has provided a strong rationale for focusing policy efforts into raising public awareness and understanding of dementia risk. Increased public knowledge, attitudes and beliefs will, it is hoped, see uptake of these messages and corresponding actions to reduce risk at individual and community level.

The recent National Academy of Medicine (2017) review of current evidence however suggests that there are no specific interventions with sufficient evidence to warrant a public health campaign targeted at individuals (Kane et al., 2017). It has also been acknowledged

that some changes will not make a difference to individuals, not everyone will be able to make the suggested changes and some dementia risk (e.g. genetic factors) are not currently modifiable (Mitchell, Ridley, Sancho, & Norton, 2017). Such comments suggest caution and highlight risks to particular sub-populations in terms of ‘victim blaming’ for example those whose circumstances may make it difficult to adopt changes (Beard, Knauss, & Moyer, 2009; Peel, 2014). Nonetheless, the need to be “ambitious about prevention” regarding dementia has been proposed (Livingston et al., 2017, p. 2673). The evidence that certain factors fit overall health recommendations for improved cardio-vascular health and share risk factors in common with other non-communicable diseases that may benefit brain health (Livingston et al., 2017) have thus been suggested for inclusion in overall campaigns (Yaffe, 2018).

The recent ACT NOW (2017) Welsh Campaign models that approach. The campaign posits that lifestyle changes which are good for the heart and lungs will be good for the brain too, and is bolstered by arguments that a healthier lifestyle can reduce dementia risk by up to 60% (Elwood et al., 2013). The campaign remains heavily focused on advising the uptake of personal behaviours to reduce disease risk, lacking a broader social change perspective that could include recommended stigma reduction strategies (Werner & Kermel Schiffman, 2017). Thus while a good beginning, the campaign falls short of recommendations for well-designed health literacy and promotion campaigns (Devlin et al., 2007; Randolph & Viswanath, 2004). Advocating broad brush approaches without recognising limitations (as previously identified) and the potential for unexpected adverse consequences such as increased fear, stigma and victim blaming, can have detrimental effects to the success of a campaign (Devlin et al., 2007; Randolph & Viswanath, 2004). Exposing people to fear about risks, who are not experiencing symptoms, and may never experience the health outcomes may constitute unreasonable coercion according to newly suggested ethics literature proposed within the health promotion arena (Carter et al., 2011). Lack of clear and transparent messages about what may or may not work leaves a gap to be filled by myths around what may work. Exaggeration of the likely effects that individual action can realistically hope to achieve may increase distrust of ‘experts’. Incorporating dementia into mainstream chronic disease prevention alongside heart disease, stroke and cancer – with their many shared risk factors – may however serve to normalise and place dementia onto a similar footing as these other disease conditions (Irving et al 2018).

Next steps for Dementia Literacy

The concept of dementia literacy has not as yet reached the same level of awareness or benefitted from the same scrutiny and advancement as health literacy. However, it has potential if lessons from the developments of health literacy and some of the other disease specific literacies are taken into account. Findings of this study have demonstrated that one cannot assume that what will work in one situation may be directly transferred successfully to another situation. The specific context of dementia needs to be taken into account.

Cancer is a good example that has benefitted from a multipronged approach to raise disease-specific literacy (Bevan & Pecchioni, 2008; Diviani & Schulz, 2011). Commentators have noted that dementia has replaced cancer as the scourge of modern times (Van Gorp and Vercruyse, 2012). Parallels drawn between cancer and dementia have led to claims that how cancer was regarded thirty years ago, “a taboo – an illness that wasn’t talked about in polite society and was inevitably fatal” is how dementia is perceived today (Department of Health, 2008). There has been a general attitude changes about cancer - so what has changed and why?

An assumption within disease-specific literacies such as cancer is that increasing specialised knowledge in conjunction with beliefs about that illness can promote actions including behaviour changes (e.g. help seeking and screening). Key factors in this equation include beliefs that the illness can be prevented, treated or cured – and that the individual may have control over such outcomes (Diviani & Schulz, 2011; Morris et al., 2013). Cancer literacy campaigns have resulted in cancer becoming less of a stigmatised illness or a taboo topic. Celebrities speak openly about their own cancer diagnosis. High profile fundraising campaigns such as “Stand Up To Cancer” a now annual Cancer Research UK and Channel 4 TV campaign ("Stand Up To Cancer", 2019) alongside well promoted annual site specific cancer awareness days or weeks have undoubtedly contributed to the success of making cancer a talked about topic. People do not now tend to be referred to as frequently as cancer ‘sufferers’, but as living with (and beyond) cancer. Although there are still issues regarding the most acceptable terms and language used to convey the state of post diagnosis and treatment - the debate at least is open (Surbone, Annunziata, Santoro, Tirelli, & Tralongo, 2013). A series of scientific breakthroughs and treatment advances for cancer has meant that far more people survive cancer now. There is an increased awareness of this possibility within the general population. For those with terminal conditions, there are palliative interventions

and a range of well publicised supports available, thus creating an increased sense of the possible.

For dementia a cure remains elusive. Dementia has overtaken cardiovascular disease as the leading cause of death in England and Wales (Office for National Statistics, 2018), and with the news in Jan 2018 that Pfizer was pulling out of its research into Alzheimer's disease following a succession of failed pharmaceutical trials (Hawkes, 2018), dementia lags behind cancer. The possible with respect to cure seems much further off. In such circumstances there is a moral imperative as The Lancet Commission advocates, to ensure there is no delay in seeking and implementing evidence based services, treatments and care for people with dementia and their carers (Livingston et al., 2017).

Lessons from Mental Health Literacy

There is increasing evidence to suggest that there are significantly greater barriers to receiving mental health care as compared to physical health care (Henderson & Thornicroft, 2009). Barriers are related to mental health literacy: lack of knowledge of mental illness; of how to access treatment; and prejudicial and discriminatory attitudes towards those who have mental illness. UK campaigns to addressing stigma within specific population groups have met with mixed success (Evans-Lacko, Henderson, & Thornicroft, 2013). Although some improvements in knowledge and attitudes toward help seeking were observed following interventions, a lack of reduction in negative experiences with health professionals may still deter people from seeking help (Evans-Lacko et al., 2013). This study has indicated that similar issues may arise with respect to consultations regarding cognitive health. A recent review of mental health interventions suggest that increased social contact is the most effective type of intervention to improve knowledge and reduce negative attitudes, although there were also mixed views on what constituted destigmatising knowledge (Thornicroft et al., 2016).

The apparent discrepancy between health and dementia literacy levels in this study could at least be in part due to insufficient consideration of the distinct contextual requirements and barriers to being dementia literate. Dementia literacy falls within the growing family of disease specific literacies that can potentially offer learning opportunities. Like cancer literacy, there is a sense of fatalism as dementia is an incurable condition with a consistently expressed belief that nothing can be done about it or for those living with the

condition. Like mental health literacy there is stigma attached to the condition. So, dementia literacy is distinct and complex because it has elements of both of these (mediating) factors: fatalism and stigma that can impact on becoming more dementia literate (engagement and action) and should perhaps be more explicitly taken into account.

Dementia literacy - towards the possible?

Is dementia literacy a useful concept? If so are the key components of knowledge and motivations (attitudes) sufficient to encapsulate the concept? There is a fundamental disconnect between what the general public wants to know about dementia (generally - very little) and what dementia knowledge is currently being measured and therefore incorporated into efforts to improve this knowledge. This study has demonstrated that there are motivating factors and barriers to becoming dementia literate. Widely held societal views (replicated within social networks) impact individual and population dementia literacy. A large part of our fears of dementia are grounded not just in the disease trajectory but the societal response to cognitive impairment. This was manifest in this study in participants' attempts to distance themselves from the disease and in how dementia was more generally perceived and portrayed in anecdotes and often derogatory or fatalistic language.

There are some major challenges in moving towards greater population dementia literacy. Globally there is an ethical imperative within broader social contexts to "leave no one behind" in terms of improving the lives of people with dementia and their carers and of limiting the future societal impact (Prince, 2017, p. 51). What then is possible within a dementia literacy context? The World Health Organisation Global Action Plan on the Public Health Response to Dementia proposed a staged process which moves through steps of increased awareness, building dementia infrastructure, implementation of policies and dementia plans to a final stage which entails normalisation of dementia and its acceptance as a disability with full rights accorded (Dua et al., 2017). All require a foundational (or a different) understanding of dementia at the societal level.

What is dementia knowledge?

So what is dementia knowledge and who determines it? There are a number of ways of framing dementia as discussed previously, with some of the main conceptualisations introduced in chapter two. The privileging of biomedical knowledge of dementia over alternative social models has been considered to reinforce negative stereotypes (Kelly &

Innes, 2013). If we are to address gaps and misconceptions in dementia knowledge, we must be prepared to acknowledge (and respond to) the existence of other knowledge/ belief systems and illness representations more widely held. This study demonstrated that there were different understandings of dementia with dissonance arising when confronting seemingly conflicting views dependent on circumstances. Different cultural models are fairly common, based on implicit assumptions and ways of thinking in order to make sense of the world around us (Elwell-Sutton, Marshall & Bibby, 2019). Dementia conceptualisations have often developed from personal experiences and from diverse sources and have been reinforced over the life course. It was evident from this study that what was known, believed and felt about dementia was inextricably linked.

Arguably a contemporary and more balanced knowledge of dementia would benefit from an understanding of the social impacts on the disease and the person living with it. Kitwood (1997) considered that dementia could be viewed as the combination of both the neurological impairment and the malignant social psychologies that are required to create the disease state in an individual. Within this conceptualisation there is the potential to shift the emphasis away from the fear of the incurable condition (neurological impairment) to the empowerment of possibilities of changing what can be changed - for instance the perception and treatment by others (Beard et al., 2009). A recent study found that greater “personhood-based knowledge” (knowledge based on observations of the capabilities and perspectives of persons with dementia) and less personal fear of dementia, helped increase individual’s overall social comfort of dementia (Ebert, Kulibert, & McFadden, 2019, p. 1). Social comfort was the term used to differentiate between physical comfort (as associated with a favourite chair) or personal comfort equated with self-confidence (Ebert et al., 2019, p. 1). Such personhood-based knowledge is likely to have been the type displayed in this study by those very close to someone living with dementia, such as spousal carers. This is similar to the findings of Thornicroft and colleagues (2016) that increased social contact is likely to be effective in improving aspects of mental health literacy and in particular attitudes towards those with mental illness.

In addition as Bond (1999) suggested “There is much that can be done to improve the quality of life for people with dementia while waiting for the “magic bullets” of biomedical science” (1999, p. 564). Twenty years on there is more evidence available that this is the case (NICE, 2018) although gaps in the evidence base remain (Dawson, Bowes, Kelly, Velzke, &

Ward, 2015; Laver et al., 2016). Perhaps the time has come to shift the emphasis on what can and should be done to ensure such evidence based interventions are known about and more readily available.

9 RECOMMENDATIONS

Key barriers to improving or engaging with dementia literacy identified in this study include fear, fatalism and stigma. The following are recommendations to address these issues and provide a focus for further investigation.

With a backdrop of increasing dementia prevalence, dementia strategies have proliferated (Chow et al., 2018). Two key aims of these strategies include the development of dementia supportive communities that can facilitate the ongoing participation of those affected by dementia within their communities and dementia risk reduction by encouraging the uptake of healthy lifestyle behaviours. The bold statements in recent UK dementia strategies for example with the aim of achieving “a society where the public thinks and feels differently about dementia, where there is less fear, stigma and discrimination” (Department of Health, 2015 p. 6) and that “recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities” (Welsh Government, 2018 p. 3) must be implemented. Matching action with aspiration is important for a belief in the possibility of change. Participant’s experiences – their reality - in this study did not match these stated ambitions.

Recommendations for elements within a proposed dementia literacy campaign

There do not appear to be widespread interventions in place currently aimed at reducing the generalised perspective of loss and hopelessness about dementia as observed in this study. Multi-pronged carefully designed campaigns and concurrent infrastructure development offer greater potential for engaging people in all aspects of dementia literacy. Intervention strategies might be used to highlight feasible approaches to dementia risk reduction as well as improvements to the quality of life of those affected by it, and thus offers the potential to counter some of the negative perspectives held.

As reflected in this study dementia continues to be overwhelmingly negatively viewed, with a consistently expressed belief that nothing can be done about the disease or for those living with it. Providing a credible alternative perspective to this seems not only logical but an ethical imperative. Caution needs to be taken when promising the option of living well and “feeling valued” with dementia without the necessary infrastructure and attitude changes that could at least make this a possibility (Welsh Government, 2018 p. 3). Also reducing the options for those affected by dementia to either one of tragedy or living well does not account

for “the multiple realities of dementia necessary for social inclusion to occur” (McParland et al., 2017, p. 258). Any attempts at tackling dementia literacy should take a multifaceted approach. Understanding the perceptions of dementia and why people do not want to know – can help us to begin to address these issues.

Alternative language and visions

The portrayal of dementia impacts on how the public perceive the condition - “language shapes and limits thinking” (MacRae, 2008, p. 397). Rather than increasing the public’s sense of urgency and motivation when describing rising rates of chronic diseases such as dementia in terms of ‘epidemics’ and the strains on the NHS as a ‘crisis’, research has shown that such alarmist or crisis messaging reinforces fear and a sense of fatalism (Elwell-Sutton et al., 2019). Similarly stereotypes of people with dementia as vulnerable, dependent and a potential burden can contribute towards fear of dementia and of those who have it (Gerritsen et al., 2018). Negative terminology can create and intensify prejudice (Swaffer, 2014; Zeilig, 2015). Therefore, when reframing the dementia conversation ‘crisis messaging’ should be avoided as should stereotyping and grouping those living with dementia under one banner. Progress may be more likely to occur when the language and imageries used to depict dementia evokes empathy and an understanding of changes in personhood and a focus on how people living with dementia can be more meaningfully included in everyday activities. More accurate and realistic portrayals aimed at demystifying and ‘normalising’ may reduce some of the dread of dementia. The possibility of living a relatively ‘normal’ and socially engaged life for more extended periods of time than is currently perceived as possible and the retention of personhood throughout should be emphasised (Devlin et al., 2007).

Addressing stigma

Addressing the stigmatized nature of the condition and underlying health belief systems is another important step into opening up the receptiveness of the population to new messages. The impact of stigma should not be underestimated. How one feels about a diagnosis of dementia and how one perceives others will react may lead some to avoidance of a diagnosis or even discussing the condition (Bunn et al., 2012). The evidence of effectiveness of social marketing campaigns aimed at reducing dementia stigma is limited (Mukadam & Livingston, 2012). There has been more extensive investigation in this respect with regard to mental health literacy (Clement et al., 2013; Evans-Lacko et al., 2013; Jorm, Christensen, & Griffiths, 2006b; Thornicroft et al., 2016). A New Zealand campaign aimed at

combatting the stigma surrounding mental illness used celebrities and members of the public with personal experience of mental illness in a positive manner which conveyed their “commonality” with the audience (Vaughan & Hansen, 2004, p. 115). Participant’s engagement with and recall of celebrities or fictional characters with dementia in this study suggest that this could be a useful strategy. There is scope to learn from past successful and (unsuccessful) campaigns. Providing more information in the hope of raising awareness is a poor intervention. Improvements by addressing specific components that comprise stigma (as for example found in this study relating to ‘othering’ and a desire to distance oneself from someone with dementia) could offer a more nuanced and effective approach. Interventions based on those previously described that can increase social comfort (or reduce social distance) by promoting personhood-based knowledge should be further investigated (Beard et al., 2009; Ebert et al., 2019). A greater understanding of the cognitive representations of those involved in stigmatisation could also be further investigated (Yeh et al., 2017).

It has been proposed that stigma is less prominent in countries where people with dementia have greater access to memory clinics and innovative services (Vernooij-Dassen et al., 2005). A recent innovative piece of research run by psychologists at Bangor University found the company of young nursery aged children helped to improve the well-being of people living with dementia ("The Toddlers who took on Dementia – Research at Bangor, Bangor University", 2018). A BBC Wales documentary *The Toddlers who Took on Dementia* followed three days of planned activities in a day care centre (BBC Wales "The Toddlers who took on Dementia", 2018). If people affected by dementia are to continue to enjoy as full a life as possible in their communities then the behaviours and attitudes of those they will interact with will contribute to this possibility.

Rather than being ‘other’ an aim is for dementia is to be ‘normalised’ within society. This requires dementia to become an accepted and visible part of our society similar to physical disability (Shakespeare et al., 2017). The sense of othering or being a burden may be challenged by normalising strategies which can combat negative views associated with dementia. This approach has been successful within other chronic conditions (Millen & Walker, 2001). Kitwood’s work on personhood was instrumental in a cultural change in dementia care in particular. It is this emphasis on personhood that is also foundational to efforts to create dementia-friendly communities. Communities can thus focus on the possibilities for those living with dementia to retain meaning and purpose in their lives

“despite a highly stigmatized diagnosis” (Ebert et al., 2019, p. 2). Personhood-based knowledge and attitudes, acknowledging the inherent personhood of those with dementia could also reduce the pressure on carers who may feel obliged to explain behaviours which do not meet other social norms. Personhood-based knowledge was identified by Ebert and colleagues (2019) as being based on “observations of the capabilities and perspectives of persons with dementia” as opposed to the emphasis on specific knowledge about Alzheimer’s disease such as causes, risk and treatments (a biomedical focus) and which are generally developed by academic researchers with some input from professionals in dementia care (Ebert et al., 2019, p. 4). As indicated previously a better biological understanding of a mental illness does not always translate to greater social acceptance of those with the illness (Schomerus et al., 2012).

Dementia Risk Reduction

The possibility of dementia risk reduction is another dominant theme in dementia strategies and public health messages. In order for people to act on advice such as the uptake of lifestyle behaviours to reduce risk, then there should be clear and consistent evidence and recommendations that support such actions. This study, building on previous research, found the existence of misconceptions about dementia and some suggestions (mainly erroneous) about the possibility of risk reduction (Cahill et al., 2015; Cations et al., 2018; Glynn et al., 2017; Low & Anstey, 2009). While this indicates that there may well be receptiveness to health promotion messages, there was limited evidence of assessment of the veracity of information presented by participants in this research. The research also indicated that information acquisition was somewhat haphazard. In a crowded arena of health information the transparency regarding the proposers interests and a form of accreditation by a recognised authority and approved by relevant health and lay experts could be beneficial (Maddock, Camporesi, Lewis, Ahmad, & Sullivan, 2012, p. 1055). This would serve to ensure easier identification of the credentials of those promoting dementia messages.

In the absence of sufficient evidence to commit to public health interventions aimed at preventing dementia (Kane et al., 2017), adhering to the mantra that ‘what’s good for your heart is good for your brain’ and taking advantage of linked beliefs between cardiovascular care and a healthy lifestyle have been proposed on the premise that this can do no harm (Livingston et al., 2017). Transparency regarding what is likely to be personally achievable in terms of risk reduction should be maintained and avoidance of overpromising any anticipated

effects (Hodes et al., 2019). There are potential harms in over-emphasising the role that individual choices and behaviours make over the relevance of broader societal and contextual determinants of health (socioeconomic status, education and environment) which can detract from collective and public responsibilities and solutions to dementia (Lawless et al., 2018). In addition as previously described there is a potential for victim blaming.

Supporting the support networks

There are assumptions and expectations about the provision of support available to individuals from within their networks when considering the management of their general health conditions. However limited dementia knowledge and desire to discuss the topic even within one's own networks, result in resources more usually expected within support networks not necessarily readily available to do the same regarding dementia support.

This research has found that there are those who may, because of their own health literacy skills or support network type, be less likely to either know about or be able to access resources required to maximise their general health. Intermediate responses may be required at the individual level and/or network level to provide interventions that can enhance existing support networks and health literacy resources within communities. This research suggests that information and/or other resources required may vary considerably according to specific contexts and needs. Thus someone with dementia may perhaps desire to know about peer support or befriending, a carer may wish to enjoy an activity with the person they care for or an opportunity for a supported break and those wishing to remain dementia free may want evidence-based information that could support that aim. Stakeholders in the position to offer support should work together with those requiring the support to develop integrated and accessible resources.

Models and definitions

Currently Dementia Literacy is understood to include the following components; an ability to recognise dementia as it develops; knowledge about dementia that may aid this recognition, knowledge of risks, causes treatments and management of the condition; and finally attitudes that may encourage appropriate actions to be taken to reduce the risks or improve condition management (Low & Anstey, 2009; H. Zhang et al., 2017). Lessons from the development and understanding of other health and disease specific literacies should be

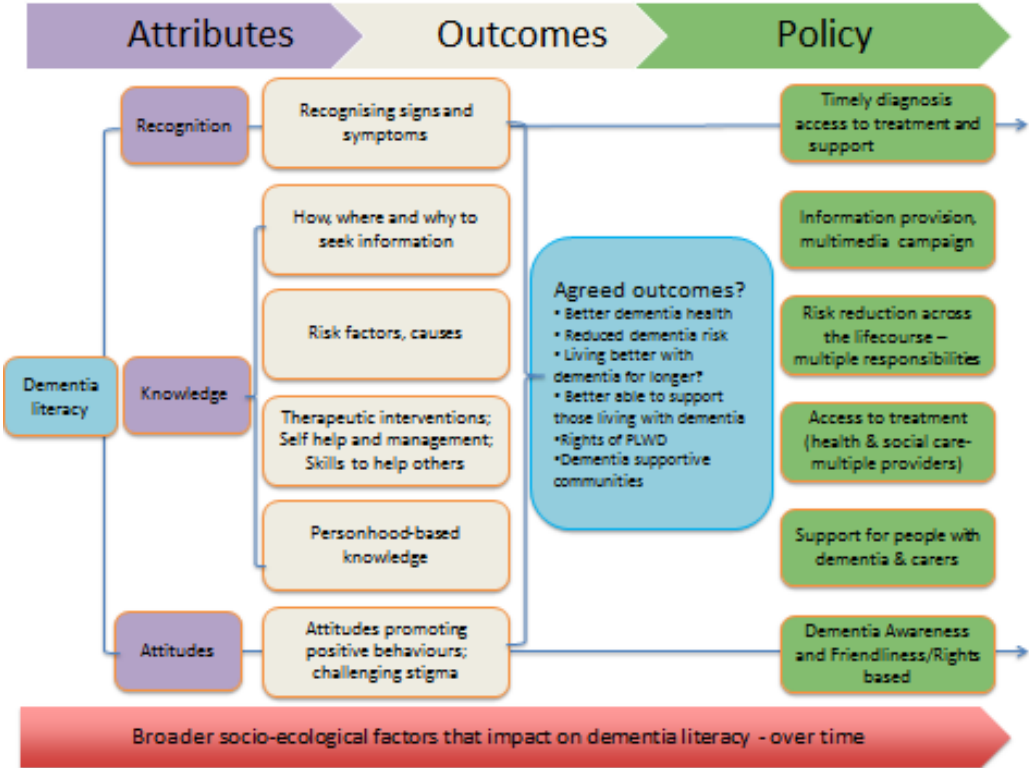
considered, although cautiously (considering transferability), when thinking how dementia literacy conceptualisations may benefit from further enhancement.

Based on findings from this research and principles of dementia literacy developed through engagement with the other health literacy literatures, a proposed alternative definition and dementia literacy model are recommended (Figure 10-1). The definition below includes additional elements that take into account the importance of personhood-based and reduction of stigma that take into account this study’s findings.

Definition

Dementia literacy involves a broad understanding of the dementias including: 1) Recognition of developing disorders; 2) Knowledge of: when and where to seek help; causes and risks; therapeutic interventions; competencies designed to maintain and/or improve one’s cognitive health care; skills to help others; personhood-based knowledge and 3) Attitudes that challenge stigma, assert the continuing personhood of those with dementia and encourage promotion or maintenance of behaviours supportive of good cognitive health.

Figure 10-1 Proposed dementia literacy model and potential supportive policies



This study identified the importance of acknowledging the broader socio-ecological factors that impact on dementia literacy (political and social priorities for care, main stream media and dissemination of wider societal understandings). Knowledge is not static and scientific and cultural representations of dementia change over time (for example dementia as either a natural part of the aging process or due to brain disease) which should be acknowledged in any model of dementia literacy. Knowledge and attitudes as core attributes of the definition of dementia literacy are not necessarily equally or similarly understood by all. Adopting alternative ways of framing dementia can lead to changes in the way the public think about and engage with relevant issues (Elwell-Sutton et al., 2019; Van Gorp & Vercruyse, 2012). Biomedical interpretations of dementia, while important, have led to a discourse of loss (Beard et al., 2009). In the light of the findings of this research I conclude that placing greater emphasis on personhood-based knowledge of dementia with a strong focus on reducing fatalistic and stigmatising attitudes towards dementias can frame the condition in a way that is more likely to engage people in dementia issues. These elements have been specifically included in the model.

In order to situate the model in the current contexts of public discourse and policy, the model includes not only core attributes and possible outcomes of dementia literacy but how actions outlined in current dementia action plans (e.g. The Dementia Action Plan for Wales 2018-2022) and strategies could support required changes (Dua et al., 2017). The Dementia Action Plan for Wales, frames dementia as a rights-based approach, aimed at achieving “a dementia friendly nation” where people with dementia feel valued and can live as independently as possible in their communities (Welsh Government, 2018, p. 3). This framing provides the basis for developing a clear focus for ensuring that people with dementia are considered in terms of their personhood and humanity rather than their symptoms and deficits.

Recognition of dementia, as per Low and Anstey’s (2009) original dementia literacy definition, is an important precursor to help seeking. This study confirms the findings of other research that there are difficulties for many in distinguishing dementia from other conditions and many associate symptoms with expectations of normal ageing. It is particularly in the area of attitudes and beliefs about dementia (including fear, fatalism and stigma) that impacts on the desire to engage in dementia literacy. Among participants in this study, there was little knowledge of availability and benefits of therapeutic interventions and the support available

to people living with dementia. Those with dementia were largely understood as a load to be borne by close families, not the wider society.

The conceptualisation of dementia is perhaps even more complex where lay understandings and experiences are at odds with alternative framings of dementia and may be interpreted differently and resisted by people within social networks (Hillman & Latimer, 2017). There remains considerable uncertainty and confusion about dementia. This research has demonstrated the limited alternative (positive) framings of dementia and a general reluctance to discuss dementia understandings. Higgs and Gilleard (2017) argue the need to see dementia as a sociological problem within and beyond the broader context of family life into the institutions of old age and caring sectors. They suggest that the social processes involved in dementia and dementia care should be taken into account alongside the cultural and social representations of dementia that are ubiquitous in everyday life. Several recent academic papers have proposed alternatives to the tragedy discourse and are providing conceptual and empirical means for establishing alternative understandings of dementia (Beard, 2017; Hillman & Latimer, 2017; McParland et al., 2012). These alternate understandings do not as yet appear to have filtered across into more general perspectives.

10 CONCLUDING COMMENTS

This study was conducted as a separate project within the overarching Cognitive Functioning and Ageing Studies Wales. One of the questions this study addresses was how might social support networks influence the dementia literacy of older adults in Wales? Initially dementia literacy was examined within the broader construct of health literacy. The health literacy measure derived for this study presented an estimate of health literacy for those aged 65 and over in Wales. This thesis supports the notion that social support networks can impact on health literacy. It is suggested that resources such as social capital within individual's support networks are the likely mechanism.

There are three key findings from this study.

1. The first is that knowledge of dementia is imbalanced, fragmentary and distorted. This thesis argues for a broader conceptualisation of dementia knowledge within the definition of dementia literacy.
2. The second is that attitudes toward dementia knowledge acquisition are negative. Offering alternatives to the “tragedy” discourse and different ways of appreciating the experiences of living with dementia may lead to a greater likelihood of improved wellbeing for those affected (Reed et al., 2017).
3. The third is that social support networks reflect broader societal views and do not generally facilitate dementia literacy. Fundamental changes to widely-held public dementia knowledge and attitudes need to occur initially. These may then be reinforced within social networks when confronted by dementia and when attributing meaning to situations arising.

Based on the results of this thesis there is limited evidence that social support networks are currently in a position to offer dementia literacy support or resources to those within their networks. This has broader implications for expectations from health and social services in particular with regard to the support and management of those living with dementia or encouragement within networks to promote actions supporting cognitive health. The general population level of older adults' dementia literacy may be currently insufficient to achieve aims as set out in the Dementia Action Plan for Wales.

Nevertheless dementia strategies and action plans can provide the impetus for action. The challenge is to create the environments that value and includes people living with dementia. Reframing public narratives from those of loss of self and status to recognition of enduring personhood and the possibility of living well with dementia for as long as possible can shift the emphasis currently implied in much risk reduction discussions. Raising awareness of the possibilities of what may be done for dementia and simultaneously ensuring the availability of effective management and support for those affected (including carers) could reduce some of the fear and fatalism associated with dementia.

This thesis has added to the body of knowledge on dementia literacy. It has considered existing developments in the fields of health and mental health literacy as well as the nascent body of dementia literacy to propose suggested learnings that may further enhance our understanding of dementia literacy. A proposed model (Fig 10-1) has been suggested as a starting point for to facilitate this understanding. Such a model could support concerted actions aimed at addressing dementia literacy interventions that aim to broadly address some of the issues found in this research around misconceptions, fear and fatalism and stigma. A shift in emphasis from current dialogues of fear and loss to one of retained personhood, shared responsibilities in achievements of dementia rights/citizenship is key. The model considers that cognitive health in older age is shaped by broader social, systemic, and contextual determinants of health such as socioeconomic status, education and environment throughout the life course as well as individual choices and behaviours. Dementia literacy should be viewed as an individual and collective asset for populations.

11 APPENDICES

APPENDIX A: ETHICAL APPROVAL (SECONDARY ANALYSIS)

Ethical Approval: Swansea University to conduct secondary analysis of data including access to CFAS Wales, ELSA and UCL held Health Literacy data

Ethical Approval

Ethics Committee Use Only

Principal Investigator	Carol Maddock
Title of Proposed Research	The role of social support networks in the dementia health literacy of older people

Application approved	Yes	<input checked="" type="checkbox"/> (see note below)	No	
Date	14/5/15			
Name	Charles Musselwhite			
Signature	By email.			
Position (please state if a member or Chair of ethics committee and name of committee)	Reader/Associate Professor in Gerontology			

This application has not been granted ethical approval in its current form. Please ensure that you take account of the comments and feedback provided below and prepare a revised submission:

Please note:

I am sorry this has taken so long. I have asked Carol for extra information to satisfy that the secondary data is available to be used in the way specified. Participants must have signed consent for their data to be used in further projects and that they have understood what will happen with their data in terms of anonymity and confidentiality. Apologies it has taken so long but hopefully this helps Carol when writing about her ethics in her thesis too. I am satisfied with the following:

ELSA

Statement from ELSA:

The proposal involves secondary data analysis using data that is freely and publicly available to bona fide researchers once they have registered as an ELSA data user. Registration involves agreeing to the standard end user license – see

<http://ukdataservice.ac.uk/get-data/how-to-access/conditions.aspx>

There are no special permissions or additional agreements to sign.

The ELSA data is held at the UK data archive and accessed by registering through the Economic and Social Data Service. ELSA was developed by a team of researchers based at the NatCen Social Research, University College London and the Institute for Fiscal Studies. The PI of the study is Prof Andrew Steptoe (UCL). The data were collected by NatCen Social Research. The data is freely available to eligible researchers.

UCL data has been used previously without need for ethical consideration:

e.g. Von Wagner et al. 2007

“Because this survey ensured complete anonymity of respondents throughout data collection, analysis and reporting, it was exempt from formal ethics committee approval in accordance with guidelines issued by the University College London Research Ethics Committee and the WorldHealth Organization.”

CFAS Wales (from the original information to participants)

Depending on future funding we may invite participants to take part in new areas of research such as brain imaging. Any future new research would require specific ethical approval.

Confidentiality

All the information collected by the study is completely confidential; confidentiality would only ever be broken if this became a legal requirement because a person was considered at risk of harm. All information is stored without personal details on secure systems in compliance with the Data Protection Act 1998. Occasionally, as mentioned above, we may ask to tape record an interview; audio tapes are anonymised before the interview is analysed; they may also be used for training and quality control purposes and will be destroyed when no longer required.

Anonymised data collected by the study may be analysed by researchers from other centres, approved either by the CFAS team or by the UK Data Archive, where anonymised data will be held after the study has been completed.

This study has been considered by the North Wales Research Ethics Committee (West).

If the addressee is unable to respond, we would be grateful if a relative or carer could discuss with us whether an interview can take place or whether the relative/carer would be willing to be interviewed instead.

If you have any concerns or complaints about anything to do with the study please contact us on 01792 602906 (CFAS Wales team), who if unable to help you will direct you to the appropriate person. Indemnity arrangements for the study are provided by Bangor University and the NHS. If you would like any further information or have any questions please contact us on 01792 602906/602186.

Professor Ness Burholt
Local Principal Investigator

<http://cfaswales.bangor.ac.uk/>

APPENDIX B: ADDITIONAL ANALYSIS ELSA STUDY

This appendix gives additional details of the work conducted with the English Longitudinal Study of Ageing (ELSA) data that mainly replicates that carried out with the University College London (UCL) Study of Functional Health Literacy (FHL) in the British population data as detailed in Chapter 5. This study's aim of deriving an imputed measure of health literacy initially made use of the data from three different studies: 1) CFAS Wales – the primary data set 2) University College London (UCL) Study of Functional Health Literacy in the British population and 3) The English Longitudinal Study of Ageing (ELSA). The focus within this appendix is on the ELSA study as the main body of the thesis contains the final methods and results using the UCL data set.

It was initially proposed that the measures and predictive variables from both UCL and ELSA study would be used to produce two imputed measures before finally selecting the best-fit model. However having attempted to achieve a suitable model using a variety of methods, the ELSA data (and its health literacy measure) proved to be inappropriate for this study's analysis. It appeared that the brevity and limited scoring ability of the measure prevented the required level of detail for the analysis. The following section will in brief describe both the ELSA health literacy measure and processes aimed at deriving the imputed health literacy measure.

The ELSA Health Literacy measure

The ELSA functional health literacy measure formed part of the Cognitive Function (CF) module of the ELSA questionnaire. It assessed respondents' comprehension of a fictitious medicine label (see Fig 1) by posing four questions regarding administration of the medicine. The health literacy measure was intended to represent an activity that would be realistic and relevant in the lives of older adults and as such assesses similar skills to those assessed by the Test of Functional Health literacy (TOFHLA). A number of studies have used the measure (Bostock & Steptoe, 2012; Kobayashi, Wardle, & Wagner, 2014, p. 101). The test was also previously used as part of the International Adult Literacy Survey (IALS) (OECD & Statistics Canada, 2000) and the Adult Literacy and Life Skills Survey (Statistics Canada & OECD, 2005).

Figure 1 (Appendix B)

MEDCO TABLET
INDICATIONS: Headaches, muscle pains, rheumatic pains, toothaches, earaches.

RELIEVES COMMON COLD SYMPTOMS

DOSAGE: ORAL. 1 or 2 tablets every 6 hours, preferably accompanied by food, for not longer than 7 days. Store in a cool, dry place.

CAUTION: Do not use for gastritis or peptic ulcer. Do not use if taking anticoagulant drugs. Do not use for serious liver illness or bronchial asthma. If taken in large doses and for an extended period, may cause harm to kidneys. Before using this medication for chicken pox or influenza in children, consult with a doctor about Reyes Syndrome, a rare but serious illness. During lactation and pregnancy, consult with a doctor before using this product, especially in the last trimester of pregnancy. If symptoms persist, or in the case of an accidental overdose, consult a doctor. Keep out of reach of children.

INGREDIENTS: Each tablet contains
500 mg acetylsalicylic acid.
Excipient c.b.p 1 tablet
Reg. No. 88246

Made in Canada by STERLING PRODUCTS, INC
1600 Industrial Blvd. Montreal, Quebec H9J 3P1

Comparing data sets for suitability to derive health literacy measure

In order to ensure the applicability and reliability of the selected data sets to derive weightings for the CFAS-DAHL in this study's analysis some overarching comparisons were carried out across the studies. Key methodological approaches of all three of the surveys were compared and are displayed in table 1.

The English Longitudinal study of Ageing (ELSA) was designed to explore the relationship between health and functioning, social networks, participation, and economic position as people approach and prepare for retirement and beyond (Banks, Batty, Nazroo, & Steptoe, 2016). The focus of both ELSA and CFAS Wales studies therefore aimed to understand more about the complex interplay between individuals and their physical and social environments as they age as well as variations between individuals and different social groups and generations. The content of many of the modules within the questions asked in both these separate studies, were guided by the desire to use standardised instruments and measures that would allow comparison between studies. Initially the ELSA study appeared to

be more suitable match for the purposes of the study, until the limitations of the measure were discovered. The ELSA data sources used in the analysis will initially be described below before describing how the sample was prepared for analysis.

The English Longitudinal Study of Ageing (ELSA): preparation for analysis

The English Longitudinal Study of Ageing (ELSA) is a large representative sample of men and women aged 50 years and over living in private households in England. ELSA was developed as a companion study to the Health and Retirement Study (HRS) in the USA. ELSA commenced in 2002 and data were collected using computer assisted personal interviews and self-completion questionnaires every two years for a total of 7 waves of data collection (Marmot et al, 2016). The average field response rate across all the cohorts, among core sample members was 79% at wave 5¹. The data from wave five of the ELSA survey was used to develop the weightings for the DAHL as this was the closest in time-frame (between May 2010 and June 2011) to the collection of the CFAS Wales data (2012-14).

All core ELSA participants aged 65 or over up to 90 years old (to match with the CFAS study) at wave 5 who completed the health literacy assessment were eligible for this study's analysis. Of those eligible to carry out the literacy test in the 65 - 90 age range (n=5377); those for whom the item was not applicable (eg participants giving a proxy interview were ineligible for this item) were excluded from the analysis reducing the sample to n=5077. Those participants, who at this stage, refused to undertake the health literacy questions for the reasons described below, were included in the numbers for analysis and coded as having limited health literacy. It is perhaps more likely that they would have difficulties performing similar functions in real life situations and thus this better maintains the population representativeness of the sample. Refusals were due to sight difficulties (n= 109), health problems (n= 45), reading problems (n= 37), deaf/hard of hearing (n=3), too tired (10), other illness/physical impairment affecting ability to perform test (5), impaired concentration (7), very nervous or anxious (1), other mental impairment (14), refusal-did not want to take part (28), did not know what to do/understand (18), no distressed/upset (3), other interruption/phone call (3) other answer (27) or irrelevant response (1), other refusal (15) and don't know (13). =339 (4738 + 339+ 300NA= 5377). A similar decision was made in a

¹ (Response from the UK data service -natcen.ac.uk team) regarding confirmation of the response rate for W5 and the definition of field response rate –correspondence received 16th May 2015

comparable analysis by Kobayashi and colleagues (Kobayashi, Wardle, & von Wagner, 2014).

CFAS, UCL and ELSA variables comparison

As detailed in table one ELSA and CFAS are large nationally representative longitudinal studies of England and Wales respectively. The UCL study included participants from the whole of the UK (excluding Northern Ireland and Scottish Isles). As this study aimed to derive weightings from two separate data sets (ELSA and UCL) from which to select the ‘best fit’ and then apply them to predictor variables in the CFAS data set, it is important that this method uses an approach that takes into consideration study designs and methodology. There are potentially cultural differences between the English (ELSA) and Welsh (CFAS) samples and therefore some basic cross-country comparisons, (including cross tabulations and χ^2 tests, were conducted to take this into account). The UCL data set including data from both England and Wales would be a useful survey to allow comparisons across these countries using consistent measures within the one data set, however the numbers within the sample covering the age range of interest were small. Out of the original sample of 759 adults there were only 172 participants in the 65-90 year age group, with 150 of those being from England and eight from Wales. There were 39 people from Wales and 626 from England in the full UCL data set.

There were close similarities for a range of population characteristics between CFAS, ELSA and UCL cohorts (as seen in table two). There were however notable differences particularly around education levels even when considering the reduced data sets reflecting the same age groups. This could in part be due to differences in capturing these educational levels in each of the individual studies and how I have then further reduced them to match the core CFAS Wales data set. A more detailed description of the variables selected for use and their recoding to allow comparable analysis, follows. Closer similarities between the data sets of interest is more reassuring with respect to transferability of the weighting results from one research population (ELSA/UCL) to another, CFAS Wales.

Table 1 (aB) Comparing core samples and key variables of interest - CFAS and ELSA

	ELSA age 65-90yrs	CFAS age 65-90yrs	UCL age 65-90yrs
Study sample μ σ	n = 4990 73.8 \pm 6.4	3474 74.5 \pm 6.6 (3409 without proxy interview)	153 73.8 \pm 6.5 (n= 719 full eligible data set)
Age bands			
65-69	30.8	29.9	28.8
70-74	28.0	26.4	31.4
75-79	20.7	19.1	19
80-84	12.8	14.4	15
85-90	7.6	10.2	5.9
Sex (F) %	54.7 %	54.4 %	51%
Educational Qualifications			
none	33.4	47.3	52.3
School leaving & trade	22.5	14.3	17
A & vocational	6.1	11	5.9
Hed not degree	14.2	10.6	7.8
Hed degree equiv	14.8	8.6	7.8
foreign & other	9.1	8.2	9.2
Retired or not			
No (employed)	7.3	8.3	9
Yes (retired)	87.7	89.1	92.2
never worked	5.0	2.5	2
Self rated health			
excellent	35.4	21.5	30.7
good	33.5	46.2	37.9
fair	22	24.9	21.6
poor	9.1	7.5	9.8
Current smoker			
No	80.3 : 9.7	89.6 : 9.3	82.4: 17.6

Socio-demographic predictors identified as influencing health literacy

Previously identified factors significantly influencing health literacy available within all three data sets include age, education, sex, race/ethnicity (Hanchate et al., 2008; Laursen et al., 2015; Liu, Liu, Li, & Chen, 2015; Martin et al., 2009; Miller et al., 2007). Predictive variables examining a broader set of demographic or socio-economic factors available in

CFAS and one of the other data sets include household income (Laursen et al., 2015; von Wagner et al., 2007), marital status and former occupation (Liu et al., 2015), difficulty in reading and understanding forms, frequency of reading newspapers (Haun, Luther, Dodd, & Donaldson, 2012; Murray, Hagey, Willms, Shillington, & Desjardins, 2008) employment status, home ownership and socio-economic deprivation level (using Index of Multiple Deprivation) (Laursen et al., 2015).

The use of indicators of socioeconomic status in particular, are considered to be more challenging in older age groups. Three commonly used SES indicators; education, occupation and income (all interrelated to an extent) are likely to be considerably different in the 65 years and over group than in those aged under 65 (Grundy, 2001). With respect to occupation in the UK, in general fewer than 10% of men and 5% of women aged 65 and over are in employment (Grundy, 2001) and this is borne out in this study's analysis (see table two). Similarly, income is very much dependent on occupation. Potentially the further away the individual is from being employed (and associated likelihood of achieving higher levels of income) other factors alone or in combination may have a greater impact on FHL. Grundy and colleague's (2001) search for more appropriate measures of socioeconomic status indicators in studies of health inequalities in older populations found no ideal stand-alone variable and limitations with most of those commonly available surveys. However their suggested measures for health inequality studies were indicators of occupational social class or education in combination with the Townsend deprivation indicator or a combination household resource/Townsend deprivation indicator (Grundy, 2001). The National Statistics Socio-economic Classification (NS-SEC) data was considered to be the best available option for this study's analysis and was available for both the CFAS and ELSA studies. The NS-SEC is a theoretically based, validated measure based on class and current or last main occupation where class (in terms of the last main occupation) continues to be associated with health throughout retirement (Rose, Pevalin, & O'Reilly (2005). Although a measure of deprivation (Index of Multiple Deprivation, England - IMD or Welsh Index of Multiple Deprivation - WIMD) was available in all three data sets (UCL, ELSA and CFAS) the derivation of each index is based on different data sources and methodologies, and they are thus not directly comparable (Payne & Abel, 2012). Additionally to access these separately stored ELSA geographical variables was prohibitively expensive following an enquiry to obtain them. The variable equating to the Index of Multiple Deprivation was considered to be potentially highly disclosive, and although an alternative variable using quintiles of the IMD had a lower risk of

disclosivity, an additional request process (and cost) was also in place for this variable. The postcode of the interview address was used to match geographical information such as IMD and Government Office Region (GOR) and (IMD)².

The selection of variables for use in this thesis analysis therefore, reflects a careful balance of availability, theoretical choice and similarity in the original questions and responses across data sets to ensure minimal recoding (reducing the potential to misclassify responses).

Data handling and coding: Developing the CFAS-DAHL

In order to create the best model for the CFAS-DAHL, a number of models were tested using a combination of variables that were indicated as predictors of health literacy. Predictor socio-demographic variables used for this study's analysis were age, sex, education, retired/employment status, self-reported health). Variables were recoded if required to harmonise across the data sets and match those within the other data sets.

There are no specific guidelines available to support the harmonisation of variables across studies or indeed how to report this to ensure transparency and reproducibility (Winters & Netscher, 2016). The variable harmonisation conducted in this study has thus been undertaken with careful consideration of associated technical manuals where provided and also where possible to the conceptual underpinnings of the original survey questions used. The decision criteria for recoding the data is intended to be as explicit as possible.

Age and Sex

Variables detailing age and sex were measured consistently between all three data sets (UCL, ELSA and CFAS Wales).

Educational Level

In addition when working across national data sets as in this study, Wales has over several generations had a different education system to that of England. In the original CFAS study which included sites in both England and Wales, the analysis attempted to compensate for these differences (Clare et al., 2017). This study's analysis also attempts to do likewise,

² 5050 User Guide for Geographical Variables

and when harmonising the data, equivalents were considered carefully, returning to the technical guides³ for ELSA for example, to understand how the variables were defined and collapsed originally. The ELSA variable for highest educational qualification was derived from the information given in previous waves of data collection and was reduced to seven educational qualification options from a large number of possible options. The technical guide's detail of recoding aided in this study's, cross study data harmonisation. Educational qualifications that covered a range of qualifications were harmonised between the studies to capture vocational and trade as well as more formal academic qualifications, thus eventually covering five educational qualification options (table 3). The education variable in this analysis is measured as a categorical variable and to an extent assumes that certain educational achievements may have a greater impact on health literacy (Grundy, 2001).

Recoding the educational variable

Educational status was described differently across the three data sets. Recoded variables for ELSA as compared to CFAS Wales are detailed in the table 3 below.

Table 2 (aB) Recoding the educational variable

CFAS → recoded to →	Recoded variable	←recoded to ←ELSA
None	None	no qualifications
School leaving certificate	School leaving and trade	NVQ1_CSE&Otrade
Technical college	School leaving and trade	NVQ1/CSE other grade equiv
Secretarial college	School leaving and trade	5 -NVQ1/CSE other grade equiv
Trade qualifications	School leaving and trade	-
Completed apprenticeship	'A' level and vocational	NVQ3/GCE Alevel equiv
Higher professional qualifications < degree	Higher education < degree	Higher Education below degree level
University degree	Higher education equivalent to degree	NVQ4/NVQ5/degree or equiv
Other	foreign/other	Foreign/other qualifications

³ Cox, Kate et al. *ELSA Wave 5- Derived Variables: User Guide*. NatCen, 2013. Web. 27 May 2017. <http://www.elsa-project.ac.uk/publicationDetails/id/6792>

Recoding the employment/retirement status variable

A variable reflecting current employment/retirement status that could be adapted from the three separate studies datasets was developed for this analysis (Table 3aB). It included categories: retired, not retired (ie employed) and those who have never worked to align with the CFAS Wales data. Paasche-Orlow and Wolf's (2007) conceptual causal model details that socioeconomic indicators are the basic factors influencing health literacy and they include occupation and income as well as level of education reached, ethnicity and age within the model (Paasche-Orlow & Wolf, 2007). In the case of this analysis less than 10% of the UCL, ELSA or CFAS Wales samples were in employment. It is a possibility that circumstances such as poor health could have precipitated early retirement, or that poor financial circumstances have required continued employment.

The variable that best reflected employment status within ELSA reflects a self described employment situation. To achieve the categories: retired, not retired (ie employed) and those who have never worked to align with the CFAS Wales data, the ELSA data was recoded as follows.

Table 3 (aB) Recoding the employment/retirement variables

CFAS Wales	←recoded to ← ELSA variable
Retired	retired from paid employment
Retired	disabled/long term sick
Not retired (employed)	employed
Not retired (employed)	self-employed
Not retired (employed)	Unemployed and semi-retired
Never worked	not in paid employment/looking after house or home

Self reported health

Due to the differences in responses available in the self-reported health question between UCL, ELSA and CFAS where ELSA and UCL responses had included an additional level - 'very good' in their scale (excellent, *very good*, good, fair or poor) the variable was therefore recoded. The variable was dichotomised into 0 'excellent/good health' versus 1 'fair/poor health' to ensure that any potential recoding imprecisions were minimised (Grundy, 2001). This was used in the logistic regression with ELSA.

Analysis

The goal of this analysis was the ability to predict FHL from socio-demographic characteristics present in the studies available. Preparation of the data for analysis and testing alternative models involved examination of protocols, technical manuals and journal articles relating to the three studies used in order to provide additional background to their ethos and approach. Articles describing approaches for deriving imputed measures were reviewed for possible alternative methodologies that could be used.

Analysis using the ELSA data to develop FHL Predictive models

Use of the ELSA data initially appeared to be a better option for deriving the imputed measure. Although the ELSA data set only included participants from England, both ELSA and CFAS Wales studies were very similar in purpose and design. There were also several additional variables in both these data sets that were tested in model development. These variables included daily reading, marital status, NSSEC and home ownership – all previously identified as predictors of health literacy in other studies.

The measure of functional health literacy within the ELSA study was captured by responses to four questions about the fictitious medical label described previously. Linear regression was initially used and models were tested for their suitability for the development of an imputed measure of FHL. The limitations of the ELSA measure (having a scale of only 5 points (0 – 4) meant that it was a blunt tool for developing an imputed scale measure.

Results for the final version

For the final model developed, the ELSA FHL measure was tested using a dichotomised version of the measure. Adequate health literacy was defined as all those with a maximum score of four and any other score was described as limited FHL – i.e. the point at which people may begin to struggle with health instructions or information (Kobayashi, Wardle, & von Wagner, 2014). Logistic regression was carried out using the dichotomised ELSA FHL measure. Predictor variables (covariates) included age up to 90 as a continuous variable (sex, reads daily paper, homeownership as categorical) education, NSSEC and self-rated health were either treated as continuous variables and thus not labelled categorical or were split into the component parts and used as ‘dummy’ variables and then inserted as categorical variables).

Although significant models were achieved using combinations of the variables (see Table 4), the contribution of the variables to the best models developed was only 9% (For model 1 and model 2: Adjusted R square = .094 and .095 respectively). Performing a ROC analysis confirmed that the models was not particularly good ones. The Area Under the Receiver Operating Characteristic (AUROC) curve is 66.7% (CI 0.65, 0.684) which is categorised as a poor model.

Table 4 (aB) Predictive HL models - ELSA

Predictor variables	1) Beta (8 factor)	p	2) Beta (6 factor)	p
Educational qualifications	.04	.000*	.04	.000*
Age	-.025	.000*	-.025	.000*
Retired or not	.035	.427		
Sex	.127	.000*	.135	.000*
Self Reported health	-.138	.000*	-.137	.000*
Home ownership	-.228	.000*	-.225	.000*
Reads paper daily	.085	.008*	.083	.009*
Nssec5	-.068	.000*	-.068	.000*
Marital status	.007	.652		.000*
Adjusted R Square	.094		.095	.000*

$$1 = (F_{9,4342}=51.379, p < .0005), 2 = (F_{7,4350} 66.135, p < .0005)$$

The plan to use the English Longitudinal Study of Ageing in a similar way to the UCL derived measure that would be suitable and robust was abandoned after many attempts and using various analyses (linear and multiple regressions). Data availability or compatibility between the studies restricted the range of potentially important characteristics that may have been used in the prediction models. As can be seen from the R square statistics the variables included in the models account for a relatively small contribution to the final model. It is likely that unmeasured or unavailable characteristics such as cognitive abilities, language proficiency and self-efficacy for example could con

APPENDIX C: ETHICAL APPROVAL QUALITATIVE INTERVIEWS

Ethical Approval: Wales Research Ethics Committee, Bangor: To conduct additional section of qualitative interviews as part of CFAS Wales wave 2.



Gwasanaeth Moezeg Ymchwil
Research Ethics Service



Pwyllgor Moezeg Ymchwil Cymru 5
Wales Research Ethics Committee 5
Bangor

Clinical Academic Office
Ysbyty Gwynedd Hospital
Betsi Cadwaladr University Health Board
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877

Email: [REDACTED]

Website : www.nres.nhs.uk

20 August 2015

Professor Robert Woods
Bangor University
DSDC Wales, Ardudwy, Normal Site,
Holyhead Road,
Bangor, Gwynedd
LL57 2PX

[REDACTED]
c/o: [REDACTED]

Dear Professor Woods,

Study title:	Maintaining function and well-being in later life
REC reference:	10/WNo01/37
Amendment number:	AM08
Amendment date:	05 August 2015
IRAS project ID:	40092

The above amendment was reviewed at the meeting of the Sub-Committee held on 20 August 2015.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Committee noted that the amendment relates to undertaking qualitative interviews with participants in wave 2 of the study (i.e. 2 years after their initial study interview). Wording changes were made to the Participant Information Sheet and Participant Invitation letter, to clarify the follow-up nature of the interview and the content to be covered during the interview.

On the basis of the submitted documentation the Sub-Committee decided that this amendment raises no ethical issues.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)	8	05 August 2015
Letters of invitation to participant [Invitation letter (Swansea) Qualitative II]	2	04 August 2015
Participant information sheet [(Swansea) Qualitative II]	2	04 August 2015

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet. No declarations of interest were made in relation to this application.

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

10/WNo01/37:	Please quote this number on all correspondence
---------------------	---

Yours sincerely

[Redacted signature]

Dr Philip Wayman White, MBChB, FRCGP
Chair

E-mail: [Redacted]

Enclosures: List of names and professions of members who took part in the review

Copy to: Sponsor: Professor Oliver Turnbull,
Head of College, COHABS, Bangor University
Brigantia Building, Penrallt Road
Bangor, Gwynedd, LL57 2AS [Redacted]

R&D Office: Mr Sion Lewis
Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd, LL57 2PW [Redacted]

Wales Research Ethics Committee 5

Attendance at Sub-Committee meeting on 20 August 2015

Committee Members

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>	<i>Present</i>
Dr Philip W White	General Practitioner (Chairman)	Expert	Yes
Dr Jason D Walker	Consultant Anaesthetist (Vice-Chairman)	Expert	Yes

In attendance

<i>Name</i>	<i>Position (or reason for attending)</i>
Dr Rossela Roberts	Clinical Governance Officer / RES Manager

APPENDIX D: SELECTING QUALITATIVE INTERVIEW SAMPLE

Process for selecting Wave 2 Qualitative interview sample

Wave 2 sample (start n=147) - (July 2015)

1. Removed all health literacy interviews (N=81 remaining)
2. Removed all those that had refused, moved, too frail to interview (N=64)
3. Removed all those where Wave 2 data was not yet available (kept to one side to increase sample if required) (n=54 left)
4. Removed 1 case which was inconclusive @ W2 (n=53)
5. Selected those changed networks from T1 to T2 – new dataset (N=17)
 - a. All selected for W2 (The main Wave 2 CFAS Wales qualitative study focused on changed network types between the two interview waves, therefore the selection of interviews was also dictated by this requirement).
6. Selected those stable networks from T1 to T2 – new dataset (N=36)
 - a. Split file by network type (see xls sheets)
 - b. Used SPSS to randomly select 1 case in N Wales, and then 1 case in S Wales for each stable network type.
 - c. Exceptions
 - i. Selected MCI for PR (only 1 case in PR).
 - ii. Where there was only 1 case in N or S Wales these were selected
 - iii. For WCF only 2 cases both located in N Wales so both selected.

For the larger CFAS Wales qualitative study a focus of the Wave 2 interviews was on changed network types between the two interview waves, meaning that the selection of interviews was also dictated by this requirement.

APPENDIX E: INTERVIEW SCHEDULE

Interview Schedule for Qualitative Interviews

Opening interview- prior to full CFAS Wales wave 2 interview

Thank you for agreeing to be interviewed today. The interview today will be more like a conversation and we will not use a laptop computer like your previous interview. In our conversation we will talk about the provision of support to and the receipt of help from friends and family and how this has remained the same or changed over the last two years. We will talk for about 40-60 minutes and if you feel like we need to take a break just let me know. I am going to tape the interview so that our research team can type up a transcript of our conversation later, and we can look back over what we have talked about. Anything we talk about will be treated with confidentiality and will not be discussed with anyone outside our research team. Your real name will not be used in any reporting of our research.

Introduction to the next two sub sections – this study’s interview schedule

I’d now like to move on from talking about support within your network of family and friends to exchanges of information

We are particularly interested in people’s knowledge of dementia. The word dementia describes a set of problems of symptoms that may include memory loss, difficulties with thinking and problem solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s disease, Lewy Bodies or a series of strokes (referred to as vascular dementia).

1. Do you know anybody who has or had dementia or problems with their memory? (*ask who if they don’t say*)
 - a. Can you tell me a bit more about that? (e.g. how long ago, how did it manifest, speed of progression, was there a diagnosis by doctor)
 - b. Was this person’s dementia or memory problems discussed with family or friends? (*prompt can you tell me more?*)
2. What do you know about dementia? (prompts - how common it is, how it affects people, can it be prevented?)
 - a. What sort of problems or difficulties (symptoms) do you think people with dementia may have? (*How may it affect their everyday life?*)
3. Have you ever looked for information about dementia or memory problems?

If Yes (Q4)

If No (Skip to Q5)

4. Why were you interested in getting this information?
 - a. Where did you look and get the information from? (internet, leaflets, asked people within your family and friendship groups, Health Professionals, support groups)

- b. What did you think of the information you found? -was some information more useful than others?
 - c. *(if not covered above)* What sort of things did you learn – practical/ factual?
 - d. What did you do with the information? How did you use it? Eg Did you discuss any of the information with anyone?
5. If you wanted (more)-*if have already looked*) information about dementia (for yourself or) for a friend/family member where would you get that information?
 - a. Why this person/resource in particular? (Where do they get their information from? Try and get some more details on their preference of sources)
 - b. Would you discuss the information you'd found with your family and friends?
 6. We have already talked about the people that you would talk to about your health concerns. Would you talk to the same people or different people, or no one if you had a memory problem or dementia?
 - a. *(if wouldn't talk to family or friends-* Are there any reasons why you decide not to talk to your family or friends?)
 7. If either you or someone from your family or a friend needed help at home or support getting out and about that was due to a memory problem (dementia) or maybe you/they couldn't do some routine activities like cooking etc – where would you go for information about support (*Why?*)
 8. Rather than information that you have actually searched for, what sort of information have you heard about or seen recently that mentions or discusses dementia (*articles in the newspapers, on the news/ other TV programmes in general or campaigns about dementia*)? (*If nothing go to Q9*)
 - a. What did you think of this information - was some information more useful than others?
 - b. *(if not covered above)* What sort of things did you learn from them – practical? – factual?
 - c. Have you discussed what you've seen or heard with anyone?
 9. (Recap)-So what would be the best place or source of information of information about dementia for you?
 10. How would you feel about sharing information about memory problems or dementia with anyone? (*Would it matter who that person was?*)

Finally, we would like to find out about health information sharing with your family, friends, neighbours and formal care providers. I'm going to read five descriptions of different ways in which people may share health information. I'd like you to select one description that best fits your situation, and describe the way it is similar (or different) from the way in which your network of family, friends, neighbours and professionals share information.

Vignettes

We've divided these into 5 network types

Network type 1. People with this network type are likely to say: “I’m very lucky to have my family around me. They meet all of my health information needs. The family only asks a professional for health advice if (between them) they don’t know, or can’t find any information”

Network type 2. People with this network type are likely to say: “We all know each other round here and look out for each other. There’s always someone popping in to see how I am and we can chat about health concerns and health information needs”

Network type 3. People with this network type are likely to say: “I like to keep myself to myself, and I can manage my health information needs myself.”

Network type 4. People with this network type are likely to say: “I can generally manage to find health information for myself (or with my spouse) through a variety of means. Although my family live away I can contact them on the phone if I need any health information. Furthermore I’ve got good friends nearby that can also advise me on health information if I needed it.”

Network type 5. People with this network type are likely to say: “I don’t really have much to do with the people round here but then I’ve always been independent. I don’t bother looking for any health information and rely on what I (or my spouse) already knows”

Thank you very much for taking part in our research it is very much appreciated

Closing Interview

Thank you for being part of our CFAS Wales research project and taking the time to talk to me today.

APPENDIX F: QUALITATIVE TRAINING AGENDA

CFAS Qualitative Training Agenda

CFAS Qualitative Training Agenda: 19th October 2015 9.00am -1.00pm (approx.)
Convened by Vanessa Burholt

Attending: Penny Leonard, Aelwyn Williams, Carol Maddock, Judith Phillips and Sarah Miles

1. Introduction and the questions being addressed by the qualitative study (VB).
2. Dementia Literacy PhD and the questions being addressed by the qualitative study (CM)
3. Sampling strategy and timing of batches
4. Allocation of batches to researchers
5. Posting letters/information to participants (Welsh translations)
6. Making appointments and explaining the nature of the study
7. Consent
8. Qualitative protocol, Convoy model
9. Recording and downloading interviews
10. Taking interview notes and downloading information
11. Practice sessions with feedback
12. Quality checks
13. Remaining summaries and coding: communication between the team

Materials to be supplied on the day

- Interview schedule
- Convoy Circles
- Convoy Grid
- Voice recorders and batteries
- Introductory letters
- Participant Information sheets
- Consent forms

APPENDIX G: INVITATION LETTER

Letter of invitation to participate in qualitative interview



Centre for Innovative Ageing
College of Human and Health
Sciences
Swansea University
Room 313, Vivian Building
Singleton Park
Swansea SA2 8PP

Maintaining function and well-being in later life: A longitudinal cohort study (CFAS Wales)

Dear

Thank you for your valuable contribution to this research so far. When you were last interviewed, you agreed that we could contact you again. We are now approaching a small proportion of those who have taken part so far. This is to take part in a more detailed interview about your social life, the people that you help, and who help you and friendships. You will have the opportunity to tell us about your experiences of accessing information, help and support in your own words. This interview is less structured and more conversational, and will take approximately 40-60 minutes. The enclosed information sheet provides more information.

The interviewers for this study will be calling in the next week or so to ask if you would be able to help. The research will be most valuable if as many as possible of those of you who are approached are willing to take part. The project has full NHS ethics approval and R&D approval from Betsi Cadwaladr & Abertawe Bro Morgannwg University Health Boards. All the interviewers are fully trained, and have Criminal Records Bureau / Disclosure & Barring Service clearance.

In the first instance, if we have your telephone number, the interviewer shall telephone to arrange a convenient visit. When the research interviewer visits s/he will produce identification and explain the study in more detail. If s/he visits at an inconvenient time s/he will be happy to visit again later. Your cooperation is, of course, voluntary and your decision

will not affect your medical care. I have enclosed an information sheet explaining the study in further detail.

If you have any questions, please telephone the research team on (01792) 602906 to discuss your queries. We hope you will take up the opportunity to support this research.

Yours Sincerely

Professor Vanessa Burholt, Lead Investigator (Swansea)



Cyngor Cyllido Addysg
Uwch Cymru
Higher Education Funding
Council for Wales

hefcw

A Collaborating Centre in the Medical Research Council Cognitive Function and Ageing Study II

Invitation letter (Swansea) Version 2 Qualitative II 04/08/2015

APPENDIX H: PARTICIPANT INFORMATION SHEET

Participant Information Sheet



Centre for Innovative Ageing

College of Human and Health
Sciences

Swansea University

Room 313, Vivian Building

Singleton Park

Swansea SA2 8PP

Maintaining function and well-being in later life (CFAS Wales)

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a further aspect of this research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

Purpose of the study

Ageing is now recognized as one of the major challenges facing the world's populations. It presents challenges to national and local policy makers and service providers in planning and providing for the needs of the older population.

This study is based on the original MRC Cognitive Function and Ageing Study (CFAS) which looked at ageing and health in six centres in the UK; Newcastle, Nottingham, Liverpool, North West Wales, Cambridgeshire and Oxford. The study began in 1991 with 18,000 participants, and it still continues today.

The purpose of this part of the study is to understand the sources of information, help and support for older people in Wales. Since the start of the original study there have been considerable changes in society. We are interested in who you currently provide with information, help or support, and who provides you with information, help or support. We are also interested in how these patterns of support may have changed over the last two years.

Why have I been chosen?

You have been chosen because you have indicated in a previous CFAS Wales interview that you would not mind taking part in a further study. We are interested to find out whether anything has changed for you in terms of your social life, the people that you help, and who help you and friendships since our last visit two years ago.

Do I have to take part?

There is no obligation to take part and you can withdraw at any stage, without giving any reason. This study is being carried out as a part of a medical research project and your decision will not affect your medical care or legal rights.

What will happen if I decide to take part?

If you should decide to take part, a research interviewer will phone you or visit you at your home to make an appointment for a convenient time for an interview. They will go through this information sheet with you and answer any questions you may have about the study. You will then be asked to sign a consent form to say you have read the information sheet, have had the opportunity to ask questions, and would like to take part in the study.

Following this you will be asked questions about current or expected sources of information, help and support from friends and family and formal sources and how this may have changed over the last 2 years. You will have the opportunity to tell us about your experiences of accessing information, help and support in your own words. The interview should take approximately 40-60 minutes and the interview will be audio taped.

Confidentiality

All the information collected by the study is completely confidential; confidentiality would only ever be broken if this became a legal requirement because a person was considered at risk of harm. All information is stored without personal details on secure systems in

compliance with the Data Protection Act 1998. Audio tapes are anonymised before the interview is analysed; they may also be used for training and quality control purposes and will be destroyed when no longer required. Anonymised data collected by the study may be analysed by researchers from other centres, approved either by the CFAS team or by the UK Data Archive, where anonymised data will be held after the study has been completed.

This study has been reviewed and given a favourable opinion by the North Wales Research Ethics Committee (West).

If you have any concerns or complaints about anything to do with the study please contact us on 01792 602906 (Mrs Carissa Philippart or Dr Marie Gabe), who if unable to help you will direct you to the appropriate person. Indemnity arrangements for the study are provided by Bangor University and the NHS. If you would like any further information or have any questions please contact us on 01792 602906/602186.

Professor Vanessa Burholt Mrs Carissa Philippart and Dr Marie Gabe
Swansea Principal Investigator Research Co-ordinators CFAS-Wales

A Collaborating Centre in the Cognitive Function and Ageing Study II
Participant Information Sheet (Swansea) Version 2 Qualitative II 04/08/2015

APPENDIX I: CONSENT FORM

CONSENT FORM



CFASCYMRU
GWEITHREDIAD GWYBYDDOL A HENEIDDIO
CFASWALES
COGNITIVE FUNCTION AND AGEING



Prifysgol Abertawe
Swansea University

Centre for Innovative Ageing

College of Human and Health
Sciences

Swansea University

Room 313, Vivian Building

Singleton Park

Swansea SA2 8PP

Maintaining function and well-being in later life

CONSENT FORM

Respondent identifier: _____

Please Initial

I confirm that I have read and understood the information sheet (Version 2 <u>Qualitative II dated 04/08/2015</u>) for the above study and have had the opportunity to ask questions.	<input type="checkbox"/>
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.	<input type="checkbox"/>
I agree to take part in the above study.	<input type="checkbox"/>
I understand that this interview may be recorded for later analysis or training and quality control purposes. I agree to this interview being audio recorded.	<input type="checkbox"/>
I understand that confidentiality will only be broken if this becomes a legal requirement because of risk of harm.	<input type="checkbox"/>

--	--

All the information collected by the study is completely confidential and is stored anonymously, without personal details. Audio tapes are anonymised and used for analysis and training and quality control purposes only and will be destroyed when no longer required.

Name of Respondent.....

Signature of Respondent..... Date.....

Name of Interviewer.....

Signature of Interviewer..... Date.....

A Collaborating Centre in the Cognitive Function and Ageing Study II

Consent Form (Swansea)

Version 2 Qualitative II 04/08/2015

APPENDIX J: FRAMEWORK MATRICES THEMES

Early Overarching themes used in framework matrices

Thematic Framework	
Themes (related to dementia literacy categories and emergent themes)	Sub themes
Dementia knowledge and beliefs	Contexts of knowing General knowledge and awareness Understanding/beliefs and misconceptions Causes and risks Prevention Signs and symptoms (recognition) Treatment Management and support/what & where is help available?
Attitudes	Ageing and dementia Changing attitudes and own attitudes Language: describing dementia and PLWD Expressed views (and wishes) Fear and Stigma Perception of others' attitudes
Accessing Information	Sources of information (media, papers, real life and fiction and talking with friends) Active and passive – preferences Receiving and Sharing (not/discussing dementia) Barriers and motivators to getting information Reliability/ questioning its truth
Sharing information/asking and telling others	Sharing general health concerns and dementia With who? (Family and friends and networks)

Reluctant (private /versus people may have to know
Others with experience (advice) / HPs

Experience of dementia

Who is known with dementia/ in their network
(emotional closeness)
Experiences described (incidents and behaviours)
Time frame/disease progress and impact
(Participants) role or involvement
Past and current including of services

Developing dementia literacy skills

Navigating systems and accessing services
Lived experiences guiding knowledge acquisition
Learning from others (including professionals)
Motivation and actions

APPENDIX K

Limitations

This study attempted a methodological approach to derive a population assessment of the health literacy (HL) of the Welsh population that had not been used in the UK to date. There has been no Welsh population health literacy surveys conducted. The premise behind developing an imputed HL measure is based on the advantages of using large existing population based surveys, with the availability of a data set comparable to the population of interest containing a relevant measure of health literacy.

Issues with the only two UK population surveys containing a measure of health literacy are now detailed. The English Longitudinal Study of Ageing (ELSA) survey initially looked suitable for the purposes of the study due to its similarities in overall design and function to the CFAS Wales primary study population of interest. It had a sufficiently large population within the age group of interest (n= 4990) but used a specific four item functional health literacy (FHL) measure. Despite a variety of analyses (logistic and linear regressions) the measure proved to be insufficiently detailed to provide the range of scores required for the development of suitable models and so further analyses with this data set was abandoned. Conversely the UCL study used a UK adapted Test of Functional Health Literacy in Adults (TOFHLA) measure as per the original analysis which this study emulated and was therefore ideal. Therefore after repeated testing, using alternative variables, models and statistical analysis between the two data sets, the UCL study had the only viable combination of study population and measure that could be used. However, the UCL study population was limited within the age range of interest - those aged 65 and over (n = 152). It appeared that the model ‘worked’ differently by age (18 - 64 and 65+). There were a limited number of additional variables available within the UCL survey from which to obtain both suitable variables to arrive at the best possible model and to provide additional checks as to the efficacy of the derived health literacy measure. Nevertheless positive correlations obtained between the CFAS DAHL and the raw measured TOFHLA for both UCL age ranges gave added confidence in the use of the full UCL sample for the development of the final CFAS DAHL. These correlations were not as highly significant as that found in Hanchate et al’s (2007) original study (which this study emulated). However alongside results of the Area Under the Receiver Operating Characteristic (AUROC) categorising the resultant model as fair (see Fig 5-3), gave sufficient confidence to serve this study’s purpose. It has allowed indicative

patterns with other variables of interest for this study to be observed. Use of an alternative data set containing a relevant measure of health literacy was considered when the limitations of the other studies were apparent. However there were no available UK viable alternatives. Previous research on imputed measures of health literacy has suggested that using data from another country for this purpose would be inappropriate as health literacy depends on the balance between individuals' competencies and national systems and settings (van der Heide et al., 2016). It is worth noting that the inherent complexity in measuring the complete construct of health literacy has been noted amongst all current measures - including test based measures (Haun, Valerio, McCormack, Sørensen, & Paasche-Orlow, 2014b)

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