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**Perceptions of dementia:
The impact on people with and without a diagnosis**

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This thesis is submitted in partial fulfilment of the requirements
for the degree of Doctor of Clinical Psychology

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M	RADIX questionnaire
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O	PwD BADLS questionnaire
P	Debrief form
Q	Carer participant information sheet
R	Carer informed consent form
S	Carer ECog questionnaire
T	Carer BADLS questionnaire
U	PwD ethnicity demographics

- V PwD living arrangement demographics
- W PwD prior occupation demographics
- X Hypothesis 1 linear multiple regression assumptions
- Y Hypothesis 2 linear multiple regression assumptions

List of Abbreviations

ACE-III	Addenbrooke's Cognitive Assessment
AD	Alzheimer's Disease
BADLS	Bristol Activities of Daily Living Scale
BPS	British Psychological Society
CINAHL	The Cumulative Index to Nursing and Allied Health Literature
DW	Dementia Worry
ECog	Everyday Cognition Scale
IRAS	Integrated Research Application System
MCI	Mild Cognitive Impairment
Medline	Medical Literature Analysis and Retrieval System Online
MS	Multiple Sclerosis
NHS	National Health Service
PICO	Problem, Impact, Client Group, Outcome
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-analyses
PwD	Person with Dementia
RADIX	Representations and Adjustment to Dementia Index
SPSS	Statistical Package for Social Sciences
SRM	Self-Regulation Model
ToL	Tree of Life
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation

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Declaration

This thesis has been submitted in partial fulfillment of the requirements for the degree of Doctor of Clinical Psychology at the Universities of Coventry and Warwick. The work presented has been carried out and written by myself and has not been submitted for any other qualification or to any other institution. This thesis is an original piece of my own work, which was undertaken with the academic supervision of Dr Tom Patterson (Coventry University) and Dr Magda Marczak (Coventry University), and the clinical supervision of Dr Orazio Giuffrida (Gloucestershire Health and Care NHS Foundation Trust).

The systematic literature review and empirical paper were both written in preparation for submission to the journal, *Dementia*.

Word count (excluding tables, figures, references and appendices)

Chapter 1: 6608

Chapter 2: 5421

Chapter 3: 3154

Total: 15,183

Summary

This thesis explores the impact that perceptions of dementia can have on individuals with and without a diagnosis of dementia. Chapter 1 is a systematic literature review investigating the implications of dementia worry in people without a diagnosis of dementia. A narrative thematic synthesis of 16 articles identified three main themes of the literature. Dementia worry was found to have implications for individuals well-being, memory concerns, and help-seeking behaviours. The study's findings suggested that individuals who are concerned about their memory in the absence of cognitive impairment should be routinely assessed for dementia worry and offered appropriate support to manage associated psychological needs.

Chapter 2 examines the impact illness representations have on perceptions of cognitive ability and functional ability in people with a diagnosis of dementia. A total of 114 individuals participated in the study, comprised of 57 people with a diagnosis of dementia, and 57 paired carers. Statistical analysis revealed that illness representations predicted perceptions of cognitive ability and functional ability. Equally, significant differences were found between patient and carer ratings of functional ability and cognitive ability. The study highlighted the impact that illness representations can have on perceptions of cognitive and functional ability in people with dementia, suggesting there is a clinical need to ascertain how individuals view their dementia following diagnosis, and to appropriately support those who may hold especially negative illness representations.

Chapter 3 presents a first-person reflective account of the author's experience of conducting research with a dementia population. The author considers the shift from being a clinician to a researcher, feeling powerless to elicit change, and her personal research journey.

Chapter 1: Systematic Literature Review

The Implications of Dementia Worry in People

Who Do Not Have a Diagnosis of Dementia:

A Narrative Thematic Synthesis

In preparation for submission to the journal, *Dementia* (See Appendix A)

Overall chapter word count (excluding tables, figures and references): 6608

1.0 Abstract

AIM: The present review set out to critically evaluate empirical evidence regarding the implications of dementia worry in people who do not have a diagnosis of dementia.

METHODS: Five databases (Medline, PsychINFO, CINAHL, Embase, and Scopus) were systematically searched using terms informed by the aim of the review. The search resulted in 16 studies which met the inclusion criteria and were considered relevant to the review aims.

A narrative thematic synthesis of these studies was completed. **RESULTS:** Three main themes emerged from the review: (1) well-being, comprised of the impact on both psychological well-being and physical health, (2) memory concerns, including the influence dementia worry has on memory appraisals and subjective memory concerns, and (3) help-seeking, comprised of sharing concerns with others, engaging in screening, and changing lifestyles. **CONCLUSION:** The findings have important clinical implications for both policy and practice. In particular, they highlight that individuals who present to services with concerns about cognitive decline in the absence of underlying cognitive impairment, should be routinely assessed for dementia worry and offered appropriate support to manage associated psychological symptoms. Future research directions are also indicated.

1.1 Introduction

1.1.1 Background

In recent years, the average person's 'contact' with dementia has steadily increased (Kessler et al., 2012). Indeed, an ageing population has been accompanied by higher incidence rates of dementia, meaning more people now personally know somebody who is living with dementia (MetLife Foundation, 2011; Werner et al., 2016). In the United Kingdom (UK), in 2019 it was estimated that almost 885,000 people were living with dementia (Wittenberg et al., 2019). Globally, dementia is estimated to affect around 50 million people at present, with this figure projected to rise to 82 million by 2030 and 152 million by 2050 (World Health Organisation [WHO], 2019). Alongside this, mass media has enabled the dissemination of scientific progress in understanding, treating, and preventing dementia, coupled with an increasing number of media reports depicting the life of people living with dementia (Kessler & Schwender, 2012). These cumulative factors mean that dementia is currently among the most feared health conditions, being second only to cancer (Alzheimer's Research UK, 2011; MetLife Foundation, 2011). As personal contact with dementia increases, it is important for clinicians and researchers to understand both helpful and less helpful responses that may occur at an individual level.

1.1.1.1 Dementia Worry

Dementia worry (DW) is one phenomenon that may accompany heightened contact with dementia. It is well documented that media exposure and personal experience with a physical condition can alter an individual's perceived vulnerability to a disease (Clarke & Everest, 2006; Towers et al., 2015). Consistent with this observation, DW refers to a heightened

perception of susceptibility to illness, which has been defined as an individual's "emotional reaction to the perceived threat of developing dementia" (Kessler et al., 2012, p. 277).

Comparable concepts such as anticipatory dementia (Cutler & Hodgson, 1996), fear of Alzheimer's disease (AD; French et al., 2012), and dementia related anxiety (Alberts et al., 2011) have previously been used to describe similar concerns about developing dementia. For the purposes of this review, DW will be the term used to refer to these concepts.

DW is, perhaps unsurprisingly, widespread among the general public (Roberts et al., 2014). For instance, large-scale surveys of adults in the United States of America (USA; Cutler, 2015), Australia (Low & Antsey, 2009), France (Cantegreil-Kallen & Pin, 2012) and the UK (YouGov, 2012), found that 30, 48, 60, and 63% of the respondents respectively reported being at least *somewhat worried* about developing either AD and/or other forms of dementia. Whilst DW is perhaps more expected among people with a first-degree relative with dementia (Cutler, 2015), concerns about developing dementia extends to affect people of all ages (Jonker et al., 2000; Lineweaver & Herzog, 1998). Indeed, a YouGov (2012) poll of 4,276 UK adults over the age of 18 found that whilst those aged over 55 were the most worried (66%), 61% of adults aged 18 to 24 were also worried about developing dementia in the future, suggesting a need to understand the role of DW within the general population. Whilst existing research has primarily focused on the prevalence of DW and predictors for its occurrence, less attention has been given to the consequences of these fears.

1.1.1.2 Evaluation of Previous Studies

Kessler et al. (2012) published a conceptual review of DW, with the aim of better integrating the phenomenon of DW into current and future ageing research. Kessler et al. (2012) suggested that DW constitutes an overlap of affective components (e.g. fear), and cognitive

components (e.g. associations and thoughts), related to the perceived threat of developing dementia. The authors suggested that DW is a hybrid concept, combining elements of ageing anxiety and health anxiety, which can be best understood within a framework combining psychological, cultural, philosophical, and other disciplinary elements (Kessler et al., 2012). Further, they argued that social-cognitive models of health behaviour may offer a heuristically fruitful way of hypothesising the antecedents, correlates, and consequences of DW. Indeed, Kessler et al. (2012) utilised the Health Belief Model (Rosenstock, 1974) to propose that inter-individual differences in DW may be related to: (1) perceived risks, (2) perceptions regarding the consequences of dementia, and (3) perceived coping resources. Notably, the authors reported that insufficient research regarding the possible implications of DW was available to draw conclusions, however, they postulated that these may include consequences for individuals' well-being, physical health, and actions. The authors concluded that DW continues to be a relatively unexplored phenomenon, requiring closer and more systematic investigation (Kessler et al., 2012).

1.1.2 Rationale

While other specific health worries such as cancer worry (e.g. Hay et al., 2005) and heart-focused anxiety (e.g. Eifert et al., 2000) have been extensively investigated, DW has received relatively limited conceptual and empirical research attention. This is unfortunate because DW is not only a widespread phenomenon in our rapidly ageing society, but also an experience which may hinder or promote both psychological well-being and successful ageing.

Over recent years, increased attention has been paid to the prevention of dementia through health behaviours aimed at decreasing and managing risk factors associated with its

development (Frankish & Horton, 2017). This heightened focus on dementia risk reduction, coupled with the increase in dementia ‘contact’ previously described, appears to have prompted a number of new studies exploring DW, and specifically the implications of DW. However, to date, no systematic review has examined the phenomenon of DW, or the impact that concerns about developing dementia have at an individual or a social level. Both the prevalence of DW and a recent increase in empirical studies in this area, suggest a review of the research is now merited.

1.1.3 Aims and Objectives

This present systematic review aimed to critically evaluate empirical evidence to answer the following research question: What are the implications of DW in people who do not have a diagnosis of dementia? A narrative thematic synthesis of existing literature was carried out to answer this question.

1.2 Methods

1.2.1 Systematic Literature Search

1.2.1.1 Process

An initial scoping search on google scholar was completed to ensure the topic was viable. Following ethical approval from Coventry University Ethics Committee (Appendix B), a systematic search of the literature for studies which have explored the implications of DW was carried out during March 2020. The most relevant databases covered literature within the disciplines of psychology and nursing, and therefore included: Medical Literature Analysis

and Retrieval System Online (Medline), PsychINFO, The Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, and Scopus¹. Grey literature was searched to ensure any research which had gone on to be peer reviewed and published was not missed.

1.2.1.2 Search Terms

Table 1.1 presents an overview of the key search terms used which were considered to be relevant to the subject area. These terms include the key concept (dementia worry), alongside synonyms (fear of Alzheimer’s, anticipatory dementia, worries about dementia, perceived threat of dementia, dementia related anxiety) and the location of these key words (title, abstract). The key search terms and synonyms were derived based on terms identified within the initial scoping search. Whilst attempts were made to include additional search terms related to the population, implications, and outcomes, due to the relatively new nature of this topic it became apparent that using additional search terms was narrowing the search to such an extent that the key studies would be missed.

Table 1.1

Search Terms

Key Search Term	Synonyms (2nd wave)	Location
Dementia worry	Fear of Alzheimer’s, anticipatory dementia, worries about dementia, perceived threat of dementia, dementia related anxiety	Title Abstract

¹ Further manual searches were completed and grey literature was accessed through the use of Coventry Locate Library service and the Proquest dissertations and theses: UK and Ireland database.

1.2.1.3 Strategy

The search strategy employed Boolean logic; as such the operator ‘or’ was used to connect search terms within searching catalogues, databases, and web search tools. The search strategy included: ‘Dementia worry’ OR ‘fear of Alzheimer’s’ OR ‘anticipatory dementia’ OR ‘worries about dementia’ OR ‘perceived threat of dementia’ OR ‘dementia related anxiety’. The final search was completed in March 2020.

1.2.2 Inclusion and Exclusion Criteria

Article titles and abstracts were initially screened and retained if they: (a) were written in English, (b) were peer reviewed, (c) were empirical studies, (d) empirically examined the concept of DW, and (e) the full text was accessible. Following initial screening, full text articles were obtained and assessed against the inclusion criteria (see Table 1.2) for eligibility.

The inclusion and exclusion criteria was formed using the PICO (problem, impact, client group, outcome) framework (Schardt et al., 2007) to ensure that all relevant studies were identified. Studies were included if they (a) were empirical studies examining the concept of DW, (b) had a quantitative, qualitative, or mixed methodology, (c) used any method of data collection, (d) were written in the English language, (e) were peer reviewed, (f) were published before March 2020, (g) investigated the implications of DW, and (h) used a sample of people over the age of 18 who did not have a diagnosis of dementia or mild cognitive impairment (MCI).

Table 1.2*Inclusion and Exclusion Criteria*

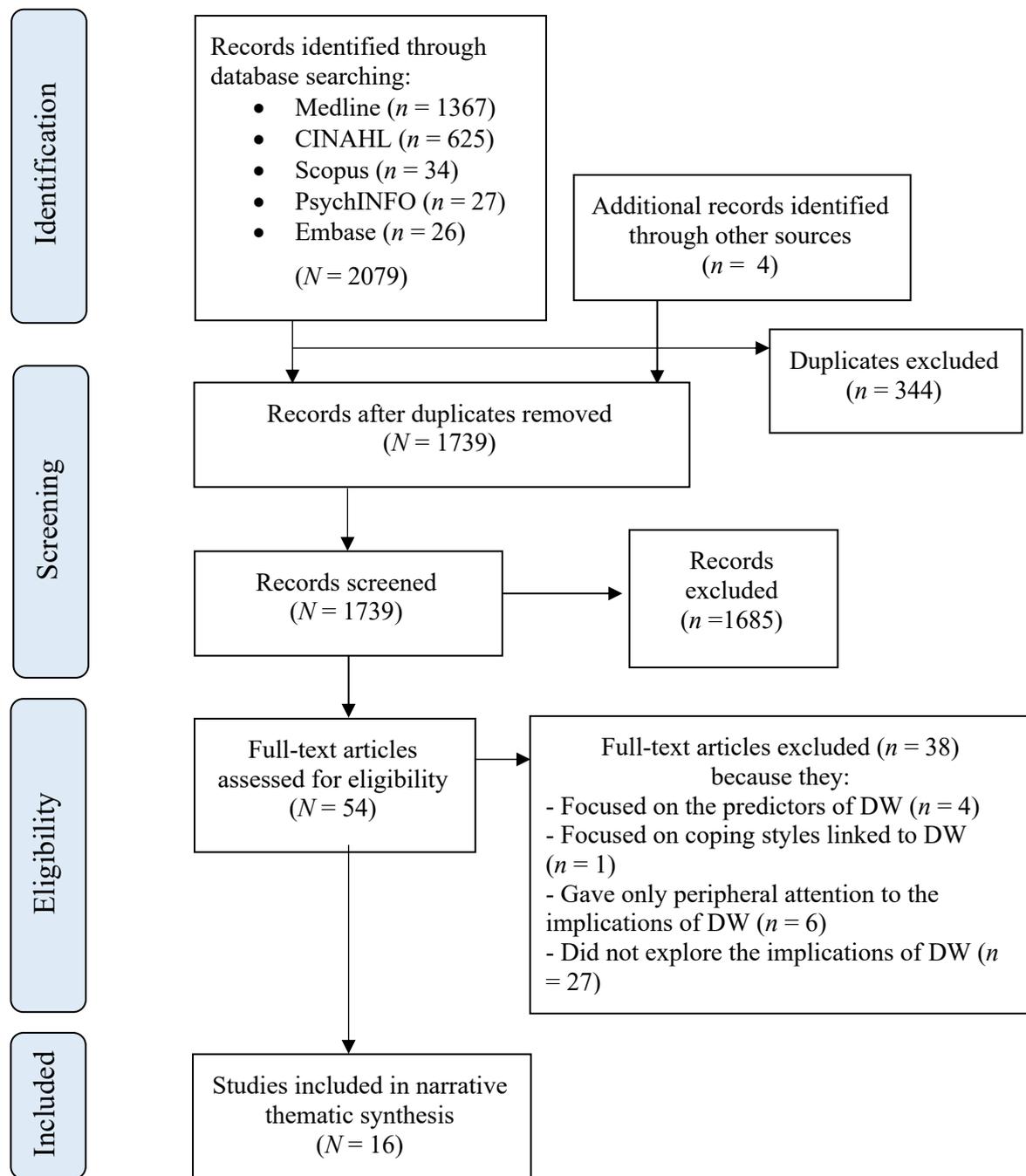
Criteria	Include	Exclude
Study type	Empirical study examining the concept of DW	Literature reviews, commentaries, reports
Research design	Quantitative, qualitative, mixed	Single case designs
Method of data collection	Any	None
Language	English	Language other than English
Published	Peer reviewed	Non-peer reviewed, grey literature
Time Period	Before March 2020	After March 2020
Problem	Papers which explore the concept of DW	Papers which do not explore the concept of DW
Impact	Papers which investigate the implications of DW	Papers which do not consider the implications of DW
Client group	Adults, people without a diagnosis of dementia or MCI	Samples with participants under the age of 18 years, people with a diagnosis of dementia or MCI

1.2.3 Classification of Studies

The process of study selection was recorded on a ‘Preferred Reporting Items for Systematic Reviews and Meta-Analyses’ (PRISMA; Moher et al., 2009) flow diagram (Figure 1.1).

Figure 1.1

PRISMA Flow Diagram of the Study Selection Procedure (Moher et al., 2009)



In total, 2083 articles were initially identified, of which 344 were duplicates, resulting in 1739 which were considered to be suitable for further screening. Following a manual review of the title and abstracts, a further 1685 records were excluded as they did not meet the inclusion criteria. The full text for the remaining 54 eligible articles were reviewed and a further 38 were excluded due to the fact they focused on the predictors of DW, focused on coping styles linked to DW, focused on the implications of DW only peripherally, or did not explore the implications of DW. This resulted in 16 studies which were retained for quality assessment.

1.2.3.1 Quality Assessment Checks

In order to assess the quality of the 16 studies retained following the search, an assessment framework developed by Caldwell et al. (2011; Appendix C) was used. This framework was considered to be suitable due to its applicability to quantitative and qualitative research methodologies, and frequent use within health and clinical psychology research. All studies were rated against 18 quality criteria, where 0 was given if the criterion was not met, 1 if the criterion was partially met, and 2 if the criterion was fully met. The rating for each article was calculated by adding the scores for all 18 criteria, so that each article received a score between 0 and 36. Papers scoring below a midpoint of 18 were considered to not reach a satisfactory level of rigour, however, all 16 papers screened scored between 22 and 35 ($M = 28.5$) and were therefore judged to be of good quality and eligible for inclusion in the review. Appendix D details the full results of the quality assessment checks.

To ensure reliability of the quality assessment, a second researcher independently rated all articles against the same quality assessment criteria (Appendix E). Statistical analysis was used to determine inter-rater reliability using a Kappa coefficient. The overall Kappa

coefficient was $\kappa = .935$. The Kappa reliability coefficient for each paper is included in Table 1.3, and full researcher scores can be found in Appendix F. It can be seen that the range of coefficient reliability values was between $\kappa = 0.8$ and $\kappa = 1.0$ which, according to Altman (1991) represents a consistently strong pattern of inter-rater reliability.

1.2.4 Analytic Review Strategy

The review adopted a narrative thematic synthesis review strategy. Narrative synthesis refers to a process which aims to ‘tell the story’ of the findings from the included studies, relying primarily on the words and text to summarise findings, enabling the inclusion of both quantitative and qualitative studies (Popay et al., 2006). However, some researchers argue that a limitation of the narrative synthesis approach is a lack of formal methods and guidance for its completion (Dixon-Woods, 2005). Thematic analysis is a common technique for the analysis of data in primary research, which aims to identify the main, recurrent, and/or most important themes across multiple studies (Mays et al., 2005). The present review therefore applied the core features of a narrative synthesis to explore and report research findings on the implications of DW, supported by the extraction of key themes, developed in an inductive manner.

1.3 Results

The characteristics of the literature included in the current review are presented in Table 1.3.

Table 1.3*Characteristics of Studies*

Author, Year of Publication, Country of Origin, Quality Checklist Score, Kappa (κ)	Aims (* relevant to current study)	Research Design and Sampling Method	Sample Characteristics	Data Collection and Data Analysis	Key Findings
Bowen et al. 2019 Germany 32/36 $\kappa = 1.000$	To examine the extent to which DW was related to: 1.Sociodemographic characteristics 2. Contact with people with dementia 3.Physical health-related factors 4.Well-being* 5.Ageing self-perceptions* 6.Social-cognitive health beliefs about dementia*	Quantitative, Cross-sectional Convenience sample	$N = 219$ German adults aged 40+ reporting no dementia or cognitive impairment Age: 40-94 years ($M = 65.50$ years, $SD = 11.34$) Gender: 55.3% female 44.7% male	Questionnaires DW scale Well-being questionnaire Adapted scales of the Metamemory in Adulthood Questionnaire Correlations and linear regressions	Within the sample - not at all worried - 17.8% - hardly worried – 41.1% - somewhat worried – 37.9% - very worried – 3.2% DW was associated with: - age ($r = .16, p \leq .05$) - female gender ($r = .15, p \leq .05$) - education ($r = -.13, p \leq .05$) - subjective health ($r = -.23, p \leq .01$) - life satisfaction ($r = -.37, p \leq .01$) - psychological distress ($r = .49, p \leq .01$) - perceived memory capacity ($r = .16, p \leq .05$) - perceived memory change ($r = -.17, p \leq .05$) - ageing anxiety ($r = .62, p \leq .01$)

- personal risk perception ($r = .51, p \leq .01$)
- perceived consequences ($r = .31, p \leq .01$)
- perceived controllability ($r = -.37, p \leq .01$)

Together the predictor variables explained 53.3% of the variance in DW based on the adjusted R^2 . 33.8% of the variance in DW was shared among the predictor variables. Sociodemographic characteristics uniquely explained 3% of the variance, well-being 5.1%, ageing self-perceptions 5.4%, and social-cognitive health beliefs about dementia 6.0% respectively

The saturated model was significant, $F(23, 195) = 11.55$ to 12.44 across the five data sets, all $p < .001$

Cui et al. 2019 America 22/36 $\kappa = .800$	To investigate whether: 1. Dementia-related anxiety and coping styles were associated with suicidal ideation* 2. Coping styles moderated the	Quantitative, cross-sectional Not stated	$N = 330$ Adults over the age of 18 without a diagnosis of dementia or MCI Age: $M = 49.5$ years ($SD = 17.0$)	Online self-report questionnaire completion Miller Behavioural Style scale DW scale Patient Health Questionnaire-9	Individuals with suicidal ideation, compared to those without, had lower self-reported health (ideation present $\frac{1}{4}$ 1.8 vs absent $\frac{1}{4}$ 2.3; $b \frac{1}{4}$.58, Wald $\chi^2(1) \frac{1}{4}$ 12.14, $p < .01$) and monitoring style of coping (ideation present $\frac{1}{4}$ 3.5 vs absent $\frac{1}{4}$ 5.5; $b \frac{1}{4}$.12, Wald $\chi^2(1) \frac{1}{4}$ 10.55, $p < .01$), as well as greater depressive symptoms (ideation present $\frac{1}{4}$ 19.6 vs absent $\frac{1}{4}$ 11.8; $b \frac{1}{4}$.30, Wald $\chi^2(1) \frac{1}{4}$
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	relation between dementia-related anxiety and suicidal ideation		Gender: 66.6% female, 33.4% male	Self-perceived health questionnaire Univariate logistic regression analyses and multivariate logistic regression	61.83, $p < .01$) and dementia-related anxiety (ideation present $\frac{1}{4}$ 27.7 vs absent $\frac{1}{4}$ 18.3; b $\frac{1}{4}$.09, Wald $v^2(1)$ $\frac{1}{4}$ 35.28, $p < .01$) Controlling for covariates DW predicted suicidal ideation, however, the relation between DW and suicidal ideation was not moderated by coping styles
Cutler & Bragaru 2017 America 29/36 $\kappa = 1.000$	To investigate whether: 1. Cognitive concerns and fear of developing AD affect psychological well-being* 2. Such concerns and worries exert short-term effects, long-term effects, or both?* 3. Do concerns and fears affect well-being more so among persons with a parental history of AD?	Quantitative, longitudinal, using multi-wave data collected over an 11-year period Not stated	Wave 1: $N = 258$ Wave 2: $N = 206$ Wave 3: $N = 177$ Three waves of data collected in 2000, 2005, and 2011 from two samples of people aged 40-60 years who were either adult children of someone with a diagnosis of dementia, or a matched control group with no parental history of AD Age: 40-60 years Gender:	Wave 1: Telephone interviews Wave 2 and 3: Mailed questionnaires The Short Inventory of Memory Experiences (SIME) Alzheimer's Likelihood subscale of the Aging Concerns Inventory (asked in wave 2 and wave 3) The Centre for Epidemiological Studies Depression Scale (CESD-20) The Global Measure of Perceived Stress	Cognitive concerns and worries about developing AD at time point one was significantly related to each of the four psychological well-being outcome variables. The greater the concerns one has about one's cognitive functioning and the greater the worries about developing AD at a particular time, the lower the persons psychological well-being at that time Effects were similar across both groups of adult children of someone with a diagnosis of dementia, and the matched group: - depression: $\chi^2 = 15.019, p = .450$ - life satisfaction: $\chi^2 = 21.746, p = .115$ - stress: $\chi^2 = 12.088, p = .672$ - mastery: $\chi^2 = 11.133, p = .743$ The data suggests that the effects of cognitive worries and concerns about developing AD were restricted to

			Not stated	Mullan's Mastery Scale Life satisfaction single question Structural equation modelling and multiple group analysis within a structural equation modelling framework	contemporaneous effects; there were no instances of these factors having a lagged effect on a measure of psychological well-being at a later time
Cutler & Hodgson 1996 America 29/36 $\kappa = 1.000$	To examine how personal concerns about the development of AD may be linked to subjective perceptions of normal age-associated memory changes*	Quantitative, exploratory study Matched groups, convenience sample	$N = 50$ 25 participants with a living parent with a diagnosis of probable AD or other dementia. 25 participants who are a matched control group and have no family history of the disease Age: Adult children: $M = 46$ years ($SD = 4$) Control group: $M = 45$ years ($SD = 3$) Gender:	Self-report questionnaire completion Concern about developing Alzheimer's question The Short Inventory of Memory Experiences (SIME) Memory Assessment Index (MAI) Pearson correlation coefficients and multiple regression analysis	People who have more negative assessments of their memory functioning are more concerned with personally developing AD (SIME: $r = .265, p < .05$; MAI: $r = .358, p < .01$) Adult children with living parents who have AD are more concerned than those for whom there is no family history of dementia ($r = -.257, p < .05$)

			Adult children: 64% female, 36% male. Control group: 76% female, 24% male		
Cutler & Hodgson 2013 America 27/36 $\kappa = .882$	To determine whether psychological well-being is affected by concerns about cognitive functioning and worries about developing dementia*	Quantitative, longitudinal, using multi-wave data collected over an 11-year period Not stated	Wave 1: $N = 258$ Wave 2: $N = 206$ Wave 3: $N = 177$ Three waves of data collected in 2000, 2005, and 2011 from two samples of people aged 40-60 years who were either adult children of someone with a diagnosis of dementia, or a matched control group with no parental history of AD Age: 40-60 years Gender: Not stated	Wave 1: Telephone interviews. Wave 2 and 3: Mailed questionnaires The Short Inventory of Memory Experiences (SIME) Alzheimer's Likelihood subscale of the Aging Concerns Inventory (asked in wave 2 and wave 3) Centre for Epidemiological Studies Depression Scale (CESD-20) The Global Measure of Perceived Stress Bivariate correlations between the predictor and	The composite measure of cognitive and dementia concerns is a statistically significant predictor of each of the four psychological well-being outcomes: - stress: $r = .435, p < .001$ - depression: $r = .457, p < .001$ - life satisfaction: $r = .356, p < .001$ - mastery: $r = .305, p < .001$

				outcome variables, and stepwise regression analyses for each of the psychological well-being outcomes	
Cutler & Hodgson 2014 America 27/36 $\kappa = .889$	To determine whether health is affected by concerns about cognitive functioning and worries about developing dementia*	Quantitative, longitudinal, using multi-wave data collected over an 11-year period Not stated	Wave 1: $N = 258$ Wave 2: $N = 206$ Wave 3: $N = 177$ Three waves of data collected in 2000, 2005, and 2011 from two samples of people aged 40-60 years who were either adult children of someone with a diagnosis of dementia, or a matched control group with no parental history of AD Age: 40-60 years Gender: Not stated	Wave 1: Telephone interviews Wave 2 and 3: Mailed questionnaires The Short Inventory of Memory Experiences (SIME) Alzheimer's Likelihood subscale of the Aging Concerns Inventory (asked in wave 2 and wave 3) Composite measure of objective and subjective health Bivariate correlations between the predictor and outcome variables, and stepwise regression analysis with the composite health indicator as the	The composite measure of cognitive and dementia concern was a statistically significant predictor ($r = .226$; $p < .01$), indicating that those who expressed greater concerns about their cognitive functioning and about AD across the three waves of the study were more likely to be in poorer health over the three years Significant, bivariate concerns-by-subsample interaction effect were found ($r = .174$; $p < .05$), indicating that adult children of people who have dementia exhibit significantly stronger bivariate relationships between their cognition, dementia concerns, and health than adult children of parents who do not have dementia

				dependent variable was run against the six predictors	
Harada et al. 2017 Japan 33/36 $\kappa = .824$	To examine whether participation in screening for cognitive impairment was predicted by: 1. The constructs of the health belief model 2. DW* 3. Behavioural intentions to undergo screening among older adults*	Quantitative, prospective design Not stated	$N = 10,023$ All people aged 70 or over living in Midori ward, Nagiyam without long-term care needs or support Age: 70 years or older, $M = 75.8$ ($SD = 4.6$) Gender: 4943 women 5080 men	Questionnaire survey Constructs of Health Belief Scale DW single question Behavioural intention to undergo screening single-item Binary associations between each demographic and psychological factor through an χ^2 -test or t -test. Path analysis to identify psychological predictors of participation in screening for cognitive impairment	The χ^2 -tests and t -tests showed that the following were significantly associated with screening participation: - subjective memory complaints - decline in the instrumental activities of daily living - engagement in paid work - history of screening for cognitive impairment - age - number of years of education - all psychological factors A path analysis showed that the behavioural intention to undergo screening (path coefficient = 0.29) directly predicted participation in screening for cognitive impairment, whereas other psychological and demographic factors did not directly predict participation. The behavioural intention was explained by the perceived benefits of screening (path coefficient = 0.51), perceived barriers to screening (path coefficient = -0.19) and perceived susceptibility to dementia (path coefficient = 0.16)

Hodgson & Cutler 1997 America 25/36 $\kappa = 1.000$	To examine the relationship between well-being and anticipatory dementia*	Mixed Purposive sampling	$N = 50$ 25 individuals who had a living parent with probable dementia. A control group of 25 individuals who did not have a parent with dementia were recruited from the friendship networks of the original sample Age: 40-60 years ($M = 45$) Gender: 70% women 30% men	Directed interview and structured questionnaire Memory Assessment Index (MAI) Centre for Epidemiological Studies Depression Scale (CES-D) Pfeiffer's Short Psychiatric Evaluation Scale Life satisfaction question Measure of self-reported health Quantitative: Correlations Qualitative: Not stated	Quantitative: Higher levels of concern about one's memory and developing AD were associated with higher levels of depression ($r = .329, p < .02$) and psychiatric symptomatology ($r = .403, p < .005$). Respondents who reported higher levels of anticipatory dementia also reported lower levels of life satisfaction ($r = -.368, p < .01$) and poorer self-reported health ($r = -.297, p < .05$) Anticipatory dementia was found to be related to a variety of help-seeking behaviours. Those who reported higher levels of anticipatory dementia were significantly more likely to speak to friends and family about their concerns ($r = .664, p < .001$ and $r = .587, p < .01$, respectively). They were also marginally more likely to speak to professionals about their concerns ($r = .380, p < .10$) Qualitative: The significant relationships reported in the quantitative analyses were corroborated by the commentary of participants who spoke to the specific day-to-day consequences of their anxiety. Participants reported being mindful of every instance of forgetfulness where
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					memory lapses took on ominous meanings. They reported taking their fears into the workplace, home, and occasionally the doctor's office
Hodgson et al. 1999 America 25/36 $\kappa = .904$	To offer a descriptive analysis of symptom-seeking behaviour in anticipatory dementia*	Qualitative Purposive sampling	$N = 50$ 25 individuals who had a living parent with probable dementia. A control group of 25 individuals who did not have a parent with dementia were recruited from the friendship networks of the original sample. Age: 40-60 years old ($M = 45$) Gender: 70% women 30% men	Face-to-face interviews Multiple method approach combining a structured questionnaire with elements of a focused interview Memory Assessment Index (MAI) DW single question Self-reported memory functioning Contextual analysis Common theme analysis of open and closed ended questions	68% of the sample reported being 'very' or 'somewhat' concerned about developing AD. Two thirds provided evidence of symptom-seeking in their responses. Based on respondent's accounts, symptom-seeking was categorised into three discrete behaviours: 1) repeatedly checking oneself for signs of AD 2) interpreting cognitive changes as symptoms of the disease 3) asking for external validation of concerns
Hodgson & Cutler 2004	To examine the patterns and predictors of help-seeking behaviour	Quantitative, no further details reported	$N = 169$ Two groups:	Telephone interviews DW single question	68% of the total sample reported having talked about their concerns with:

America 32/36 $\kappa = 1.000$	for personal concerns about developing AD among middle-aged persons*	Subsample of adult children: Purposive and self-selected sampling Comparison group: Random sample	a) 99 adult children with a living parent with a diagnosis of probable AD and b) 70 matched comparison group of men and women with no parental history of the disease Age: 40-60 years ($M = 49.9$) Gender: 74% women 26% men	Memory Assessment Index (MAI) The Short Inventory of Memory Experiences (SIME) Adapted Help-seeking Instrument Descriptive analyses of the types of help-seeking, correlations and stepwise regression analyses	- members of their family (spouses 56.3%, sisters 47.4%, brothers 30.3%, daughters 21.8%, other relatives 18.9%, sons 18.8%, mothers 13%, fathers 7.8%) - other informal sources (friends 46.7%, co-workers 25%, neighbours 8.9%) - members of formal networks (physicians 20.1%, support group members 14.8%, mental health professionals 14.2%, other professionals 4.1%, clergy 3.6%, lawyers 3.6%) Four predictors emerged as significantly associated with talking to people within social and helping networks about their AD concerns. Arrayed by the magnitude of the effects, such behaviour was more likely if: (1) they were the children of parents with AD, $\beta = -.367, p < .001$, (2) they were better informed about AD, $\beta = .186, p < .01$, (3) they reported a higher level of concern about personally developing AD, $\beta = .162, p < .05$, and (4) they reported others had noticed changes in their memory, $\beta = .150, p < .05$
Kim et al. 2015 Australia	To investigate perceptions of dementia and dementia risk reduction held by	Qualitative descriptive study	$N = 34$ Participants who responded to an advertisement in a	Focus groups Reflective and open ended questions were used to facilitate	Four a priori themes were identified: 1. dementia and dementia risk factors - literacy, age, and genetics were the most recognised non-modifiable risk factors, whereas lack of cognitive engagement

35/36 $\kappa = 1.000$	people without dementia*	Convenience sample	community newspaper distributed to homes in the Australian Capital Territory and Queanbeyan. Age: 52-90 years ($M = 67.03$, $SD = 8.85$) Gender: 73.5% women 26.5% men	discussions and allow group participants to talk freely. Questions focused on the topics of 'literacy', 'perceived susceptibility', 'motivators and perceived benefits' and 'perceived barriers' The long-table approach was used to identify themes and categorise results. The analyses of each focus group discussion were combined, and each category was reviewed	was the most recognised modifiable risk factor 2. perceived susceptibility - three response types were formed: fear, rational, and cynical 3. motivators and perceived benefits to lifestyle change - fear of developing dementia was the main motivator to life style and behavioural change 4. perceived barriers to lifestyle change – the most commonly identified barrier to behavioural and lifestyle changes was the lack of knowledge about dementia
Kim et al. 2016 South Korea 35/36 $\kappa = .889$	To describe the lived experience of dementia-related anxiety in middle-aged female caregivers for family members with dementia*	Qualitative descriptive phenomenological study Snowball sampling	$N = 12$ Participants were recruited from a speciality clinic for dementia disorders in Korea. Participants were recruited if they were caring for a family member with dementia Age:	Face-to-face interviews Interviews began with semi-structured, open-ended questions. As the interview progressed researchers used prompts such as "what do you think about the relationship between dementia and you?" Data was analysed according to Giorgi's	The core finding was a fear of losing self-identity, represented by six components: 1. keenly feeling the effects of ageing because of memory deficit 2. continuous comparison of the family member's behaviour with that of the participant's 3. finding it painful to see a family member with dementia 4. not knowing the conclusion of the disease process 5. reducing the risk of dementia 6. trying to change one's lifestyle from what it used to be in the past

			40-59 years ($M = 51.90$)	phenomenological analysis method	
			Gender: 100% women		
Kinzer & Suhr 2016 America 27/36 $\kappa = .895$	To examine the construct of DW and its relationship to subjective memory concerns in 100 older adults without signs of dementia*	Quantitative, no further details provided Community sampling	$N = 100$ Individuals who previously participated in studies in cognitive impairment in older adults were recruited. Individuals had originally been recruited from the community based on responses to adverts for studies offering free memory screens for older adults. Demographic details were only available for 89 of the 100 participants	Postal questionnaires Memory Controllability Inventory Geriatric Depression Scale Abbreviated version of the Penn State Worry Questionnaire (PSWQ-A) DW scale Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) Correlations, t -tests, ANOVA	A one-way ANOVA showed significant differences in DW among those with genetic exposure, non-genetic exposure, and no exposure to dementia, $F(2, 97) = 9.16, p < .001$. Follow-up t -tests showed that individuals with genetic exposure to dementia reported significantly more DW ($M = 22.60, SD = 9.06$) than did those with no dementia exposure ($M = 14.20, SD = 2.55; d = 1.26, p < .001$), and those with non-genetic exposure to dementia ($M = 17.36, SD = 6.89; d = 0.65, p = .002$) Higher DW was related to higher depressive symptoms ($r = .51, p < .001$) and higher levels of general worry ($r = .53, p < .001$) in the total sample. Higher DW was also associated with higher memory concern ($r = .37, p < .001$) and higher belief in personal likelihood of having AD ($r = .61, p < .001$) In participants with no evidence of cognitive impairment, those with low worry showed significantly lower memory concern ($N = 34; M = 11.5, SD =$

			Gender: 64% female 36% male		2.6) relative to those with high worry ($N = 30$; $M = 17.1$, $SD = 4.7$; $t = 5.98$, $d = -1.48$, $p < .001$). The group with no objective memory impairment but high worry reported memory concern similar to that of individuals with objective memory impairment but very low worry ($d = -0.19$), and individuals with objective memory impairment but with high worry ($d = -0.16$)
Norman et al. 2020 America 31/36 $\kappa = 1.000$	To determine if the fear of developing AD construct, in combination with similar psychoemotional factors, could help elucidate the nature of older adults' subjective memory complaints* and subsequent objective memory performance*	Quantitative, longitudinal Not stated	$N = 202$ Participants were healthy older adults, primarily recruited from senior centres in Illinois and Wisconsin. Participants with cognitive impairment were excluded Age: $M = 76.6$, ($SD = 6.8$) Gender: 76% female 24% male	Postal questionnaires Fear of developing AD question Abbreviated version of the Penn State Worry Questionnaire (PSWQ-A) Illness Attitudes Scale (IAS) State-Trait Anxiety Inventory (STAI) Hamilton Anxiety Rating Scale (HAM-A) Memory Functioning Questionnaire (MFQ)	Greater fear of developing AD was associated with greater self-reported frequency of forgetting after accounting for age and education ($r = -.19$, $p < .01$) Fear of developing AD was not associated with self-reported frequency of forgetting for individuals with a current mood or anxiety diagnosis ($p > .05$) Fear of developing AD was not associated with objective memory performance ($p > .05$) Total and direct effects of fear of developing AD on self-reported subjective memory were -6.32 ($p = .005$) and -1.92 ($p = .335$) respectively. For all mediators, greater symptomology (e.g. worry, anxiety) was associated with greater self-reported frequency of forgetting

				Rey Auditory Verbal Learning Test (RAVLT)	
				Fisher's exact tests, Spearman's correlations, and multiple regression models	
Shinan-Altman & Werner 2017 Israel 26/36 $\kappa = .898$	To examine the relationship between help-seeking for early detection of AD and lay persons' beliefs and emotional reactions towards AD*	Quantitative, no further details provided Convenience sample	$N = 236$ Community dwelling adults over the age of 50 years Age: 50-86 years ($M = 59.5$, $SD = 7.21$) Gender: 49.4% male 50.6% female	Face-to-face structured interviews Revised Illness Perception Questionnaire Willingness to seek help for early detection of AD questions List of help-seeking sources Descriptive statistics, Pearson correlations, and multivariate regressions	Significant correlations were found between help-seeking and the following illness representations: - perceived consequences of AD ($r = -0.21$, $p < 0.0001$) - perceived illness coherence ($r = 0.14$, $p < 0.01$) AD consequences ($F(4,230) = -3.23$, $p < 0.001$; $\beta = -0.20$) and perceived threat ($F(4,230) = -2.04$, $p < 0.05$; $\beta = -0.13$) emerged as significant predictors for help-seeking for early detection of AD
Tang et al. 2017 America	To explore the relationship between peoples' concerns about developing AD or dementia and:	Quantitative, cross sectional	$N = 4033$ The online survey was sent to 6105 panelists aged 18 and over	Online survey Concern about developing AD question	Findings support a relationship between respondents' level of worry and their likelihood of agreeing to being screened or tested. Among the 556 individuals who were 'very worried' or 'worried' about getting AD or dementia, 74.8% were very

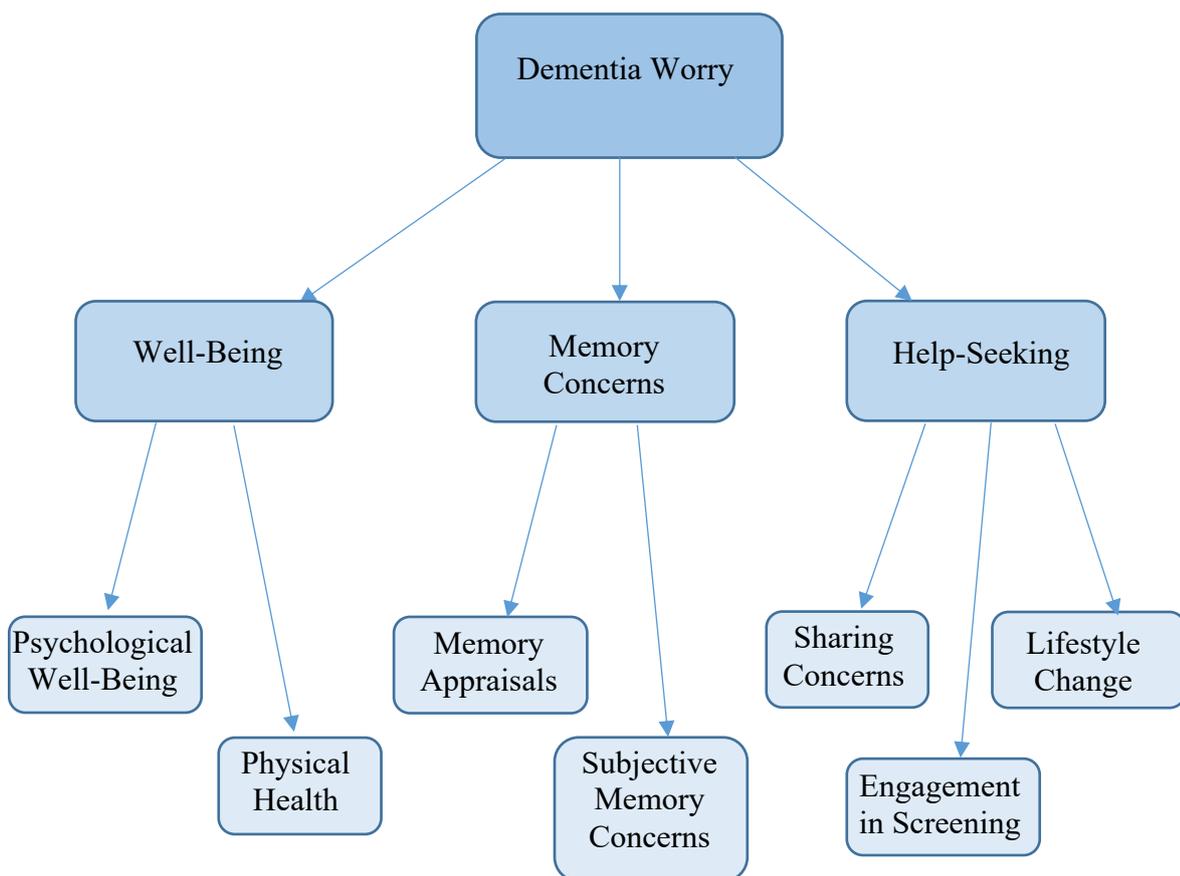
29/36 $\kappa = 1.000$	1. Likelihood to be screened* 2. Likelihood to be tested, if experiencing changes in cognitive status or functioning* 3. Concerns about sharing the diagnostic information with others	Probability-based sampling	Age: 18-91 years ($M = 46.5$, $SD = 17.2$) Gender: 51.8% female 48.2% male	Likelihood to be screened question Concerns about sharing diagnosis questions Chi-square tests and logistic regression analysis	likely or likely to be screened or tested ($p < .001$)
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1.3.1 Themes Derived from Analysis

Following in-depth analysis of the identified texts, three main themes representing implications of DW emerged: *Well-Being*, *Memory Concerns*, and *Help-Seeking*. The following narrative will summarise the key findings from the papers which led to the main themes and sub-themes highlighted in Figure 1.2. Furthermore, Appendix G indicates the contributions each article made to the development of the main themes and sub-themes.

Figure 1.2

Map of Main Themes and Sub-themes



1.3.2 Well-Being

Well-being implications were a main feature of several studies, whilst others discussed well-being as an outcome only peripherally. The Well-Being main theme comprises two sub-themes: *Psychological Well-Being* and *Physical Health*.

1.3.2.1 Psychological Well-Being

Bowen et al. (2019) found that DW was related to higher levels of psychological distress ($r = .49, p \leq .01$) and ageing anxiety ($r = .62, p \leq .01$), and lower levels of life-satisfaction ($r = -.37, p \leq .01$). Similarly, Cutler and Hodgson (2013) found that DW was a predictor of four psychological well-being outcomes (stress: $r = .435, p < .001$, depression: $r = .457, p < .001$, life satisfaction: $r = .356, p < .001$, and mastery: $r = .305, p < .001$). Kinzer and Suhr (2016) echoed these findings, reporting that higher levels of DW was related to higher depressive symptoms ($r = .51, p < .001$), and higher levels of general worry ($r = .53, p < .001$).

Moreover, Hodgson and Cutler (1997) found that DW was linked to higher levels of depression ($r = .329, p < .02$) and psychiatric symptomatology ($r = .403, p < .005$), and lower levels of life satisfaction ($r = -.368, p < .01$). Cutler and Hodgson (2013) and Cutler and Bragaru (2017) explored the long-term impact of DW on psychological well-being. Over an 11-year period the researchers found that the more persistent DW was, the more likely individuals were to have detrimental consequences to their psychological wellbeing.

Importantly, Cutler and Bragaru (2017) also found that DW at an earlier time point did not affect psychological well-being at a later time in their 11-year study, suggesting that these effects are neither lagged nor enduring. Finally, whilst some studies explored specific features of psychological well-being such as depression, Cui et al. (2019) went on to report

that DW was also linked to suicidal ideation, however, the cross-sectional nature of this study precluded establishing the temporal precedence between DW and suicidal ideation.

Cutler and Bragaru (2017), Cutler and Hodgson (2013), and Kinzer and Suhr (2016) did not report their sampling methods making it difficult for future research to repeat or audit those studies, whilst Bowen et al. (2019) used convenience sampling, and Hodgson and Cutler (1997) used purposive sampling. A reliance on convenience and purposive sampling methods increases the likelihood that some samples may not be representative of the wider population, therefore limiting the generalisability of these findings at a population level.

1.3.2.2 Physical Health

Bowen et al. (2019) and Hodgson and Cutler (1997) both found that DW was associated with lower ratings of subjective health. Furthermore, Cutler and Hodgson (2014) found that those who expressed greater DW were more likely to be in poorer health based on self-report over an 11-year period ($r = .226$; $p < .01$), suggesting DW may also have implications for individuals' health in the long-term. However, it is noted that a limitation of Cutler and Hodgson's (2014) analysis was that it failed to use the data to establish temporally-informed causal relationships, suggesting a more sophisticated analytical approach could have further explicated the relationship between DW and physical health outcomes over time.

1.3.3 Memory Concerns

The studies reviewed revealed that DW had significant implications for individuals' concerns about their own memory. Through the use of a thematic analysis framework to consolidate

the results, this main theme was further broken down into two sub-themes: *Memory Appraisals* and *Subjective Memory Concerns*.

1.3.3.1 Memory Appraisals

Changes to the way people appraised their memory were shown to be related to DW. Indeed, Cutler and Hodgson (1996) found that those with higher levels of DW appraised their memory functioning more negatively than those who were not concerned about developing dementia. Qualitatively, Hodgson and Cutler (1997) found that participants with high levels of DW were mindful of every instance of forgetfulness and these memory lapses took on ominous meanings. For example, one 51-year old participant stated “every time I forgot something I thought, ‘Ah, it’s coming, I’m going to get it now.’ You know, that’s just fear” (Hodgson & Cutler, 1997, p. 65). However, Hodgson and Cutler’s (1997) study was exploratory in nature with a total sample of 50 participants, limiting the ability to generalise and offer conclusive findings. Separately, Hodgson et al. (1999) found that participants reported repeatedly checking themselves for symptoms of AD. In this study participants stated they had an acute sensitivity to their cognitive functioning and were constantly appraising their memory and actions as a way of searching for evidence for the presence of the disease.

1.3.3.2 Subjective Memory Concerns

In line with participants appraising their memory more often and more negatively, Bowen et al. (2019) found that DW was also associated with higher perceived memory change ($r = -.17, p \leq .05$), and lower perceived memory capacity ($r = .16, p \leq .05$). Kinzer and Suhr (2016) also found that higher DW was associated with higher memory concern ($r = .37, p < .001$).

Interestingly, the researchers found that the sample of participants with no objective memory impairment but high DW reported memory concern similar to that of individuals with objective memory impairment and both high and low DW. These findings suggest that subjective memory ratings may not provide an accurate depiction of actual memory impairment in people with DW. However, Kinzer and Suhr's (2016) results should be interpreted with caution as the neuropsychological data provided preceded the self-report survey by a year, and some participants may have experienced further cognitive decline during that time period. Nevertheless, these findings are supported by results from Norman et al. (2020) who found that DW was not associated with objective memory performance. Equally, greater DW was associated with greater self-reported frequency of forgetting after accounting for age and education (Norman et al., 2020). However, Norman et al.'s (2020) study had several limitations. Most notably, the study only examined verbal episodic memory (assessed through word list learning), which has limited ecological validity when applied to the variety of everyday memory problems that people with dementia report, such as misplacing items.

Qualitatively, Hodgson et al. (1999) found that a change in memory functioning was the primary symptom reported by participants, for example: "I can forget things twenty minutes later... I don't remember names, just little things to do, lots of things I have to do... Perhaps I might be showing signs of Alzheimer's" (Hodgson et al., 1999, p. 369). Similarly, Kim et al. (2016) found that participants' perception was that the frequency and level of their forgetfulness, and the deterioration of their short-term memory had become increasingly concerning over time.

1.3.4 Help-Seeking Behaviours

Shinan-Altman and Werner (2017) found that perceived threat of AD was one of two main predictors of help-seeking for early detection of AD among the lay public, indicating that individuals with DW may be more likely to engage in specific behaviours linked to their concerns about developing dementia. The main theme of Help-Seeking comprises three further sub-themes: *Sharing Concerns*, *Engagement in Screening*, and *Lifestyle Change*.

1.3.4.1 *Sharing Concerns*

It is perhaps not surprising that subjective memory assessment is linked to help-seeking behaviours. A common finding across studies was participants sharing their concerns about their own memory with those around them. Indeed, Hodgson and Cutler (1997) found that participants with higher levels of DW were significantly more likely to speak to friends and family about their concerns ($r = .664, p < .001$ and $r = .587, p < .01$, respectively), and marginally more likely to speak to professionals ($r = .380, p < .10$). Similarly, Shinan-Altman and Werner (2017) found that almost all participants (85.8%) in their study reported seeking help from their spouse or children, with 84.1% stating their general practitioner would be their preferred source of professional support, followed by a neurologist (77.9%). Similarly, Hodgson et al. (1999) found that respondents often talked about the disease with parents, spouses, siblings, and wider family members and friends: “I talk with this friend, constantly. And I say ‘I forgot this.’ She says, ‘Yeah, join the crowd. I do the same thing.’ We’re quite a pair” (Hodgson et al., 1999, p. 370). The researchers also reported that participants typically discussed their symptoms with their lay-referral network initially, to seek reassurance and advice, if this lay network failed to satisfy concerns participants sometimes sought out support groups and their doctors for help.

In a similar vein, Hodgson and Cutler (2004) found that 68% of their total sample reported that they had shared their concerns with members of their family, or other informal sources, noting that participants who had spoken to professional sources most commonly spoke to their physicians (20.1%). Hodgson and Cutler (2004) also found that help-seeking was closely associated with self-assessment of memory. Interestingly, participants who reported that others had noticed changes in their memory were more likely to have sought out support from family, whereas those who noticed changes in their own memory were more likely to have sought out formal sources of help. In addition to support from friends and loved ones, Hodgson and Cutler (2004) found that 45% of respondents had accessed one or more informational source, turning to the internet (23.7%), Alzheimer's association (20.1%), local libraries (15.4%), and other organisations (14.8%). They also found that participants who had the highest level of DW were most likely to seek out help, suggesting it is the highest level of concern which drives the next step in the help-seeking process, formal testing (Hodgson & Cutler, 2004). Hodgson and Cutler's (2004) study did however have some limitations. The study sample was somewhat homogeneous, with no participants from ethnic minorities and the sample being more female, married, well-educated, and catholic than the general population from which it was drawn, likely due to the over-representation of such groups in the recruitment venues. It is also important to note that all studies which explored the outcome of sharing concerns were conducted in the USA, and therefore these outcomes may have limited generalisability to other countries and cultures.

1.3.4.2 Engagement in Screening

DW was shown to be associated with a higher perceived risk of developing dementia (Bowen et al., 2019), which may suggest people are more likely to access screening to ascertain if they have the disease. Harada et al. (2017) found that screening for dementia was predicted

by behavioural intention, which was explained by the perceived benefits, perceived barriers, and perceived susceptibility to dementia, indicating that DW may play some role in people's intention to be screened. However, Harada et al. (2017) additionally found that perceived susceptibility, perceived severity, and DW were weaker predictors compared with the perceived benefits of being tested. Conversely, Shinan-Altman and Werner (2017) found that participants reported higher willingness to be tested for AD if the test was routine, followed by if a family member noticed the problem, with the lowest willingness to be screened being if they noticed the problem themselves. Interestingly, Tang et al. (2017) found that the greater the DW, the more likely participants were to request to be screened or tested. Indeed, among the 556 individuals who were very worried or worried about AD, 74.8% stated they were very likely to be screened or tested.

1.3.4.3 Lifestyle Change

Whilst many of the outcomes identified from the analysis could be understood to have negative implications on people's lives, several studies also reported positive outcomes that were associated with DW. For example, Kim et al. (2015) reported that being at least somewhat worried about dementia motivated people to adopt and maintain healthier lifestyles to reduce their risk of dementia. Kim et al. (2015) additionally reported that DW was the main motivator towards adopting a healthier lifestyle, stating that when the fear of developing dementia was greater than the pleasure of doing something perceived as possibly heightening the risk of dementia (e.g. smoking), changes were likely to occur which could lead to a positive and healthier lifestyle. An illustrative quotation from one study participant was, "...if someone says to me if you don't change your lifestyle you are going to be dead in five years (with dementia) I would say OK, I would change it" (Kim et al., 2015, p. 1699). Kim et al. (2016) went on to find that participants were sensitive to information in the media

which reported ways to reduce dementia risk, and many participants who were concerned about developing dementia described practising a healthier lifestyle than they used to in the past. Behaviour changes identified included a healthier diet, dietary supplements, increased exercise, good sleep, vaccinations, regular health check-ups, and better medication adherence (Kim et al., 2016). It is important to note that only two qualitative papers considered lifestyle change as a consequence of DW, limiting the conclusions that can be drawn about this sub-theme.

1.3.5 Critique of Studies

Nine of the 16 studies made no reference to considerations of ethical issues and subsequently scored zero on the quality assessment for this criterion. Although three studies did report ethical considerations at a satisfactory level (Harada et al., 2017; Kim et al., 2015; Norman et al., 2020), a further four only demonstrated partial consideration (Cui et al., 2019; Hodgson & Cutler, 2004; Kim et al., 2016; Shinan-Altman & Werner, 2017); it is unclear whether ethical issues were not considered, or simply not reported in studies.

The majority of the reviewed studies employed quantitative methodology, whilst three used qualitative methodologies (Hodgson et al., 1999; Kim et al., 2015; Kim et al., 2016), and one study used a mixed methodology (Hodgson & Cutler, 1997). The majority of studies failed to provide a clear rationale for their choice in methodology. Whilst all studies reported data collection methods, studies did not typically outline their data collection processes, limiting the possibility of accurately replicating or auditing data collection. Equally, studies typically failed to provide justification or theoretical rationale for analysis choices within the studies.

Demographically, the age of participants recruited was diverse, with studies such as Tang et al. (2017) recruiting any adults over the age of 18, whilst Harada et al. (2017) only recruited participants over the age of 70. Interestingly, all studies in the review included samples with a mean age of 45 and over, suggesting that the existing research tells us more about the experience of DW in people of middle age or above, though some samples did include younger participants. Furthermore, whilst all studies recruited ‘healthy’ participants with no diagnosis of any cognitive impairment, there were differences in sample populations, particularly in terms of participants who had a close relative and/or cared for someone with a diagnosis of dementia, and those who did not. Eight of the studies included participants who were caring for a relative with diagnosed, or probable dementia. The experiences of this population may be vastly different due to their contact with dementia, which may have skewed the results from these particular studies. Indeed, it is important to be mindful of any differences in implications for populations with differences experiences, and the potential influence of prior experiences.

Finally, it is noteworthy that sample sizes varied greatly across the studies, from 12 (Kim et al., 2016) to 10,023 (Harada et al., 2017), an expected finding due to the inclusion of both qualitative and quantitative studies. Whilst the samples sizes were appropriate to the design and methodology employed, the weighting placed on findings from studies with small sample sizes should be considered.

1.3.6 Synthesis of Findings

In summary, results from the analysis indicated that DW can have a negative impact on both psychological well-being and physical health. In addition, DW can cause individuals to experience increased vigilance for age-appropriate memory changes and subsequently, this

heightened vigilance may lead to increased subjective memory concerns. Such concerns can lead individuals to seek reassurance and advice from those around them in the first instance, but also included seeking or accessing memory assessment or other support from professionals, or engaging in lifestyle changes aimed at decreasing the risk of developing dementia.

1.4 Discussion

The present review is the first to examine the implications of DW in people who do not have a diagnosis of dementia. Broadly, the findings suggest that DW has particular implications for well-being, memory concerns, and engagement in help-seeking behaviours.

This review synthesised the existing empirical literature investigating the implications of DW, building on the conceptual review completed by Kessler et al. (2012). The researchers previously developed a set of potential implications based on conceptually related phenomena. The current review was able to explore whether these proposed implications were borne out across the literature. Kessler et al. (2012) hypothesised that DW may lead to both adaptive and maladaptive responses; an example of an adaptive response was the finding that individuals with DW reported adopting healthier lifestyles to reduce their risk of dementia (Kim et al., 2015; Kim et al., 2016). This finding is in line with research from Daviglus et al. (2010) who found that individuals who are more concerned about developing dementia may be more likely to engage in preventative health measures, such as doing crossword puzzles. However, the Extended Parallel Process Model (Witte, 1992) proposes that perceived threat does not necessarily promote appropriate behaviours. Indeed, if people do not think they can reduce the risk by actions, a perceived threat can lead to maladaptive

behaviours, suggesting that DW may not always lead to positive lifestyle changes in an attempt to mitigate risk.

The overwhelming majority of implications of DW identified in this review were considered to be negative. Kessler et al.'s (2012) conceptual review made reference to the potential for DW to impact an individual's mood, well-being, and physical health, all of which were illustrated in the findings of the current review. In particular, the impact DW was found to have on both physical and mental health is a salient concern. Certainly, it has been well documented that good physical *and* mental health are required for optimal overall well-being (Dolan et al., 2008). Separately, findings from Cui et al. (2019) linked DW to suicidal ideation. This finding is in line with the Interpersonal Theory of Suicide (Van Orden et al., 2010), which states that perceived burdensomeness and thwarted belongingness can lead to suicidal ideation; experiences which may be particularly feared by individuals who worry they will go on to develop dementia.

1.4.1 Clinical Implications

The findings of this review have several clinical implications for both practice and policy. At present, it is likely that individuals who have high levels of DW may struggle to be accommodated within mainstream services. Indeed, following raising their concerns about dementia with a GP, it is likely that a subset of these individuals would be referred to specialist memory assessment services, which, tend to discharge patients if no objective memory deficits are identified. Equally, it is unlikely that the unique and under-researched experience of DW would currently be catered for within mainstream mental health services, therefore individuals are unlikely to receive any further specialist support at this point.

However, an implication of the findings of this review is that healthcare practitioners should consider a person's psychological characteristics when deciding how to support those who present to services with DW but are subsequently found to have no underlying cognitive impairment.

The explanatory diagram (Figure 1.3) identifies potential opportunities for services to intervene in the cycle of DW. Clinically, this intervention may include the treatment of psychological symptoms. Indeed, it is possible that DW could be effectively treated under the umbrella of 'health anxiety'. Health anxiety is understood to develop in individuals who present with an enduring tendency to misinterpret bodily sensations and other ambiguous health-related information, believing they may be suffering from a serious physical illness (Salkovskis & Bass, 1997; Warwick & Salkovskis, 1990). Effective treatments for health anxiety, such as those utilising cognitive behavioural techniques have been validated in controlled trials (Clark et al., 1998; Warwick et al., 1996), and could potentially be adapted for use with this population.

Findings from the review also have implications for individuals' engagement in screening for dementia. Indeed, Tang et al. (2017) found that the greater the DW, the more likely participants would be to engage in screening for dementia. This finding is consistent with research findings from other areas where health worry or health anxiety is an issue. For example, Hay et al. (2006) found that worry about breast cancer motivates screening seeking behaviours. While screening and early diagnosis of dementia is important as it facilitates access to interventions which may improve cognitive functioning and delay institutionalisation (Alzheimer's Disease International, 2011), the findings of this review clearly indicate that DW and subjective memory ratings are not correlated with objective

memory impairment. One likely consequence of this is that individuals with DW may present an unnecessary burden on memory assessment services due to potentially unnecessary requests for screening.

Finally, with regard to the association between both DW and ageing anxiety identified by Bowen and colleagues (Bowen et al., 2019), it additionally seems paramount that public health bodies and media sources clearly communicate the fact that dementia is not synonymous with ageing, to ensure that the continued increase in dementia awareness does not negatively alter perceptions of the ageing process and old age (Bowen et al., 2019).

1.4.2 Limitations

A key limitation of the present review is the lack of *different* researchers investigating the phenomenon. Seven of the sixteen studies reviewed here included the same core researchers (Cutler & Bragaru, 2017; Cutler & Hodgson, 1996; Cutler & Hodgson, 2013; Cutler & Hodgson, 2014; Hodgson & Cutler, 1997; Hodgson & Cutler, 2004; Hodgson et al., 1999). Researcher dominance of this nature has the potential to skew the interpretation of results in a certain way; certainly, researcher bias can be present at any stage of the research process. Indeed, three of those studies relied on a single data set (Cutler & Bragaru, 2017; Cutler & Hodgson, 2013; Cutler & Hodgson, 2014), a further potential source of bias. While it would be preferable for these possible sources of bias not to be present, this is a typical problem in under-researched areas such as is the case for DW. Furthermore, there were occasions where data sets were used multiple times for different papers, for example, on two occasions one data set produced three papers (Cutler & Bragaru, 2017; Cutler & Hodgson, 2013; Cutler & Hodgson, 2014 and Cutler & Hodgson, 1996; Hodgson & Cutler, 1997; Hodgson et al.,

1999). The use of the same samples across multiple papers may provide an inaccurate representation of the experiences of a population.

In addition, there are potential limitations with the approach to analysis employed in this review. Indeed, whilst thematic analysis is flexible, this flexibility provides scope for inconsistency and poor coherence when themes are derived from the research data (Holloway & Todres, 2003). Similarly, narrative synthesis has been noted to lack transparency and clarity with regard to methods used to complete the synthesis (Mays et al., 2005).

Finally, social heterogeneity in systematic reviews encompasses not only socio-demographic and individual differences, but also historical, cultural, and spatial differences (Popay et al., 2006). In this review, the vast majority of studies were conducted in the USA, suggesting that north American views and cultural experiences of dementia and DW may have skewed the results to some degree. Indeed, as DW has been shown to be influenced by media reports and personal contact with dementia (Kessler & Schwender, 2012), these factors may vary greatly across different parts of the world, potentially resulting in different implications.

1.4.3 Future Research Directions

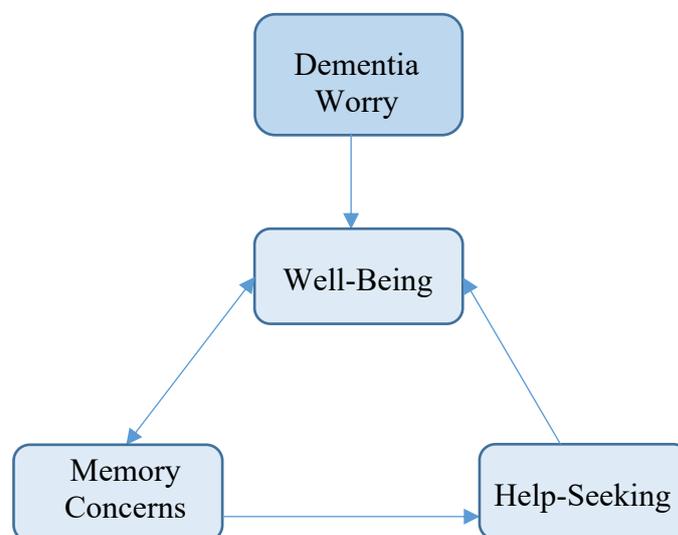
The current evidence base for DW remains in its infancy and would benefit from continued research to further enhance our understanding of its implications. Future research on DW could help to identify factors that mediate and moderate the relationship between DW and adaptive or maladaptive responses, which could have considerable implications for interventions at both an individual and a public health level.

Whilst the current review has offered substantial insight into the implications of DW, there is still a lot that is not known in this relatively under-researched area. Indeed, whilst we can make certain assumptions based on the evidence reviewed here, it is still unclear what the impact of DW is on memory assessment services. In particular, it would be useful to better understand the reasons that lead some people to present for memory assessment screenings despite having no obvious cognitive impairment; there is a need for more carefully designed studies to robustly address the question of whether DW is a predictor in this context.

The findings of the review can be represented in a simplistic explanatory diagram detailed in Figure 1.3, which may be useful when considering future directions. This diagram highlights how DW appears to initially impact an individual's well-being, leading to increased memory concerns and help-seeking behaviours. It is possible that depending on the outcome of the help-seeking behaviours, there may be further impact on an individual's well-being and the cycle may continue.

Figure 1.3

Explanatory Representation of Findings



It is possible that interventions which interrupt the cycle of DW (outlined in Figure 1.3) could reduce or mitigate the negative implications for individuals, and for healthcare services. However, it is initially necessary for further research to be completed on the efficacy of such interventions. These interventions may include those focused on ameliorating the psychological symptoms of DW, such as an adapted version of a cognitive behavioural therapy for health anxiety intervention, or interventions aimed at ensuring individuals help-seeking behaviours are responded to in a way that offers adequate acknowledgement of their concerns, but does not contribute to maintaining unnecessary help-seeking behaviours.

1.5 Conclusion

As populations age and more people face the possibility of developing dementia, it is important that unhelpful reactions such as DW are responded to appropriately to minimise the implications for people with these concerns, and also to ensure that memory/cognitive assessment services are not over-burdened by fundamentally well individuals concerned for their cognitive health. Indeed, the results of the present review highlight the potential value of adopting a cross-disciplinary perspective to better understand and address this relatively widespread phenomenon.

1.6 References

- Alberts, N. M., Hadjistavropoulos, H. D., Pugh, N. E., & Jones, S. L. (2011). Dementia anxiety among older adult caregivers: An exploratory study of older adult caregivers in Canada. *International Psychogeriatrics*, 23(6), 880–886.
<https://doi.org/10.1017/S1041610211000299>
- Altman, D. G. (1991). *Practical statistics for medical research*. Chapman & Hall/CRC Press.
[http://tropical-dendrochronology.org/SHARE/ALTMAN \(1991\) - Practical statistics for medical research.pdf](http://tropical-dendrochronology.org/SHARE/ALTMAN (1991) - Practical statistics for medical research.pdf)
- Alzheimer's Disease International. (2011). *World Alzheimer's report: The benefits of early diagnosis and intervention*. <https://www.alz.co.uk/research/WorldAlzheimerReport-2011.pdf>
- Alzheimer's Research UK. (2011). *Global Alzheimer's fears risk*.
<https://www.alzheimersresearchuk.org/global-alzheimers-fears-rise/>
- Bowen, C. E., Kessler, E., & Segler, J. (2019). Dementia worry in middle-aged and older adults in Germany: Sociodemographic, health-related and psychological correlates. *European Journal of Ageing*, 16(1), 39-52. <https://doi.org/10.1007/s10433-018-0462-7>
- Caldwell, K., Henshaw, L., & Taylor, G. (2011). Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today*, 31(8), 1-7.
<https://doi.org/10.1016/j.nedt.2010.11.025>

- Cantegreil-Kallen, I., & Pin, S. (2012). Fear of Alzheimer's disease in the French population: Impact of age and proximity to the disease. *International Psychogeriatrics*, 24(1), 108-116. <https://doi.org/10.1017/S1041610211001529>
- Clark, D. M., Salkovskis, P. M., Hackmann, A., Wells, A., Fennell, M., Ludgate, J., Ahmad, S., Richards, H. C., & Gelder, M. (1998). Two psychological treatments for hypochondriasis. A randomised controlled trial. *British Journal of Psychiatry* 173(3), 218–225. <https://doi.org/10.1192/bjp.173.3.218>
- Clarke, J. N., & Everest, M. M. (2006). Cancer in the mass print media: Fear, uncertainty and the medical model. *Social Science and Medicine*, 62(10), 2591-2600. <https://doi.org/10.1016/j.socscimed.2005.11.021>
- Cui, R., Maxfield, M., & Fiske, A. (2019). Dementia-related anxiety and coping styles associated with suicidal ideation. *Aging and Mental Health*, 4, 1-4. <https://doi.org/10.1080/13607863.2019.1636205>
- Cutler, S. J. (2015). Worries about getting Alzheimer's: Who's concerned? *American Journal of Alzheimer's Disease and Other Dementia's*, 30(6), 591-458. <https://doi.org/10.1177/1533317514568889>
- Cutler, S. J., & Bragaru, C. (2017). Do worries about cognitive functioning and concerns about developing Alzheimer's disease affect psychological well-being? *Journal of Aging and Health*, 29(8), 1271-1287. <https://doi.org/10.1177/0898264316674535>

- Cutler, S. J., & Hodgson, L. G. (1996). Anticipatory dementia: A link between memory appraisals and concerns about developing Alzheimer's disease. *Gerontologist, 36*(5), 657–664. <https://doi.org/10.1093/geront/36.5.657>
- Cutler, S. J., & Hodgson, L. G. (2013). Concerns about cognitive functioning, dementia worries, and psychological well-being. *Social Work Review, 12*(3), 77-86. <https://www.cceol.com/search/article-detail?id=257955>
- Cutler, S. J., & Hodgson, L. G. (2014). Is health affected by dementia worries and concerns about cognitive functioning? *Social Work Review, 13*(3), 7-15. <https://www.cceol.com/search/article-detail?id=278968>
- Daviglus, M. L., Bell, C. C., Berrettini, W., Bowen, P. E., Connolly, E. S., Cox, N. J., Dunbar-Jacob, J. M., Granieri, E. C., Hunt, G., McGarry, K., Patel, D., Potosky, A. L., Sanders-Bush, E., Silberberg, D., & Trevisan, M. (2010). National institutes of health state-of-the-science conference statement: Preventing Alzheimer's disease and cognitive decline. *Annals of Internal Medicine, 153*(3), 176-181. <https://doi.org/10.7326/0003-4819-153-3-201008030-00260>
- Dixon-Woods, M. (2005). Synthesising qualitative and quantitative evidence: A review of possible methods. *Journal of Health Service Research and Policy, 10*(1), 45–53. <https://doi.org/10.1177/135581960501000110>
- Dolan, P., Peasgood, T., & White, M. (2008). Do we really know what makes us happy? A review of the economic literature on the factors associated with subjective well-being.

Journal of Economic Psychology, 29(1), 94-122.

<https://doi.org/10.1016/j.joep.2007.09.001>

Eifert, G. H., Zvolensky, M. J., & Lejuez, C. W. (2000). Heart-focused anxiety and chest pain: A conceptual and clinical review. *Clinical Psychology*, 7(4), 403-417. <https://doi.org/10.1093/clipsy/7.4.403>

Frankish, H., & Horton, R. (2017). Prevention and management of dementia: A priority for public health. *Lancet*, 390(10113), 2614-2615. [https://doi.org/10.1016/S0140-6736\(17\)31756-7](https://doi.org/10.1016/S0140-6736(17)31756-7)

French, S. L., Floyd, M., Wilkins, S., & Osato, S. (2012). The fear of Alzheimer's disease scale: A new measure designed to assess anticipatory dementia in older adults. *International Journal of Geriatric Psychiatry*, 27(5), 521–528. <https://doi.org/10.1002/gps.2747>

Harada, K., Lee, S., Shimada, H., Lee, S., Bae, S., Anan, Y., Harada, K., & Suzuki, T. (2017). Psychological predictors of participation in screening for cognitive impairment among community-dwelling older adults. *Geriatrics Gerontology International*, 17(8), 1197-1204. <https://doi.org/10.1111/ggi.12841>

Hay, J. L., Buckley, T. R., & Ostroff, J. S. (2005). The role of cancer worry in cancer screening: A theoretical and empirical review of the literature. *Psychooncology*, 14(7), 517–534. <https://doi.org/10.1002/pon.864>

- Hay, J. L., McCaul, K. D., & Magnan, R. E. (2006). Does worry about breast cancer predict screening behaviours? A meta-analysis of the prospective evidence. *Preventative Medicine, 42*(6), 401-408. <https://doi.org/10.1016/j.ypmed.2006.03.002>
- Hodgson, L. G., & Cutler, S. J. (1997). Anticipatory dementia and well-being. *American Journal of Alzheimer's Disease, 12*(2), 62-66.
<https://doi.org/10.1177/153331759701200203>
- Hodgson, L. G., & Cutler, S. J. (2004). Help-seeking for personal concerns about developing Alzheimer's disease. *The Journal of Applied Gerontology, 23*(4), 385-410.
<https://doi.org/10.1177/0733464804270587>
- Hodgson, L. G., Cutler, S. J., & Livingston, K. (1999). Alzheimer's disease and symptom seeking. *American Journal of Alzheimer's disease, 14*(6), 364-374.
<https://doi.org/10.1177/153331759901400606>
- Holloway, I., & Todres, L. (2003). The status of method: Flexibility, consistency and coherence. *Qualitative Research, 3*(3), 345-357.
<https://doi.org/10.1177/1468794103033004>
- Jonker, C., Geerlings, M., & Schmand, B. (2000). Are memory complaints predictive for dementia? A review of clinical and population based studies. *International Journal of Geriatric Psychiatry, 15*(11), 983-991. [https://doi.org/10.1002/1099-1166\(200011\)15:11<983::aid-gps238>3.0.co;2-5](https://doi.org/10.1002/1099-1166(200011)15:11<983::aid-gps238>3.0.co;2-5)

- Kessler, E. M., Bowen, C. E., Baer, M., Froelich, L., & Wahl, H. W. (2012). Dementia worry: A psychological examination of an unexplored phenomenon. *European Journal of Ageing, 9*(4), 275-284. <https://doi.org/10.1007/s10433-012-0242-8>
- Kessler, E. M., & Schwender, C. (2012). Giving dementia a face? The portrayal of older people with dementia in German weekly news magazines between the year 2000 and 2009. *Journal of Gerontology Series B Psychological Sciences and Social Sciences, 67*(2), 261-270. <https://doi.org/10.1093/geronb/gbr156>
- Kim, J. S., Kim, E. H., & An, M. (2016). Experience of dementia-related anxiety in middle-aged female caregivers for family members with dementia: A phenomenological study. *Asian Nursing Research, 10*(2), 128-135. <https://doi.org/10.1016/j.anr.2016.02.001>
- Kim, S., Sargent-Cox, A., & Anstey, K. J. (2015). A qualitative study of older and middle-aged adults' perception and attitudes towards dementia and dementia risk reduction. *Journal of Advanced Nursing, 71*(7), 1694-1703. <https://doi.org/10.1111/jan.12641>
- Kinzer, A., & Suhr, J. A. (2016). Dementia worry and its relationship to dementia exposure, psychological factors, and subjective memory concerns. *Applied Neuropsychology: Adult, 23*(3), 196-204. <https://doi.org/10.1080/23279095.2015.1030669>
- Lineweaver, T. T., & Hertzog, C. (1998). Adults' efficacy and control beliefs regarding memory and aging: Separating general from personal beliefs. *Neuropsychology, Development, and Cognition. Section B, Aging and Cognition, 5*(4), 264–296. <https://doi.org/10.1076/anec.5.4.264.771>

- Low, L. F., & Anstey, K. J. (2009). Dementia literacy: Recognition and beliefs on dementia of the Australian public. *Alzheimer's and Dementia*, 5(1), 43-49.
<https://doi.org/10.1016/j.jalz.2008.03.011>
- Mays, N., Pope, C., & Popay, J. (2005). Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field. *Journal of Health Services Research and Policy*, 10(1), 6-20. <https://doi.org/10.1258/1355819054308576>
- MetLife Foundation. (2011). *What America thinks: The MetLife Foundation Alzheimer's survey*. <https://www.metlife.com/content/dam/microsites/about/corporate-profile/alzheimers-2011.pdf>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *Annals of Internal Medicine*, 151(4), 264-269. <https://doi.org/10.1136/bmj.b2535>
- Norman, A. L., Woodard, J. L., Calamari, J. E., Gross, E. Z., Pontarelli, N., Socha, J., DeJong, B., & Armstrong, K. (2020). The fear of Alzheimer's disease: Mediating effects of anxiety on subjective memory complaints. *Aging and Mental Health*, 24(2), 308-314.
<https://doi.org/10.1080/13607863.2018.1534081>
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews: A product of the ESRC methods programme (Version 1)*. University of Lancaster. <https://doi.org/10.13140/2.1.1018.4643>

- Roberts, J. S., McLaughlin, S. J., & Connell, C. M. (2014). Public beliefs and knowledge about risk and protective factors for Alzheimer's disease. *Alzheimer's and Dementia*, *10*(5), 381-389. <https://doi.org/10.1016/j.jalz.2013.07.001>
- Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs*, *2*(4), 328-335. <https://doi.org/10.1177/109019817400200403>
- Salkovskis, P. M., & Bass, C. (1997). Hypochondriasis. In D. M. Clark & C. G. Fairburn (Eds.), *The science and practice of cognitive-behaviour therapy* (pp. 313–339). Oxford University Press
- Schardt, C., Adams, M. B., Owens, T., Keitz, S., & Fontelo, P. (2007). Utilization of the PICO framework to improve searching PubMed for clinical questions. *BMC Medical Informatics and Decision Making*, *15*(7), 16. <https://bmcmmedinformdecismak.biomedcentral.com/articles/10.1186/1472-6947-7-16>
- Shinan-Altman, S., & Werner, P. (2017). Is there an association between help-seeking for early detection of Alzheimer's disease and illness representations of this disease among the lay public? *International Journal of Geriatric Psychiatry*, *32*(12), 100-106. <https://doi.org/10.1002/gps.4661>
- Tang, W., Kannaley, K., Friedman, D. B., Edwards, V. J., Wilcox, S., Levkoff, S. E., Hunter, R. H., Irmiter, C., & Belza, B. (2017). Concern about developing Alzheimer's disease or dementia and intention to be screened: An analysis of national survey data. *Archives of Gerontology and Geriatrics*, *71*, 43-49. <https://doi.org/10.1016/j.archger.2017.02.013>

- Towers, S., Afzal, S., Bernal, G., Bliss, N., Brown, S., Espinoza, B., Jackson, J., Judson-Garcia, J., Khan, M., Lin, M., Mamada, R., Moreno, V. M., Nazari, F., Okuneye, K., Ross, M. L., Rodriguez, C., Medlock, J., Ebert, D., & Castillo-Chavez, C. (2015). Mass media and the contagion of fear: The case of Ebola in America. *Public Library of Science, 10*(6), e0129179. <https://doi.org/10.1371/journal.pone.0129179>
- Van Orden, K. A., Witte, T. K., Cukrowicz, K. C., Braithwaite, S. R., Selby, E. A., & Joiner, T. E. (2010). The interpersonal theory of suicide. *Psychological Review, 117*(2), 575-600. <https://doi.org/10.1037/a0018697>
- Warwick, H. M., Clark, D. M., Cobb, A., & Salkovskis, P. M. (1996). A controlled trial of cognitive-behavioural treatment of hypochondriasis. *British Journal of Psychiatry 169*(2), 189–195. <https://doi.org/10.1192/bjp.169.2.189>
- Warwick, H. M., & Salkovskis, P. M. (1990). Hypochondriasis. *Behaviour Research and Therapy 28*(2), 105–117. [https://doi.org/10.1016/0005-7967\(90\)90023-c](https://doi.org/10.1016/0005-7967(90)90023-c)
- Werner, P., Savva, G. M., & Maidment, I. (2016). Dementia: Introduction, epidemiology and economic impact. In C. A. Chew-Graham & M. Ray (Eds.), *Mental health and older people* (pp. 197-209). Springer International Publishing. <https://doi.org/10.1007/978-3-319-29492-6>
- Witte, K. (1992). Putting the fear back into fear appeals: The extended parallel process model. *Communication Monographs, 59*(4), 329-349. <https://doi.org/10.1080/03637759209376276>

Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). *Projections of older people with dementia and cost of dementia care in the United Kingdom 2019-2040*.

https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

World Health Organisation. (2019). *Dementia*. <https://www.who.int/news-room/factsheets/detail/dementia>

YouGov. (2012). *Are you worried about dementia?*

<https://yougov.co.uk/topics/politics/articles-reports/2012/05/22/are-you-worried-about-dementia>

Chapter 2: Empirical Paper

The Impact of Illness Representations on Perceptions of Cognitive Ability and Functional Ability in People With Dementia

In preparation for submission to the journal, *Dementia* (See Appendix A)

Overall chapter word count (excluding tables, figures and references): 5421

2.0 Abstract

AIM: This study examines the perspectives of both people with a diagnosis of dementia and their carers in order to better understand the impact of illness representations on perceptions of cognitive and functional ability in people with a diagnosis of dementia. **METHODS:** The study employed a quantitative design. In total, 114 participants took part in the study, comprising 57 people who had received a diagnosis of dementia during the previous six months ($M_{age} = 78.77, SD = 6.39$) and 57 paired carers ($M_{age} = 70.53, SD = 13.03$). Participants completed a series of questionnaires exploring perceptions of the dementia diagnosis, cognitive ability, and functional ability. **RESULTS:** Data was analysed using multiple linear regressions, correlations, and Mann-Whitney tests. The level of illness representation predicted the level of perceived cognitive ability, $F(4, 52) = 47.09, p < .001$, adj. $R^2 = .68$. The level of illness representation predicted the level of perceived functional ability, $F(4, 52) = 49.94, p < .001$, adj. $R^2 = .77$. Significant differences were found between patient and carer ratings of functional ability, $U = 1098.0, N^1 = 57, N^2 = 57, p = .003$. There were also significant differences between patient and carer ratings of cognitive ability, $t(112) = 6.75, p < .001$. **CONCLUSION:** These findings highlight the impact illness representations can have on perceptions of cognitive ability and functional ability in people with dementia. The findings suggest that there is a clinical need to ascertain how individuals view their dementia following diagnosis, and to appropriately support those who may hold especially negative illness representations. Such interventions should seek to ensure that people who are diagnosed with dementia are able to enjoy their optimal quality of life without excess disability, for as long as possible.

2.1 Introduction

2.1.1 Research Aim and Significance

This study set out to explore the impact that illness representations of a dementia diagnosis have on perceptions of cognitive and functional ability in people with a diagnosis of dementia.

Dementia is considered to be one of the major causes of disability and dependency among older people worldwide (World Health Organisation [WHO], 2019). Globally, dementia is estimated to affect around 50 million people at present, with this figure projected to rise to 82 million by 2030 and 152 million by 2050 (WHO, 2019). Financially, Wittenberg et al. (2019) found that in 2015 the total estimated annual cost of dementia in England alone was £24.2 billion, comprising healthcare costs (£3.8 billion), social care costs (£10.2 billion), and the cost of unpaid carers (£10.1 billion); figures which exceed the estimated cost of care for cancer, stroke, and cardiovascular diseases combined. While many associated costs of dementia are anticipated and unavoidable, *excess disability* refers to a decline in functioning not attributable solely to a physical illness or organic cause (Fenn et al., 1993). In patients with dementia, premature decline in cognitive or social functioning may lead to excess disability, financial burden, and poor quality of life (Yury & Fisher, 2007).

Illness representations have been defined as the organised cognitive representations or beliefs that individuals hold about their illness (Leventhal et al., 1997). Illness representations are considered to be important determinants of behaviour and health related outcomes such as treatment adherence and functional recovery (Weinman & Petrie, 1997). To date, only a few studies have examined the impact of psychosocial factors on functional outcomes in the field

of dementia. It is plausible that psychosocial factors such as illness representations may influence the way that a person with dementia (PwD) perceives both their cognitive ability and functional ability, with consequences for their subjective and/or objective need for assistance. Developing an understanding of the role of illness representations in dementia will enhance awareness of factors that may influence an individual's ability to maintain optimal levels of functioning and independence, thus potentially informing clinical interventions in this area.

2.1.2 Previous Literature

Patients' beliefs regarding the cause and prognosis of their illness are core to a number of theoretical models of illness behaviour (Rosenstock, 1974; Wade & Halligan, 2003). For example, the Common Sense Model (Leventhal et al., 1980; Leventhal et al., 1997) argues that a person makes sense of their illness through a set of mental representations, which ultimately influence the individual's ability to cope. Likewise, the Self-Regulation Model (SRM) proposes that the beliefs people hold about their illness may impact on their emotional, behavioural, and coping responses (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003; Heijmans, 1999).

Illness representations have been shown to influence outcomes in many conditions including rheumatoid arthritis (Groarke et al., 2004), cancer (Watson et al., 1999), chronic pain (Goossens et al., 2005), HIV (Reynolds et al., 2009), as well as recovery from cardiac surgery (Juergens et al., 2010).

The study of illness representations in cancer is already well established. For example, De Rooj et al. (2018) explored the link between illness representations, health-related quality of

life, and survival rates in cancer survivors. They found that compared with survivors with more realistic illness representations, those with optimistic illness representations had a higher health-related quality of life, and a lower all-cause mortality². Conversely, individuals with a pessimistic illness representation had a lower health-related quality of life and a higher all-cause mortality (De Rooj et al., 2018). These results suggest that optimistic illness representations are associated with better health-related quality of life and survival outcomes, even if they are unrealistic with respect to an individual's prognosis. Earlier research in the field of cancer shows similar findings (Ashley et al., 2015; Scharloo et al., 2005; Thong et al., 2016).

Currently, only limited research has explored the role of illness representations in degenerative neurological disorders such as dementia. Vaughan et al. (2003) investigated the relationship between the illness representations of individuals with multiple sclerosis (MS) and outcome, finding that when individuals held the perception that MS had many negative effects on their life, they had greater levels of difficulty in all of the outcome areas (Vaughan et al., 2003). Of particular relevance, Lin and Heidrich (2012) explored the role of illness representations in coping with mild cognitive impairment (MCI), finding that individuals who held negative representations about their illness reported more negative consequences, unpredictability, and negative emotional impact attributed to their MCI. In contrast, individuals who held positive representations used significantly fewer memory aids and possessed more effective coping strategies; suggesting that an individual's representations about their MCI influenced coping and adaptation (Lin & Heidrich, 2012).

² The term all-cause mortality is utilised in reference to a disease or a harmful exposure in a statistical context. It is typically expressed as the total number of deaths due to that condition during a specific time period.

Related to this, a qualitative study by Harman and Clare (2006) explored how illness representations influenced the daily lived experience of individuals with early-stage dementia. The researchers reported two overarching themes: “It will get worse” (Harman & Clare, 2006, p. 490), reflecting an understanding of the development of dementia over time, and “I want to be me” (Harman & Clare, 2006, p. 494), reflecting a desire to maintain a sense of identity. They concluded that illness representations were closely linked to participants’ efforts at coping with everyday tasks. The authors suggested that, as a result, future clinical interventions should aim to support a sense of identity, reduce excess disability, enhance self-efficacy, or maximise wellbeing.

Finally, Clare et al. (2016) sought to improve understanding of illness representations held by people with dementia in the context of adjustment and coping post diagnosis. The researchers identified three profiles: people who felt their problems were due to ‘illness’, people who attributed problems to ‘ageing’, and people who felt they had ‘no problem’. They found that ‘illness’ profile participants had better cognition and awareness, but lower mood and a more negative perception of the practical consequences of their dementia than ‘ageing’ profile participants.

2.1.3 Rationale and Research Question

Whilst the impact of illness representations has been explored in relation to numerous health conditions, there is a dearth of literature regarding dementia. This is surprising given the prevalence of dementia and the number of people affected (Werner et al., 2016). Whereas previous research has focused on how illness representations may influence coping in dementia, the potential impact on perceptions of cognitive and functional ability, or

estimations of assistance required have not been examined. The current research attempts to bridge this gap in the literature by addressing the following research question: Do illness representations influence perception of cognitive and functional ability following a diagnosis of dementia?

2.2 Methods

2.2.1 Research Design

The present study adopted a cross-sectional research design, enabling the comparison of samples drawn from separate, distinguishable groups within a population (Coolican, 2019). Questionnaires measuring illness representations, cognitive ability, and functional ability were used to collect quantitative data from participants at a set point in time. To answer the main research question, the following hypotheses have been stated:

H1: The level of illness representation will predict the level of perceived cognitive ability

H2: The level of illness representation will predict the level of perceived functional ability

H3: There will be a positive, significant relationship between objective cognitive ability and objective functional ability

H4: There will be significant differences between objective cognitive ability and perceived cognitive ability

H5: There will be significant differences between the PwD and carer ratings of functional ability

H6: There will be significant differences between the PwD and carer ratings of cognitive ability

2.2.1.1 Sampling Method

The research employed a non-probability, purposive sampling design.

2.2.1.2 Sample Access

Participants were accessed through three United Kingdom (UK) NHS memory assessment services. In each case, links were made with the lead psychologists and teams were briefed on the study so that they could support the initial identification of participants.

2.2.1.3 Sample Size

A sample of around 120 participants, comprising 60 people with a diagnosis of dementia and 60 carers was considered to be sufficient, based on similar studies and research methods literature (Coolican, 2019). It was anticipated that this sample size would achieve a medium (.30) effect size (Cohen, 1988).

2.2.1.4 Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for the study are highlighted in Table 2.1.

Table 2.1*Inclusion and Exclusion Criteria*

Criteria	Inclusion	Exclusion
Gender	Any gender	No exclusions
Age	Over 65 years of age	Under 65
Location	Individuals assessed by three NHS memory assessment services	Any other location
Accommodation	Community dwelling	Individuals in a residential care home or hospital
Primary diagnosis	A diagnosis of dementia	- Any other neurocognitive condition - Disease progression which would impair ability to provide informed consent
Co-morbid conditions	- Mild-moderate symptoms of anxiety or depression - Physical health conditions that have no day to day impact on functioning	- Severe anxiety or depression, or a severe and enduring mental health condition - Physical health conditions that increase daily need for assistance
Time passed since diagnosis	Up to 6-months since ACE-III completion	Over 6-months since ACE-III completion
Main carer	An informal/family carer who lives with, or is in contact with the PwD at least once per week and can accompany the PwD and participate in research	No informal/family carer available or willing to participate

To summarise, the study recruited participants of any gender who were over 65 years of age, as those younger than this threshold would hold a diagnosis of ‘early onset’ dementia, which was not the focus of this study. Participants were required to be community dwelling, as individuals in a residential care home or hospital are likely to be receiving additional assistance for their needs, which may not be solely attributable to their dementia diagnosis. Equally, all participants were required to have completed the Addenbrooke’s Cognitive Assessment (ACE-III) as part of their initial diagnostic assessment, within the past six months. A timeline of six months was selected based on clinical judgement that a time frame of longer than this may invalidate the reliability of the ACE-III score, or provide an inaccurate representation of participants’ actual cognitive ability. There were no exclusions based on the type of dementia, however, disease progression which impaired ability to provide informed consent warranted exclusion from the study. Co-morbid neurocognitive diagnoses such as Huntington’s disease, Parkinson’s disease, or MS were excluded as it would not be possible to identify whether outcomes were associated to the co-morbid condition, or the dementia. Similarly, whilst mild-moderate symptoms of anxiety or depression were expected, severe anxiety or depression, or a severe and enduring mental health condition such as psychosis, warranted exclusion from the study. Equally, exclusion occurred where there were physical health conditions which increased the daily support required. Finally, each participant was required to have an informal/family carer who either lived with, or was in contact with the PwD at least once per week and who was also willing to participate in the research. Carers were included in the study for several reasons. Principally, the data that carers provide offers an alternative and *potentially* more objective account of the assistance people with dementia require. Indeed, prior literature has revealed that individuals with dementia may underreport difficulties, potentially due to reduced cognitive ability, suggesting a proxy report is useful (Sheehan et al., 2012).

2.3 Measures

Basic demographic data was collected from each PwD, including: age, gender, ethnicity, prior-occupation, and their current living status (e.g. living alone, living with other people). Similarly, carers were asked about their age, gender, relationship to the PwD, how long they had known the person they cared for, and their frequency of contact with them.

2.3.1 Objective Cognitive Ability

Objective cognitive ability was measured using the Addenbrooke's Cognitive Examination-III (ACE-III; Hsieh et al., 2013). The ACE-III is a brief cognitive test which assesses five cognitive domains: attention, language, memory, verbal fluency, and visuospatial abilities. The measure is scored out of 100, with higher scores indicating better cognitive ability. The ACE-III provides a baseline score of objective cognitive ability for each participant and was routinely carried out as part of the initial diagnostic assessment prior to the research commencing. Internal reliability of the ACE-III has been shown to be high, $\alpha = .88$ (Noone, 2015).

2.3.2 Illness Representations

Illness representations were measured using the Representations and Adjustment to Dementia Index (RADIX; Quinn et al., 2018). The RADIX is the first scale designed specifically to measure illness representations in people with dementia. The measure assesses five domains of illness representations: identity, cause, timeline, control, and consequences, which are used to gain a profile of an individual's beliefs about their dementia. The present study utilised three of these domains judged to be particularly salient for the research: the perceptions a

PwD has about the ‘timeline’ of their dementia, how much ‘control’ they feel they have, and their perceptions of both the ‘emotional’ and ‘practical’ consequences of the illness. The measure consists of 23 questions, including 9 screening questions. The RADIX demonstrates acceptable psychometric properties, with good acceptability, internal reliability, and test-retest reliability (Quinn et al., 2018). In this study, the RADIX was administered to the PwD only, and the internal reliability (Cronbach’s alpha) was good (questions 1-9 = .74, questions 15-18 = .77, questions 19-23 = .88).

2.3.3 Perceived Cognitive Ability

Perception of cognitive ability was measured using the Everyday Cognition Scale (ECog; Farias et al., 2008). The ECog is an informant-rated 39-item measure of neuropsychological functioning related to cognitive impairment that has both patient and carer versions, with higher scores representing poorer perceived cognitive ability. The ECog has established utility in dementia samples (Farias et al., 2013; Park et al., 2015) and shows good test-retest reliability ($r = .82, p < .0001$). The internal reliability of the patient ECog within the present study was .98, whilst the internal reliability for the carer ECog within this study was .96.

2.3.4 Perceived Functional Ability and Actual Functional Ability

Perceived functional ability and actual functional ability were measured using the Bristol Activities of Daily Living Scale (BADLS; Bucks et al., 1996). The BADLS is a 20-item carer-rated instrument which assesses daily-living abilities by assessing ability to complete daily tasks such as ‘preparing food’, ‘hygiene’, and ‘shopping’. The scale was developed specifically for use with people with dementia and has acceptable face validity, construct validity, concurrent validity, and test-retest reliability (Bucks et al., 1996). Whilst the

BADLS validity is appropriate in terms of its specificity, for the purposes of the present study, it was not considered to be sufficiently sensitive to capture subtle differences in perceived functional ability. For this reason, the rating scale for the 20-item categories was adapted to: (1) always, (2) frequently, (3) sometimes, (4) rarely, and (5) never, with participants rating how often daily-living tasks could be completed independently, and where higher scores indicated lower functional ability. Literature suggests that patient versus proxy ratings of cognitive and functional abilities can vary in individuals with cognitive deficits (Howland et al., 2017). For the purposes of the present study, actual functional ability was operationalised as scores derived from carer-rated BADLS, whereas perceived functional ability was defined as the score on the patient-rated BADLS. The adjusted BADLS was therefore administered to both the PwD, and their carer. Analysis of the internal reliability of the adapted BADLS within the present study revealed the Cronbach's α coefficient for the patient form to be .91, whilst the carer form was .92, suggesting the measure remains internally coherent in the adapted format.

2.3.5 Methods of Data Collection

Both the PwD and carer participants were supported to complete the battery of questionnaires either at home, or in clinic. On average, questionnaire completion took approximately 45-minutes.

2.3.6 Ethical Considerations

The British Psychological Society (BPS; 2018) Code of Ethics and Conduct was adhered to throughout all stages of the research. Ethical approval was granted by both Coventry

University (Appendix H) and the Health Research Authority through the Integrated Research Application System (IRAS; Appendix I).

2.3.7 Data Analysis

Data was analysed using IBM Statistical Package for Social Sciences (SPSS software, version 25). The following methods of analysis were utilised for hypotheses 1-6:

H1: Linear regression (IV: Radix, DV: ECog; Patient)

H2: Linear regression (IV: Radix, DV: BADLS; Patient)

H3: Correlation (IV: ACE-III, DV: BADLS; Carer)

H4: Independent t-test or its non-parametric equivalent (IV: ACE-III, DV: ECog; Patient)

H5: Independent t-test or its non-parametric equivalent (IV: BADLS; Patient, DV: BADLS; Carer)

H6: Independent t-test or its non-parametric equivalent (IV: ECog; Patient, DV: ECog; Carer)

2.4 Results

A total of 114 participants were included in the study; 57 people with a diagnosis of dementia and 57 paired carers. Within the patient (PwD) group, participant ages ranged from 66-91 ($M_{age} = 78.77$, $SD = 6.39$). The patient group comprised 26 males and 31 females. Of the 57 patient participants, 53 were White English, Welsh, Scottish, Northern Irish, or British, two were White Irish, one was Indian, and one was White and Black Caribbean (Appendix U).

Furthermore, 10 patients lived alone, 44 lived with a partner, and three lived with family (Appendix V). Details surrounding patients' prior occupations can be found in Appendix W. Within the carer group, participants' ages ranged from 36-87 ($M_{age} = 70.53$, $SD = 13.03$). The carer group included 23 males and 34 females. Of the 57 carers, 45 were a spouse, 10 were a child, and two were a friend of the patient. Table 2.2 summarises the participant gender and age demographics.

Table 2.2

Participant Gender and Age Demographics

Participant Group	Gender	<i>n</i>	Age
Patient	Male	26	66-91 years ($M_{age} = 79.04$, $SD = 7.13$)
	Female	31	68-89 years ($M_{age} = 78.55$, $SD = 5.81$)
Carer	Male	23	60-87 years ($M_{age} = 76.30$, $SD = 7.14$)
	Female	34	36-85 years ($M_{age} = 66.62$, $SD = 14.66$)

H1: The level of illness representation will predict the level of perceived cognitive ability

A multiple regression was run to predict the patients' perceived level of cognitive ability (score on the patient ECog) based on their illness representations, as measured by the RADIX. Assumptions for multiple regression were checked and satisfied. There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.12. All partial regression plots demonstrated a linear relationship (see Appendix X). There was homoscedasticity, as assessed by a visual inspection of a plot of studentized deleted residuals versus unstandardised predicted values. SPSS detects multicollinearity through an inspection of correlation coefficients and tolerance values; as no tolerance values were below 0.1, these

were acceptable. There were no outliers identified. The cases did not exhibit high leverage and ranged between .24 and .01. There were no influential points in the data set as checked by Cook's Distance values that ranged from .151 to .000. A histogram with a superimposed normal curved and a P-P Plot (Appendix X) confirmed normality of the residuals.

The model indicates that illness representations predict perceived cognitive ability. R^2 for the overall model was 70.6% with an adjusted R^2 of 68.3%, a large effect size according to Cohen (1988). The RADIX significantly predicted the patient ECog, $F(4, 52) = 47.09, p < .001, adj. R^2 = .68$. Emotional consequences and control were significant predictors of perceived cognitive ability, while timeline and practical consequences were not significant predictors. A summary of the model statistics is shown in Table 2.3.

Table 2.3

Coefficients, Standard Errors, Beta, t-test and Significance Value for Predictors of Perceived Cognitive Ability

Variable	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>
Timeline	6.957	4.388	.142	1.585	.119
Control	-9.219	3.735	-.252	-2.468	.017
Practical Consequences	11.399	6.365	.238	1.791	.079
Emotional Consequences	16.725	5.386	.384	3.105	.003

H2: The level of illness representation will predict the level of perceived functional ability

A multiple regression was run to predict the level of perceived functional ability, as measured by the patient BADLS, from illness representations, as measured by the RADIX.

Assumptions for multiple regression were checked and satisfied. There was independence of residuals, as assessed by a Durbin-Watson statistic of 2.47. There was linearity as assessed by partial regression plots and a plot of studentized residuals against the predicted values (Appendix Y). There was homoscedasticity, as assessed by visual inspection of a plot of studentized deleted residuals versus unstandardised predicted values. There was no evidence of multicollinearity, as assessed by tolerance values greater than 0.1. There were no studentized deleted residuals greater than ± 3 standard deviations and no leverage values greater than 0.2. There were no influential points in the data set as checked by Cook's Distance values that ranged from .221 to .000. A histogram with a superimposed normal curve and a P-P Plot (Appendix Y) confirmed normality of the residuals.

The multiple regression model predicted perceived functional ability. R^2 for the overall model was 78.4% with an adjusted R^2 of 76.7%, a large effect size according to Cohen (1988). $F(4, 52) = 49.94, p < .001, adj. R^2 = .77$. Two of the four variables added significantly to the prediction, $p < .05$; control, and practical consequences. A summary of the model statistics is shown in Table 2.4.

Table 2.4

Coefficients, Standard Errors, Beta, t-test and Significance Value for Predictors of Perceived Functional Ability

Variable	B	SE	β	t	p
Timeline	.585	1.533	.029	.381	.704
Control	-6.211	1.305	-.416	-4.760	.000
Practical Consequences	7.407	2.223	.379	3.332	.002
Emotional Consequences	3.451	1.881	.195	1.834	.072

H3: There will be a positive, significant relationship between actual cognitive ability and actual functional ability

There was a very weak non-significant negative relationship between actual cognitive ability, as measured by the ACE-III, and carer perceptions of functional ability, as measured by the carer BADLS ($r = -.020, p = .441$).

H4: There will be significant differences between actual cognitive ability and perceived cognitive ability

The Kolomogorov-Smirnov test of normality revealed that data was not normally distributed, $D(114) = .151, p < .001$. A non-parametric equivalent Mann-Whitney Test showed no significant differences between actual and perceived cognitive ability, $U = 1334.5, N^1 = 57, N^2 = 57, p = .100$ (two-tailed).

H5: There will be significant differences between PwD and carer ratings of functional ability

The Kolomogorov-Smirnov test of normality revealed that data was not normally distributed, $D(57) = .127, p = .023$. A non-parametric equivalent Mann-Whitney Test showed significant results $U = 1098.0, N^1 = 57, N^2 = 57, p = .003$ (two-tailed), suggesting there were significant differences between patient and carer perceptions of functional ability.

H6: There will be significant differences between PwD and carer ratings of cognitive ability

The Kolomogorov-Smirnov test of normality revealed that data was normally distributed $D(57) = .071, p = .200$. An independent samples *t*-test showed significant differences between patient and carer perceptions of cognitive ability, $t(112) = 6.75, p < .001$.

A summary of the results obtained can be found in Table 2.5.

Table 2.5*Summary Outcomes of Hypotheses Tested*

Hypothesis	Outcome
H1: Level of illness representation will predict level of perceived cognitive ability	Met
H2: Level of illness representation will predict level of perceived functional ability	Met
H3: There will be a positive, significant relationship between actual cognitive ability and actual functional ability	Not met
H4: There will be significant differences between actual cognitive ability and perceived cognitive ability	Not met
H5: There will be significant differences between PwD and carer ratings of functional ability	Met
H6: There will be significant differences between PwD and carer ratings of cognitive ability	Met

2.5 Discussion

This is the first study to examine the impact of illness representations on perceptions of cognitive and functional ability in dementia, and to consider how this might relate to actual functional ability (an indicator of PwD need for assistance). The results suggest that perceptions of cognitive and functional ability are predicted by illness representations. In addition, the study found significant differences between patient and carer perceptions of both cognitive and functional ability.

2.5.1 The Impact of Illness Representations on Cognitive and Functional Ability

Hypotheses one and two were met, confirming that illness representations predict perceptions of both cognitive and functional ability in people with dementia.

For perceptions of cognitive ability, analysis found the strongest predictor to be emotional consequences. A key implication of this finding is that a PwD who associates their diagnosis with negative emotional consequences such as worry, low mood, anger, frustration, or reduced confidence are more likely to perceive their cognitive ability as lower than those who do not experience these emotional consequences. This finding is consistent with research from Ross et al. (2010), who found that cognitive and functional impairment were both significantly related to negative emotional experiences such as depression in patients with Alzheimer's disease. Our study's findings further build on this by identifying a need for professionals to take both perceived and actual emotional consequences into account when evaluating the impact of dementia on the person's perception of their cognitive ability.

Estimations of control were found to be the strongest predictor for perceptions of functional ability, and the second strongest predictor for perceptions of cognitive ability. For perceptions of functional ability, this result suggests that a PwD who believes that there is a lot they can do to control the effects of their dementia is more likely to perceive their functional ability as higher than those who believe they have little control. This finding is in line with research by Hallas et al. (2010) who found that patients' perception of control was the core category related to quality of life following cardiac surgery. This finding suggests that for those with dementia, believing that there is little they can do to control the effects of

their dementia will lead them to perceive both their cognitive and functional ability to be more impaired.

Practical consequences were found to be the second strongest predictor of perceptions of functional ability. This finding suggests that a PwD who perceives that there are greater (negative) practical consequences associated with their dementia diagnosis, such as being treated differently, not going out as much, not being able to do things they used to do, or feeling like they have lost control over their life, is more likely to rate their functional abilities as lower than individuals who do not perceive these practical consequences. These findings are in line with Vaughan et al.'s (2003) research into illness representations in MS, which also found that individuals who perceived their MS to have many negative effects on their life had greater levels of difficulty in all outcome areas.

For both hypotheses one and two, the PwD representations of how their dementia would progress over time was not a significant predictor of how they perceived their cognitive or functional ability. Interestingly, this finding suggests that being 'realistic' or 'unrealistic' about how the dementia may progress over time was not important; in line with De Rooj et al.'s (2018) study which reported that optimistic illness representations were associated with better outcomes, despite being unrealistic with respect to actual cancer prognosis.

2.5.2 The Relationship Between Actual Cognitive Ability and Functional Ability

Hypothesis three was not met, confirming there was no significant relationship between actual cognitive ability and actual functional ability. Despite the null finding, this result is

still interesting. It would seem reasonable to expect that patients who score very highly on the ACE-III, indicating milder dementia symptoms, would retain a high level of functional ability, whilst those scoring very poorly, would have a reduced level of functional ability and independence, but that was not the case in this study. While the reason for this is unclear, it may be that PwD illness representations play a role here. Equally, the lag in time between the ACE-III administration (at the point of the initial diagnostic assessment) and other study measures, means that it is possible that the actual cognitive status of some participants at the time of the study may have been different to that indicated by the ACE-III score. Future studies may therefore want to consider including a measure of objective cognitive ability administered concurrently alongside all other study measures.

2.5.3 Differences in Perceptions of Abilities

Hypothesis four was not met, confirming there was no significant difference between actual cognitive ability and patients' perceptions of their cognitive ability. Interestingly, this finding suggests that within this study, patients had a reasonably accurate perception of their cognitive abilities. However, results from hypothesis five showed that there were significant differences between patient and carer perceptions of functional ability. Similarly, hypothesis six revealed significant differences between patient and carer perceptions of cognitive ability. These findings could be interpreted to mean that either patients believed they could do more, and were more cognitively able, than carers did, or vice versa. We know from other literature that differences are commonly found between the PwD and carer ratings and perceptions of functioning and also of quality of life, which have generally been interpreted as indicating a need to include a proxy (carer) measurement in assessments (Howland et al., 2017; Onandia-Hinchado & Diaz-Orueta, 2019; Sheehan et al., 2013).

2.5.4 Clinical Implications

The findings of this study indicate that there is a need to ascertain how individuals view their dementia diagnosis, and to appropriately support those who may hold especially negative illness representations. Indeed, it has been shown that illness representations can predict both perceptions of cognitive and functional ability in dementia, suggesting these representations may lead to excess disability, a premature reduction in independence, and a potentially elevated need for support.

The findings from this study may be useful in developing interventions to support individuals following a diagnosis of dementia. Such interventions would seek to ensure that people who are diagnosed with dementia are able to enjoy their optimal quality of life, reducing excess disability, for as long as possible. Whilst current literature has not explored the effects of attempting to change illness representations in the field of dementia, research in other fields suggests that it is possible to adjust illness representations (Arcoleo & Feldman, 2017).

Indeed, Balck et al. (2012) assessed the change of illness representations during a course of psychotherapeutic-psychosomatic treatment, and found that patients reported a reduction in perceived consequences and an increase in control following this therapeutic intervention. In particular, interventions aiming to adjust unhelpful illness representations should focus on emotional consequences, practical consequences, and perceptions of control, as these factors were found to be the biggest predictors within the present study.

2.5.5 Limitations

There were a number of study limitations. Firstly, the study sampled from a narrow range of ethnicity, with 53 of the 57 PwD participants being either White English, Welsh, Scottish,

Northern Irish or British. Research should represent population diversity where possible (Allmark, 2004). Whilst efforts were made to ensure that the sample was representative of a UK dementia population by recruiting across three separate memory services, it was apparent that participants who consented to participate in the research were predominantly not from ethnic minorities, despite research suggesting people from black ethnic groups have a higher incidence of dementia diagnosis compared with the white ethnic group in the UK (Pham et al., 2018).

Furthermore, the study utilised an adapted format of the BADLS questionnaire. Questionnaire development involves rigorous testing to ensure validity and reliability, and research has found that adaptations of questionnaires can lead participants to comprehend adapted items differently (Sousa et al., 2017). However, adapted measures have been successfully used in research with people with dementia (Ablitt et al., 2010). Reassuringly, analysis of the internal reliability of the adapted BADLS was carried out and revealed that the measure remained internally coherent in the adapted form.

Finally, the study did not include a behavioural measure of functional ability due to restraints on time, instead opting to utilise the BADLS carer rating as an indication of actual functional ability. Future studies may benefit from including a measure which contains a behavioural component to provide a more ecologically valid indication of objective functional ability.

2.5.6 Future Research Directions

It is considered imperative to publish replication studies (Cousineau, 2014). Indeed, to assess whether the findings of this study can be generalised to the larger population, a replication

study would be beneficial. In addition, intervention based-studies which examine which components of illness representations may be amenable to psychological or other clinical interventions specifically in the field of dementia would help to inform clinical guidelines in this field.

2.6 Conclusion

Illness representations have been shown to be important for outcomes in many conditions, but little attention has previously been paid to the role of illness representations in dementia. This study has found that illness representations do predict perceptions of cognitive and functional ability in a dementia population. This finding in turn suggests that illness representations are likely to influence the need for assistance in dementia, an inference that is supported by the findings on carer-rated (actual) functional ability reported here. With this in mind, and in the context of predictions of a substantial increase in rates of dementia over the next two to three decades, it is important that attention is paid to the role of illness representations in dementia. It is hoped that with further research and focus in this area, a PwD holding negative illness representations can be offered additional support following their diagnosis to identify and modify negative illness representations, in order to remain as functionally independent and engaged in activities for as long as possible.

2.7 References

- Ablitt, A., Jones, G., & Muers, J. (2010). Awareness of carer distress in people with dementia. *International Journal of Geriatric Psychiatry*, 25(12), 1246-1252.
<https://doi.org/10.1002/gps.2461>
- Allmark, P. (2004). Should research samples reflect the diversity of the population? *Journal of Medical Ethics*, 30(2), 185-189. <https://doi.org/10.1136/jme.2003.004374>
- Arcoleo, K., & Feldman, J. (2017). Asthma illness representations: Do they really change over time? *Biological Psychology*, 129, 370-385.
<https://doi.org/10.1016/j.biopsycho.2017.08.027>
- Ashley, L., Marti, J., Jones, H., Velikova, G., & Wright, P. (2015). Illness perceptions within 6 months of cancer diagnosis are an independent prospective predictor of health-related quality of life 15 months post-diagnosis. *Psychooncology*, 24(11), 1463-1470.
<https://doi.org/10.1002/pon.3812>
- Balck, F., Preuss, M., Hendrichke, A., & Lippmann, M. (2012). Change of illness representations and quality of life during a course of a psychotherapeutic-psychosomatic treatment. *Journal of Psychosomatic Medicine and Psychotherapy*, 58(4), 357-373.
<https://doi.org/10.13109/zptm.2012.58.4.357>
- British Psychological Society. (2018). *Code of ethics and conduct*.
<https://www.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct>

- Bucks, R. S., Ashworth, D. L., Wilcock, G. K., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: Development of the Bristol activities of daily living scale. *Age Ageing*, 25(2), 113-120. https://doi.org/10.1007/978-0-387-79948-3_1929
- Clare, L., Quinn, C., Jones, I. R., & Woods, R. T. (2016). "I don't think of it as an illness": Illness representations in mild to moderate dementia. *Journal of Alzheimer's Disease*, 51(1), 139-150. <https://doi.org/10.3233/JAD-150794>
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Erlbaum. <https://doi.org/10.4324/9780203771587>
- Coolican, H. (2019). *Research methods and statistics in psychology* (7th ed.). Routledge. <https://doi.org/10.4324/9780203769836>
- Cousineau, D. (2014). Restoring confidence in psychological science findings: A call for direct replication studies. *Tutorials in Quantitative Methods for Psychology*, 10(2), 77-79. <https://doi.org/10.20982/tqmp.10.2.p077>
- De Rooj, B. H., Thong, M. S., van Rooij, J., Bonhof, C. S., Husson, O., & Ezendam, N. P. (2018). Optimistic, realistic, and pessimistic illness perceptions; quality of life; and survival among 2457 cancer survivors: The population based PROFILES registry. *Cancer*, 124(17), 3609-3617. <https://doi.org/10.1002/cncr.31634>

- Diefenbach, M. A., & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress and the Homeless*, 5(1), 11–38. <https://doi.org/10.1007/BF02090456>
- Farias, S. T., Chou, E., Harvey, D. J., Mungas, D., Reed, B., DeCarli, C., Park, L. Q., & Beckett, L. (2013). Longitudinal trajectories of everyday function by diagnostic status. *Psychology and Aging*, 28(4), 1070-1075. <https://doi.org/10.1037/a0034069>
- Farias, S. T., Mungas, D., Reed, B. R., Cahn-Weiner, D., Jagust, W., Baynes, K., & Decarli, C. (2008). The measurement of everyday cognition (ECog): Scale development and psychometric properties. *Neuropsychology*, 22(4), 531–544. <https://doi.org/10.1037/0894-4105.22.4.531>
- Fenn, H., Luby, V., & Yesavage, J. A. (1993). Subtypes in Alzheimer's Disease and the impact of excess disability: Recent findings. *International Journal of Geriatric Psychiatry*, 8(1), 67-73. <https://doi.org/10.1002/gps.930080111>
- Goossens, M. E., Vlaeyen, J. W., Hidding, A., Kole-Snijders, A., & Evers, S. M. (2005). Treatment expectancy affects the outcome of cognitive-behavioral interventions in chronic pain. *The Clinical Journal of Pain*, 21(1), 18-26. <https://doi.org/10.1097/00002508-200501000-00003>
- Groarke, A., Curtis, R., Coughlan, R., & Gsel, A. (2004). The role of perceived and actual disease status in adjustment to rheumatoid arthritis. *Rheumatology*, 43(9), 1142-1149. <https://doi.org/10.1093/rheumatology/keh262>

- Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141-184.
<https://doi.org/10.1080/088704403100081321>
- Hallas, C. N., Burke, J. L., White, D. G., & Connelly, D. T. (2010). Pre-ICD illness beliefs affect postimplant perceptions of control and patient quality of life. *Pacing and Clinical Electrophysiology, 33*(3), 256-265. <https://doi.org/10.1111/j.1540-8159.2009.02641.x>
- Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research, 16*(4), 484-502.
<https://doi.org/10.1177/1049732306286851>
- Heijmans, M. (1999). The role of patients' illness representations in coping and functioning with Addison's disease. *British Journal of Health Psychology, 4*(2), 137-149.
<https://doi.org/10.1348/135910799168533>
- Howland, M., Allan, K. C., Carlton, C. E., Tatsuoka, C., Smyth, K. A., & Sajatovic, M. (2017). Patient-rated versus proxy-rated cognitive and functional measures in older adults. *Patient Related Outcome Measures, 8*, 33-42.
<https://doi.org/10.2147/PROM.S126919>
- Hsieh, S., Schubert, S., Hoon, C., Mioshi, E., & Hodges, J. R. (2013). Validation of the addenbrooke's cognitive examination-III in frontotemporal dementia and Alzheimer's disease. *Dementia Geriatric Cognitive Disorders, 36*, 242-250.
<https://doi.org/10.1159/000351671>

Juergens, M. C., Seekatz, B., Moosdorf, R. G., Petrie, K. J., & Rief, W. (2010). Illness beliefs before cardiac surgery predict disability, quality of life, and depression 3 months later.

Journal of Psychosomatic Research, 68(6), 553-560.

<https://doi.org/10.1016/j.jpsychores.2009.10.004>

Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E. A., Patrick-Miller, L., & Robitaille, C. (1997). Illness representations: Theoretical foundations. In K. J. Petrie & J. Weinman (Eds.), *Perceptions of health and illness* (pp. 155-188). Harwood Academic. <https://doi.org/10.1017/S0033291799218806>

Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. In S. Rachman (Ed.), *Medical psychology, Volume 2* (pp. 7-30). Pergamon Press. https://www.academia.edu/259452/The_Common_Sense_Representation_of_Illness_Danger

Lin, F., & Heidrich, S. M. (2012). Role of older adult's illness schemata in coping with mild cognitive impairment. *Journal of Psychosomatic Research*, 72(5), 357-363.

<https://doi.org/10.1016/j.jpsychores.2012.01.008>

Noone, P. (2015). Addenbrooke's cognitive examination-III. *Occupational Medicine*, 65(5), 418-420. <https://doi.org/10.1093/occmed/kqv041>

Onandia-Hinchado, I., & Diaz-Orueta, U. (2019). Health related quality of life in individuals with cognitive decline and discrepancies between patients and their proxies. *Archives of Gerontology and Geriatrics*, 85, 103914. <https://doi.org/10.1016/j.archger.2019.103914>

Park, L. Q., Harvey, D., Johnson, J., & Farias, S. T. (2015). Deficits in everyday function differ in AD and FTD. *Alzheimer Disease and Associated Disorders*, 29(4), 301-306.
<https://doi.org/10.1097/WAD.0000000000000081>

Pham, T. M., Petersen, I., Walters, K., Raine, R., Manthorpe, J., Mukadam, N., & Cooper, C. (2018). Trends in dementia diagnosis rates in UK ethnic groups: Analysis of UK primary care data. *Clinical Epidemiology Journal*, 10, 949-960.
<https://doi.org/10.2147/CLEP.S152647>

Quinn, C., Morris, R. G., & Clare, L. (2018). Beliefs about dementia: Development and validation of the representations and adjustment to dementia index (RADIX). *American Journal of Geriatric Psychiatry*, 26(6), 680-689.
<https://doi.org/10.1016/j.jagp.2018.02.004>

Reynolds, N. R., Eller, L. S., Nicholas, P. K., Corless, I. B., Kirksey, K., Hamilton, M. J., Kemppainen, J. K., Bunch, E., Dole, P., Wantland, D., Sefcik, E., Nokes, K. M., Coleman, C. L., Rivero, M., Canaval, G. E., Tsai, Y. G., & Holzemer, W. L. (2009). HIV illness representation as a predictor of self-care management and health outcomes: A multi-site, cross-cultural study. *Aids and Behavior*, 13(2), 258-267.
<https://doi.org/10.1007/s10461-007-9297-5>

Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs*, 2(4), 328-335. <https://doi.org/10.1177/109019817400200403>

- Ross, L. K., Arnsberger, P., & Fox, P. J. (2010). The relationship between cognitive functioning and disease severity with depression in dementia of the Alzheimer's type. *Aging and Mental Health, 2*(4), 319-327. <https://doi.org/10.1080/13607869856579>
- Scharloo, M., Baatenburg de Jong, R. J., Langeveld, T. P., van Velzen-Verkaik, E., Doorn - op den Akker, M. M., & Kaptein, A. A. (2005). Quality of life and illness perceptions in patients with recently diagnosed head and neck cancer. *Head and Neck, 27*(10), 857-863. <https://doi.org/10.1002/hed.20251>
- Sheehan, B. D., Lall, R., Stinton, C., Mitchell, K., Gage, H., Holland, C., & Katz, J. (2012). Patient and proxy measurement of quality of life among general hospital in-patients with dementia. *Aging and Mental Health, 16*(5), 603-607. <https://doi.org/10.1080/13607863.2011.653955>
- Sousa, V. E., Matson, J., & Dunn Lopez, K. (2017). Questionnaire adapting: Little changes mean a lot. *Western Journal of Nursing Research, 39*(9), 1289-1300. <https://doi.org/10.1177/0193945916678212>
- Thong, M. S., Kaptein, A. A., Vissers, P. A., Vreugdenhil, G., & van de Poll-Franse, L. V. (2016). Illness perceptions are associated with mortality among 1552 colorectal cancer survivors: A study from the population-based PROFILES registry. *Journal of Cancer Survivorship, 10*, 898-905. <https://doi.org/10.1007/s11764-016-0536-5>

- Vaughan, R., Morrison, L., & Miller, E. (2003). The illness representations of multiple sclerosis and their relations to outcome. *British Journal of Health Psychology*, 8(3), 287-301. <https://doi.org/10.1348/135910703322370860>
- Wade, D. T., & Halligan P. (2003). New wine in old bottles: The WHO ICF as an explanatory model of human behaviour. *Clinical Rehabilitation*, 17(4), 349-54. <https://doi.org/10.1191/0269215503cr619ed>
- Watson, M., Haviland, J., Greer, S., Davidson, J., & Bliss, J. (1999). Influence of psychological response on survival in breast cancer: A population-based cohort study. *The Lancet*, 354(9187), 1331-1336. [https://doi.org/10.1016/s0140-6736\(98\)11392-2](https://doi.org/10.1016/s0140-6736(98)11392-2)
- Weinman, J., & Petrie, K. J. (1997). Illness perceptions: A new paradigm for psychosomatics? *Journal of Psychosomatic Research*, 42(2), 113-116. [https://doi.org/10.1016/s0022-3999\(96\)00294-2](https://doi.org/10.1016/s0022-3999(96)00294-2)
- Werner, P., Savva, G. M., & Maidment, I. (2016). Dementia: Introduction, epidemiology and economic impact. In C. A. Chew-Graham & M. Ray (Eds.), *Mental health and older people* (pp. 197-209). Springer International Publishing. https://doi.org/10.1007/978-3-319-29492-6_16
- Wittenberg, R., Knapp, M., Hu, B., Comas-Herrera, A., King, D., Rehill, A., Shi, C., Banerjee, S., Patel, A., Jagger, C., & Kingston, A. (2019). The cost of dementia in England. *International Journal of Geriatric Psychiatry*, 34(7), 1095-1103. <https://doi.org/10.1002/gps.5113>

World Health Organisation. (2019). *Dementia*. <https://www.who.int/news-room/fact-sheets/detail/dementia>

Yury, C. A., & Fisher, J. E. (2007). Preventing excess disability in an elderly person with Alzheimer's disease. *Clinical Case Studies*, 6(4), 295-306.
<https://doi.org/10.1177/1534650106288233>

Chapter 3: Reflective Paper

Reflecting on the Research Journey: Working With a Dementia Population

Overall chapter word count (excluding tables, figures and references): 3154

3.1 Introduction

This paper provides an opportunity for in-depth, personal reflection on the process of undertaking this thesis. In particular, the paper will focus on the experience of completing research with a population of older people with a diagnosis of dementia. The research process entailed numerous stressors and challenges, however, interactions with the participants recruited in the empirical study were among some of the most momentous points of my clinical psychology doctorate journey. Through maintaining a reflective journal, particularly poignant experiences have been selected to reflect upon, including: (1) the perplexing balance between being a researcher and a clinician, (2) feeling powerless to elicit immediate change for individuals, and (3) my personal journey.

3.1.1 The Process of Reflection

Reflective practice is considered to be a key strand of continuing professional development, work based learning, and lifelong learning (Health Professions Council, 2006). As a Trainee Clinical Psychologist, reflective practice has provided an invaluable platform to tentatively explore emotional responses and develop both professionally and personally across clinical placements. Equally, reflection is a crucial process within the research field (Dahlberg et al., 2002). Indeed, Mortari (2015) reports that the mental experience of the researcher conditions the research. Mortari (2015) suggests researchers should therefore be conscious of what structures their internal lives, to understand how these experiences and underlying cognitive artefacts may mould the research process.

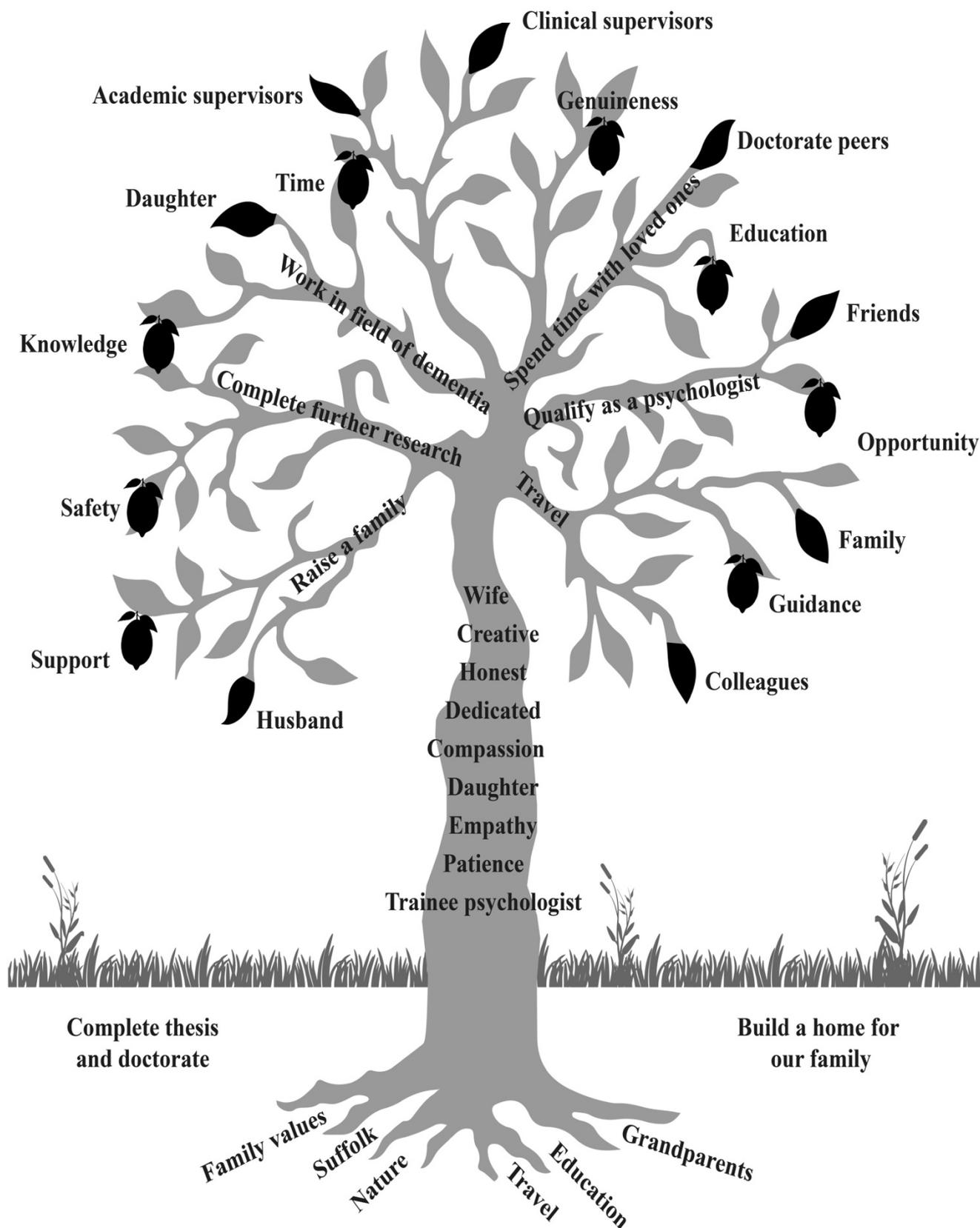
To aid the process of reflection, the paper will draw upon the ‘Tree of Life’ (ToL; Ncube, 2006; Ncube & Denborough, 2007) therapeutic tool. Based on narrative therapy principles, the ToL was originally designed to support children experiencing adversity, uniquely utilising a tree metaphor to represent different elements of a person’s life. Within the model, ‘roots’ represent an individual’s history, background, culture, and what sustains them. The ‘ground’ represents important things happening in the present moment. The ‘trunk’ represents a person’s skills, abilities, and roles. ‘Leaves’ reflect significant people in somebody’s life. ‘Branches’ signify hopes and dreams, and ‘fruit’ symbolises things they have given and received (Denborough, 2014; Ncube, 2017; Ncube & Denborough, 2007). For me, the tool provided a unique opportunity to consider my personal ToL and how this has been shaped by the research process. Certainly, whilst it would be entirely feasible to provide surface level reflections about these experiences, I am acutely aware that this experience has in fact altered me more than I had anticipated; both professionally and personally. My personal ToL is illustrated in Figure 3.1, and will be referred to throughout the paper.

3.2 Researcher Versus Clinician

The empirical project contained a variety of challenges, such as the time pressures associated with balancing recruitment and other doctoral deadlines, and the logistical minefield of recruiting 114 participants across three counties. These experiences were undeniably stressful at the time, however, they were relatively short-lived. On the other hand, the personal experiences I had with the participants I worked with stuck with me throughout the entirety of the process, and quite probably beyond. Notably, some of these experiences were challenging; the most prominent of these being the new territory of adjusting my usual, well versed role as a clinician, to that of a researcher.

Figure 3.1

Personal ToL



Prior to the doctorate, I worked as a clinician in numerous different capacities and ultimately felt that working therapeutically was where my passion laid. As such, I chose to complete my thesis in an area that enabled me to maintain this interest and work directly with clients and their carers. What I had not anticipated, was the inevitable shift associated with working alongside clients as a *researcher*, and not in a therapeutic capacity. A pertinent example of this was illustrated during the first data collection.

3.2.1 Case Example 1

The first participants recruited were an elderly lady and her husband, who lived in the countryside with their small dog. I arrived for our scheduled appointment, equipped with the relevant paperwork and questionnaires to hand, eager to get started. Trepidation was present as I knocked on their front door; a great deal of preparation had preceded the meeting. Equally, I had scheduled several further meetings throughout the day, so I knew there was an additional element of time pressure present.

I was kindly invited into the couple's home and we made our introductions. As I sat in their living room, I recall having an overwhelming sense of gratitude for this couple who had willingly offered their time to meet with me. We began completing the paperwork together. Just a few minutes in, the gentleman asked me for advice on the lady's wound dressing as she was awaiting a call from the community nurse, followed by questions about their dog's pet insurance, and a letter they had received from the council. As we refocused on the paperwork, further obstacles surfaced; the gentleman required assistance with the forms as he had misplaced his reading glasses, I was offered my second cup of tea, and the couple were keen to tell me the story of how they adopted their dog. It became apparent that the couple had no children or close family. I found myself completely torn; more than anything I wanted

to help and support the couple with their requests and questions. However, I had an allocated amount of time to complete the research and needed to ensure this was done in an appropriate way. I would usually adeptly deal with comparable situations in therapeutic work, where I would typically rely my ability to build a positive therapeutic relationship which would ‘buffer’ the implementation of necessary boundaries. However, in this very different context I did not want to come across as though I was merely discounting the couple’s requests, at the expense of completing the research.

3.2.2 Boundaries in Research

Boundaries are widely discussed in the field of psychology, with ‘boundary blurring’ often found to occur therapeutically (Webb, 1997). However, the boundary issues faced by researchers have received far less attention (Dickson-Swift et al., 2006). Gilbert (2001) argued that boundaries are an important aspect of research, stating that there are dangers associated with being “too far in, or too far out of the lives of the researched” (Gilbert, 2001, p. 12). Whilst the literature chiefly investigates the experiences of qualitative researchers due to their close contact with participants, the nature of the data collection process coupled with the openness of the client group within this project, meant that as a quantitative researcher I felt equally as involved in the experiences of the participants.

As the recruitment process continued I began to navigate the fine balance between my usual persona as a clinician, whilst ensuring the integrity of the research was maintained with appropriate boundaries. Indeed, when completing my personal ToL (Figure 3.1) I initially considered the ‘skills’ detailed therein, such as empathy, compassion, and patience, to represent those of a clinician. Looking back at these now, I see that these skills may additionally make me an effective researcher. Indeed, over time I appreciated that my ability

to build positive therapeutic relationships was not redundant within this role, in fact it was as important as ever; I was entering potentially vulnerable adults' homes and asking them to open up to me about an incredibly sensitive and possibly raw topic. Dementia has no cure; participants had received this life-altering diagnosis within the past six months. Therefore, understandably, there were numerous occasions where the PwD or their carer became upset when talking about the dementia diagnosis. To not acknowledge and validate this perfectly normal response to what must be an incredibly difficult time in an individual's life would not be ethical. Similarly, to enter participants' homes, and to not engage in some conversation or interact with them, would not have been human. On reflection, I now realise that it was naïve to assume I needed to be purely a researcher or a clinician, instead, I have learnt how my skill set enables me to fulfil both roles.

3.3 Feeling Powerless to Elicit Change

A further poignant challenge was meeting with participants who would quite clearly benefit *now* from the changes that the research would hope to initiate. This experience can be illustrated through an example of one such meeting.

3.3.1 Case Example 2

As recruitment continued into summer 2019, I met with a gentleman and his wife, both of whom were in their late 60s. The gentleman proudly explained that he had previously worked as a builder, and was a keen gardener. As it was a warm day we took the opportunity to sit in the couple's garden to complete the research. To my surprise, the garden's borders were teeming with weeds and unkempt plants, and a half-built workshop lay dormant at the end of

the garden. As we progressed with the questionnaires, it became clear that the gentleman held exceptionally negative illness representations with regard to his diagnosis of dementia. He told me that he felt he was now no longer in control of his life, the diagnosis consumed him emotionally, and as a result he felt completely unable to do anything that he had previously been capable of doing. His wife confirmed that these changes had occurred almost overnight, upon hearing of the diagnosis. This was a visibly difficult conversation for the gentleman's wife, who explained that she had attempted to encourage him to get out in the garden, or continue with his workshop project, to no avail. The gentleman presented with the exact phenomenon the research sought to highlight and address. Whilst I expected to meet participants in this predicament, meeting this couple in person was entirely different than the theoretical knowledge I held about the impact of illness representations; I struggled with the potentially unnecessary reduction in quality of life this gentleman was experiencing.

After completing the research questionnaires, I felt compelled to explain a little more about why the research was being completed, and what research in other health conditions had found with regard to illness representations. Looking back, I suppose I had hoped to plant a seed with the gentleman that the way he currently viewed his diagnosis may have profound implications for his quality of life, but that this did not have to be the case. Yet, I was once again mindful that I was not here to 'treat' or 'change' participants' illness representations, so I navigated this conversation with caution. I additionally reminded the couple of some of the post-diagnostic support that was available within the memory assessment services. Despite this, I felt that this information still fell short of what was actually required. I considered how this gentleman may benefit from group or individual support which aimed to help him to adjust his current illness representations, and the potential impact this could have on his quality of life going forward.

Unfortunately, as demonstrated within the findings from the empirical project, this experience was not uncommon. As such, I soon developed a way of gently informing participants of the potential support they could access. Certainly, whilst I was unable to refer individuals to ‘ready-made’ sources of support, I was not entirely powerless. Memory assessment services often have provision to offer therapeutic support to individuals alongside post-diagnostic support. Ultimately, while I felt frustrated at not being able to do more, the experience of these participants further fuelled my motivation to complete the research and publish the findings, so that the voices and experiences of participants were not lost.

3.3.2 Dementia-Related Stigma

Notably, participants were sometimes reluctant to access the post-diagnostic support from their local memory assessment service, typically stating that they feared this would mean other people may ‘find out’ about their diagnosis. Indeed, participants appeared to be ashamed of their diagnosis, and often stated they were keen that no one outside of their immediate family was told. I initially found this saddening, however, when I stopped to consider what the term ‘dementia’ elicits for most people, I could understand this hesitation. Powerful discourses remain around dementia; issues with confusion, decline, distress, burden, and incompetence are all associated with the term.

Offord and Field (2013) note that stigma of dementia remains rife, as people with dementia are callously placed in a worthless position within a society that values cognition, speed, and independence. Dementia-related stigma is suggested to be due to fear and a lack of awareness and/or understanding about the disease (Mukadam & Livingston, 2012). Of particular concern, it is reported that dementia-related stigma can cause significant negative effects such

as isolation, low-self-esteem, poor quality of life, and poor mental health in individuals with a diagnosis of dementia (Werner et al., 2012). Furthermore, it is identified as one of the most important factors contributing to the avoidance of help-seeking behaviours in dementia (Werner et al., 2014). This reality reminded me that overcoming the challenges faced by those with a diagnosis was a multi-faceted problem. Indeed, whilst services and clinicians need to become more attuned to the role and impact of illness representations, further change is still needed more widely than this, within society.

Ultimately, reflection enabled me to take several steps back and find an acceptance that contributing to the research base was a move in the right direction. Whilst this may never feel as though it is 'enough', this is likely to be a recurring theme in my career as a Clinical Psychologist. The creation of my ToL provided further balance to this thought process through acknowledgement that many of my 'branches', which represented my professional and personal hopes for the future, include hopes to contribute to the research evidence base in the field of dementia, and work with this population, hopefully making meaningful change to the individuals I work with.

3.4 My Personal Journey

Since I began considering my thesis topic, I was certain about one thing; the population. It therefore felt meaningful to consider how my personal journey may have led me to be drawn to this population, not only for the purposes of completing a thesis, but for my future career.

I have always enjoyed and valued the company of, and time spent with older people. Professionally, whilst working in an Improving Access to Psychological Therapies (IAPT) service I sought out the opportunity to become the lead practitioner for older adults, leading on the design and provision of a 'fear of falling' workshop. Throughout this role I found that the individuals I worked with were incredibly grateful for any support they were offered, and recall the enjoyment I experienced being told countless fascinating stories from clients' younger years.

Personally, I am aware that my parents and grandparents have always been extremely important to me. In particular, my grandparents have always been heavily involved in my upbringing and life, and my nana, who is my only surviving grandparent, continues to be one of the most significant and influential people in my life. The ToL model provided me with a deeper understanding of just how important these connections are. Indeed, the 'roots' of my tree were easily completed, but I did this in a relatively absent-minded way. Yet, I now realise that without the strong influence of my parents and grandparents I would not have been provided with such firm and stable foundations to grow, and it is these roots which I have come back to time and time again throughout the research process and doctorate journey.

A deep admiration for older generations further fuels my passion to work with this client group. This appreciation may have been formed from hearing stories about my grandad's life and experiences during World War 2, and my admiration for my nana who worked as a carer for the elderly, despite being well into her 70s herself. Yet, I am aware that working with this client group has also brought up difficult experiences for me personally. Greenberg (2016) found that more than any other client group, treating older people stirs up a range of complex

and intense emotions for clinicians. From a psychoanalytic stance, Grotjahn (1955) normalises the tendency among young therapists to idealise older clients, proposing that idealisation is related to unanalysed material regarding therapists' own parents or grandparents. Knight (2004) went on to coin a term 'grandparent countertransference'; the experience of encountering clients who remind therapists of their own grandparent. For me, meeting individuals who reminded me of my grandparents who were no longer here renewed a sense of loss, whilst individuals who reminded me of my nana, prompted recognition that I am not able to see her as much as I would like. I currently live three hours away from my family, and admittedly there will always be times when I experience guilt about this decision. With these reflections in mind, I wonder whether part of my desire to work with older people is to 'help' those in society who I personally value the most, but also to unconsciously compensate for not being able to see my own nana as much as I would like.

Through the process of reflection, I have come to acknowledge these factors and the role of my personal experiences. Indeed, I initially began creating a 'professional ToL', choosing to leave out my personal experiences. However, the further I got into the process the more I realised that the two are inevitably intertwined. The roots of my ToL undoubtedly enabled me to develop the skills needed to progress into the roles I currently hold, and significant people in my life have come from both professional and personal avenues. Finally, I have recognised that professional hopes for the future do not lie in isolation. Amongst these, I have personal life goals which provide a balance and sense of fulfilment, which ultimately enables me to accomplish my professional role to the best of my ability.

3.5 Future Directions

As I approach the completion of this thesis, the most important project I have completed to date, I feel humbled by the experience and grateful to the individuals I have had the pleasure of working with. Perhaps unsurprisingly, I have sought out a qualified post within a dementia service. For me to succeed in this post and do this role to the best of my ability, I need to remain aware of the issues I have considered throughout this paper. Ultimately, I am only human, and need to ensure that I practice the same compassion and empathy towards myself that I strive to show towards the clients I work with. I plan to continue to develop my ToL over time, reminding myself of my core values, developing skills, and ever changing hopes for the future.

Whilst I initially viewed myself as primarily a clinician, the completion of this thesis has highlighted my passion to actively elicit change in the field of dementia. Therefore, looking forward to life as a qualified psychologist, I hope to maintain involvement in research projects. I am optimistic that I now have a fuller understanding of the potential challenges that may accompany completing research with older people, but crucially also acknowledge the multitude of rewards completing research brings.

3.6 References

Dahlberg, K., Drew, N., & Nystrom, M. (2002). *Reflective lifeworld research*.

Studentlitterature.

https://www.researchgate.net/publication/265657817_Reflective_Life-World_Research

Dickson-Swift, V. A., James, E., Kippen, S., & Liamputtong, P. (2006). Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research*, 16(6),

853-871. <https://doi.org/10.1177/1049732306287526>

Gilbert, K. R. (2001). Introduction: Why are we interested in emotions? In K. R. Gilbert

(Ed.), *The emotional nature of qualitative research* (pp. 3-15). CRC Press.

https://www.researchgate.net/publication/329543483_Introduction_Why_are_we_interested_in_emotions

Greenberg, T. (2016). *Psychodynamic perspectives on aging and illness*. Springer.

<https://doi.org/10.1007/978-3-319-24289-7>

Grotjahn, M. (1955). Analytic psychotherapy with the elderly. *Psychoanalytic Review*, 42,

419–427. <https://psycnet.apa.org/record/1956-07264-001>

Health Professions Council. (2006). *Your guide to our standards for continuing professional development*. <https://www.hcpc-uk.org/standards/standards-of-continuing-professional-development/>

Knight, B. G. (2004). *Psychotherapy with older adults*. Sage.

<http://doi.org/10.4135/9781452204574>

Mortari, L. (2015). Reflectivity in research practice: An overview of different perspectives.

International Journal of Qualitative Perspectives, 14(5), 1-9.

<https://doi.org/10.1177/1609406915618045>

Mukadam, N., & Livingston, G. (2012). Reducing the stigma associated with dementia:

Approaches and goals. *Aging Health*, 8(4), 377–386. <https://doi.org/10.2217/ahe.12.42>

Ncube, N. (2006). The tree of life project: Using narrative ideas in work with vulnerable

children in Southern Africa. *International Journal of Narrative Therapy and Community*

Work, 1, 3–16. [http://www.narrativetherapylibrary.com/the-tree-of-life-project-using-](http://www.narrativetherapylibrary.com/the-tree-of-life-project-using-narrative-ideas-in-work-with-vulnerable-children-in-southern-africa.html)

[narrative-ideas-in-work-with-vulnerable-children-in-southern-africa.html](http://www.narrativetherapylibrary.com/the-tree-of-life-project-using-narrative-ideas-in-work-with-vulnerable-children-in-southern-africa.html)

Ncube, N., & Denborough, D. (2007). *The tree of life: The mainstreaming psychosocial care*

and support: A manual for facilitators. Regional Psychosocial Support Initiative

(REPSSI). [http://www.repssi.org/Att.aspx?fn=4f1b8f41-157d-42db-bc96-](http://www.repssi.org/Att.aspx?fn=4f1b8f41-157d-42db-bc96-3331aa6435af.pdf)

[3331aa6435af.pdf](http://www.repssi.org/Att.aspx?fn=4f1b8f41-157d-42db-bc96-3331aa6435af.pdf)

Offord, R., & Field, E. (2013). Why practitioners in dementia care should be working in

narratives. *Faculty for the Psychology of Older People*, 122, 12-17.

[https://www.bps.org.uk/member-microsites/dcp-faculty-psychology-older-](https://www.bps.org.uk/member-microsites/dcp-faculty-psychology-older-people/publications)

[people/publications](https://www.bps.org.uk/member-microsites/dcp-faculty-psychology-older-people/publications)

Steier, F. (1995). *Research and reflexivity*. Sage. <https://philpapers.org/rec/STERAR-13>

Webb, S. B. (1997). Training for maintaining appropriate boundaries in counselling. *British Journal of Guidance and Counselling*, 25(2), 175-188.

<https://doi.org/10.1080/03069889708253800>

Werner, P., Goldstein, D., Karpas, D. S., Chan, L., & Lai, C. (2014). Help-seeking for dementia: A systematic review of the literature. *Alzheimers Disease and Associated Disorders*, 28(4), 299–310. <https://doi.org/10.1097/wad.0000000000000065>

Werner, P., Mittelman, M. S., Goldstein, D., & Heinik, J. (2012). Family stigma and caregiver burden in Alzheimer's disease. *Gerontology*, 52(1), 89–97.

<https://doi.org/10.1093/geront/gnr117>

Appendices

Appendix A. Author guidelines for submission to the journal, *Dementia*

Manuscript Submission Guidelines:

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Dementia*, please ensure you have read the Aims & Scope.

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia.

Brief articles should be up to 3000 words and more substantial articles between 5000 and 6000 words (references are not included in this word limit). At their discretion, the Editors will also consider articles of greater length.

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March. Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible. As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their

fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support. Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

2.5 Declaration of conflicting interests

It is the policy of Dementia to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations here.

2.6 Research ethics and patient consent

For research articles, authors are required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal. Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics' International Standards for Authors and view the Publication Ethics page on the SAGE Author Gateway.

3.1.1 Plagiarism

Dementia and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

3.2 Contributor's publishing agreement

Before publication, SAGE requires the author as the rights holder to sign a Journal Contributor's Publishing Agreement. SAGE's Journal Contributor's Publishing Agreement is an exclusive licence agreement which means that the author retains copyright in the work but grants SAGE the sole and exclusive right and licence to publish for the full legal term of copyright. Exceptions may exist where an assignment of copyright is required or preferred by a proprietor other than SAGE. In this case copyright in the work will be assigned from the author to the society. For more information please visit the SAGE Author Gateway.

4. Preparing your manuscript for submission

4.1 Formatting

The preferred format for your manuscript is Word.

4.2 Language

Language and terminology. Jargon or unnecessary technical language should be avoided, as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. demented). Language that might be deemed sexist or racist should not be used. All submissions should avoid the use of insensitive or demeaning language. In particular, authors should use 'dementia-friendly' language in positioning people living with dementia in their article and avoid using pejorative terms such as 'demented' or 'suffering from dementia'.

Please also consider how you are using abbreviations in your submission. As far as possible, please avoid the use of initials, except for terms in common use. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviations in brackets) the first time they are mentioned in the text.

Useful websites to refer to for guidance

We recommend that authors refer to the Dementia Engagement and Empowerment Project (DEEP) guidance which was developed by people living with dementia and offers a range of advice and support, including writing dementia-friendly information.

Alternatively, Alzheimer's Australia sets out guidelines for dementia-friendly language, as do the Alzheimer Society of Canada, both of which are useful for guidance.

4.3 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines.

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.5 Reference style

Dementia adheres to the APA reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services.

5. Submitting your manuscript

Dementia is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/dementia> to login and submit your article online.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. The affiliation listed in the manuscript should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway.

Appendix B. Coventry University certificate of ethical approval for systematic literature review



Certificate of Ethical Approval

Applicant:

Laura Sawyer

Project Title:

THE IMPLICATIONS OF DEMENTIA WORRY FOR PEOPLE WHO DO NOT HAVE
A DIAGNOSIS OF DEMENTIA: A NARRATIVE THEMATIC SYNTHESIS

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval:

20 March 2020

Project Reference Number:

P105242

Appendix C. Caldwell et al. (2011) process of quality assessments outline



Appendix D. Quality assessment framework results - Principal rater

Quality Framework	Bowen et al. (2019)	Cui et al. (2019)	Cutler & Bragaru (2017)	Cutler & Hodgson (1996)	Cutler & Hodgson (2013)	Cutler & Hodgson (2014)	Harada et al. (2017)	Hodgson & Cutler (1997)
1. Does the title reflect the content?	2	2	2	2	2	2	2	1
2. Are the authors credible?	2	2	2	2	2	2	2	2
3. Does the abstract summarise the key components?	2	2	2	2	2	2	2	2
4. Is the rationale for undertaking the research clearly outlined?	2	2	2	2	2	2	2	2
5. Is the literature review comprehensive and up to date?	2	1	2	2	2	2	2	2
6. Is the aim of the research clearly stated?	2	1	2	2	2	2	2	2
7. Are all ethical issues identified and addressed?	0	1	0	0	0	0	2	0
8. Is the Methodology identified and justified?	2	1	1	1	1	1	1	1
Quantitative								
9. Is the study design clearly identified, and is the rationale for choice of design evident?	2	2	2	1	0	0	1	1
Qualitative								
9. Are the philosophical background and study design identified and the rationale for choice of design evident?								
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	1	1	1	2	1	1	1	1
10. Are the major concepts identified?								

11. Is the population identified?	11. Is the context of the study outlined?	2	1	2	2	2	2	2	2
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	2	1	1	1	1	1	2	1
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	2	2	2	2	2	2	2	2
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	2	2	2	2	2	2	2	1
15. Are the results presented in a way that is appropriate and clear?		2	1	2	2	2	2	2	2
16. Is the discussion comprehensive?		2	1	2	2	2	2	2	1
17. Are the results generalizable?	17. Are the results transferable?	1	1	0	0	0	0	2	1
18. Is the conclusion comprehensive?		2	1	2	2	2	2	2	1
	Score	32	22	29	29	27	27	33	25

Quality Framework		Hodgson et al. (1999)	Hodgson & Cutler (2004)	Kim, et al. (2015)	Kim et al. (2016)	Kinzer & Suhr (2016)	Norman et al. (2020)	Shinan- Altman & Werner (2017)	Tang et al. (2017)
1. Does the title reflect the content?		0	2	2	2	2	2	2	2
2. Are the authors credible?		2	2	2	1	2	2	1	1
3. Does the abstract summarise the key components?		1	2	2	2	2	2	2	2
4. Is the rationale for undertaking the research clearly outlined?		2	2	2	2	2	2	2	2
5. Is the literature review comprehensive and up to date?		2	2	2	2	2	2	2	2
6. Is the aim of the research clearly stated?		2	2	2	2	2	2	2	2
7. Are all ethical issues identified and addressed?		0	1	2	1	0	2	1	0
8. Is the Methodology identified and justified?		1	2	2	1	1	1	0	1
Quantitative	Qualitative								
9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?	0	1	2	1	0	1	0	1
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	1	2	2	1	1	2	0	1
11. Is the population identified?	11. Is the context of the study outlined?	2	2	2	1	2	2	2	1

12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	2	1	2	1	1	1	2	2
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	2	2	2	2	2	2	2	2
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	2	2	2	2	2	2	2	2
15. Are the results presented in a way that is appropriate and clear?		2	2	2	2	2	2	2	2
16. Is the discussion comprehensive?		2	2	2	2	2	2	2	2
17. Are the results generalizable?	17. Are the results transferable?	1	1	1	1	1	1	1	2
18. Is the conclusion comprehensive?		1	2	2	1	1	1	1	2
	Score	25	32	35	27	27	31	26	29

Appendix E. Quality assessment framework results - Second rater

Quality Framework	Bowen et al. (2019)	Cui et al. (2019)	Cutler & Bragaru (2017)	Cutler & Hodgson (1996)	Cutler & Hodgson (2013)	Cutler & Hodgson (2014)	Harada et al. (2017)	Hodgson & Cutler (1997)
1. Does the title reflect the content?	2	2	2	2	2	2	2	1
2. Are the authors credible?	2	2	2	2	2	2	2	2
3. Does the abstract summarise the key components?	2	2	2	2	2	2	2	2
4. Is the rationale for undertaking the research clearly outlined?	2	2	2	2	2	2	2	2
5. Is the literature review comprehensive and up to date?	2	1	2	2	2	2	2	2
6. Is the aim of the research clearly stated?	2	2	2	2	2	2	2	2
7. Are all ethical issues identified and addressed?	0	1	0	0	0	0	1	0
8. Is the Methodology identified and justified?	2	1	1	1	2	1	1	1
Quantitative								
9. Is the study design clearly identified, and is the rationale for choice of design evident?	2	1	2	1	0	1	1	1
Qualitative								
9. Are the philosophical background and study design identified and the rationale for choice of design evident?								
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	1	0	1	2	1	1	1	1
10. Are the major concepts identified?								

11. Is the population identified?	11. Is the context of the study outlined?	2	1	2	2	2	2	2	2
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	2	1	1	1	1	1	2	1
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	2	2	2	2	2	2	2	2
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	2	2	2	2	2	2	2	1
15. Are the results presented in a way that is appropriate and clear?		2	1	2	2	2	2	2	2
16. Is the discussion comprehensive?		2	1	2	2	2	2	2	1
17. Are the results generalizable?	17. Are the results transferable?	1	1	0	0	0	0	2	1
18. Is the conclusion comprehensive?		2	1	2	2	2	2	2	1
	Score	32	24	29	29	28	28	32	25

Quality Framework		Hodgson et al. (1999)	Hodgson & Cutler (2004)	Kim et al. (2015)	Kim et al. (2016)	Kinzer & Suhr (2016)	Norman et al. (2020)	Shinan-Altman & Werner (2017)	Tang et al. (2017)
1. Does the title reflect the content?		1	2	2	2	2	2	2	2
2. Are the authors credible?		2	2	2	1	2	2	1	1
3. Does the abstract summarise the key components?		1	2	2	2	2	2	2	2
4. Is the rationale for undertaking the research clearly outlined?		2	2	2	2	2	2	2	2
5. Is the literature review comprehensive and up to date?		2	2	2	2	2	2	2	2
6. Is the aim of the research clearly stated?		2	2	2	2	2	2	2	2
7. Are all ethical issues identified and addressed?		0	1	2	1	0	2	1	0
8. Is the Methodology identified and justified?		1	2	2	1	1	1	0	1
Quantitative									
Qualitative									
9. Is the study design clearly identified, and is the rationale for choice of design evident?	9. Are the philosophical background and study design identified and the rationale for choice of design evident?	0	1	2	1	1	1	0	1
10. Is there an experimental hypothesis clearly stated? Are the key variables clearly defined?	10. Are the major concepts identified?	1	2	2	1	1	2	1	1

11. Is the population identified?	11. Is the context of the study outlined?	2	2	2	2	2	2	2	1
12. Is the sample adequately described and reflective of the population?	12. Is the selection of participants described and the sampling method identified?	2	1	2	1	1	1	2	2
13. Is the method of data collection valid and reliable?	13. Is the method of data collection auditable?	2	2	2	2	2	2	2	2
14. Is the method of data analysis valid and reliable?	14. Is the method of data analysis credible and confirmable?	2	2	2	2	2	2	2	2
15. Are the results presented in a way that is appropriate and clear?		2	2	2	2	2	2	2	2
16. Is the discussion comprehensive?		2	2	2	2	2	2	2	2
17. Are the results generalizable?	17. Are the results transferable?	1	1	1	1	1	1	1	2
18. Is the conclusion comprehensive?		1	2	2	1	1	1	1	2
	Score	26	32	35	28	28	31	27	29

Appendix F. Inter-rater reliability coefficient (Kappa) outputs for all papers reviewed

Paper	κ value	Significance (<i>p</i> value)
Bowen et al. (2019)	1.000	.000
Cui et al. (2019)	.800	.000
Cutler & Bragaru (2017)	1.000	.000
Cutler & Hodgson (1996)	1.000	.000
Cutler & Hodgson (2013)	.882	.000
Cutler & Hodgson (2014)	.880	.000
Harada et al. (2017)	.824	.000
Hodgson & Cutler (1997)	1.000	.000
Hodgson et al. (1999)	.904	.000
Hodgson & Cutler (2004)	1.000	.000
Kim et al. (2015)	1.000	.000
Kim et al. (2016)	.889	.000
Kinzer & Suhr (2016)	.895	.000
Norman et al. (2020)	1.000	.000
Shinan-Altman & Werner (2017)	.898	.000
Tang et al. (2017)	1.000	.000
Overall	.935	.000

Appendix G. Table showing studies that contributed to each main theme/ sub-theme

Paper	Well-being		Memory concerns		Help-seeking		
	Psychological wellbeing	Physical Health	Memory appraisals	Subjective memory concerns	Sharing concerns	Engagement in Screening	Lifestyle changes
Bowen et al. (2019)							
Cui et al. (2019)							
Cutler & Bragaru (2017)							
Cutler & Hodgson (1996)							
Cutler & Hodgson (2013)							
Cutler & Hodgson (2014)							
Harada et al. (2017)							
Hodgson & Cutler (1997)							
Hodgson et al. (1999)							
Hodgson & Cutler (2004)							
Kim et al. (2015)							
Kim et al. (2016)							
Kinzer & Suhr (2016)							
Norman et al. (2020)							
Shinan-Altman & Werner (2017)							
Tang et al. (2017)							

Appendix H. Coventry University ethical approval for empirical paper



Certificate of Ethical Approval

Applicant:

Laura Sawyer

Project Title:

The impact of having dementia on people's abilities and their need for support from others.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

21 January 2019

Project Reference Number:

P76874

Appendix I. HRA ethical approval for empirical paper



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Mrs Laura Sawyer
Clinical Psychology Doctorate, School of Psychological,
Social and Behavioural Sciences
Coventry University, Charles Ward Building
Priory Street, Coventry
CV1 5FB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

16 April 2019

Dear Mrs Sawyer

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: The impact of having dementia on people's abilities and their need for support from others
IRAS project ID: 256925
REC reference: 19/LO/0290
Sponsor: Coventry University

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **256925**. Please quote this on all correspondence.

Yours Sincerely

Beverley Mashegede

Email: hra.approval@nhs.net

Copy to: Dr Tom Patterson, Sponsor Contact

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Multicentre study	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	A statement of activities has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No funds will be provided to participating organisations to support this study.	A PI expected at the participating organisation.	Where arrangements are not already in place, research team members undertaking activities that do not impact on the quality of care of the participant (for example, administering questionnaires), a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.

--

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Coventry University Ethical Approval]	1	22 January 2019
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Document of ethical approval]	1	22 January 2019
Copies of advertisement materials for research participants [Research Leaflet]	1	22 January 2019
Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only) [Professional Indemnity Letter]		22 January 2019
HRA Schedule of Events	1	07 March 2019
HRA Statement of Activities	2	07 March 2019
IRAS Application Form [IRAS_Form_25012019]		25 January 2019
IRAS Application Form XML file [IRAS_Form_25012019]		25 January 2019
IRAS Checklist XML [Checklist_17032019]		17 March 2019
Letter from sponsor [Sponsor Letter]		22 January 2019
Non-validated questionnaire [Patient Adapted BADLS]	1	22 January 2019
Non-validated questionnaire [Carer Adapted BADLS]	1	22 January 2019
Non-validated questionnaire [ECog patient English]	2	17 March 2019
Non-validated questionnaire [ECOG carer English]	2	17 March 2019
Other [Debrief form]	1	22 January 2019
Other [Patient and carer reviewer comments 2]	1	22 January 2019
Other [Patient and carer reviewer comments]	1	22 January 2019
Other [Risk Assessment Form]	1	23 January 2019
Other [Ethics review feedback - Coventry University]	1	22 January 2019
Other [Signed student CV]	2	23 January 2019
Participant consent form [Informed consent form carer V2]	2	17 March 2019
Participant consent form [Consent form patient]	2	17 March 2019
Participant information sheet (PIS) [Participant Information Sheet V2]	2	17 March 2019
Participant information sheet (PIS) [Carer participant information sheet V2]	2	17 March 2019
Research protocol or project proposal [Research Protocol]	1	22 January 2019
Summary CV for Chief Investigator (CI) [CV document]	1	22 January 2019
Summary CV for student [Student (CI) CV]	1	22 January 2019
Summary CV for supervisor (student research) [Supervisor CV]	1	22 January 2019
Summary CV for supervisor (student research) [Supervisor CV]	1	22 January 2019
Validated questionnaire [RADIX Measure]	1	22 January 2019
Validated questionnaire [Patient ECOG]	1	22 January 2019
Validated questionnaire [Carer ECOG]	1	22 January 2019



Research is currently being carried out within your local NHS memory assessment service.

The study is investigating whether having dementia influences how people view their own abilities and their need for help and support from others.

If you are interested in taking part in this research, and would like some more information about participating, please let a member of your healthcare team within the memory assessment service know.

Alternatively, contact the lead researcher (Laura Sawyer) on:

[REDACTED]



THE IMPACT OF HAVING DEMENTIA ON PEOPLE'S ABILITIES & THEIR NEED FOR SUPPORT FROM OTHERS

PARTICIPANT INFORMATION SHEET

Both you and your carer are being invited to take part in research that explores whether having dementia affects how people view their own abilities and their need for help and support from others. Laura Sawyer, a Trainee Clinical Psychologist at Coventry University is leading this research. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to better understand how a person sees their illness and their need for support, following a diagnosis of dementia.

Why have I been chosen to take part?

You are invited to participate in this study because you have recently received a diagnosis of dementia.

What are the benefits of taking part?

By sharing your experiences with us, you will be helping the researchers to better understand how the way that patients see their dementia affects their abilities and need for support. In this way healthcare staff will be better informed about how to support those living with dementia. Developing a clinical understanding of this could raise awareness of factors that may help or hinder an individual's ability to live well with dementia after a diagnosis.

Are there any risks associated with taking part?

This study has been reviewed and approved by the Research Ethics Committee to London-Bromley. There are no anticipated risks associated with participation, however should you wish to access

support following participation you can contact a member of your healthcare team, or access the following services:

Samaritans: Telephone: 116 123 (Freephone) Postal: Freepost RSRB-KKBY-CYJK, PO Box 9090, STIRLING, FK8 2SA

Dementia UK: Telephone: 0800 888 6678 Email: helpline@dementiauk.org

Alzheimer's Society: Telephone: 0300 222 1122

Do I have to take part?

- No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate.
- Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date.
- Both you and your carer are free to withdraw your information from the project data set until 01/02/2020, at which point your data will be fully anonymised and withdrawal will not be possible. If either you or your carer chooses to withdraw your information, both sets of data will be withdrawn at the same time. You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study.
- To withdraw, please contact the lead researcher (contact details are provided below). Please also contact the Ethics Support Office [email: ethics.hls@coventry.ac.uk] so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked a number of questions about your views about your dementia diagnosis and your thoughts about your current abilities and needs for assistance. The questionnaires can be completed at a place

and time that is convenient to you. The questionnaires should take around 45 minutes to complete. If any concerns regarding risk to you or anyone else arise as a result of information provided it may be necessary to inform social services or other relevant professionals, in accordance with safeguarding protocols.

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

ADDITIONAL INFORMATION

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. Your data will only be viewed by the researcher/research team. Your questionnaire responses will be stored on a password protected memory stick. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. All data will be securely stored for a period of five years after the project end date (30/09/2025), it will then be destroyed.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit

www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

Making a Complaint

If you are unhappy with any aspect of this research, please first contact the lead researcher, Laura Sawyer symesl@uni.coventry.ac.uk. If you still have concerns and wish to make a formal complaint, please write to:

Dr Tom Patterson – Principal Lecturer in Clinical Psychology
(Project Supervisor) Coventry University, Coventry, CV1 5FB

Telephone: [REDACTED]

Email: [REDACTED]

In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

INFORMED CONSENT FORM:

THE IMPACT OF HAVING DEMENTIA ON PEOPLE’S ABILITIES AND THEIR NEED FOR SUPPORT FROM OTHERS

You are invited to take part in this research study for the purpose of collecting data on whether having dementia affects how people view their own abilities and their need for help and support from others.

Before you decide to take part, you must **read the accompanying Participant Information Sheet.**

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling YES against each of the below statements and then signing and dating the form as participant.

1	I confirm that I have read and understood the <u>Participant Information Sheet</u> for the above study and have had the opportunity to ask questions	YES	NO
2	I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office <u>at any time</u> until the date specified in the Participant Information Sheet (01/02/2020)	YES	NO
3	I have noted down my participant number (top left of this Consent Form) which may be required	YES	NO

	by the lead researcher if I wish to withdraw from the study		
4	I understand that all the information I provide will be held securely and treated confidentially	YES	NO
5	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs	YES	NO
6	I consent to sharing the details of my diagnosis, including the type of dementia and score on the memory assessment measure (Addenbrooke's Cognitive Examination) completed during my initial assessment with the research team	YES	NO
7	I agree to take part in the above study	YES	NO

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Researcher	Date	Signature

Appendix M. RADIX questionnaire

Representations and Adjustment Index (RADIX)

Catherine Quinn, Robin Morris and Linda Clare

Background

The RADIX assesses elements of Dementia Representations. Dementia Representations reflect a person's understanding of dementia. They have five components. The first of these is the identity the person ascribes to the condition; this is captured in the term the person uses to describe the condition. The other elements of DRs concern beliefs about cause, timeline, possibilities for cure/control, and consequences.

Administration

The RADIX is designed to be administered to people with mild to moderate dementia (any type), having been validated for people in this severity range.

Step 1: RADIX Screening Checklist

Questions 1 to 9 form the screening checklist.

First administer the screening checklist to identify whether it is appropriate to administer the rest of the questionnaire. If the person responds 'no' to all of the questions in the checklist then the RADIX should be discontinued. If the person responds 'yes' to one or more of the screening questions continue to Step 2.

Step 2: RADIX Questionnaire

The questionnaire clusters the questions according to the five main Dementia Representations components as follows:

Identity

Questions 10-11 provide a profile of the way the person views the condition.

Question 10 elicits the term the person uses to describe the condition

Question 11 explores whether the person is aware of a diagnostic term that describes the condition.

From the responses to these two questions, ascertain the main term the person prefers to use when referring to the condition (e.g. 'memory problems' or 'Alzheimer's') and then use this term where you see [identity label] in all subsequent questions. If the person cannot provide a term that describes the condition, please use "condition" or "difficulties" instead.

Cause

Question 12 explores the person's beliefs about the causes of the condition.

The person is asked "What do you think caused or causes your [identity label]?" Record the response, even if it is 'don't know.' If the person does not spontaneously provide a response, ask him/her to choose from the list of possible causes which is provided in Q12a. If the person selects more than one option, you then need to ask him/her to select the most important one and record this response in Q12b.

Timeline

Question 13 explores the person's beliefs about the duration of these changes.

The person is asked "What do you think will happen to your [identity label] over time?" There are 4 fixed-choice response options, and the person should select one response.

Control

Question 14 explores the beliefs about possibilities for controlling or managing the condition. In response to the statement "There is a lot which I can do to control the effects of my [identity label]", there are 4 fixed-choice response options to select from and the person should select one response.

Consequences

Questions 15-18 explore the person's perceptions of the practical consequences of the condition, and Questions 19-23 explore the emotional consequences.

There are 4 fixed-choice response options to select from for each question, from which the person should select one response.

Scoring

The responses to the open ended questions on Identity and Cause can be categorised using the lists in Appendix A and B (pages 7-8). Questions on Timeline and Control are single items and the scores are recorded individually. For Practical Consequences, responses to the questions can be summed to give an overall score and then divided by 4 to give the mean score for Practical Consequences. For Emotional Consequences, responses to the questions can be summed to give an overall score and then divided by 5 to give the mean score for Emotional Consequences.

Citing the RADIX

The development and validation of the RADIX is described in: Quinn, C., Morris, R. G., & Clare, L. (in press). Beliefs about Dementia: Development and validation of the Representations and Adjustment to Dementia Index (RADIX). *The American Journal of Geriatric Psychiatry*. doi:10.1016/j.jagp.2018.02.004 [please use the most up-to-date citation details when citing the RADIX paper]

Representations and Adjustment Index (RADIX)

Catherine Quinn, Robin Morris, Linda Clare

Did the person answer 'yes' to one or more questions in the screening checklist? No Yes

Was the RADIX administered? No Yes

Dementia Representations Profile

Please use this section to record a summary of the person's responses to the questions

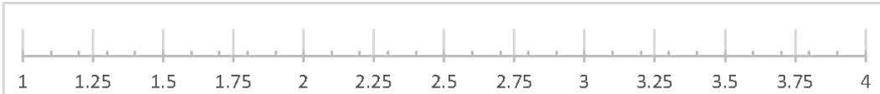
1. IDENTITY: _____

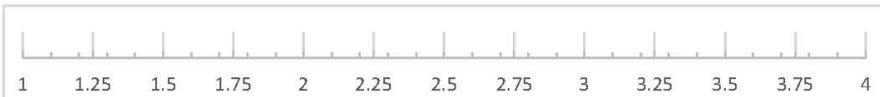
2. DIAGNOSTIC IDENTITY: _____

3. CAUSE: _____

4. TIMELINE: GET BETTER STAY SAME GET WORSE UNSURE

5. POSSIBLE TO CONTROL: STRONGLY AGREE AGREE DISAGREE STRONGLY DISAGREE

6. PRACTICAL CONSEQUENCES MEAN SCORE: 

7. EMOTIONAL CONSEQUENCES MEAN SCORE: 

SECTION 1: SCREENING CHECKLIST

I would like to talk to you about any changes that you have been experiencing.

1. Have you, a family member or doctor noticed that you have been having difficulty with concentration?

No Yes

2. Have you, a family member or doctor noticed that you have been forgetful?

No Yes

3. Have you, a family member or doctor noticed that you have been having difficulty with remembering (e.g. recent events)?

No Yes

4. Have you, a family member or doctor noticed that you have been having difficulty with thinking?

No Yes

5. Have you, a family member or doctor noticed that you have been having difficulty with your ability to say what you want to say?

No Yes

6. Have you, a family member or doctor noticed that you have been having difficulty with your ability to manage your day-to-day activities?

No Yes

7. Have you, a family member or doctor noticed that you have been having difficulty with planning ahead?

No Yes

8. Have you, a family member or doctor noticed that you have been having difficulty with making decisions?

No Yes

9. Are you different in some way to how you used to be?

No Yes

Instructions for the researcher: Did the participant identify one or more changes? No Yes

If **YES** you can continue with the RADIX

SECTION 2: RADIX

10. What do you call [this difficulty/these difficulties, or condition] that you have?

11. Are you aware of a specific diagnosis? What does the doctor call it?

Instructions for the researcher: Record the person's label for the condition. How does s/he refer to the condition; does s/he call it dementia or something else e.g. short-term memory problems, forgetfulness. Use this term, referred to as [identity label] in all subsequent questions. If the participant does not give a label, replace [identity label] with "condition" or "difficulties" instead.

POSSIBLE CAUSES OF MEMORY DIFFICULTIES

12. What do you think caused or causes your [identity label]?

a) Instructions for the researcher: If no instant response then follow up with: **These are some of the things that other people say causes their problems; which one do you think applies to you?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

- Ageing
- Changes within the brain (e.g. something in your brain dies off)
- Illness or disease or physical condition (e.g. diabetes)
- Hereditary condition (e.g. genetics)
- Lifestyle/life events (e.g. stress, bereavement)
- Don't know (record if given as a spontaneous response)

b) Instructions for the researcher: If more than one cause identified, ask him/her to nominate the most important one and cross the appropriate box below:

- Ageing
- Changes within the brain (e.g. something in your brain dies off)
- Illness or disease or physical condition (e.g. diabetes)
- Hereditary condition (e.g. genetics)
- Lifestyle/life events (e.g. stress, bereavement)
- Don't know (record if given as a spontaneous response)

DURATION OF THESE CHANGES (*Timeline*)

13. What do you think will happen to your [identity label] over time? Will it/they

Get better (1)

Stay the same as it is now (2)

Get worse (3)

Unsure (4)

CONSEQUENCES OF THESE CHANGES

Please indicate how much you agree or disagree with the following statements. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

Control

14. There is a lot which I can do to control the effects of my [identity label]

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

Practical Consequences

15. As a result of my [identity label] people treat me differently

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

16. As a result of my [identity label] I do not go out as much as I used to

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

17. As a result of my [identity label] I cannot do some of the things that I used to do

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

18. As a result of my [identity label] I feel I have lost control over my life

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

TO GENERATE MEAN SCORE: First record the TOTAL score (SUM of Q15~Q18): _____

Second divide (÷) the TOTAL score by 4= _____ This generates the MEAN SCORE

Emotional Consequences

19. As a result of my [identity label] I get annoyed or frustrated with myself

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

20. As a result of my [identity label] I get very angry about what is happening to me

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

21. As a result of my [identity label] I feel I have lost confidence in myself

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

22. I feel low or upset when I think about my [identity label]

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

23. I find myself worrying about my [identity label]

Strongly disagree (1) Disagree (2) Agree (3) Strongly agree (4)

TO GENERATE MEAN SCORE: First record the TOTAL score (SUM of Q19~Q23): _____

Second divide (÷) the TOTAL score by 5= _____ This generates the MEAN SCORE

Appendix N. PwD ECog questionnaire

Everyday Capabilities – Patient Form

DIRECTIONS: Please rate your ability to perform certain everyday tasks **NOW, as compared to your ability to do these same tasks 10 years ago**. In other words, try to remember how you were doing 10 years ago and indicate any change in your level of ability. Rate the amount of change on a five-point scale ranging from:

1	There has been no change in my ability or I actually perform better compared to 10 years ago.
2	I occasionally perform the task worse but not all of the time.
3	I consistently perform the task a little worse than 10 years ago.
4	I consistently perform the task much worse than 10 years ago.
9	I don't know.

Before we get started... Are you concerned that you have a memory or other thinking problem? Yes/ No

<i>Compared to 10 years ago, has there been any change in...</i>	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Memory					
1. Remembering a few shopping items.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Remembering things that happened recently (such as recent outings, events in the news).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Recalling conversations a few days later.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Remembering where I have placed objects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Repeating stories and/or questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Remembering the current date or day of the week.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Remembering I have already told someone something.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Remembering appointments, meetings or engagements.	<input type="checkbox"/>				
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<i>Compared to 10 years ago, has there been any change in...</i>	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
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Language

1. Forgetting the names of objects.	<input type="checkbox"/>				
2. Verbally giving instructions to others.	<input type="checkbox"/>				
3. Finding the right words to use in a conversation.	<input type="checkbox"/>				
4. Communicating thoughts in a conversation.	<input type="checkbox"/>				
5. Following a story in a book or on TV.	<input type="checkbox"/>				
6. Understanding the point of what other people are trying to say.	<input type="checkbox"/>				
7. Remembering the meaning of common words.	<input type="checkbox"/>				
8. Describing a programme I have watched on TV.	<input type="checkbox"/>				
9. Understanding spoken directions or instructions.	<input type="checkbox"/>				

Visual-spatial and Perceptual Abilities

1. Following a map to find a new location.	<input type="checkbox"/>				
2. Reading a map and helping with directions when someone else is driving.	<input type="checkbox"/>				
3. Finding my car in a car park.	<input type="checkbox"/>				
4. Finding my way back to a meeting point in the shopping centre or other location.	<input type="checkbox"/>				
5. Finding my way around a familiar neighbourhood.	<input type="checkbox"/>				
6. Finding my way around a familiar shop.	<input type="checkbox"/>				
7. Finding my way around a house visited many times.	<input type="checkbox"/>				

<i>Compared to 10 years ago, has there been any change in...</i>	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
Executive Functioning: Planning					
1. Planning the sequence of stops on a shopping trip.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Anticipating weather changes and planning accordingly (i.e. taking a coat or umbrella with you).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Ability to plan ahead for forthcoming events.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Thinking things through before acting.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Thinking ahead.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Executive Functioning: Organisation					
1. Keeping living and work space organised.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Keeping an accurate track of cheque book transactions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Keeping financial records organised.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Prioritising tasks by importance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Keeping post and papers organised.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Using a system to manage a medication schedule involving multiple medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Executive Functioning: Divided Attention					
1. My ability to do two things at once.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Returning to a task after being interrupted.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My ability to concentrate on a task without being distracted by external things in the environment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Cooking or working and talking at the same time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix O. PwD BADLS questionnaire

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another. For each activity, please score each item considering how often you have been able to complete this task independently over the past two weeks. If in doubt about which number to choose, choose the level of ability which represents your average ability over the last 2 Weeks. Please score 'Not applicable' if you have never been able to do an activity.

Over the past two weeks I have completed this task independently...						
Selecting and preparing food independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Eating independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Drinking independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Selecting appropriate clothing and dressing self independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Washes self regularly and independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Cleaning own teeth regularly and independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Bathes/showers regularly and independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Using toilet independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable

Getting in and out of a chair independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Walking independently with or without aids	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Knowing the date, day, and time of day	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Being aware of where I am	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Holding a conversation with another person	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Using the telephone independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Doing either housework or gardening independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Shopping independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Managing my own finances	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Keeping up with my usual hobbies or pastimes	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Driving, cycling, or using public transport independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable

THE IMPACT OF HAVING DEMENTIA ON PEOPLE'S ABILITIES AND THEIR NEED FOR SUPPORT FROM OTHERS

Thank you for taking the time to participate in this study. As discussed, this study aims to explore whether having dementia affects how people view their own abilities and their need for help and support from others. Should you feel that you need any personal or emotional support following participation in this study the following services can be contacted.

Samaritans:

The Samaritans offer a safe place for you to talk any time you like, in your own way – about whatever's getting to you.

Telephone: 116 123 (Freephone)

Postal: Freepost RSRB-KKBY-CYJK, PO Box 9090, STIRLING, FK8 2SA

Dementia UK:

The Admiral Nurse Dementia Helpline is for anyone with a question or concern about dementia.

Telephone: 0800 888 6678

Email: helpline@dementiauk.org

Alzheimer's Society:

The Alzheimer's Society helpline provides information, support and advice about dementia.

Telephone: 0300 222 1122

Carers Direct:

Carers Direct has a national helpline service for carers, offering confidential information and advice. This service is part of the NHS.

Telephone: 0300 123 1053

Alternatively, you may decide to contact your GP for support, if needed. *Thank you again for taking part in this study!*

THE IMPACT OF HAVING DEMENTIA ON PEOPLE'S ABILITIES & THEIR NEED FOR SUPPORT FROM OTHERS

CARER INFORMATION SHEET

Both you and the person you care for are being invited to take part in research exploring the impact having dementia affects how a person thinks about their abilities and their need for help or support from others. Laura Sawyer, a Trainee Clinical Psychologist at Coventry University is leading this research. Before you decide to take part it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to better understand how a recent diagnosis of dementia affects how a person sees their illness and their need for support, following a diagnosis of dementia.

Why have I been chosen to take part?

You are invited to participate in this study because someone you care for has recently received a diagnosis of dementia.

What are the benefits of taking part?

By sharing your experiences with us, you will be helping the researchers to better understand how the way that patients see their dementia affects their abilities and need for support. In this way healthcare staff will be better informed about how to support those living with dementia. Developing a clinical understanding of this could raise awareness of factors that may help or hinder an individual's ability to live well with dementia after a diagnosis.

Are there any risks associated with taking part?

This study has been reviewed and approved the Research Ethics Committee to London-Bromley. There are no anticipated risks

associated with participation, however should you wish to access support following participation in the study you can contact Carers Direct on: 0300 123 1053.

Do I have to take part?

- No – it is entirely up to you. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate.
- Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you seek to withdraw from the study at a later date.
- Both you and the person you care for are free to withdraw your information from the project data set until 01/02/2020, at which point data will be fully anonymised and withdrawal will not be possible. If either you or the person you care for choose to withdraw your information, both sets of data will be withdrawn at the same time. You should note that your data may be used in the production of formal research outputs (e.g. journal articles, conference papers, theses and reports) prior to this date and so you are advised to contact the university at the earliest opportunity should you wish to withdraw from the study.
- To withdraw, please contact the lead researcher (contact details are provided below). Please also contact the Ethics Support Office [email: ethics.hls@coventry.ac.uk] so that your request can be dealt with promptly in the event of the lead researcher's absence. You do not need to give a reason. A decision to withdraw, or not to take part, will not affect you in any way.

What will happen if I decide to take part?

You will be asked to complete questionnaires regarding the assistance the person you care for requires and other questions about the person's abilities. The questionnaires can be completed at a place and time that is convenient to you. The questionnaires should take around 15 minutes to complete. If any concerns regarding risk to you or anyone else arise as a result of information provided it may be necessary to inform social

services or other relevant professionals, in accordance with safeguarding protocols.

What will happen with the results of this study?

The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

ADDITIONAL INFORMATION

Data Protection and Confidentiality

Your data will be processed in accordance with the General Data Protection Regulation 2016 (GDPR) and the Data Protection Act 2018. All information collected about you will be kept strictly confidential. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. Your data will only be viewed by the researcher/research team. Your questionnaire responses will be stored on a password protected memory stick. Your consent information will be kept separately from your responses in order to minimise risk in the event of a data breach. All data will be securely stored for a period of five years after the project end date (30/09/2025), it will then be destroyed.

Data Protection Rights

Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner's Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.ipu@coventry.ac.uk

Making a Complaint

If you are unhappy with any aspect of this research, please first contact the lead researcher, Laura Sawyer, [REDACTED]. If you still have concerns and wish to make a formal complaint, please write to:

Dr Tom Patterson – Principal Lecturer in Clinical Psychology
(Project Supervisor)

Coventry University, Coventry, CV1 5FB

Telephone: [REDACTED]

Email: [REDACTED]

In your letter please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.

INFORMED CONSENT FORM:

THE IMPACT OF HAVING DEMENTIA ON PEOPLE'S ABILITIES AND THEIR NEED FOR SUPPORT FROM OTHERS

You are invited to take part in this research study because you care for a person who has recently received a diagnosis of dementia. The study will explore whether having dementia affects how people view their own abilities and their need for help and support from others.

Before you decide to take part, you must **read the accompanying Participant Information Sheet.**

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling YES against each of the below statements and then signing and dating the form as participant.

1	I confirm that I have read and understood the <u>Participant Information Sheet</u> for the above study and have had the opportunity to ask questions	YES	NO
2	I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office <u>at any time</u> until the date specified in the Participant Information Sheet (01/02/2020)	YES	NO

3	I have noted down my participant number (top left of this Consent Form) which may be required by the lead researcher if I wish to withdraw from the study	YES	NO
4	I understand that all the information I provide will be held securely and treated confidentially	YES	NO
5	I am happy for the information I provide to be used (anonymously) in academic papers and other formal research outputs	YES	NO
7	I agree to take part in the above study	YES	NO

Thank you for your participation in this study. Your help is very much appreciated.

Participant's Name	Date	Signature
Researcher	Date	Signature

Appendix S. Carer ECog questionnaire

Everyday Capabilities – Informant/Caregiver Form

DIRECTIONS: Please rate the participant’s ability to perform certain everyday tasks **NOW, as compared to his/her ability to do these same tasks 10 years ago**. In other words, try to remember how he/she was doing 10 years ago and indicate any change you have seen. Rate the amount of change on a five-point scale ranging from:

1	No change or actually performs better than 10 years ago.
2	Occasionally performs the task worse but not all of the time.
3	Consistently performs the task a little worse than 10 years ago.
4	Consistently performs the task much worse than 10 years ago.
9	I don’t know.

<i>Compared to 10 years ago, has there been any change in...</i>	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don’t know
Memory					
1. Remembering a few shopping items.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Remembering things that happened recently (such as recent outings, events in the news).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Recalling conversations a few days later.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Remembering where he/she has placed objects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Repeating stories and/or questions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Remembering the current date or day of the week.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Remembering he/she has already told someone something.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. Remembering appointments, meetings or engagements.	<input type="checkbox"/>				
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	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
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Language

1. Forgetting the names of objects.	<input type="checkbox"/>				
2. Verbally giving instructions to others.	<input type="checkbox"/>				
3. Finding the right words to use in a conversation.	<input type="checkbox"/>				
4. Communicating thoughts in a conversation.	<input type="checkbox"/>				
5. Following a story in a book or on TV.	<input type="checkbox"/>				
6. Understanding the point of what other people are trying to say.	<input type="checkbox"/>				
7. Remembering the meaning of common words.	<input type="checkbox"/>				
8. Describing a programme he/she has watched on TV.	<input type="checkbox"/>				
9. Understanding spoken directions or instructions.	<input type="checkbox"/>				

Visual-spatial and Perceptual Abilities

1. Following a map to find a new location.	<input type="checkbox"/>				
2. Reading a map and helping with directions when someone else is driving.	<input type="checkbox"/>				
3. Finding his/her car in a car park.	<input type="checkbox"/>				
4. Finding the way back to a meeting point in the shopping centre or other location.	<input type="checkbox"/>				
5. Finding his/her way around a familiar neighbourhood.	<input type="checkbox"/>				
6. Finding his/her way around a familiar shop.	<input type="checkbox"/>				

7. Finding his/her way around a house visited many times.	<input type="checkbox"/>				
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	Better or no change	Questionable/ occasionally worse	Consistently a little worse	Consistently much worse	I don't know
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Executive Functioning: Planning

1. Planning the sequence of stops on a shopping trip.	<input type="checkbox"/>				
2. Anticipating weather changes and planning accordingly (i.e. taking a coat or umbrella with him/her).	<input type="checkbox"/>				
3. Ability to plan ahead for forthcoming events.	<input type="checkbox"/>				
4. Thinking things through before acting.	<input type="checkbox"/>				
5. Thinking ahead.	<input type="checkbox"/>				

Executive Functioning: Organisation

1. Keeping living and work space organised.	<input type="checkbox"/>				
2. Keeping an accurate track of cheque book transactions.	<input type="checkbox"/>				
3. Keeping financial records organised.	<input type="checkbox"/>				
4. Prioritising tasks by importance.	<input type="checkbox"/>				
5. Keeping post and papers organised.	<input type="checkbox"/>				
6. Using a system to manage a medication schedule involving multiple medications.	<input type="checkbox"/>				

Executive Functioning: Divided Attention

1. His/her ability to do two things at once.	<input type="checkbox"/>				
2. Returning to a task after being interrupted.	<input type="checkbox"/>				
3. His/her ability to concentrate on a task without being distracted by external things in the environment.	<input type="checkbox"/>				

4. Cooking or working and talking at the same time.	<input type="checkbox"/>				
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Please answer the following questions about yourself:

- | | |
|---|--|
| <p>1) What is your relationship to the patient/study participant?</p> <p>1 Wife/husband/significant other</p> <p>2 Son</p> <p>3 Daughter</p> <p>4 Son-in-law</p> <p>5 Daughter-in-law</p> <p>6 Other family member</p> <p>7 Friend</p> <p>8 Other</p> | <p>2) How often do you see him or her?</p> <p>1 Every day</p> <p>2 4-6 days per week</p> <p>3 2-3 days per week</p> <p>4 Once a week</p> <p>5 Once every two weeks</p> <p>6 Once a month</p> <p>7 Less than once a month</p> |
| <p>3) On average, how many <u>hours</u> per week do you spend with him or her? _____ hours [Note: 1 week = 168 hours.]</p> | <p>4) How many years have you known the patient/ study participant? _____ years</p> |
| <p>5) What is your gender? 1 Male 2 Female</p> | <p>6) How old are you? ____ years</p> |

Appendix T. Carer BADLS questionnaire

This questionnaire is designed to reveal the everyday ability of people who have memory difficulties of one form or another. For each activity, please score each item considering how often your friend or relative has been able to complete this task independently over the past two weeks. If in doubt about which number to choose, choose the level of ability which represents their average performance over the last 2 Weeks. Please score 'Not applicable' if they have never been able to do an activity.

Over the past two weeks my friend/relative has completed this task independently...						
Selecting and preparing food independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Eating independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Drinking independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Selecting appropriate clothing and dressing self independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Bathing/washing regularly and independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Cleaning own teeth regularly and independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Bathing regularly and independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Using toilet independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable

Getting in and out of a chair independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Walking independently with or without aids	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Knowing the date, day, and time of day	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Being aware of where they are	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Holding a conversation with another person	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Using the telephone independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Doing either housework or gardening independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Shopping independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Managing their own finances	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Keeping up with usual hobbies or pastimes	Always	Frequently	Sometimes	Rarely	Never	Not Applicable
Driving, cycling, or using public transport independently	Always	Frequently	Sometimes	Rarely	Never	Not Applicable

Appendix U. PwD ethnicity demographics

Gender	White English / Welsh / Scottish / Northern Irish / British	White Irish	Indian	White and Black Caribbean	Total
Male	22	2	1	1	26
Female	31	0	0	0	31

Appendix V: PwD living arrangement demographics

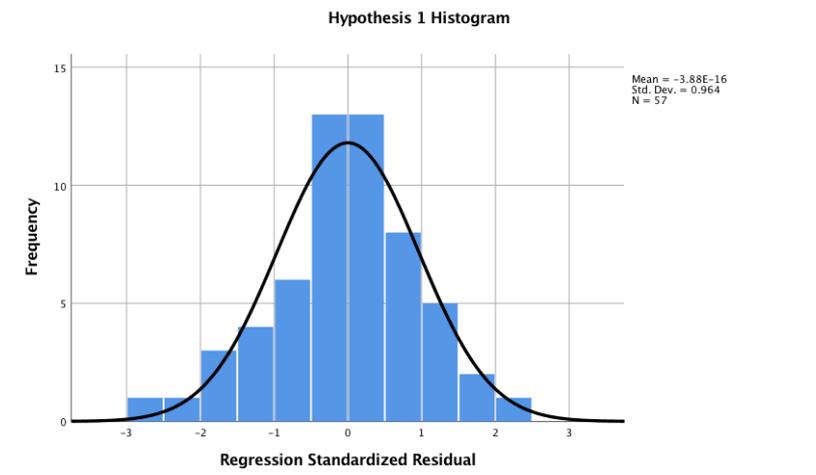
Gender	Live alone	Live with partner	Live with family	Total
Male	4	22	0	26
Female	6	22	3	31

Appendix W. PwD prior occupation demographics

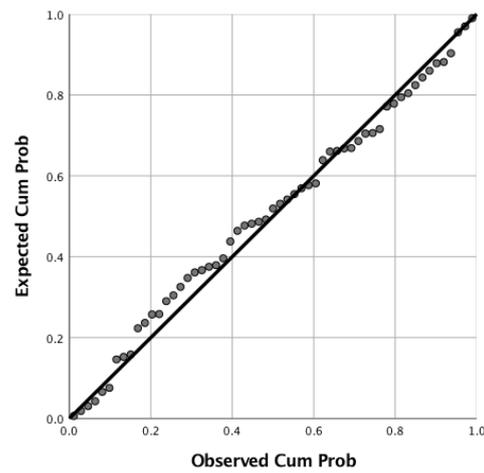
Gender	Agriculture food and natural resources	Architecture and construction	Business management and administration	Education and training	Government and public administration	Health Science
Male	5	3	0	3	0	2
Female	0	0	7	7	1	3
Total	5	3	7	10	1	5

Gender	Hospitality and tourism	Human services	Manufac turing	Marketing sales and service	Science, technology, engineering and mathematics	Transportation , distribution and logistics
Male	0	3	3	2	3	2
Female	3	3	1	6	0	0
Total	3	6	4	8	3	2

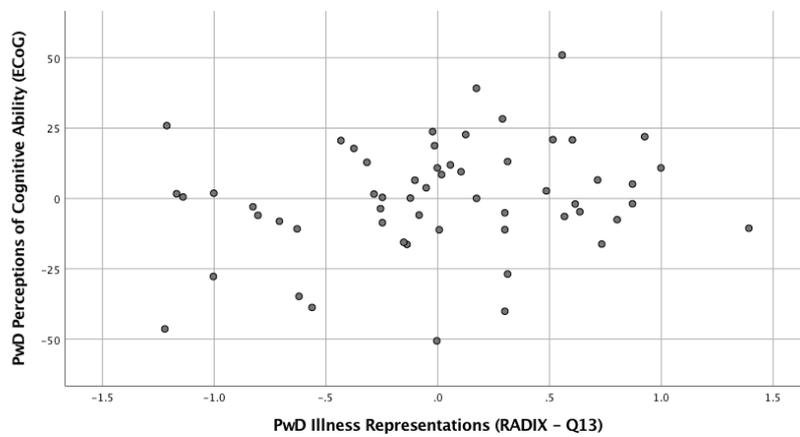
Appendix X. Hypothesis 1 linear multiple regression assumptions



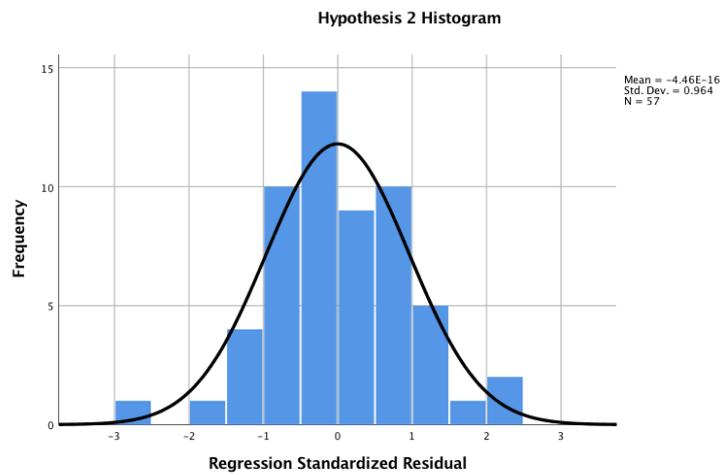
Hypothesis 1 P-P Plot of Regression Standardized Residual



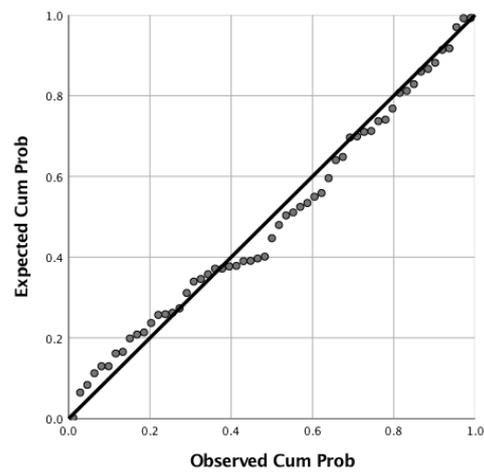
Hypothesis 1 Partial Regression Plot



Appendix Y. Hypothesis 2 linear multiple regression assumptions



Hypothesis 2 Normal P-P Plot of Regression Standardized Residual



Hypothesis 2 Partial Regression Plot

