Conceptualising and Challenging Dementia Related Stigma

Jemini Bhatt

DClinPsy thesis (Volume 1) 2024

University College London (UCL)

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name:

Jemini Dineshkumar Bhatt

Date: 10th July 2024

Overview

This thesis investigates dementia-related stigma in two parts. Part one is a systematic review and meta-analysis where I present the use of the Dementia Attitudes Scale in intervention studies designed to improve attitudes towards people living with dementia. The findings presented in part one indicate that interventions that are education based as well as those that combine education and contact-based elements improve attitudes towards dementia. The meta-analysis results suggest high levels of heterogeneity between included studies and therefore results should be interpreted with caution.

Part two is an empirical paper where I present a psychometric validation of the Stigma Impact Scale in a global sample of people living with dementia from 42 countries. The findings of the psychometric validation indicated that the SIS had ‘good’ to ‘excellent’ internal consistency however convergent reliability could not be concluded as the correlations between well-being and quality of life with the SIS were not as predicted. Participants strongly endorsed the SIS items, which indicates that the item level concepts are relevant for people living with dementia. In the factor analysis, there were marginal improvements in the global fit indices between the theoretical and proposed models however, none of the indices surpassed the cut off points. Further investigation of factor structure and validity is required for future use. Part three is a critical appraisal of specific aspects of the research process such as the theoretical underpinnings of the SIS and the methodological choices that were made in the empirical paper.

Impact statement

In this thesis, I provide insights into dementia-related stigma with findings that have the potential to impact clinical practice with people living with dementia, future work in the field of psychosocial dementia research and health and social care policy.

1. Clinical practice with people living with dementia

The implementation of evidence-based interventions is the cornerstone of psychological practice therefore the findings of my systematic review and meta-analysis have several key implications. First, educational interventions can be used to improve attitudes towards dementia in our clinical workforces (IAPT, NHS physical health settings) where clinical psychology can play an active role in training design and delivery. Secondly, clinical training programmes (medicine, clinical psychology, nursing) can successfully improve attitudes towards dementia and the likelihood of students or trainees wanting to pursue careers in dementia through education and education with contact based interventional approaches.

The findings of my empirical chapter reinforce the debilitating psychological and social consequences as a result of stigma for people living with dementia in a global sample. It is imperative to build stigma measurement using the SIS in to various levels of clinical provision from initial assessments in community mental health or memory services, to physical health settings such as general practice. It is critical for mental health professionals (community clinical psychologists, dementia navigators) and physical health professionals (e.g. diabetes nurses, GPs) involved in the care of people living with dementia, to recognise the impact of stigma and have access to a reliable and robust measurement tool to assess self-stigma.

2. Future work in psychosocial dementia research

I provide the first validation of the Stigma Impact Scale in a global population of people living with dementia, building on my existing work using this measure in European populations. I make recommendations for future research whereby further work to validate the SIS factor structure needs to be considered particularly as my findings indicate how heavily endorsed the measure was in a global sample of people living with dementia, speaking to the universality of the stigma experience in dementia. It is imperative that future work builds on the revised three-factor model of self-stigma comprised of rejection and secrecy, loneliness and belonging and perceived social isolation in order to develop this conceptualisation further through mixed methods to inform testing of the SIS. Revising the theoretical model and therefore the resulting measurement instrument would ensure a robust and validated measure of self-stigma in dementia is utilised to evaluate efforts of stigma reduction.

3. Health and social care policy

Several organisations have prioritised anti-stigma work to promote positive attitudes towards dementia and in turn improve the lives of those living with the syndrome. In this thesis I present interventions that significantly improve attitudes towards dementia, future policy can implement this existing knowledge rather than reinvent the wheel when designing campaigns and awareness raising agendas. I also present a model through which self-stigma in dementia can be conceptualised and quantified, both critical steps required to improve psychological and social outcomes for people living with dementia.

Table of Contents

Part One: Literature Review

Part Two: Empirical Chapter

Part Three: Critical Appraisal

Appendices

List of Tables

Part One: Literature Review

Part Two: Empirical Paper

List of Figures

Part One: Literature Review

Part Two: Empirical Paper

Acknowledgements

I would like to thank Katrina Scior, Rob Saunders, Georgina Charlesworth and Sara Evans for their supervisory support, guidance and unwavering commitment to my learning. I am grateful to Alzheimer's Disease International for the permission to use data gathered in the World Alzheimer Report 2019 and to the people living with dementia who took the time to take part in the survey.

I am thankful to my wonderful family for putting up with me, making sure the kettle is always hot and snacks are near. Hemani and Dad, thank you for sticking by me even in my most stressful times, you kept me smiling and moving forward. Dylan, thanks for coming along and teaching me so much about what matters. To my fantastic husband Mishal, without your support I would not have been able to deliver this thesis. Mum your absence is felt every day, but wherever you are I hope you are watching and I hope you are proud.

.

Part 1: Literature Review

Ameliorating Attitudes towards People Living with Dementia: A Systematic Review and Meta-analysis of intervention outcomes as Measured by the Dementia Attitudes Scale

Aim: This review and meta-analysis evaluates change pre and post intervention in studies that aimed at improving attitudes towards people living with dementia and used the Dementia Attitudes Scale.

Method: Ovid (Medline, PsycINFO), EBSCOHost (CINAHL) and Web of Science were searched to identify studies that reported findings with an experimental design using the DAS. A meta-analysis of DAS scores and meta-regressions of intervention characteristics were performed.

Results: Fourteen intervention studies were included in the review and data from 5070 participants were pooled in the meta-analysis. The majority of the studies were quasi-experimental and one was an RCT. Of the 14 interventions, eight were education based and six combined education and contact-based components. The pooled effect size of studies indicated that there was a significant improvement in the overall DAS score as measured before and after the intervention.

Conclusion: The results of this meta-analysis suggest that various education and education+contact based interventions can improve attitudes towards people living with dementia. A notable amount of between study heterogeneity was found, which given the

inclusion criteria of this review was to be expected but this was not explained by intervention type, intervention length or follow-up period.

1. Introduction

1.1 Dementia

Dementia is characterised by a decline in cognitive functioning abilities such as memory, decision-making, planning, attention, awareness, language and inhibition. The Diagnostic and Statistical Manual of Mental Disorders 5th Edition, categorises dementia as a major neurocognitive disorder (American Psychiatric Association, 2013). Dementia is a syndrome in which a number of neurological diseases or pathologies can ultimately lead to a type of dementia, for example, Alzheimer's disease which accounts for 60 to 70% of the global prevalence of dementia.

According to the World Health Organisation (WHO), 55 million people worldwide currently live with dementia with approximately 10 million new cases per year and two thirds of people reside in low and middle-income countries (WHO, 2013). A leading cause of death and disability in older adults, dementia costs the global economy £1.3 trillion US dollars, almost half of which can be accounted for by the work of informal unpaid carers (WHO, 2013).

1.2 Global focus on stigma and dementia

In 2019, the World Alzheimer Report provided the first prevalence data for unfair treatment of people living with dementia (Alzheimer's Disease International, 2019). The findings presented in this report amplified the need to put stigma on the list of priorities for psychosocial dementia research. Alongside this report, in 2017 the WHO World Health Assembly endorsed the 'Global Action plan on the public health response to dementia 2017-2025'. This outlined seven areas to improve the lives of people living with dementia, their carers and their family units. Of importance to this chapter and thesis, is area number 2, ‘Dementia Awareness and Friendliness’, which outlines proposed actions for member states that focus on challenging the stigma of dementia (WHO, 2017). Stigma reduction efforts in dementia were framed by the WHO as a way to promote the basic human rights of people living with dementia, under the Convention on the Rights of Persons with Disabilities, more specifically the WHO call for interventions to improve attitudes towards dementia to create dementia-friendly environments.

1.3 Defining Attitudes

An attitude has been defined as an evaluation of an object (Maio, Verplanken, & Haddock, 2018). Negative attitudes, defined as negative beliefs assigned to particular social entities (e.g. someone living with dementia), are widely considered a necessary prerequisite to the stigmatisation process (Corrigan & Watson, 2002; Link & Phelan, 2006; Pescosolido & Martin, 2015; Thornicroft, Rose, Kassam, & Sartorius, 2007). Negative attitudes, also referred to as stereotypes, interact with the endorsement of beliefs (prejudices), a lack of knowledge and the performance of negative behaviours (discrimination) that target a “discredited” individual due to a particular characteristic such as a diagnosis of dementia to form public stigma (Thornicroft, 2003). Therefore, stigma reduction interventions often seek to improve attitudes in the hope that these will lead to behaviour change. However, they often fail to examine behaviour, even though acts of ostracism, rejection and discrimination are what has the most negative impact on the lives of members of stigmatised groups.

1.4 Stigma Reduction Interventions to Improve Attitudes

Stigma reduction interventions can be categorised based on Corrigan and Penn’s (1999) stigma reduction framework, accordingly, interventions aimed at reducing public stigma in dementia have been categorised as educational (debunk myths, raise awareness), contact-based (physical interaction with people living with dementia), protest (actively challenge negative beliefs and stereotypes) and some that are a mixture of these components (Corrigan & Penn, 1999). There is a large body of evidence that speaks to education and contact-based interventions improving attitudes towards people with mental health conditions.

A meta-analysis of outcome data from 72 studies of mental health stigma reduction interventions, both education and contact-based interventions significantly improved attitudes and intended behaviours towards people with mental health conditions. However, greater improvement was seen in contact-based interventions which contained face to face contact rather than video material (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). A meta-analysis of 15 awareness campaigns found attitudes towards depression and suicide improved in the short term (Dumesnil & Verger, 2009). In a Cochrane Review, Clement et al. (2013) analysed data from 19 studies in their meta-analysis of mass media interventions designed to reduce the stigma of mental health, they found small to medium effects in improving attitudes immediately post intervention and approximately 9 months after (Clement et al., 2013). Lastly, a review of 216 systematic reviews found that interventions with contact based components such as social contact in the form of in person, virtual or indirect contact were most successful at reducing the stigma of mental health, so long as they were appropriately grounded within the respective cultural context (Thornicroft et al., 2022).

In other stigmatised populations such as HIV/AIDS, a recent systematic review of 14 intervention studies demonstrated effective stigma reduction when interventions had education based components (Sengupta, Banks, Jonas, Miles, & Smith, 2011). A review of interventions designed to reduce the stigma of substance use disorder, another heavily stigmatised condition, concluded that education and contact-based approaches targeting particular groups, such as medical students and the police, are effective in reducing stigma (Livingston, Milne, Fang, & Amari, 2012). Collectively, the evidence I have reviewed shows that education and contact-based interventions can improve attitudes towards stigmatised populations, in terms of reducing prejudice and increasing knowledge. They have also been shown to shift behavioural intentions in a positive way but, as noted earlier, their effects on actual behaviour is far less clear and under-researched.

1.5 Measurement of attitudes towards dementia

There is no gold standard measure of attitudes towards dementia in the dementia-related stigma field. This has negative consequences for evaluating stigma reduction interventions as measures of low quality, not validated in large samples and diverse settings, may lead to inaccurate interpretations regarding the effectiveness of interventions (Bacsu et al., 2022; Herrmann et al., 2018).

In a recent review, Herrmann et al. (2018) concluded that there was no gold standard measure to assess stigma. They identified three standardised measures designed to assess dementia-related stigma in the general public: the

STIG-MA survey (Piver et al., 2013), Dementia Stigma Questionnaire (Woo & Chung, 2013), and the Stigma Questionnaire (Cheng et al., 2011). However, none of these measures focus specifically on attitudes nor were they originally designed for measuring attitudes towards dementia. Specifically, the STIG-MA survey was originally designed for people with leprosy in India and the instructions for completing the dementia version ask participants to imagine themselves with a dementia diagnosis which is semantically different to appraising one's attitudes towards dementia more generally. The Dementia Stigma Questionnaire (Woo & Chung, 2013) and the Stigma Questionnaire (Cheng et al., 2011) were developed through selecting various items from several measures to serve the purposes of a particular study. This approach to scale development lacks validation and therefore cannot be considered psychometrically sound.

Other instruments include ageism scales such as the Kogan Attitudes towards Older People Scale (Kogan, 1961) and the Fraboni Scale of Ageism (Fraboni, Saltstone, & Hughes, 1990). Both scales are psychometrically sound but were not specifically designed for testing attitudes towards dementia and have been criticised for their limited generalisability, item transparency and social desirability (Antonak & Livneh, 1995; Thomas, Palmer, Coker-Juneau, & Williams, 2003).

In addition to the above mentioned measures, Bacsu and Colleagues (2022) reviewed stigma reduction interventions in a scoping review. Several studies (3 of 8 quantitative studies) used the Dementia Attitudes Scale (DAS; O'Connor & McFadden, 2010), which was the only measure used more than once in the included studies. The DAS has also been used in several cross sectional studies that report good internal consistency (Cronbach's Alpha 0.77-0.85;

Abdalrahim et al., 2023; Korkmaz Aslan, Kılınç İşleyen, & Kartal, 2023; Zhu, Schall, Paulitsch, Pantel, & Tesky, 2023).

1.6 The Dementia Attitudes Scale

One of the most frequently used and validated measures of attitudes towards dementia is the Dementia Attitudes Scale (DAS; O'Connor & McFadden, 2010). The DAS was developed based on the tripartite model of attitudes (Breckler, 1984) and used a strategy for the development of close-ended psychometric instruments in older adult populations (Krause, 2002). The tripartite model of attitudes conceptualises attitudes as comprising of three components: affect (sympathetic nervous response), behaviour (overt actions) and cognition (perceptual responses) – all three of these components can be verbally communicated as statements about one's affect, behaviour and cognitions towards social entities (Breckler, 1984).

The DAS has two subscales: the 12-item 'comfort' subscale, which relates to cognitions towards people living with dementia such as "I cannot imagine taking care of someone with Alzheimer's disease or related dementias (ADRD)" and "I am comfortable touching people with ADRD", and the 'knowledge' subscale, which consists of eight items relating to affective and behavioural components of attitudes towards people living with dementia, such as "I admire the coping skills of people with ADRD" and "it is possible to enjoy interacting with people with ADRD". The items are scored on a 7-point Likert scale, therefore total scores range from 20-140, with higher scores indicative of more positive attitudes towards people living with dementia.

1.7 Rationale for undertaking the current review

Attitudes towards dementia are a key component of the stigma process. In populations such as mental health and HIV/AIDS, one evidenced method of stigma reduction is to improve attitudes towards stigmatised individuals. Stigma reduction in dementia is a global priority and therefore interventions to improve attitudes have been tested but often with low quality measures that have not undergone psychometric assessment. Interventions designed to improve attitudes towards dementia are varied and include components such as education, contact or a combination of the two (J. D. Bacsu et al., 2022). However, there is a lack of evidence that speaks to their overall effectiveness or whether one particular component is more effective than another. A common measure of attitudes towards dementia, specifically developed for people living with dementia and with good reliability is the DAS. Previous reviews have noted the variability in quality of instruments used to measure attitudes towards dementia – in contrast, the DAS appears to be a versatile and psychometrically robust measure. Although a recent scoping review has described interventions aimed at improving attitudes towards dementia, no attempt at a meta-analysis of interventions has been made. To fill the knowledge gap, this systematic review and meta-analysis chapter will therefore focus specifically on studies that have used the DAS to evaluate interventions aimed at improving attitudes towards dementia.

1.8 Aim

This review set out to evaluate pre and post change in DAS scores using a meta-analysis of intervention studies aimed at improving attitudes towards people living with dementia.

2. Methods

2.1 Systematic review eligibility criteria

The following were the eligibility criteria for the review

- *Study Design.* Studies reporting findings with an experimental design that sought to evaluate an intervention, e.g. quasi-experimental or randomised controlled trials (RCT)
- *Outcome measure.* Studies that used the Dementia Attitudes Scale (DAS) in any capacity (e.g. primary, secondary or otherwise) to evaluate an intervention
- *Intervention.* Studies of interventions related to dementia, in any format or topic within the broad umbrella of "dementia"
- *Publication language:* Published in the English language
- *Publication Year.* Published 2010 onwards as this was the year the DAS was published
- *Study Focus.* Studies using the DAS to evaluate an intervention aimed to improve attitudes towards people living with dementia

2.2 Search Strategy

The search took place in April 2024 and was conducted in Ovid (Medline, PsycINFO), EBSCOHost (CINAHL) and Web of Science, using the search term "Dementia Attitudes Scale". Filters were set so that only papers that were published in the English language between 2010 to present with humans appeared. Attempts to find additional articles were made by searching the reference lists of a recent scoping review on interventions for stigma reduction in dementia (Bacsu et al., 2022).

2.3 Study Selection and Data Extraction

JB undertook the study selection and data extraction processes. There were several stages to the screening process conducted in Microsoft Excel and Mendeley Desktop. First, the titles and abstracts of all identified articles were screened for the inclusion of the DAS. Titles and abstract that did not mention the DAS as an outcome measure (primary, secondary or otherwise) were excluded and all other articles were retrieved. Secondly, the retrieved full texts were searched against the eligibility criteria for the study, specifically with regards to the study design and intervention where these could not be fully ascertained at the title and abstract level. Only studies that had appropriate designs, used the DAS to evaluate an intervention specific to dementia remained and were subjected to analysis. Data extraction was carried out in Microsoft Excel. The extraction database was informed by the Joanna Briggs Institute (JBI) data extraction tool and the PRISMA guidelines (Page et al., 2021).

2.4 Risk of Bias Assessment

The JBI quasi-experimental quality appraisal tool (Barker et al., 2024) was used to assess the risk of bias in intervention studies, which comprised of nine questions with the following response categories “yes”, “no”, “unclear and “not applicable (n/a)” for each question. The JBI RCT quality appraisal tool for RCTs (Barker et al., 2023) was used for studies that were described as RCTs. The tool consisted of 13 questions with the same response categories outlined above. In order to aid comparison of quasi-experimental studies, each study was given a total quality appraisal score where one (yes) or 0 (no, unclear and n/a) referred to specific response categories which were summed to calculate a total score for each study. The same scoring was also used for consistency for the RCT although no comparisons were made between the RCT and quasi-experimental studies as the respective tools each had different numbers of questions which were specific to the nature of the design and therefore not comparable.

Barker and colleagues recommended that the quality appraisal tools be seen as a way to integrate critical appraisals of included articles into the results rather than to omit studies from systematic reviews. Based on this recommendation, no articles were excluded due to the quality appraisal score but limitations of studies were discussed in detail in the last section of this chapter.

2.5 Statistical Analysis

2.5.1 Meta-Analyses

R (Version 4.3.2) was used to conduct a meta-analysis with the aim of pooling the effect sizes of all the studies which reported pre and post DAS scores whilst examining the between studies heterogeneity. First the effect size (Cohen's d) was calculated using the mean, standard deviation and number of participants for the DAS measurement at baseline and follow-up using the 'effectsize' and 'esc' package in R. Upper and lower bounds calculated from the interquartile range (IQR) were used for outlier detection.

Intervention studies with multiple intervention arms, e.g. multiple interventions to reduce stigma, were submitted as separate data points to the meta-analysis. However, intervention studies that included control arms that were 'no intervention' or 'treatment as usual' were not included in the statistical analyses.

The 'meta' and 'metagen' package in R was used to conduct the meta-analysis. Differences in sample, intervention, follow-up and other characteristics were explored narratively to hypothesise levels of between study heterogeneity. A random-effects model was used for pooling effect sizes so that between-study heterogeneity was accounted for using a restricted maximum likelihood estimator, the Knapp-Hartung adjustments were used to minimise the risk of a false positive result.

The Higgins & Thompson's I^2 statistic was calculated to quantify between study heterogeneity, more specifically the statistic represents the proportion of the variability of effect sizes that is not caused by sampling error (Harrer, Cuijpers, & Ebert, 2021). I^2 was interpreted using three categories, where ≤ 25% was considered low heterogeneity, ≤ 50% moderate and ≥ 75% high heterogeneity (Higgins & Thompson, 2002). A forest plot was calculated to give a graphical representation of the effect sizes across studies and a funnel plot provided a visual representation of effect sizes and standard error of each study to assess publication bias. In the funnel plot, the effect size (intervention effect) was plotted on the horizontal axis and the standard error on the vertical axis, 95% confidence intervals were used to create a funnel shaped plot area (Higgins & Green, 2008). In the presence of publication bias, funnel plots follow an asymmetrical pattern indicative of an overestimation of intervention effect (Higgins & Green, 2008).

When studies varied considerably in design (e.g. quasi-experimental, RCT) a sensitivity analysis was performed to control for the influence of studies with control arms versus those without. This involved re-running the meta-analyses again separating studies with and without control conditions.

2.5.2 Meta-Regression

Meta-regression, using a mixed effects model, with categorical predictors was carried out for potential intervention characteristics that may explain between-study heterogeneity found in the meta-analysis. Dummy-coding was used to assign values of one or two to each predictor, namely intervention type (1= education interventions, 2 = education and contact-based interventions), length (1 = ≤ 1 day; 2 = >1 day), and follow-up period (1 = immediately post intervention; 2 = any other periods e.g. 1 day to 24 months). The R^2 statistic was used to interpret the variance explained in true effect sizes of DAS scores of intervention studies, specifically amount of heterogeneity accounted for by intervention type, length and follow-up period. These meta-regressions were also performed for each subscale of the DAS to uncover potential explanations for difference between studies.

3. Results

3.1 Overview of the Studies Included

The PRISMA flow diagram (

) displays search results and the studies excluded at each stage. Twenty studies fulfilled the inclusion criteria but only data from 14 were submitted to the meta-analysis due to lack of available data (n=4) or as a result of studies that duplicated data already included in the review (n=2). Authors from the four studies with missing data were contacted for the missing data but did not reply. In the included studies, data from 5070 participants were pooled in the meta-analysis presented below.

3.2 Study Characteristics

3.2.1 Design, Participants and Location

Study characteristics are presented in

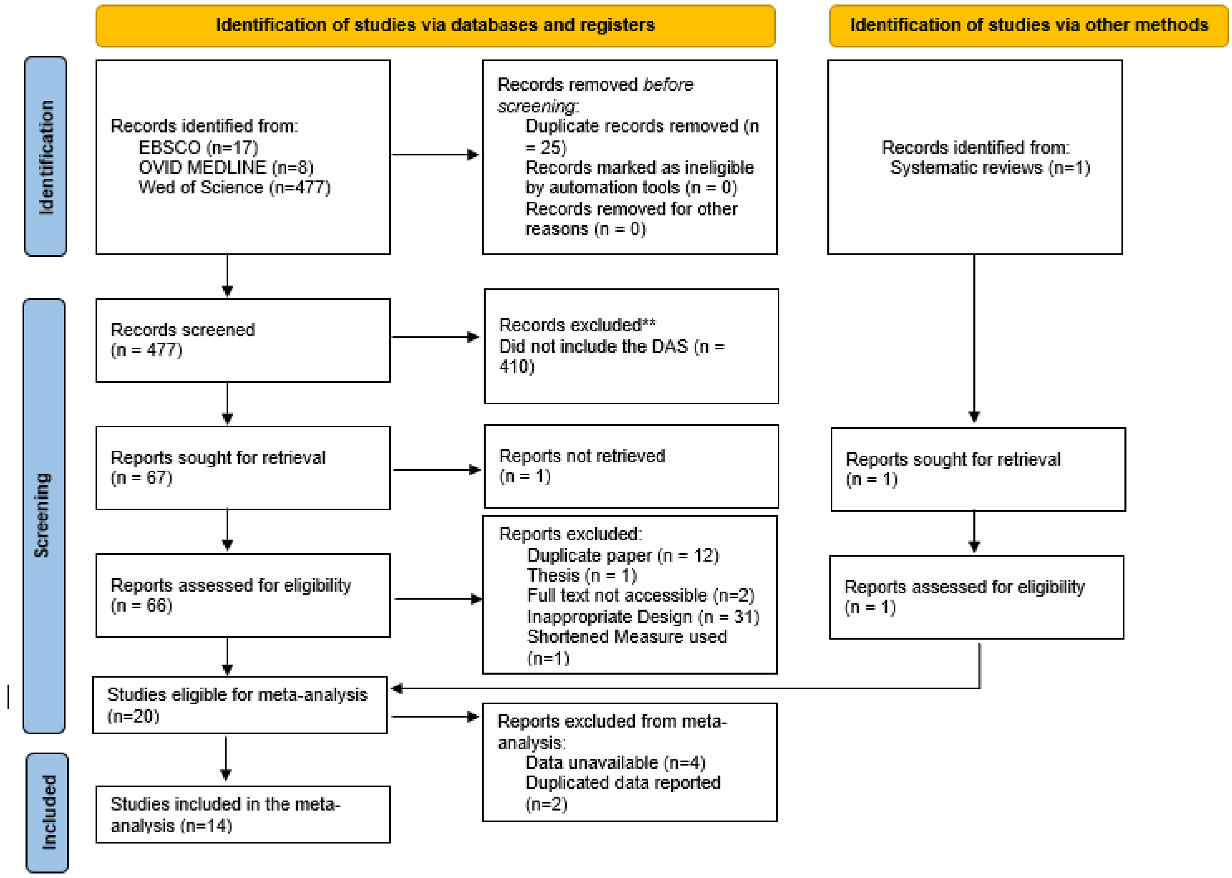


Figure 3.1. PRISMA flow diagram representing the identification, screening and inclusion of studies

Table 3.1. Thirteen out of 14 studies had quasi-experimental designs whereby attitudes towards dementia were measured pre and post intervention (Berning et al., 2023; Cetingok, Irmak, & Gultekin, 2023; Chan et al., 2020; Cheung, Ho, Kwok, Lai, & Lai, 2022; Cowan, 2021; Daley et al., 2023; Natalia Duarte, Alves, & Gomes, 2023; George, Stuckey, & Whitehead, 2014; Lokon, Li, & Parajuli, 2017; Maskeliunas, Damasevicius, et al., 2019; Roberts & Noble, 2015; Tirado-Rafferty et al., 2023; Yordy, Stuart Pope, & Wang, 2019). The final study was an RCT (Wang, Cheung, Leung, & Davidson, 2021). The majority of

participants were university students from a range of academic programmes including medicine and nursing. Other participants included health and social care professionals, carers, and members of the general public and a mixture of these groups

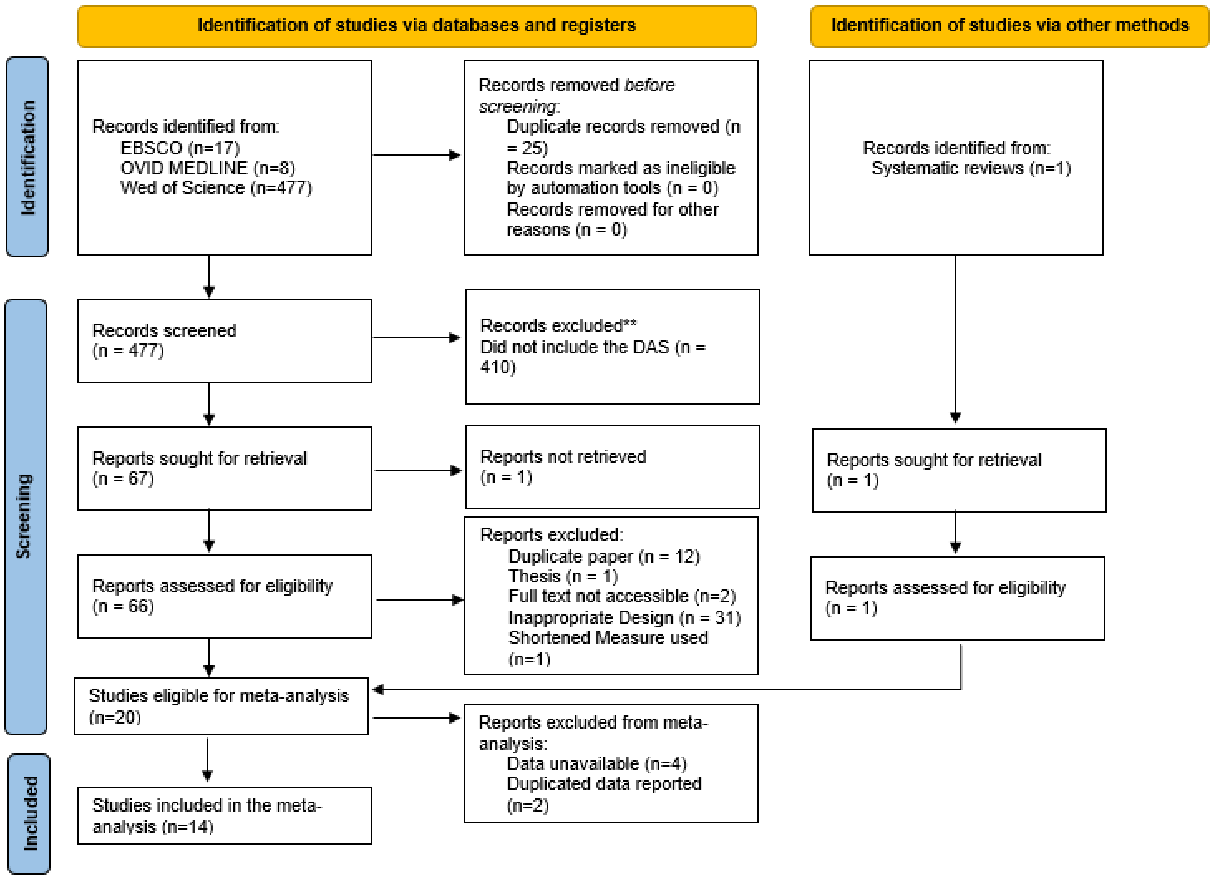


Figure 3.1. PRISMA flow diagram representing the identification, screening and inclusion of studies

Table 3.1. Summary of study characteristics, interventions and main findings

Reference	Location	Design	Nature of participants	Number of Participants	Type of intervention	Intervention[a]	Effect size (Cohen's d)	Main Findings	Quality Score[b]
Berning et al. 2023	US	Pre/Post	University Students	102	Educational	Dementia Friends Information Session	-1.31	One-hour Dementia Friends session improved attitudes towards people living with dementia	7/9
Çetingök et al. 2023	Turkey	Pre/Post	University Students	116	Contact/Education	Educational Intervention	-0.66	Both education and contact based components of the intervention improved attitudes and the contact-based component made students more satisfied with their education	7/9
Chan et al. 2020	Scotland	Pre/Post	Health and Social Care Experts	1264	Education	Best Practice in Dementia Care Learning Programme	-0.84	Improvement in attitudes was found in DAS scores and also themes within reflective journals kept by participants	7/9
Cowan 2021	US	Pre/Post	Mixed	101		Dementia Friends	-0.82	One-hour Dementia Friends session improved attitudes towards people living with dementia	6/9
Daley et al. 2023	UK	Pre/Post	University Students	3262	Contact/Education	Time for Dementia	-0.33	Participants who received the intervention showed improvements in attitudes towards dementia but not on other measures	9/9
Duarte et al. 2023	Portugal	Pre/Post	Health Professionals	101	Education	Training Course	-0.52	Improved attitudes towards people living with dementia following intervention	7/9
George et al. 2014	US	Mixed Methods	University Students	22	Contact/Education	TimeSlips	-1.51	Both qualitative data and DAS scores suggest improved attitudes towards dementia and acceptable internal consistency of the DAS	7/9

Lokon et al. 2017	US	Pre/Post	University Students	156	Contact/Educational	Service-Learning Experience (Open Minds through Art)	-1.84	Overall improvement in DAS scores across students but greatest difference pre-post in non-nursing students	7/9
Maskeliunas et al. 2019	Lithuania	Pre/Post	Carers of people living with dementia and social care professionals	48	Education	Serious Game iDO	-2.14	Improved attitudes towards people living with dementia following game participation	7/9
Roberts et al. 2015	US	Pre/Post	University Students	19	Contact/Education	Community based arts programme	-0.76	Qualitative findings and DAS scores reflect improvement in attitudes towards dementia	6/9
Tirado-Rafferty et al. 2023	US	Mixed Methods	General public	229	Education	Dementia Friends	-0.69	One-hour Dementia Friends session improved attitudes towards people living with dementia.	6/9
Yordy et al. 2019	US	Pre/Post	University Students	60	Contact/Education	CanineOutreachPromoting Engagement (COPE) a type of Animal Assisted Activities (AAA)	-1.09	Students felt more comfortable and knowledgeable about dementia following intervention as shown on DAS scores	7/9
Cheung et al. 2022	China	Randomised Clinical Hybrid Trial	General public	107	Education	Training and Enrichment Workshop (with the view to deliver the Music-with-Movement Intervention)	-0.21	Intervention improved attitudes towards people living with dementia and was associated with higher motivation to volunteer with this population	6/9

Wang et al. 2021	China	Pilot RCT	Carers of people living with dementia	60	Education	Bibliotherapy	-1.23	Carers' DAS scores improved as well as positive aspects of caregiving, well-being and personal growth	12/13

[a]Interventions are described in more detail in section 3.3.
[b]JBI quasi-experimental (out of 9) and RCT (out of 13) quality appraisal tools were used to calculate quality scores

Participants' ages ranged from 21 to 62 years of age. Of the studies that reported sex (n =12 studies), 4365 of the overall participants were female, 1087 male and two reported 'other'. Six of the included studies (n = 3158 participants) reported ethnicity; the majority of participants were white (n=2460), with some other ethnicities represented as follows: Black-African/Caribbean (n=348), Asian-Pacific Islander (n=5), Asian American (n=9), Indian Alaskan Native (n=2), Latina/Hispanic, other and mixed (n=334). Overall, 36 participants were lost to follow-up and the period of follow-up ranged from immediately post-intervention to 24 months. Studies were from seven different countries: the United States of America (n=7), China (n=2), Lithuania (n=1), Portugal (n=1), Scotland (n=1), Turkey (n=1) and the United Kingdom (n=1).

3.3 Interventions in Included Studies and Findings

3.3.1 Education-based Interventions

Eight interventions were education based (Berning et al., 2023; Chan et al., 2020; Cheung et al., 2022; Cowan, 2021; Natália Duarte, Alves, & Gomes, 2023; Maskeliunas, Damaševičius, et al., 2019; Tirado-Rafferty et al., 2023; Wang et al., 2021). Two were education interventions specifically aimed at carers (Maskeliunas, Damaševičius, et al., 2019; Wang et al., 2021), three studies tested the Dementia Friends intervention (Berning et al., 2023; Cowan, 2021; Tirado-Rafferty et al., 2023), and the remaining three tested the Dementia Care Learning Program (Chan et al., 2020), the Training and Enrichment Workshop (Cheung et al., 2022), and a dementia knowledge training course (Natalia Duarte et al., 2023).

3.3.1.1 Education-based Interventions for Carers

Two education based interventions, Bibliotherapy for carers of people living with dementia (Wang et al., 2021) and Serious Game iDO for carers and caring professionals (Maskeliunas, Damasevicius, et al., 2019), were designed to promote skills and knowledge about caring for someone living with dementia. The Bibliotherapy intervention was a self-guided manualised programme with eight chapters (each approx. ten pages focused on carer knowledge and problem solving) and eight coaching phone calls (of 20-30 minutes duration) to facilitate engagement based on the premise that carers identified with intervention materials and therefore experienced catharsis and emotional release as a result (Wang et al., 2021). Carers were randomised into control (usual care) and intervention conditions, a total of six and four carers respectively were lost to follow-up; the results indicated that participation in the Bibliotherapy intervention significantly improved attitudes towards dementia (Wang et al., 2021).

The Serious Game iDO was an online scenario-based intervention with a gameplay environment that required participants to acquire various pieces of knowledge to solve challenges that may arise when caring for a person living with dementia whilst also providing out-of-game guidance on particular scenarios and how to tackle them (Maskeliunas, Damasevicius, et al., 2019). The game encouraged players to refer to training materials, apply knowledge in contextualised random scenarios and then progress to unlock more levels and stories. Participants were followed up within four months of baseline measure administration; results indicate a significant improvement in attitudes towards dementia following participation (Maskeliunas, Damasevicius, et al., 2019).

3.3.1.2 Dementia Friends

Three studies used the DAS to evaluate the impact of the Dementia Friends Programme (Berning et al., 2023; Cowan, 2021; Tirado-Rafferty et al., 2023) on attitudes towards people living with dementia. Dementia Friends is a one-session education intervention, using a train the trainer model, which involves a one hour information awareness session delivered by a dementia champion (a person who has completed the Dementia Friends intervention and delivered it at least once). The Dementia Friends programme had five key messages: 1) dementia is not “normal” ageing, 2) several different diseases cause dementia, 3) there are more symptoms than just memory loss in dementia, 4) one can have dementia and still have a good quality of life, and 5) there is more than just dementia to a person with a diagnosis. Across all populations, including students (Berning et al., 2023; Cowan, 2021) and the general public (Tirado-Rafferty et al., 2023), significant improvements in attitudes towards dementia were observed following participation in the Dementia Friends sessions. Follow-up in all three studies was conducted immediately after the Dementia Friends session finished.

3.3.1.3 Other Education-based Interventions

The education content of the last three interventions was specifically around learning about dementia, the skills and competencies required to work with people living with dementia and their families (Chan et al., 2020; Cheung et al., 2022; Natália Duarte et al., 2023). I will now describe these interventions in more detail below.

The Best Practice in Dementia Care Learning Programme (Chan et al., 2020) adopted the train the trainer model whereby Chinese health and social care experts were trained on a curriculum comprised of topics such as person-centred care, communication and behaviour, support for carers, health and well-being and legal aspects of dementia, such that they could then proceed to train staff members in their own institutions. The curriculum was carefully tailored to the sociocultural context and community care in China and each facilitator proceeded to train approximately six members of staff; therefore, participants in this study consist of both facilitators and learners. Attitudes towards dementia were measured before and after participation in the programme and 12 months later. Significant improvements in both facilitators and learners in attitudes towards dementia were found on the DAS (Chan et al., 2020).

The Training and Enrichment Workshop (Cheung et al., 2022) comprised of five two hour mandatory workshops with ten additional enrichment sessions delivered to adult volunteers who were supported with handouts and a participation manual. The aim was to prepare volunteers to deliver the music-with-movement intervention to improve the well-being of people living with dementia and family carers through music. The first mandatory workshop was delivered by a gerontology nurse scientist and outlined information about dementia, cognition and practical skills required to lead the music intervention. The remaining mandatory workshops were led by a music therapist who delivered training on the theoretical and practical aspects of the music intervention, skills such as showing empathy and communication, along with details about the intervention. Volunteers were followed up within two weeks post intervention; attitudes towards dementia improved following the Training and Enrichment Workshops based on the DAS, further volunteers who had improved attitudes towards dementia were also more motivated to volunteer (Cheung et al., 2022).

The Training Course tested by Duarte and Colleagues comprised of a total of nine hours of education delivered over 12 sessions by 12 experts from nursing, social work, medicine and psychology and other similar disciplines (Duarte, Alves, & Gomes, 2023). The aim of the intervention was to train care professionals in recognising dementia as a public health priority, and in understanding symptoms of common types of dementia and their symptomology, various strategies for communication and the impact of dementia on carers. One week after completing the intervention, participants’ DAS scores had increased, indicative of improved attitudes towards people living with dementia (Duarte, Alves, & Gomes, 2023).

3.3.2 Education and Contact-based Interventions

Six interventions were contact-based with education and training elements (Çetingök, Irmak, & Gültekin, 2023; Daley et al., 2023; George, Stuckey, & Whitehead, 2014; Lokon, Li, & Parajuli, 2017; Roberts & Noble; Yordy, Stuart Pope, & Wang, 2019).

3.3.2.1 Arts and Animal contact-based interventions

Three studies reported various contact-based art interventions such as a Community Based Arts Programme (Roberts & Noble, 2015), the Service-Learning Experience (Lokon et al., 2017), and TimeSlips (George et al., 2014), see below. One study outlined a contact-based animal assisted activity called the Canine Outreach Promoting Engagement (COPE; Yordy et al., 2019).Participants in all four studies had significantly increased scores based on pre and post intervention DAS scores suggesting an improvement in attitudes towards people living with dementia following participation.

The Community Based Arts Programme (Roberts & Noble, 2015) was set in various art galleries and museums in New York and aimed to change medical students' perceptions of people living with dementia. The programme was delivered by a museum professional over a 90-minute period during which people living with dementia and their carers engaged in conversation whilst creating art, participants' (students) were assigned to attend one of the programme groups of people living with dementia and their carers and help facilitate the dialogue whilst attendees created pieces of art. Participants were followed up 1-3 days post intervention.

The Service-Learning Experience which was based on the Open Minds through Art intervention (Lokon et al., 2017), consisted of an education-based component (3-5 hours) whereby students were trained on how to support people living with dementia to engage in creative expression with artistic freedom. This was followed by the contact component whereby participants (students) paired up with people living with dementia for 10-12 weeks to facilitate their artistic creations. Participants were followed up immediately post intervention.

TimeSlips, encouraged creative storytelling within a group setting to create an overall group narrative based on real life experiences. Participants were medicine students, trained to deliver TimeSlips and facilitate groups for people living with dementia (George et al., 2014). Participants were trained in TimeSlips which aims to elicit improvisational skills to help one's performance. People living with dementia were given objects and props and encouraged to use their imagination to tell stories. Participants were followed up immediately after they finished facilitating TimeSlips (George et al., 2014).

One study outlined an animal assisted intervention called Canine Outreach Promoting Engagement (COPE), designed to encourage participants (student nurses) to work with cognitively impaired older adults and develop more positive attitudes towards this population (Yordy et al., 2019). The intervention had both educational and contact components: first participants (student nurses) were given training on working with people with impaired cognition after which participants were paired with an older adult whom they visited accompanied by a dog. Participants and people living with dementia were encouraged to interact with the dog as much as possible, and participants were followed up immediately after the intervention was completed (dogs and handlers left the care facility).

3.3.2.2 Other Educational and Contact-based Interventions

Two studies with student participants used a mixed education and contact-based approach with various levels of in-person experience with people living with dementia. This included Time for Dementia (Daley et al., 2023), and an educational intervention of unspecified title (Çetingök et al., 2023).

The educational intervention consisted of two parts. First, participants (Gerontology students) were taught by a multi-disciplinary team about topics such as the neurological basis of behaviour, dementia symptoms and diagnosis, standardised neuropsychology evaluation measures, and communication techniques for working with people living with dementia and their families. Secondly, participants embarked on the contact-based learning component that was facilitated through a simulation (the Dementia Simulation Toolkit) comprised of eight different modules using artificial intelligence to work through various scenarios where participants focused on exercising skills of empathy towards people living with dementia and older adults more generally (Çetingök et al., 2023). Participants were followed up immediately after each intervention component and scores on the DAS increased after each respective part (Çetingök et al., 2023).

The Time for Dementia intervention took place over a 2-year period. First participants (students: medical, nursing, paramedic, and other allied health professions e.g. occupational therapy) attended a 2-hour preparatory workshop focussed on various aspects of working with people living with dementia and their families, such as communication skills; subsequently they undertook 1 to 2-hour visits to people living with dementia and their families every 3-4 months (Daley et al., 2023). Each visit was themed, for example, the first visit focussed on the experience of obtaining a diagnosis of dementia, the steps involved, and how these were experienced by the person living with dementia and their family. Participants were assigned to an intervention and control group, the control group did not receive the intervention or anything else in its place. At follow-up, 24 months from the baseline measurement, DAS scores were higher in participants in the intervention group in comparison to the control group (Daley et al., 2023).

3.4 Interventions of Excluded Studies and Findings

Four studies were excluded from the meta-analysis due to missing data despite efforts to retrieve this data. The interventions and findings of excluded studies are described in this section. Two studies evaluated education based (Patel, Patel, Jindal, Desai, & Desai, 2021; Schneider, Schonstein, Teschauer, Kruse, & Teichmann, 2020) whilst the other two evaluated contact and education based interventions (Heuer, Douglas, Burney, & Willer, 2020; Kimzey, Mastel-Smith, & Alfred, 2016).

3.4.1 Education-based Interventions

The Sensitisation Programme (Patel et al., 2021) comprised of a two hour symposium covering various topics in dementia such as prevalence, symptoms and management, created by medical school interns and a professor of neurology. The symposium was delivered to medical students in their fourth year attending university in India, with the aim of improving attitudes towards dementia following engagement in the programme. Participants were followed up immediately after completing the programme, results indicated that according to DAS scores there were significant improvements in attitudes towards dementia (Patel et al., 2021).

The Dementia Training Programme (Schneider et al., 2020) was a two day training on dementia consisting of eight 45 minute sessions on various topics such as diagnosis, pharmacological interventions, behaviours that challenge etc. The training sessions were delivered by a member of staff from a local dementia third sector organisation to members of nursing and administration staff working in a hospital emergency department in Germany. The educational approach included the use of powerpoint, hard copy materials, videos and pair-group discussions. Participants were followed up, up to 6 months after intervention completion and results indicated a significant positive improvement in attitudes towards dementia following participation in the Dementia Training Programme (Schneider et al., 2020).

3.4.2 Education and Contact-based Interventions

TimeSlips, already described above, was evaluated with undergraduate students across two university's in the USA (Heuer et al., 2020). Participants were undergraduate students who trained in the TimeSlips interventions and thus ran creative storytelling sessions as part of the TimeSlips intervention for approximately 2-14 people living with dementia in residential care home settings. Participants also carried an additional three hours of verbal reflection and problem solving around facilitating the groups. Participants were followed up immediately after finished the TimeSlips sessions and results indicated a significant improvement in attitudes towards people living with dementia from baseline to follow up (Heuer et al., 2020)

The final study evaluated an education and contact based intervention in two experimental groups with a control condition (Kimzey et al., 2016). The educational intervention comprised of an online module covering topics related to dementia such as cognitive assessment, person-centred care management and communication with people living with dementia etc. The contact based intervention included students engaging in a 6-hour clinical day with people living with dementia in two locations a memory care unit and a dementia day centre. Participants were baccalaureate community health students in the USA. Participants in the contact intervention arm were offered the opportunity to reflect on their clinical experiences. Participants were followed up immediately after intervention completion, there was a significant improvement in DAS scores for students who completed both education and contact based interventions, descriptively the greatest improvement was seen in those who experienced the contact-based intervention however intervention type was not significant (Kimzey et al., 2016).

3.5 Risk of Bias Assessment and Critique

This section discusses the quasi-experimental studies evaluated using the respective JBI tool and the single RCT. The mean quality score for the quasi-experimental studies was 6.85 (Table 3.2). One scored 8 out of 9 (Daley et al., 2023); the majority scored 6 out of 9 (Berning et al., 2023; Çetingök et al., 2023; Chan et al., 2020; Natália Duarte et al., 2023; George et al., 2014; Lokon et al., 2017; Maskeliūnas et al., 2019; Yordy et al., 2019), and four studies scored 5 (Cheung et al., 2022; Cowan, 2021; Roberts & Noble, 2015; Tirado-Rafferty et al., 2023).

All quasi-experimental studies clearly stated that changes in the DAS scores were attributed to intervention participation (referred to in the JBI quasi-experimental tool as “cause” and “effect”; session Appendix 3) where the effect was operationalised as an increase in scores on the DAS, indicative of improved attitudes towards people living with dementia following participation. However as no control condition was present, causality cannot be inferred through temporal precedence. The majority of studies were single group studies that compared the same participants pre and post intervention with the exception of one study that included a control condition (Daley et al., 2023). As the majority of studies did not use a control condition, it is plausible that changes in DAS scores were due to other confounding factors. Given the heterogeneity between studies (e.g. population, intervention content) it would be difficult to meaningfully investigate this further.

All quasi-experimental studies compared pre and post scores of the same participants and therefore no confounding factors were introduced. With regards to the measure of interest, the DAS was used in all studies pre and post intervention. The majority of studies were able to retain the same participants pre and post intervention; of those that were not able to, two studies did not report sufficient detail on attrition during follow-up (Cheung et al., 2022; Cowan, 2021; Roberts & Noble, 2015; Tirado-Rafferty et al., 2023). All studies used appropriate statistical analyses to test changes in pre and post DAS scores.

The RCT conducted by Wang et al. (2021) scored 12 of 13; the study performed well with regards to selection and allocation of participants, the use of the DAS in a reliable way, participant retention and statistical conclusion validity (see Table 3.3). It was unclear however, whether participants were blind to the treatment assignment.

Table 3.2. JBI Critical Appraisal Tool for Quasi-Experimental Designs

Domain:	**Temporal precedence**	**Selection and allocation**	**Confounding factors**	**Administration of intervention/ exposure**	**Assessment, detection and measurement of the outcome**			**Participant retention**	**Statistical conclusion validity**	
Question No	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**TOTAL**
Berning et al. 2023	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Çetingök et al. 2023	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Chan et al. 2020	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Cowan 2021	No	no	yes	n/a	yes	Yes	yes	No	yes	6
Daley et al. 2023	No	yes	yes	yes	yes	Yes	yes	yes	yes	9
Duarte et al. 2023	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
George et al. 2014	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Lokon et al. 2017	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Maskeliunas et al. 2019	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Roberts et al. 2015	No	no	yes	n/a	yes	Yes	yes	no	yes	6
Tirado-Rafferty et al. 2023	No	no	yes	n/a	yes	Yes	yes	No	yes	6
Yordy et al. 2019	No	no	yes	n/a	yes	Yes	yes	yes	yes	7
Cheung et al. 2022	No	no	yes	n/a	yes	Yes	yes	no	yes	6

Table 3.3 JBI. Critical Appraisal Tool for Randomised Controlled Trials (RCT)

Domain:	**Selection And Allocation**			**Administration Of Intervention/Exposure**			**Assessment, Detection And Measurement Of The Outcome**			**Participant Retention**	**Statistical Conclusion Validity**			
Question No	1	2	3	4	5	6	7	8	9	10	11	12	13	**TOTAL**
Wang et al. 2021	yes	yes	yes	unclear	yes	yes	yes	yes	yes	yes	yes	yes	yes	**12**

3.6 Statistical Analyses

3.6.1 Meta-analysis

The meta-analysis of effect sizes (using Cohen's d) from pre and post data collected using the DAS total score were pooled (Figure 3.2). The pooled effect size was -0.97 (95% CI, -1.30 ; -.065), $p < .001$. There was high heterogeneity ($I^2 = 95\%$). The findings of this meta-analysis suggest that interventions in the included studies significantly improved attitudes towards people living with dementia as measured by the DAS. The funnel plot (see Figure 3.3) is asymmetrical and therefore is indicative of possible publication bias.

The pooled effect size for the comfort subscale was -0.91 (95% CI, -.1.29; -0.54), $p<.001$ (Figure 3.4). The pooled effect size for the knowledge subscale was -0.59 (95% CI, -.82; -.35), $p <.001$ (Figure 3.5). There was high heterogeneity ($I^2 = 95\%$) for both subscales. The results of these meta-analyses suggest that the interventions significantly improved participants' sense of comfort around people living with dementia and knowledge about dementia although the effect was stronger for comfort than knowledge.

3.6.1.1 Sensitivity Analysis

The meta-analysis was performed again with the removal of the RCT in order to control for design. The pooled effect size was -0.96 (95% CI, -1.30 ; -.061), $p < .001$. There was high heterogeneity ($I^2 = 95\%$). The findings of this meta-analysis suggest that interventions in the included quasi-experimental studies significantly improved attitudes towards people living with dementia as measured by the DAS.

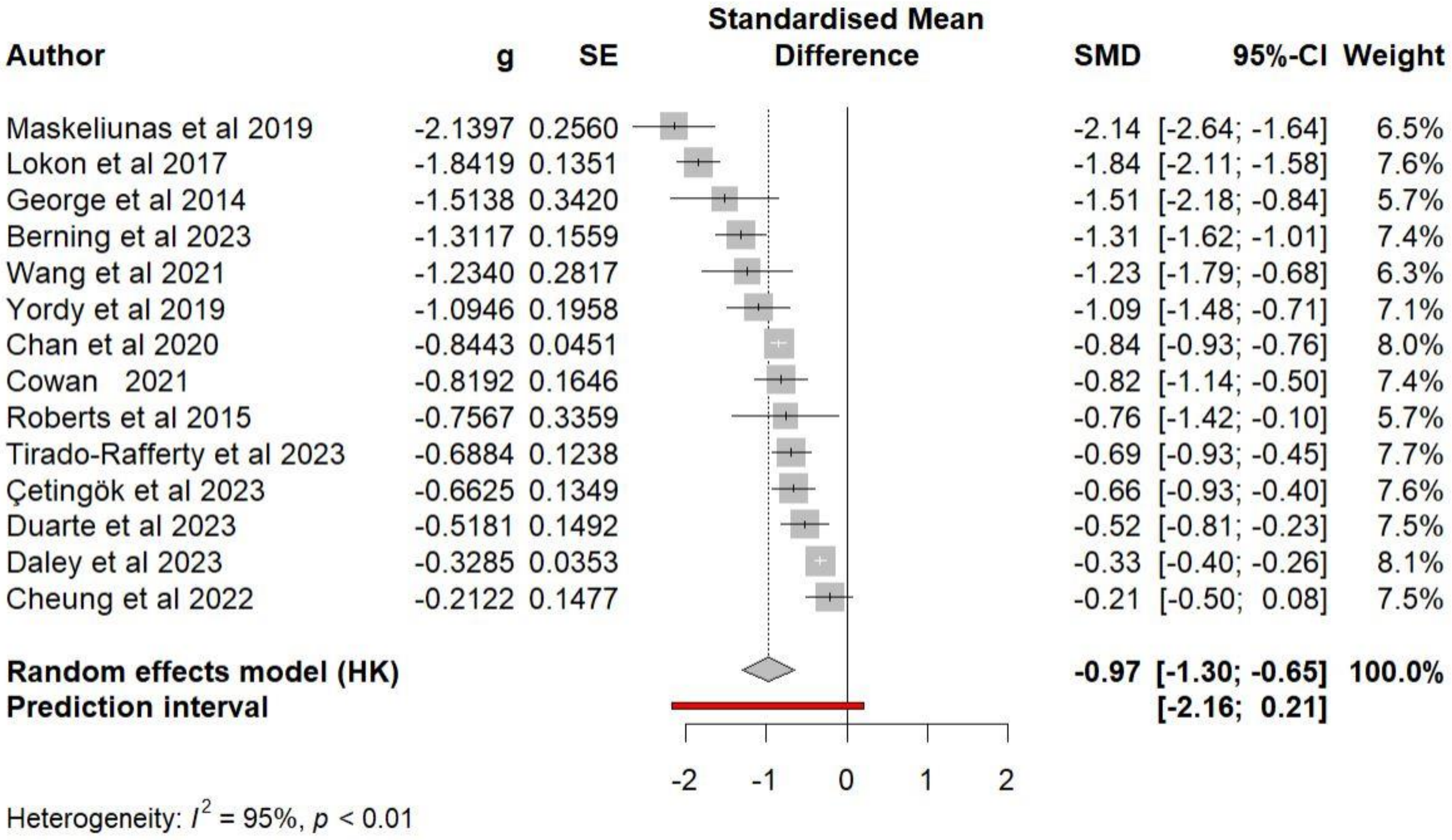
3.6.2 Meta-Regression

The meta-regression analyses found no effect of intervention type, intervention length or follow-up on intervention effect sizes based on DAS score changes (

Table 3.4), suggesting that the between study heterogeneity was not explicable through intervention characteristics. The meta-regressions found no significant effects for either DAS subscales.

Table 3.4. Summary of meta-regression statistics for the DAS and Comfort and knowledge subscales

Overall DAS				
	Estimate	***Standard Error***	***p***	***CI***
Intervention Type	-0.0699	0.3137	0.8274	-0.7533 - 0.6135
Intervention Length	-0.0485	0.3717	0.8983	-0.8583 - 0.7612
Follow-up	0.3317	0.2976	0.2869	-0.3168 - 0.9801
Comfort Subscale of DAS				
	Estimate	***Standard Error***	***p***	***CI***
Intervention Type	-0.4187	0.3234	0.2316	-1.1645 - 0.3272
Intervention Length	-0.0439	0.3829	0.9115	-0.9270 - 0.8391
Follow-up	0.5827	0.2965	0.0849	-0.1010 - 1.2664
Knowledge Subscale of DAS				
	Estimate	***Standard Error***	***p***	***CI***
Intervention Type	-0.0004	0.2222	0.9985	-0.5128 - 0.5119
Intervention Length	0.1203	0.2345	0.6219	-0.4204 - 0.6609
Follow-up	0.3518	0.1894	0.1003	-0.0849 - 0.7885



Author	g	SE	SMD	95%-CI	Weight
Maskeliunas et al 2019	-2.1397	0.2560	-2.14	[-2.64; -1.64]	6.5%
Lokon et al 2017	-1.8419	0.1351	-1.84	[-2.11; -1.58]	7.6%
George et al 2014	-1.5138	0.3420	-1.51	[-2.18; -0.84]	5.7%
Berning et al 2023	-1.3117	0.1559	-1.31	[-1.62; -1.01]	7.4%
Wang et al 2021	-1.2340	0.2817	-1.23	[-1.79; -0.68]	6.3%
Yordy et al 2019	-1.0946	0.1958	-1.09	[-1.48; -0.71]	7.1%
Chan et al 2020	-0.8443	0.0451	-0.84	[-0.93; -0.76]	8.0%
Cowan 2021	-0.8192	0.1646	-0.82	[-1.14; -0.50]	7.4%
Roberts et al 2015	-0.7567	0.3359	-0.76	[-1.42; -0.10]	5.7%
Tirado-Rafferty et al 2023	-0.6884	0.1238	-0.69	[-0.93; -0.45]	7.7%
Çetingök et al 2023	-0.6625	0.1349	-0.66	[-0.93; -0.40]	7.6%
Duarte et al 2023	-0.5181	0.1492	-0.52	[-0.81; -0.23]	7.5%
Daley et al 2023	-0.3285	0.0353	-0.33	[-0.40; -0.26]	8.1%
Cheung et al 2022	-0.2122	0.1477	-0.21	[-0.50; 0.08]	7.5%
Random effects model (HK)			**-0.97**	**[-1.30; -0.65]**	**100.0%**
Prediction interval				**[-2.16; 0.21]**	

Heterogeneity: $I^2 = 95\%$, $p < 0.01$

Figure 3.2. Forest plot showing the pooled effect size of intervention studies as measured by the Dementia Attitudes Scale

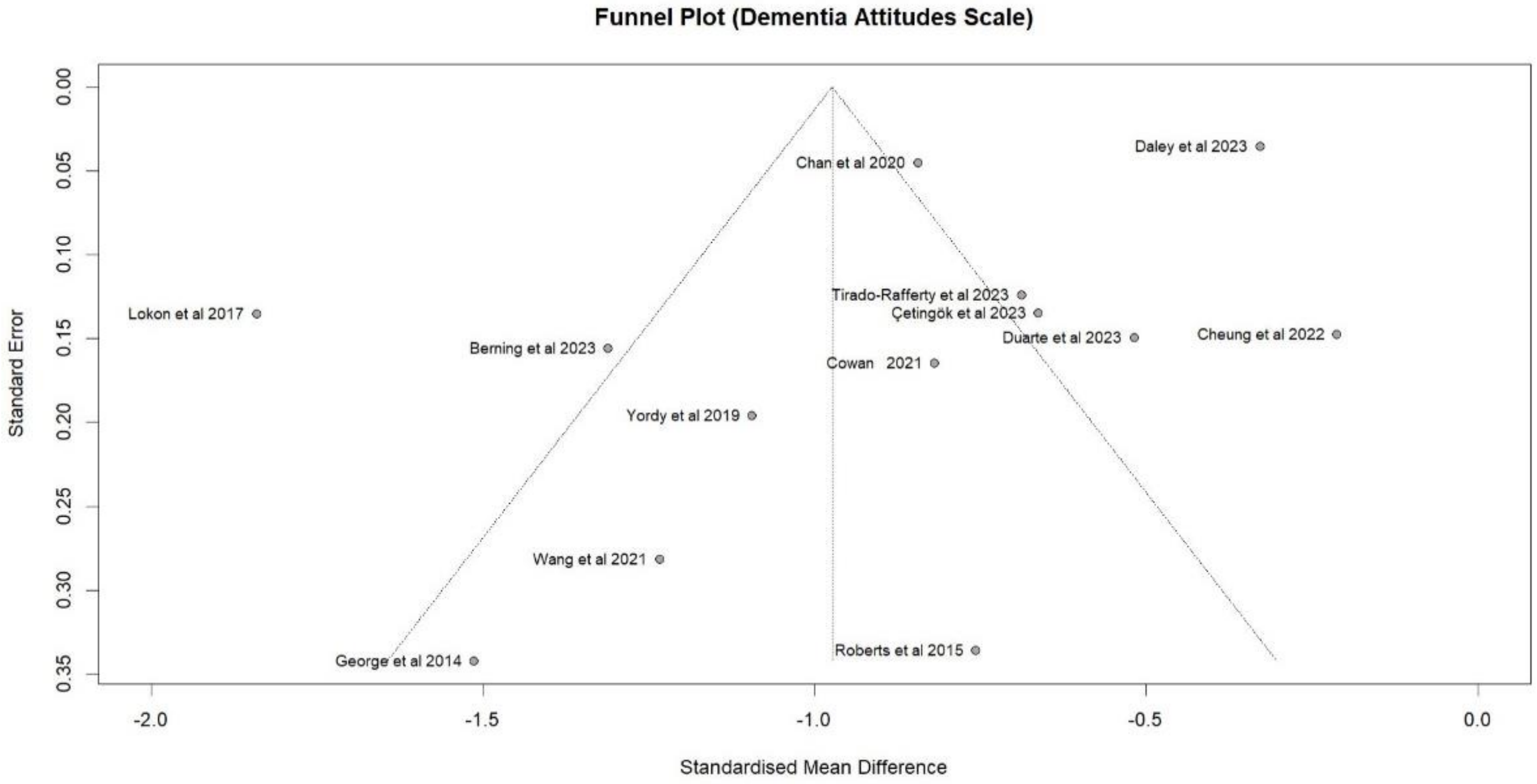
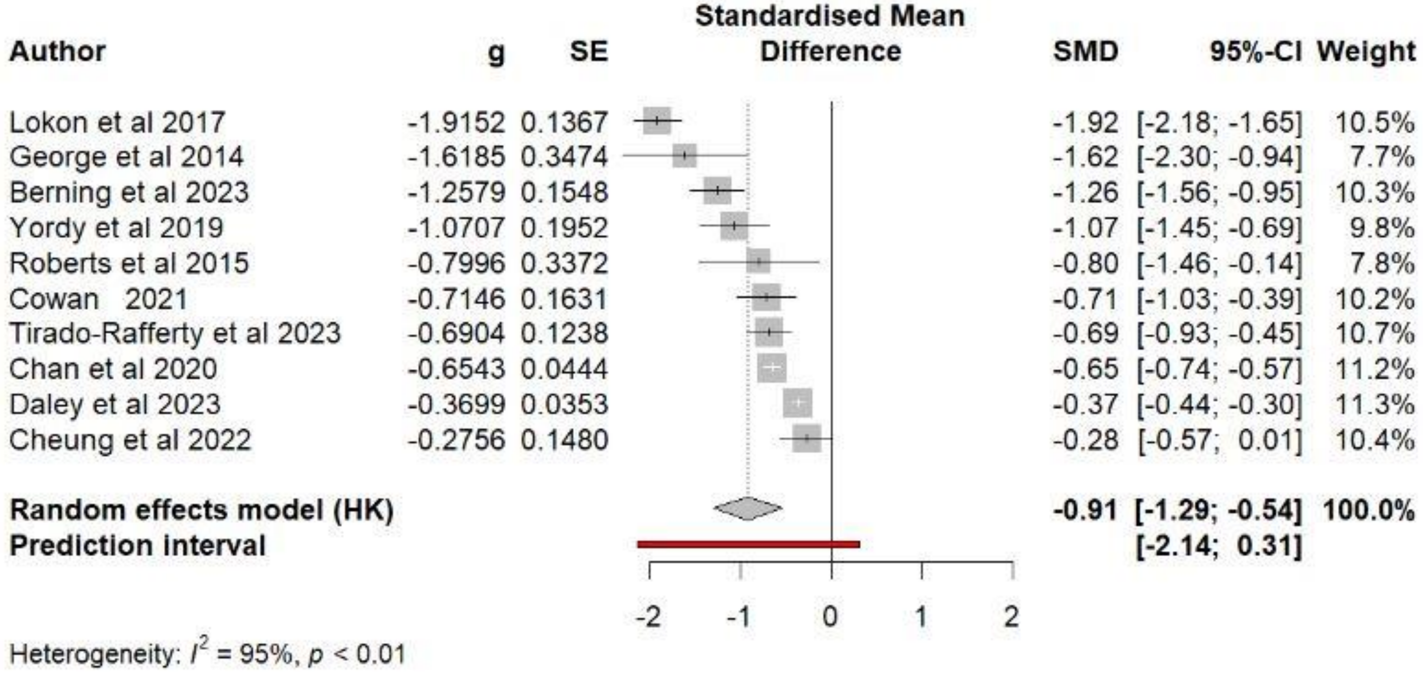


Figure 3.3. Funnel plot of the meta-analysis of pooled effect sizes of intervention studies



Author	g	SE	SMD	95%-CI	Weight
Lokon et al 2017	-1.9152	0.1367	-1.92	[-2.18; -1.65]	10.5%
George et al 2014	-1.6185	0.3474	-1.62	[-2.30; -0.94]	7.7%
Berning et al 2023	-1.2579	0.1548	-1.26	[-1.56; -0.95]	10.3%
Yordy et al 2019	-1.0707	0.1952	-1.07	[-1.45; -0.69]	9.8%
Roberts et al 2015	-0.7996	0.3372	-0.80	[-1.46; -0.14]	7.8%
Cowan 2021	-0.7146	0.1631	-0.71	[-1.03; -0.39]	10.2%
Tirado-Rafferty et al 2023	-0.6904	0.1238	-0.69	[-0.93; -0.45]	10.7%
Chan et al 2020	-0.6543	0.0444	-0.65	[-0.74; -0.57]	11.2%
Daley et al 2023	-0.3699	0.0353	-0.37	[-0.44; -0.30]	11.3%
Cheung et al 2022	-0.2756	0.1480	-0.28	[-0.57; 0.01]	10.4%
Random effects model (HK)			**-0.91**	**[-1.29; -0.54]**	**100.0%**
Prediction interval				**[-2.14; 0.31]**	

Heterogeneity: $I^2 = 95\%$, $p < 0.01$

Figure 3.4. Forest plot showing the pooled effect size of intervention studies as measured by the Comfort Subscale of the Dementia Attitudes Scale

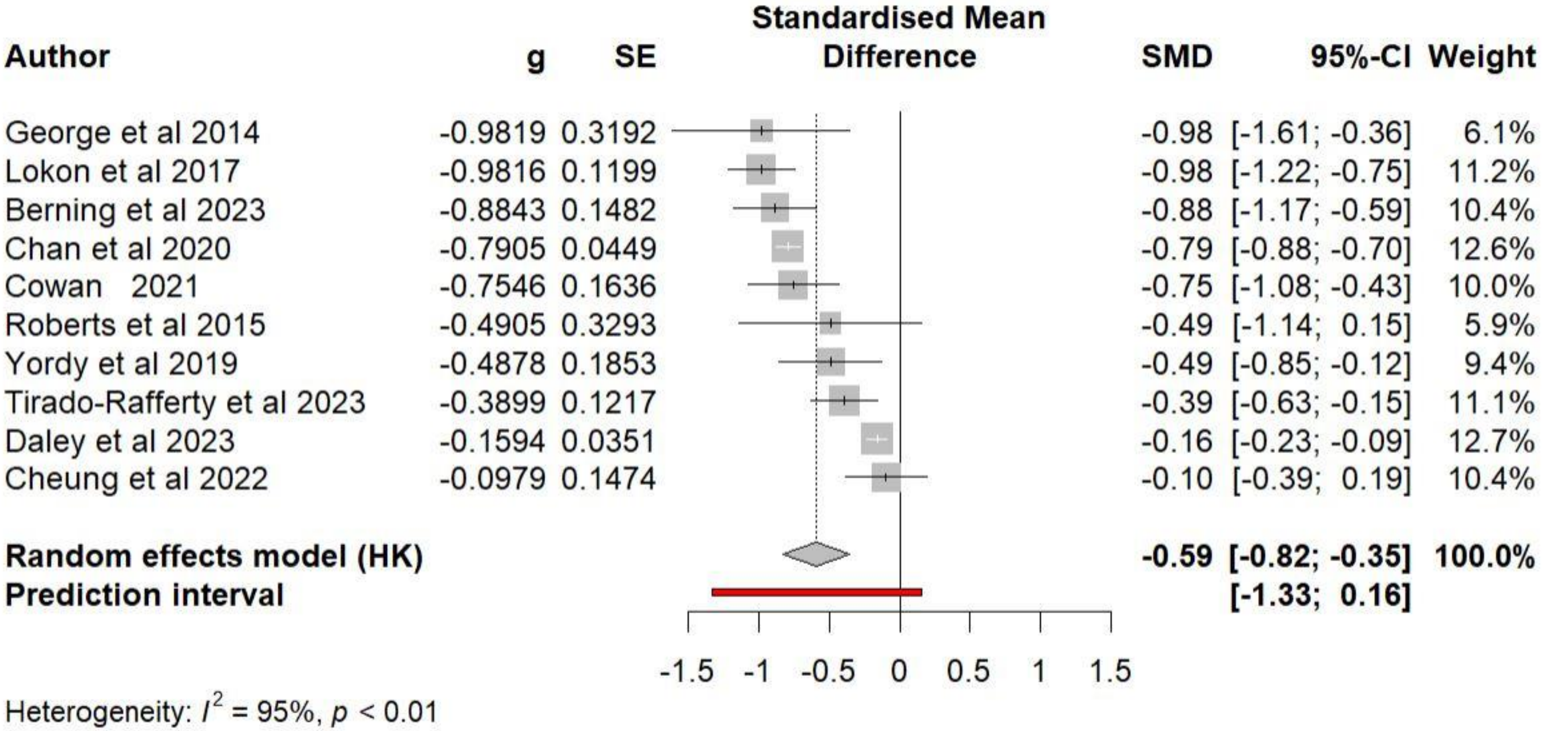


Figure 3.5. Forest plot showing the pooled effect size of intervention studies as measured by the Knowledge Subscale of the Dementia Attitudes Scale

4. Discussion

4.1 Summary of Findings

This review aimed to evaluate pre and post changes in DAS scores using a meta-analysis of intervention studies aimed at improving attitudes towards people living with dementia. The interventions included in this review were educational (n = 8) or a mixture of both educational and contact-based (n = 6). Attitudes towards people living with dementia improved unanimously across studies following intervention participation, regardless of the type of intervention. The same was found for each subscale of the DAS, where both knowledge and comfort improved following intervention participation. Meta-regression analyses suggested the changes in DAS scores (quantified as the effect size) were not associated with intervention type (education interventions, education and contact-based interventions), length (< 1 day; >1 day), or follow-up period (immediately post intervention; any other periods from 1 day to 24 months). Therefore below I will discuss other possibilities for between-study variability. The majority of quasi-experimental studies dropped quality appraisal points for not including a control group. The RCT scored almost full points but it was not clear to me whether participants were blind to the assignment of conditions.

4.2 Findings in the Context of Previous Literature

The current review showed attitudes toward people living with dementia improved following participation in education and mixed education-contact based interventions. More specifically, the result of the meta-analysis reflected the findings of previous qualitative studies (Canning, Gaetz, & Blakeborough, 2020; George, Stuckey, Dillon, & Whitehead, 2011) which validates the general direction of the present findings.

This systematic review and meta-analysis has addressed a key criticism of previous intervention studies, namely the lack of psychometric quality of outcome measurement (J. D. Bacsu et al., 2022; Herrmann et al., 2018). By focussing the present literature search only on studies that used a validated and well-tested outcome measure (the DAS), I presented an approach to collating and synthesising findings from different interventions that allows for comparison. Overall, similar to literature on other stigmatised conditions, e.g. HIV/AIDS (Sengupta et al., 2011) and substance use disorder (Livingston, Milne, Fang, & Amari, 2012), education and combined education-contact based approaches to stigma reduction yield positive results.

In other populations such as substance use disorder (Livingston et al., 2012), a mixture of educational and contact-based approaches were found to be more fruitful in improving attitudes. In this review, the meta-regression for intervention type did not yield any significant findings and therefore it was concluded that intervention type (educational or a mixture of education and contact) was not associated with differences in effect size. It should be noted that differences in attitudes towards these two populations may influence how effective certain types of interventions are. For example, substance use is aligned to stereotypes of ‘poor moral status’ and criminality, leading to societal disapproval and condemnation - therefore both education as well as contact may be required to improve attitudes (Livingston et al., 2012). In contrast, dementia is seen as a health concern aligned to death-related imagery and stereotypes of incompetence (M. L. O’Connor & McFadden, 2012), hence attitudes towards dementia may be effectively improved upon with education and or mixed interventions.

The relationship between attiutdes towards dementia and enactment of discriminatory behaviours has not been linear, therefore it is unclear whether improving attitudes actually translates into a reduction in discrimination. For example, in some previous studies participants held negative attitudes towards people living with dementia which resulted in discriminatory behaviours (Woo, 2017) but in other studies participants exhibited prosocial behaviours, greater willingness to help and empathy (Blay & Peluso, 2010; Johnson, Harkins, Cary, Sankar, & Karlawish, 2015; Wadley & Haley, 2001).

The DAS has two subscales covering both knoweldge and social comfort, items on both of these scales represent all three components of the Tripartite Model of Attitudes (cognition, affect and behaviour). However, the Comfort subscale contains items from the more cognitive domain and the knowledge subscale has more items that reflect the affect and behaviour domains. Therefore, it is plausible to suggest that participants who took part in interventions had more positive cognitions, felt more positively and intended to behave more positively towards people living with dementia. The meta-analyses of the subscales suggest a stronger effect seen in the comfort as opposed to the knowledge subscale; perhaps this reflects some of the conflicting literature about cogitions relating to dementia not translating into changes in affect and behaviour to the same magnitude.

4.3 Strengths and Limitations

This is the first systematic review to combine intervention studies that have used the DAS. Several limitations need to be considered. With regards to the review procedure, I carried out the search and conducted all of the various stages of screening hence bias may have been introduced. The search strategy identified studies that used the DAS in the title or abstract only, therefore studies that referred to the DAS within the full text would not have been identified thus limiting the rigour of both the review procedure and findings. As per JBI guidelines, no studies were excluded as a result of their quality appraisal ratings and therefore the rating process itself did not affect which studies remained in the analysis, although there was no second rater for the quality appraisal process and this may have introduced bias.

With regards to overall generalisability and interpretability, participant characteristics and study design need to be considered. Based on the six studies that reported on participant ethnicity (n = 3158 participants), most participants were of ‘white’ ethnic background (n = 2460; 78%), the remaining eight studies did not report any ethnicity data (n=1912); 80% of the sample were female. Together, the participant population was biased towards ‘white’ females which has implications for the generalisability of results. The lack of representation in the participant pool is commonplace in dementia research but, encouragingly, emerging studies seek to understand stigma in a range of groups with protected characteristics, such as race and ethnicity (Berwald, Roche, Adelman, Mukadam, & Livingston, 2016; Kafadar, Barrett, & Cheung, 2021), sexuality (Price, 2010) and migration backgrounds (Roes et al., 2022). However, these populations and many more are still under-researched and therefore often not represented in interventional literature as demonstrated in this review.

Overall, the included studies lacked experimental control and therefore cause and effect arguments about the effectiveness of interventions on attitudes towards dementia need to be treated with caution. A small number of participants were lost to follow-up and the length of follow-up varied considerably between studies, which further contributes to difficulties in concluding whether increases in DAS scores can be attributed to the interventions.

As understood from the I^2 statistic, there was considerable heterogeneity across studies. The results of the meta-regression analyses suggest that heterogeneity was not explained by type of intervention (education or education and contact based), intervention length or follow-up period. Therefore, heterogeneity could be a result of other factors, such as country or participant factors like ethnicity which were not explored due to statistical power. For this reason, the results of the meta-analysis should be interpreted with caution. Regarding the meta-regressions in particular, the coding of the various factors (intervention type, length and follow up periods) may have further introduced heterogeneity creating an additional layer of difficulty when interpreting and investigating the heterogeneity across studies. Data from four studies were not available and therefore not included in this systematic review which limits the rigour of this review.

The funnel plot was asymmetrical but it is important to consider the various reasons for this based on guidance by Page et al. (2021). Funnel plots are based on the assumption that study dispersion is a result of sampling error rather than actual differences in true effects. Therefore between studies heterogeneity, which has already been confirmed in the analysis of the current review, can cause funnel plot asymmetry. Intervention fidelity also contributes to funnel plot asymmetry whereby studies with larger samples may yield more variance in intervention procedure than studies with smaller sample sizes. Nonetheless, the large variety of interventions included within this review would render this explanation for asymmetry unlikely. Lower quality studies are more likely to result in higher risk of bias as they require less investment and therefore less rigorous methodology. A large proportion of the included studies did not have a control condition and therefore it is plausible that intervention effects were amplified. Inspecting the funnel plot alongside quality scores, generally all of the studies scored six or above and therefore would not be considered of low quality. Of the two studies that included control conditions, only one fell inside the funnel shape, suggesting that perhaps quality of study and the inclusion of a control condition alone may not explain asymmetry. Lastly, it is plausible that in some cases funnel plot asymmetry occurs by chance. However, based on the results and what I have considered thus far, it is more likely that the funnel plot asymmetry is reflective of between study heterogeneity rather than publication bias.

4.4 Implications and Recommendations for Future Research

4.4.1 Clinical Practice

The implementation of evidence-based interventions is a cornerstone of psychological practice; it is how we improve the lives of clinical populations while ensuring that we do not cause harm. The systematic review and meta-analysis presented suggest that education and education with contact-based interventions improve attitudes towards dementia. This is relevant to clinical practice in several ways: education interventions could be used to improve attitudes across an entire workforce, for example, in various staff groups perhaps across a general adult mental health settings like IAPT, in NHS health settings, in care homes or other facilities where people living with dementia are likely to present but that are not necessarily dementia specific. Many intervention studies were conducted with student samples. As attitudes in these studies improved following intervention participation, one consideration is the need to implement educational and contact-based elements to generic clinical training (e.g. medicine, nursing). Lastly, clinical psychologists are often tasked with designing and delivering interventions or carrying out quality improvement projects to destigmatise conditions such as dementia. The results of this review may encourage clinicians not to reinvent the wheel, and implement existing interventions whilst also using the DAS as an outcome measure given its success in measuring change.

4.4.2 Research, Policy and Practice

The majority of studies included in the current review did not have a control condition and therefore, although cause and effect can be implied, future research should aim to test various interventions with a control condition. The findings of the meta-analysis mirrored findings from qualitative studies regarding the impact of participation. It is therefore recommended that future research consider a mixed methods approach to understanding intervention effectiveness where the DAS can be used to aid comparability and quantification of effectiveness, whilst qualitative data can add richness of participant experience.

Stigma in relation to dementia can be thought of as a ‘double jeopardy’, whereby the stigma of ageism compounds that of dementia (Birt, Poland, Csipke, & Charlesworth, 2017). As well as age, other characteristics such as sexuality, ethnicity, culture, race, class can compound the stigma of dementia. Therefore it is of utmost importance that future research aims to recruit representative samples, undertake Patient and Public Involvement to improve the cultural humility of research practice and employ intersectional theorising and methodology (Cho, Crenshaw, & McCall, 2013; McCall, 2005) in their design, implementation and interpretation.

An integral finding for future work is that education and contact based interventions do significantly improve attitudes towards dementia. This has practice, research and policy implications. First, on a practical note, as many interventions that educate individuals about dementia and offer opportunity for contact with people living with dementia already exist, perhaps there is scope for efforts to make access to and participation in these interventions more widely available. Secondly, research has a duty to uphold existing knowledge and expertise rather than reinventing the wheel. The present review presents a series of interventions that show promising results in terms of improving attitudes, albeit with methodological flaws. Therefore future work should look to remedy these flaws in evaluating interventions and consider how such interventions may perform in different populations, settings and cultural backgrounds. Lastly, although the UK National Dementia Strategy has not been renewed, several organisations have called for a focus on improving attitudes towards dementia as a global priority (Alzheimer’s Disease International, 2019; Cahill, 2020; Gove et al., 2019; D. Gove, Small, Downs, & Vernooij-Dassen, 2017; World Health Organization, 2022). For this reason, the findings of this review can help guide future policy in the focus of anti-stigma interventions to improve the lives of people living with dementia.

4.5 Conclusion

The aim of this review was to describe the use of the DAS in intervention studies. I described 14 education and contact-based intervention studies that sought to improve attitudes towards dementia. The results of the meta-analysis suggest that various education and education-contact-based interventions improve attitudes towards people living with dementia. A notable amount of between study heterogeneity was found, which given the inclusion criteria of this review was to be expected but was not explained by intervention type, intervention length or follow-up period.

5. References

Abdalrahim, A., Alamoush, K. M., ALBashtawy, M., Hamaideh, S. H., Mohammad, K. I., Alkhawaldeh, A., … Albashtawy, B. (2023). Jordanian Community People\'s Knowledge of and Attitudes Toward Dementia. *SAGE OPEN NURSING*, *9*. https://doi.org/10.1177/23779608231201052

Aldridge, H., Fisher, P., & Laidlaw, K. (2019). Experiences of shame for people with dementia: An Interpretative Phenomenological Analysis. *Dementia*, *18*(5), 1896–1911. https://doi.org/10.1177/1471301217732430

Alzheimer's Disease International. (2019). Alzheimer's Disease International. 2019. World Alzheimer Report 2019: Attitudes to dementia. London: Alzheimer's Disease International., 311–329. https://doi.org/10.1007/978-3-030-10814-4_23

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Antonak, R. F., & Livneh, H. (1995). Direct and Indirect Methods to Measure Attitudes Toward Persons With Disabilities, With an Exegesis of the Error-Choice Test Method. *Rehabilitation Psychology*, *40*(1), 3–24. https://doi.org/10.1037/0090-5550.40.1.3

Bacsu, J. D., Johnson, S., O'Connell, M. E., Viger, M., Muhajarine, N., Hackett, P., … McIntosh, T. (2022). Stigma Reduction Interventions of Dementia: A Scoping Review. *Canadian Journal on Aging*, *41*(2), 203–213. https://doi.org/10.1017/S0714980821000192

Bacsu, J. D. R., Spiteri, R. J., Nanson, K., Rahemi, Z., Webster, C., Norman, M., & Stone, C. (2024). Understanding stigma of dementia during COVID-19: a scoping review.

Frontiers in Psychiatry, *15*(March), 1–11. https://doi.org/10.3389/fpsyt.2024.1261113

Barker, Timothy H., Habibi, N., Aromataris, E., Stone, J. C., Leonardi-Bee, J., Sears, K., … Munn, Z. (2024). The revised JBI critical appraisal tool for the assessment of risk of bias for quasi-experimental studies. *JBI Evidence Synthesis*, *22*(3), 378–388. https://doi.org/10.11124/JBIES-23-00268

Barker, Timothy Hugh, Stone, J. C., Sears, K., Klugar, M., Tufanaru, C., Leonardi-Bee, J., … Munn, Z. (2023). The revised JBI critical appraisal tool for the assessment of risk of bias for randomized controlled trials. *JBI Evidence Synthesis*, *21*(3), 494–506. https://doi.org/10.11124/JBIES-22-00430

Berning, M. J., Parkinson, A., Tessier, K. M., Pejsa, L., McCarthy, T. C., & Ratner, E. R. (2023). Effect of a dementia friends information session on health professional students' attitudes and knowledge related to dementia. *GERONTOLOGY \& GERIATRICS EDUCATION*, *44*(2), 185–195. https://doi.org/10.1080/02701960.2022.2123319

Berwald, S., Roche, M. M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British Communities' perceptions of memory problems: "We don't do dementia." *PLoS ONE*, *11*(4), 1–15. https://doi.org/10.1371/journal.pone.0151878

Bhatt, Jem, Brohan, E., Blasco, D., Oliveira, D., Bakolis, I., Comas-Herrera, A., … Evans-Lacko, S. (2023). The development and validation of the Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia). *BJPsych Open*, *9*(5), 1–8. https://doi.org/10.1192/bjo.2023.551

Bhatt, Jemini, Stoner, C., Scior, K., & Charlesworth, G. (2020). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *Submitted to BMC Geriatrics*, 0–2. https://doi.org/10.21203/rs.3.rs-21719/v1

Bhatt, Jemini, Stoner, C., Scior, K., & Charlesworth, G. (2021). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *BMC Geriatrics*, 1–12. https://doi.org/10.21203/rs.3.rs-21719/v1

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health and Illness*, *39*(2), 199–211. https://doi.org/10.1111/1467-9566.12530

Blay, S. L., & Peluso, É. T. P. (2010). Public stigma: The community's tolerance of alzheimer disease. *American Journal of Geriatric Psychiatry*, *18*(2), 163–171. https://doi.org/10.1097/JGP.0b013e3181bea900

Breckler, S. (1984). Empirical validation of affect, behavior, and cognition as distinct components of attitude. Journal of Personality and Social Psychology, 47, 1191-1205. *Journal of Personality and Social Psychology*, *47*(6), 1191–1205.

Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *Gerontologist*, *39*(1), 25–35. https://doi.org/10.1093/geront/39.1.25

Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia*, *7*(1), 31–53. https://doi.org/10.1177/1471301207085366

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, *14*(5), 609–632. https://doi.org/10.1177/1471301213504202

Burnham, J. (2018). Developments in social GRRRAAACCEEESSS: Visible-invisible and voiced-unvoiced. *Culture and Reflexivity in Systemic Psychotherapy: Mutual Perspectives*, 139–160. https://doi.org/10.4324/9780429473463-7

Cahill, S. (2020). WHO's global action plan on the public health response to dementia: some challenges and opportunities. *Aging and Mental Health*, *24*(2), 197–199. https://doi.org/10.1080/13607863.2018.1544213

Canning, S. E., Gaetz, M., & Blakeborough, D. (2020). It takes time: Building relationships and understanding through an intergenerational ballet programme. *Dementia*, *19*(2), 270–284. https://doi.org/10.1177/1471301218772895

Cantrell, M. A., & Lupinacci, P. (2007). Methodological issues in online data collection. *Journal of Advanced Nursing*, *60*(5), 544–549. https://doi.org/10.1111/j.1365-2648.2007.04448.x

Cetingok, S., Irmak, H. S., & Gultekin, T. (2023). An Interactive Way to Understand Dementia: Multimodal Experiential Learning Approach in Gerontology Education. *MEDICAL JOURNAL OF BAKIRKOY*, *19*(1), 7–14. https://doi.org/10.4274/BMJ.galenos.2023.2023.2-4

Çetingök, S., Irmak, H. S., & Gültekin, T. (2023). An Interactive Way to Understand Dementia: Multimodal Experiential Learning Approach in Gerontology Education. *Medical Journal of Bakirkoy*, *19*(1), 7–14. https://doi.org/10.4274/BMJ.galenos.2023.2023.2-4

Chan, H. Y. L., Ho, F. K. Y., Chui, K. C. M., Hui, E. Y. S., Wong, B., Chong, Y., … Kwok, T. C. Y. (2020). Capacity building for dementia care in community care services: a mixed methods approach. *BMC GERIATRICS*, *20*(1). https://doi.org/10.1186/s12877-020-01517-8

Cheng, S. T., Lam, L. C. W., Chan, L. C. K., Law, A. C. B., Fung, A. W. T., Chan, W. M. C., … Chan, W. M. C. (2011). The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. *International Psychogeriatrics, 23*(9), 1433–1441. https://doi.org/10.1017/S1041610211000834

Cheung, D. S. K., Ho, L. Y. W., Kwok, R. K. H., Lai, D. L. L., & Lai, C. K. Y. (2022). The effects of involvement in training and volunteering with families of people with dementia on the knowledge and attitudes of volunteers towards dementia. *BMC PUBLIC HEALTH, 22*(1). https://doi.org/10.1186/s12889-022-12687-y

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and Society, 38*(4), 785–810. https://doi.org/10.1086/669608

Chunga, R. E., Kim, K., Liu, Y., & Zarit, S. H. (2021). Family caregivers' distress responses to daily behavioral and psychological symptoms of dementia: The moderating role of relationship quality. *International Journal of Geriatric Psychiatry*, *36*(6), 822–830. https://doi.org/https://doi.org/10.1002/gps.5482

Clarke, C., Woods, B., Moniz-Cook, E., Mountain, G., Øksnebjerg, L., Chattat, R., … Wolverson, E. (2020). Measuring the well-being of people with dementia: a conceptual scoping review. *Health and Quality of Life Outcomes*, *18*(1), 1–14. https://doi.org/10.1186/s12955-020-01440-x

Clement, S., Lassman, F., Barley, E., Evans-Lacko, S., Williams, P., Yamaguchi, S., … Thornicroft, G. (2013). Mass media interventions for reducing mental health-related stigma. *Cochrane Database of Systematic Reviews*, *2013*(7). https://doi.org/10.1002/14651858.CD009453.pub2

CORRIGAN, P. W. (2018). *The Stigma Effect*. Columbia University Press. Retrieved from http://www.jstor.org/stable/10.7312/corr18356

Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J., & Rüsch, N. (2012). Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies. *Psychiatric Services*, *63*(10). https://doi.org/10.1176/appi.ps.005292011

Corrigan, Patrick W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, *54*(9), 765–776. https://doi.org/10.1037/0003-066X.54.9.765

Corrigan, Patrick W, & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*(1), 16–20. https://doi.org/10.1007/s00221-011-2870-1

Cowan, T. L. (2021). College students' and community members' attitudes toward dementia: The impact of dementia friends sessions. *Gerontology and Geriatrics Education*, *42*(1), 140–149. https://doi.org/10.1080/02701960.2019.1657859

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299.

Crenshaw, K. (1998). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics. In *Feminism And Politics*. Oxford: Oxford University Press.

D Szcześniak, A Kobyłko, I Wojciechowska, M Kłapciński, J. R. (2018). Internalized stigma and its correlates among patients with severe mental illness. *Neuropsychiatric Disease and Treatment*, 2599–2608.

Daley, S., Hebditch, M., Jones, C., Bremner, S., Feeney, Y., Towson, G., … Banerjee, S. (2023). Time for Dementia: Quantitative evaluation of a dementia education programme for healthcare students. *International Journal of Geriatric Psychiatry, 38*(5), e5922. https://doi.org/10.1002/gps.5922

Devlin, E., MacAskill, S., & Stead, M. (2006). 'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia. *International Journal of Nonprofit and Voluntary Sector Marketing, 21*(July), 47–58. https://doi.org/10.1002/nvsm

Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., … Zuidema, S. (2017). Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging and Mental Health, 21*(1), 4–17. https://doi.org/10.1080/13607863.2016.1254596

Duarte, Natalia, Alves, S., & Gomes, B. (2023). Evaluation of a dementia training course for staff of a center of dementia care. *DEMENTIA AND GERIATRIC COGNITIVE DISORDERS, 52*(4), 205–213. https://doi.org/10.1159/000529856

Duarte, Natália, Alves, S., & Gomes, B. (2023). Evaluation of a Dementia Training Course for Staff of a Center of Dementia Care. *Dementia and Geriatric Cognitive Disorders, 52*(4), 205–213. https://doi.org/10.1159/000529856

Dumesnil, H., & Verger, P. (2009). Public awareness campaigns about depression and suicide: A review. *Psychiatric Services, 60*(9), 1203–1213. https://doi.org/10.1176/ps.2009.60.9.1203

Eekhout, I. (2015). *Don't Miss Out!: Incomplete data can contain valuable information.*

Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *British Journal of Psychiatry, 208*(5), 429–434.

https://doi.org/10.1192/bjp.bp.114.153684

Fife, B. L., & Wright, E. R. (2000). The Dimensionality of Stigma : A Comparison of Its Impact on the Self of Persons with HIV / AIDS and Cancer. *Journal of Health and Social Behavior*, *41*(1), 50–67.

Fraboni, M., Saltstone, R., & Hughes, S. (1990). The Fraboni Scale of Ageism (FSA): An Attempt at a More Precise Measure of Ageism. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *9*(1), 56–66. https://doi.org/10.1017/S0714980800016093

George, D. R., Stuckey, H. L., Dillon, C. F., & Whitehead, M. M. (2011). Impact of participation in timeslips, a creative group-based storytelling program, on medical student attitudes toward persons with dementia: A qualitative study. *Gerontologist*, *51*(5), 699–703. https://doi.org/10.1093/geront/gnr035

George, D. R., Stuckey, H. L., & Whitehead, M. M. (2014). How a creative storytelling intervention can improve medical student attitude towards persons with dementia: A mixed methods study. *DEMENTIA-INTERNATIONAL JOURNAL OF SOCIAL RESEARCH AND PRACTICE*, *13*(3), 318–329. https://doi.org/10.1177/1471301212468732

Gilbert, P. (2010). *The compassionate mind : a new approach to life's challenges*. Oakland, Calif. SE - xxvii, 513 pages : illustrations ; 23 cm: New Harbinger Publications. https://doi.org/LK - https://worldcat.org/title/436624753

Gove, D. M., Andrews, J., Capstick, A., Geoghegan, C., Georges, J., Libert, S., … Williamson, T. (2019). Dementia as a disability: Implications for ethics , policy and practice. A Discussion Paper., 0–61. Retrieved from http://hdl.handle.net/10454/14923

Gove, D., Small, N., Downs, M., & Vernooij-Dassen, M. (2017). General practitioners' perceptions of the stigma of dementia and the role of reciprocity. *Dementia*, *16*(7). https://doi.org/10.1177/1471301215625657

Graham, J. W. (2009). Missing Data Analysis: Making It Work in the Real World. *Annual Review of Psychology*, *60*(1), 549–576. https://doi.org/10.1146/annurev.psych.58.110405.085530

Hailstone, J., Mukadam, N., Owen, T., Cooper, C., & Livingston, G. (2017). The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. *International Journal of Geriatric Psychiatry*, *32*(3), 288–296. https://doi.org/10.1002/gps.4462

Harrer, M., Cuijpers, P., A, F. T., & Ebert, D. D. (2021). *Doing Meta-Analysis With {R}: A Hands-On Guide* (1st ed.). Boca Raton, FL and London: Chapman & Hall/CRC Press.

Harris, P. B., & Caporella, C. A. (2014). An intergenerational choir formed to lessen alzheimer's disease stigma in college students and decrease the social isolation of people with alzheimer's disease and their family members: A pilot study. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(3), 270–281. https://doi.org/10.1177/1533317513517044

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? *American Journal of Geriatric Psychiatry*, *26*(3), 316–331. https://doi.org/10.1016/j.jagp.2017.09.006

Heuer, S., Douglas, N., Burney, T., & Willer, R. (2020). Service-Learning with older adults in care communities: Measures of attitude shifts in undergraduate students.

GERONTOLOGY \& GERIATRICS EDUCATION, *41*(2), 186–199. https://doi.org/10.1080/02701960.2019.1596087

Higgins, J. P., & Green, S. E. (2008). *Cochrane Handbook for Systematic Reviews of Interventions: Cochrane Book Series*. https://doi.org/10.1109/ISIT.2017.8006970

Higgins, J. P. T., & Thompson, S. G. (2002). Quantifying heterogeneity in a meta-analysis. *Statistics in Medicine*, *21*(11), 1539–1558. https://doi.org/10.1002/sim.1186

Johnson, R., Harkins, K., Cary, M., Sankar, P., & Karlawish, J. (2015). The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. *Social Science and Medicine*, *143*, 117–127. https://doi.org/10.1016/j.socscimed.2015.08.031

Kafadar, A. H., Barrett, C., & Cheung, K. L. (2021). Knowledge and perceptions of Alzheimer's disease in three ethnic groups of younger adults in the United Kingdom. *BMC PUBLIC HEALTH*, *21*(1). https://doi.org/10.1186/s12889-021-11231-8

Kimzey, M., Mastel-Smith, B., & Alfred, D. (2016). The impact of educational experiences on nursing students' knowledge and attitudes toward people with Alzheimer's disease: A mixed method study. *NURSE EDUCATION TODAY*, *46*, 57–63. https://doi.org/10.1016/j.nedt.2016.08.031

Kogan, N. (1961). Attitudes toward old people: The development of a scale and an examination of correlates. *Journal of Abnormal and Social Psychology*, *62*(1), 44–54. https://doi.org/10.1037/h0048053

Korkmaz Aslan, G., Kılınç İşleyen, E., & Kartal, A. (2023). Nursing students' knowledge and attitudes about dementia: A cross-sectional study. *Nurse Education in Practice*, *72*(August). https://doi.org/10.1016/j.nepr.2023.103800

Krause, N. (2002). A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *57*(5). https://doi.org/10.1093/geronb/57.5.S263

Lefever, S., Dal, M., & Matthíasdóttir, Á. (2007). Online data collection in academic research: Advantages and limitations. *British Journal of Educational Technology*, *38*(4), 574–582. https://doi.org/10.1111/j.1467-8535.2006.00638.x

Link, B. G, & Phelan, J. C. (2006). Stigma and its public health implications. *Lancet*, *367*(9509), 528–529. https://doi.org/10.1016/S0140-6736(06)68184-1

Link, Bruce G, & Phelan, J. C. (2001). Conceptualizing stigma. *Annu. Rev. Sociol*, *27*(Lewis 1998), 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Lion, Katarzyna Małgorzata, Szcześniak, D., Bulińska, K., Evans, S. B., Evans, S. C., Saibene, F. L., … Rymaszewska, J. (2019). Do people with dementia and mild cognitive impairments experience stigma? A cross-cultural investigation between Italy, Poland and the UK. *Aging & Mental Health*, *0*(0), 1–9. https://doi.org/10.1080/13607863.2019.1577799

Lion, Katarzyna Malgorzata, Szczesniak, D., Bulinska, K., Mazurek, J., Evans, S. B., Evans, S. C., … Rymaszewska, J. (2021). Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits? *AGING \& MENTAL HEALTH*, *25*(1), 160–169. https://doi.org/10.1080/13607863.2019.1683815

Livingston, J. D., Milne, T., Fang, M. L., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: A systematic review. *Addiction*, *107*(1), 39–50. https://doi.org/10.1111/j.1360-0443.2011.03601.x

Lokon, E., Li, Y., & Parajuli, J. (2017). Using art in an intergenerational program to improve students' attitudes toward people with dementia. *GERONTOLOGY \& GERIATRICS EDUCATION, 38*(4), 407–424. https://doi.org/10.1080/02701960.2017.1281804

Maio, G. R., Verplanken, B., & Haddock, G. (2018). The Psychology of Attitudes and Attitude Change. London: SAGE Publications Ltd. Retrieved from http://digital.casalini.it/9781526454126

Mangiaracina, F., Chattat, R., Farina, E., Saibene, F. L., Gamberini, G., Brooker, D., … Meiland, F. J. M. (2017). Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries. *Aging and Mental Health*, *21*(1), 40–48. https://doi.org/10.1080/13607863.2016.1258540

Marmara, J., Zarate, D., Vassallo, J., Patten, R., & Stavropoulos, V. (2022). Warwick Edinburgh Mental Well-Being Scale (WEMWBS): measurement invariance across genders and item response theory examination. *BMC Psychology, 10*(1), 1–17. https://doi.org/10.1186/s40359-022-00720-z

Maskeliunas, R., Damasevicius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious Game iDO: Towards Better Education in Dementia Care. *INFORMATION*, *10*(11). https://doi.org/10.3390/info10110355

Maskeliunas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious game iDO: Towards better education in dementia care. *Information (Switzerland), 10*(11), 1–15. https://doi.org/10.3390/info10110355

Maskeliūnas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious Game iDO: Towards Better Education in Dementia Care. *Information (2078-2489)*, *10*(11), 355. Retrieved from https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=l ls&AN=139863788&site=ehost-live&scope=site&custid=s8454451

McCall, L. (2005). The Complexity of Intersectionality, *38*(4), 811–845. Retrieved from http://www.jstor.org/stable/10.1086/426800

Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *BMJ Open*, *5*(9). https://doi.org/10.1136/bmjopen-2015-007990

Nguyen, T., & Li, X. (2018). Understanding public-stigma and self-stigma in the context of dementia : A systematic review of the global literature. *Dementia*. https://doi.org/10.1177/1471301218800122

O'Connor, D., Mann, J., & Wiersma, E. (2018a). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies, 44*(February), 45–51. https://doi.org/10.1016/j.jaging.2018.01.010

O'Connor, D., Mann, J., & Wiersma, E. (2018b). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies, 44*(October 2017), 45–51. https://doi.org/10.1016/j.jaging.2018.01.010

O'Connor, M. L., & McFadden, S. H. (2010). Development and psychometric validation of the dementia attitudes scale. *International Journal of Alzheimer's Disease, 2010*. https://doi.org/10.4061/2010/454218

O'Connor, M. L., & McFadden, S. H. (2012). A Terror Management Perspective on Young Adults' Ageism and Attitudes Toward Dementia. *Educational Gerontology, 38*(9), 627–643. https://doi.org/10.1080/03601277.2011.595335

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ*, *372*. https://doi.org/10.1136/bmj.n71

Patel, I., Patel, J., Jindal, S. V., Desai, D., & Desai, S. (2021). Knowledge, Awareness, and Attitude Towards Dementia Amongst Medical Undergraduate Students: Can a Sensitization Program Help? *ANNALS OF INDIAN ACADEMY OF NEUROLOGY*, *24*(5), 754–758. https://doi.org/10.4103/aian.AIAN_874_20

Pescosolido, B. A., & Martin, J. K. (2015). The Stigma Complex. *Annual Review of Sociology*, *41*(1), 87–116. https://doi.org/10.1146/annurev-soc-071312-145702

Petscher, Y., Schatschneider, C., & Compton, D. L. (2013). *Applied quantitative analysis in education and the social sciences*. *Applied Quantitative Analysis in Education and the Social Sciences*. https://doi.org/10.4324/9780203108550

Phenwan, T., Sixsmith, J., McSwiggan, L., & Buchanan, D. (2021). A rapid review of internet mediated research methods with people with dementia: Practical, technical, and ethical considerations. *Qualitative Report*, *26*(11), 3318–3341. https://doi.org/10.46743/2160-3715/2021.5089

Piver, L. C., Nubukpo, P., Faure, A., Dumoitier, N., Couratier, P., & Clément, J. P. (2013). Describing perceived stigma against Alzheimer's disease in a general population in France: The STIG-MA survey. *International Journal of Geriatric Psychiatry*, *28*(9), 933–938. https://doi.org/10.1002/gps.3903

Price, E. (2010). Coming out to care: Gay and lesbian carers' experiences of dementia services. *Health and Social Care in the Community*, *18*(2), 160–168. https://doi.org/10.1111/j.1365-2524.2009.00884.x

Rewerska-Juśko, M., & Rejdak, K. (2020). Social Stigma of People with Dementia. *Journal of Alzheimer's Disease*, *78*(4), 1339–1343. https://doi.org/10.3233/JAD-201004

Roberts, H. J., & Noble Hannah J.; ORCID: https://orcid.org/0000-0003-2110-9542 AI - Noble, James M.; ORCID: https://orcid.org/0000-0003-0648-6702, J. M. A. I.-R. (2015). Education Research: Changing medical student perceptions of dementia: An arts-centered experience. *Neurology*, *85*(8), 739–741. https://doi.org/https://dx.doi.org/10.1212/WNL.0000000000001867

Roberts, H. J., & Noble, J. M. (2015). Education Research: Changing medical student perceptions of dementia: An arts-centered experience. *Neurology*, *85*(8), 739–741. https://doi.org/10.1212/WNL.0000000000001867

Roes, M., Laporte Uribe, F., Peters-Nehrenheim, V., Smits, C., Johannessen, A., Charlesworth, G., … Tezcan-Güntekin, H. (2022). Intersectionality and its relevance for research in dementia care of people with a migration background. *Zeitschrift Fur Gerontologie Und Geriatrie*, *55*(4), 287–291. https://doi.org/10.1007/s00391-022-02058-y

Rosin, E. R., Blasco, D., Pilozzi, A. R., Yang, L. H., & Huang, X. (2020). A Narrative Review of Alzheimer’s Disease Stigma. *Journal of Alzheimer’s Disease*, *78*(2), 515–528. https://doi.org/10.3233/JAD-200932

Schneider, J., Schonstein, A., Teschauer, W., Kruse, A., & Teichmann, B. (2020). Hospital Staff’s Attitudes Toward and Knowledge About Dementia Before and After a Two-Day Dementia Training Program. *JOURNAL OF ALZHEIMERS DISEASE*, *77*(1), 355–365. https://doi.org/10.3233/JAD-200268

Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior*, *15*(6), 1075–1087. https://doi.org/10.1007/s10461-010-9847-0

Stryker, S. (1987). The Vitalization of Symbolic Interactionism. *Social Psychology*

Quarterly, *50*(1), 83–94.

Stryker, S. (2006). Traditional Symbolic Interactionism, Role Theory, and Structural Symbolic Interactionism: The Road to Identity Theory. *Handbook of Sociological Theory*, 211–231. https://doi.org/10.1007/0-387-36274-6_11

Swaffer, K. (2014). Dementia: Stigma, Language, and Dementia-friendly. *Dementia*, *13*(6), 709–716. https://doi.org/10.1177/1471301214548143

Szcześniak, D., Urbańska, K., Farina, E., Saibene, F. L., Chattat, R., Evans, S., … Rymaszewska, J. (2017). Does participation in the Meeting Centre Support Programme change the stigma experienced by people with dementia? *European Psychiatry*, *41*, S177. https://doi.org/10.1016/j.eurpsy.2017.01.2078

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., … Stewart-Brown, S. (2007). The Warwick-Dinburgh mental well-being scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes*, *5*, 1–13. https://doi.org/10.1186/1477-7525-5-63

Thomas, A., Palmer, J. K., Coker-Juneau, C. J., & Williams, D. J. (2003). Factor structure and construct validity of the interaction with disabled persons scale. *Educational and Psychological Measurement*, *63*(3), 465–483. https://doi.org/10.1177/0013164403063003008

Thornicroft, G. (2003, July 1). Shunned: Discrimination against people with mental illness. Oxford University Press. https://doi.org/10.1093/med/9780198570981.001.0001

Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: ignorance, prejudice or discrimination? *British Journal of Psychiatry*, *190*(MAR.), 1–3. https://doi.org/10.1192/bjp.bp.106.025791

Thornicroft, G., Sunkel, C., Alikhon Aliev, A., Baker, S., Brohan, E., el Chammay, R., … Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet*, *400*(10361), 1438–1480. https://doi.org/10.1016/S0140-6736(22)01470-2

Tirado-Rafferty, A., Petrescu-Prahova, M., Belza, B., Berridge, C., Zhou, Y., & La Fazia, D. M. (2023). Implementation and impact of a Dementia Friends pilot. *DEMENTIA-INTERNATIONAL JOURNAL OF SOCIAL RESEARCH AND PRACTICE*, *22*(3), 493–513. https://doi.org/10.1177/14713012221147703

Wadley, V. G., & Haley, W. E. (2001). Diagnostic attributions versus labeling: Impact of Alzheimer's disease and major depression diagnoses on emotions, beliefs, and helping intentions of family members. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *56*(4), P244–P252. Retrieved from http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L32652704%5Cnhttp://sfx.metabib.ch/sfx_locater?sid=EMBASE&issn=10795014&id=doi:&atitle=Diagnostic+attributions+versus+labeling:+Impact+of+Alzheimer's+disease+and+major+depression+di

Walmsley, B., & McCormack, L. (2016). Shame, hope, intimacy and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*, *15*(6), 1666–1684. https://doi.org/10.1177/1471301215573676

Wang, S., Cheung, D. S. K., Leung, A. Y. M., & Davidson, P. M. (2021). Bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia: A pilot randomized controlled trial. *RESEARCH IN NURSING \& HEALTH*, *44*(4), 692–703. https://doi.org/10.1002/nur.22143

WHO. (2017). Global action plan on the public health response to dementia 2017 - 2025.

Geneva: World Health Organization, 52. Retrieved from http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

Wolfe, S. E., Greenhill, B., Butchard, S., & Day, J. (2021). The meaning of autonomy when living with dementia: A Q-method investigation. *Dementia*, *20*(6), 1875–1890. https://doi.org/10.1177/1471301220973067

Woo, B. K. P. (2017). Family history and its relationship with dementia stigma beliefs among Chinese Americans. *Geriatrics and Gerontology International*, *17*(1), 122–125. https://doi.org/10.1111/ggi.12686

Woo, B. K. P., & Chung, J. O. . (2013). PUBLIC STIGMA ASSOCIATED WITH DEMENTIA IN A CHINESE-AMERICAN IMMIGRANT POPULATION. *Journal of American Geriatrics Society*, *22*(7), 1621-16–32.

World Health Organization. (2022). *A blueprint for dementia research*. Retrieved from https://www.who.int/publications/i/item/9789240058248

Yordy, B., Stuart Pope, W., & Wang, C. H. (2019). Canine Outreach Promoting Engagement: The Effect of Meaningful Activities on Students’ Attitudes Toward Cognitively Impaired Older Adults. *Nurse Educator*, *44*(2), 102–105. https://doi.org/10.1097/NNE.0000000000000549

Zhu, L., Schall, A., Paulitsch, M., Pantel, J., & Tesky, V. A. (2023). Attitudes Toward People with Dementia in Germany and China A Questionnaire Validation. *GEROPSYCH-THE JOURNAL OF GERONTOPSYCHOLOGY AND GERIATRIC PSYCHIATRY*. https://doi.org/10.1024/1662-9647/a000327

Part 2: Empirical Paper

Validation of the Stigma Impact Scale: A measure of stigma experienced by people living with dementia globally

Abstract

Aim: To evaluate the psychometric properties of the Stigma Impact Scale in a global sample of people living with dementia.

Method: Data from 710 people living with dementia were submitted for psychometric analysis. Reliability was assessed using Cronbach's alpha. Convergent validity was assessed using correlations between the SIS two measures, the Warwick-Edinburgh mental Well-being Scale (WEMWBS) and the Dementia Quality of Life instrument (DQoL). An exploratory factor analysis and confirmatory factor analysis were used to evaluate the factor structure of the SIS. Global fit indices were used to determine goodness of fit. Endorsement ratings for each SIS item were calculated to give a descriptive understanding of the overall relevance of item level concepts for people living with dementia.

Results: The SIS and subscales had 'good' to 'excellent' internal consistency. The validity correlations were not in the predicted direction further no significant correlations were noted between the SIS and the WEMWBS and weak significant positive correlations were found between the SIS and DQoL. There were marginal improvements in global fit indices when comparing the model based on observed data to the theoretical model however none of the indices surpassed the cut-offs to indicate goodness of fit. The final proposed model had three factors: rejection and secrecy, loneliness and belonging and perceived social isolation. The SIS items were heavily endorsed by people living with dementia.

Conclusion: The SIS is the most vigorously tested psychometric instrument measuring self-stigma in dementia. The SIS has good to excellent reliability and is heavily endorsed by people living with dementia, however future work is required to improve the factor structure of SIS. Further the results of the validity testing pose a number of theoretical and empirical questions for future research.

1. Introduction

1.1 Global focus on stigma and dementia

The WHO World Health Assembly endorsed the ‘Global Action plan on the public health response to dementia 2017-2025’ which framed tackling stigma as a way of ensuring equity and access to the things people living with dementia need the most to maintain a sense of autonomy and self (WHO, 2017). An emphasis was placed on stigma being a barrier to social participation (WHO, 2017) which aligns to previous research that has noted the negative internal consequences of stigma for people living with dementia - this can also be referred to as ‘self-stigma’ (Nguyen & Li, 2018; O’Connor, Mann, & Wiersma, 2018; Swaffer, 2014).

‘Self-stigma’ refers to negative feelings and behaviours directed towards oneself as a result of a stigmatised characteristic such as a diagnosis of dementia (O’Connor, Mann, & Wiersma, 2018). The negative consequences of stigma for people living with dementia include diagnostic secrecy leading to isolation from social networks (Devlin, MacAskill, & Stead, 2006; Harris & Caporella, 2014), withdrawal from daily activities and an increase in depressive symptoms (Walmsley & McCormack, 2016), delays in help seeking and reduced confidence (Hailstone, Mukadam, Owen, Cooper, & Livingston, 2017; Mukadam, Waugh, Cooper, & Livingston, 2015; Rosin, Blasco, Pilozzi, Yang, & Huang, 2020) and social isolation and loneliness (J. D. R. Bacsu et al., 2024). Thus a myriad of negative consequences of stigma, have been noted by colleagues in the field, many of which are relevant to uptake, engagement with and likely success of clinical psychology services. However, there is a critical lack of robust measurement in the field of self-stigma in dementia with only one psychometric instrument to date, the Stigma Impact Scale (SIS), that measures self-stigma in dementia (Nguyen & Li, 2018). I will now present and discuss the theoretical derivatives of the SIS.

1.2 The Multidimensional Model of Stigma Impact

The Multidimensional Model of Stigma Impact (MMSI; Fife & Wright, 2000; Figure 1.1) was based on symbolic interactionism outlined in Modified Labelling Theory where one's sense of self is based upon one's social positioning (Bruce G Link & Phelan, 2001). The MMSI was originally tested with people who had HIV and cancer using a measure derived from the model named the Stigma Impact Scale (SIS). The SIS consists of four subscales (social rejection, financial insecurity, internalised shame and social isolation; Fife & Wright, 2000). The results indicated that whether one had HIV/AIDS or cancer did not shape the way one experienced self-esteem, control or one's own body image, however the effects of the physical health condition were primarily experienced through social rejection or isolation, financial insecurity and internalised shame (Fife & Wright, 2000). The early research conducted by Fife and colleagues gave us an understanding of how self-perceptions can be harmfully affected by stigma directed at those with long term, chronic health conditions.

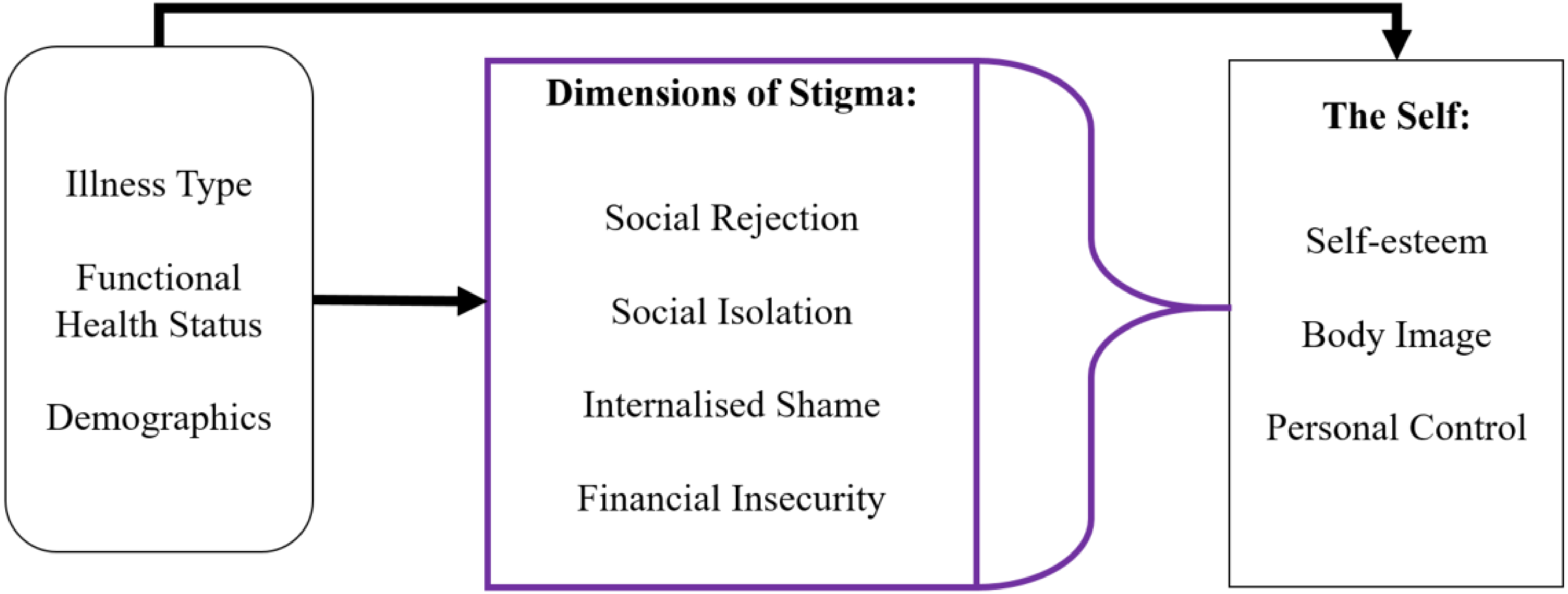


Figure 1.1Multidimensional Model of Stigma Impact – Fife and Wright, 2000

The MMSI and in turn the SIS, were later adapted by Burgener & Berger (2008) to explain the self-stigma experiences of people with Parkinson's disease and Alzheimer's Disease (Figure 1.2). The adaptation and preliminary testing of the MMSI in people with neurological impairment formed the theoretical basis for the version of the SIS currently used in dementia research and the model was renamed the Multidimensional Model of Perceived Stigma. The revised theoretical model included characteristics associated with neurological impairment such as cognitive impairment and changes in one's ability to do things. Self-awareness and insight into one's deteriorating cognitive functioning are necessary pre-requites without which stigma cannot have an impact on one's sense of self, particularly in conditions like Alzheimer's and Parkinson's disease where the illness trajectory can be anything from 2 to 20 years (Burgener & Berger, 2008).

1.3 The Stigma Impact Scale

The stigma in dementia literature has focussed heavily on public stigma and therefore there has been a lack of attention paid to self-stigma in dementia and its potential consequences (Nguyen & Li, 2018; Rosin et al., 2020). For this reason, there is no gold standard instrument to approach the study of self-stigma in dementia however, the SIS is the most widely used and cited tool, to my knowledge, in the dementia and stigma field.

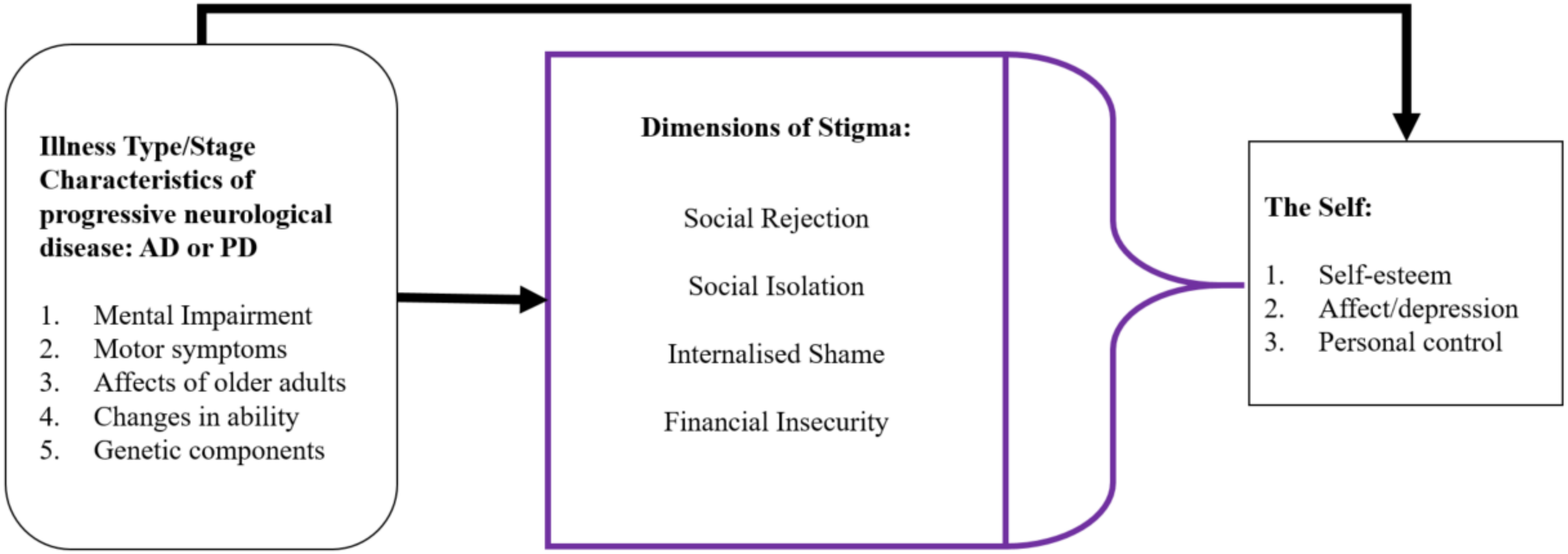


Figure 1.2. Multidimensional Model of Stigma Impact – Burgener & Berger 2008

The SIS has been used in various countries (USA, UK, Italy, the Netherlands and Poland) to understand the stigma experiences of people living with dementia (Bhatt, Stoner, Scior, & Charlesworth, 2021; Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Szcześniak, Kobyłko, Wojciechowska, Kłapciński, 2018; Lion et al., 2019; Lion et al., 2021; Szcześniak et al., 2017). These studies have used the version omitting the financial insecurity sub-scale due to lack of relevance for people living with dementia following consultation with lived experience experts and poor internal consistency (Burgener et al., 2015).

The most recent studies using the SIS have found the scale to have good to excellent internal consistency for the overall scale total (Cronbach's alpha = .906) and subscales (Cronbach's alpha = .614 to .869), as well as evidence of convergent validity in line with pre-specified hypotheses between stigma impact and self-esteem (Bhatt et al., 2021).

1.4 Rationale

As previously stated, the SIS is the only measure that has been used in several countries to capture the self-consequences of stigma for those who have dementia. The underlying theoretical model (the Multidimensional Model of Perceived Stigma) has not been subject to evaluation in a large scale global sample nor have assumptions about factor structure been investigated. The literature until now clearly points towards stigma exacerbating the negative experiences of people living with dementia. It is therefore important that we test the underlying theoretical model of the SIS to see whether it is relevant for people living with dementia. Further, a reliable and valid measure of self-stigma in dementia has implications for policy, practice, research and innovation. Measuring self-stigma in dementia with a robust, validated psychometric instrument would mean we could identify areas of concern for policy and potentially integrate the instrument into practice to understand ways in which stigma affects the lives of people living with dementia. This in turn would lead to gathering data on innovative ways to reduce or lessen this stigma.

1.5 Aims

To examine the psychometric properties of the SIS in a global sample of people living with dementia through the following objectives:

- Examine the reliability, validity and factor structure of the SIS
- Investigate the extent to which items of the SIS are endorsed in a global sample to understand the relevance of the measure for people living with dementia

2. Methods

2.1 Design

Data presented in this chapter were gathered through a large cross-sectional survey organised and commissioned by Alzheimer's Disease International (ADI) for the 2019 World Alzheimer Report (Alzheimer's Disease International, 2019), led by researchers at the London School of Economics (LSE). The survey was answered by people living with dementia, carers, health care workers, and the general public. Only data from on psychometric instrument answered by people living with dementia are presented in this paper. A full technical report can be found elsewhere (https://www.alzint.org/resource/world-alzheimer-report-2019/). Data were acquired through a data sharing agreement with LSE and ADI outlining the use of the data for secondary analysis.

2.2 Participants

The recruitment strategy was developed over several webinars with members of ADI. Participants were eligible if they self-identified as having a diagnosis dementia, regardless of having received a formal diagnosis because we wanted to ensure participation was as accessible as possible rather than an artefact of those countries who have advanced and timely diagnostic systems. For those participants with a formal diagnosis they were asked whom they were diagnosed by. Participants were recruited through online platforms, such as social media and discussion boards, mailing lists as well as social support groups and networks run by third-sector organisations e.g. faith-based groups. To ensure representation, participation from typically under-represented populations, people living with dementia in areas without internet and in rural communities were focussed on through the use of outreach activities. To this end, ADI partner organisations pooled resources to co-ordinate health and community workers to facilitate offline data collection in rural areas. This research was granted ethical approval by the London School of Economics and Political Science self-certification process (Reference: CPEC-LSE-2019-SE-06).

2.3 Materials

Qualtrics, an online survey platform, was the primary method used to collect data. Where outreach activities were organised in areas without internet to improve representation and facilitate offline completion of the survey, Mobenzi (https://www.mobenzi.com/) was used, a mobile platform for data collection. There was an option of completing the survey through proxy (via support by a family member, health worker or third sector workers), respondents were alerted to tick the 'proxy' option at the beginning of the survey if this was the case.

2.3.1 Stigma Impact Scale

The original Stigma Impact Scale (SIS; Burgener & Berger, 2008) consisted of 21 items. In the current study one item was removed (item 21 'changes in my appearance have affected my social life') following stakeholder feedback about it being irrelevant and therefore a 20-item version was used. Each item was rated on a Likert scale from 1 (strongly disagree) to 4 (strongly agree), with the addition of 0 which was used if participants deemed the item 'not applicable'. Higher total scores indicated higher levels of stigma impact. The proposed SIS consists of three subscales, internalised shame, social rejection and social isolation. Previous literature in smaller samples suggests the SIS overall has good internal consistency (Cronbach’s alpha: 0.91; Bhatt, Stoner, Scior, & Charlesworth, 2021).

2.3.2 Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

The WEMWBS is a 14-item measure designed to assess mental well-being (Tennant et al., 2007) which has been robustly tested (Marmara, Zarate, Vassallo, Patten, & Stavropoulos, 2022). Although the WEMWBS is not dementia-specific, several studies have used the measure with people living with dementia (Clarke et al., 2020). As explained above, the WEMWBS performed well in a global sample of people living with dementia (Bhatt et al., 2023). Items are answered on a 5-point Likert scale ranging from 1 (none of the time) to 5 (all of the time). Higher scores represent greater well-being and scores range from 14 to 70. The WEMWBS has good internal consistency and test re-test reliability (Cronbach’s alpha: 0.94; McDonald’s $\omega = 0.95$; Marmara et al 2022).

2.3.3 Dementia Quality of Life instrument (DQoL)

The DQoL is a dementia-specific measure of quality of life developed for use with individuals who have mild to moderate dementia (Brod, Stewart, Sands, & Walton, 1999)., Although the original scale had five subscales, only three were used (negative affect, feeling of belonging and self-esteem) as a result of feedback from those with lived experience of dementia and stigma experts deeming the other subscales (positive affect/humour, and sense of aesthetics) irrelevant. Further, the SIS had previously shown associations with the negative affect, feeling of belonging and self-esteem sub-scales but not with positive affect/humour and sense of aesthetics (Lion et al., 2019). Each subscale (negative affect, feeling of belonging and self-esteem) respectively had adequate internal consistency (Cronbach’s alpha: .89, .67, .80) and test re-test reliability (Person’s correlation coefficient: .64, .74, .68; Brod et al 1999). Higher scores indicated greater subjective quality of life.

2.3.4 Sociodemographic Characteristics

Data on country or territory of residence, gender, age, level of education, urbanicity and employment status were collected.

2.4 Data Analysis

2.4.1 Missing Data and Data Preparation

Missing data, dataset preparation and data analysis were conducted in IBM SPSS Statistics (Version 27) and R (Version 4.3.2). Missing data were analysed for patterns depending on how much data were missing and the significance of the Little's test for missing at random, and guidelines were used to determine the next steps (Eekhout, 2015; Graham, 2009). For example, in the event the missing data had a pattern either at random or otherwise, the appropriate data strategy was implemented (e.g. less than 15% of item-level responses missing completely at random would qualify for mean imputation; Graham, 2009) or in the event that data were systematically missing, only completed cases were analysed. Missing responses were coded as '999' so they were easily identifiable and were not confused with "not applicable" responses which were coded as '0'. In order to carry out the EFA and CFA, exploratory and confirmatory samples were created where, the data set was split in half while ensuring similar representation from each WHO region within the two halves.

2.4.2 Psychometric Properties: Reliability and validity

Psychometric properties of the SIS such as internal consistency (Cronbach's alpha) and convergent validity hypotheses were assessed (correlations). It was hypothesised that there would be moderate positive correlations between the SIS and the WEMWBS and the DemQoL. These statistical analyses were conducted on the theoretical model.

2.4.3 Exploratory factor analysis (EFA)

EFA was used to test the proposed three factor model that had been tested previously (Burgener & Berger, 2008). Eigenvalues, scree plots and factor loadings (≥0.5) were used to assess the factor structure and submit a model for evaluation using a confirmatory factor analysis (CFA). The EFA was conducted using the maximum likelihood method for extraction with oblique rotations, and components with eigenvalues over 1, in line with Kaiser's Criterion, were used to understand factor structure.

2.4.4 Confirmatory factor analysis (CFA)

The Lavaan Package (Version 0.6-18) in R was used to conduct the CFA. In the present study, the CFA was used to investigate the relationship between the SIS responses collected in the survey (namely, the observed variables), and how they structurally connected to help understand the impact of stigma (namely, the latent construct). The measurement model used was the original SIS structure (proposed by Burgener & Berger, 2008) and the CFA therefore examined the 'model fit' or 'goodness of fit' between observed factors and the underlying latent structure. Model fit was evaluated using guidelines by Petscher, Schatschneider, & Compton, (2013), this included the Chi-square test statistic, Comparative Fit Index (CFI, >.90 acceptable, >.95 indication of good fit) and Root Mean Square Error of Approximation (RMSEA, >.06 and <.08 are considered acceptable).

It should be noted that although the Chi-square test statistic is the most commonly cited for model fit, the statistic is heavily influenced by sample size - both very small and very large samples can result in type I and type II errors respectively, therefore a combination of other global fit indices were used to provide a better picture of model fit (Petscher et al., 2013).

2.4.5 Endorsement of the SIS

Endorsement of SIS items was calculated as the percentage of participants who responded either “strongly agree” or “agree” to each item based on the assumption that these responses signify that the content of the items resonated with the participant in a manner that can be understood as *endorsing* that aspect of stigma impact in their lives. Endorsement was calculated for the overall sample and WHO regions.

3. Results

A total of 1237 participants living with dementia completed the survey. However, in 527 cases, SIS items 12-20 were missing not at random in a systematic pattern therefore suggesting an error in the survey equipment or presentation of the questions on the online platform however it is impossible to establish the nature of this error exactly. As a result, only data with complete cases were submitted into the analysis presented below. The majority of the sample completed the study online independently (N = 608) whilst others required support (N = 48). The majority of participants had a formal diagnosis given to them by a neurologist (39.3%), other professionals included Geriatricians (15.5%), general practioner (11.1%) and psychiatrist (7.7%), some participants selected 'other' (19.3%).

3.1 Descriptive Statistics

Data from 710 participants in 42 countries were analysed, descriptive statistics of the sample are displayed in Table 3.1 Descriptive characteristics of participants. The majority of the sample were female, retired, educated to university level (60.60%), living in an urban area and from high-income countries. Participants were mostly from Europe, the Americas and the Western Pacific Region.

Table 3.1 Descriptive characteristics of participants

Variable	**N(%) or Mean(SD)**		
Sex	Male		277(39.00)
	Female		433(61.00)
Age	N=710, Range: 24-92		64.81(11.71)
Employment status	Full time paid employment		101(14.20)
	Part time paid employment		26(3.70)
	Self-employed		50(7.00)
	Unpaid/voluntary work		55(7.70)
	Unpaid carer		16(2.30)
	Retired		391(55.10)
	Student		4(0.60)
	Illness/sick-leave		43(6.10)
	Looking for/other, unemployed		54(7.60)
Education	Less than primary/elementary school		5(0. 70)
	Primary/elementary school		22(3.10)
	Secondary school/ High school (or equivalent)		163(23.00)
	Vocational training or apprenticeship		90(12.70)
	College/pre-university/university		257(36.20)
	Post graduate degree completed		173(24.40)
Area of residence	Urban		332(45.40)
	Suburban		162(22.80)
	Semi-rural		155(21.80)
	Rural		59(8.30)
Stigma Impact Scale	N= 710	Range: 78.00	42.35(16.38)
WEMWBS total	N= 681	Range: 1.70	44.40(11.28)
DEMQoL total	N= 596	Range:2.79	1.99(0.30)
WEMWBS categorical	Higher mental wellbeing ≥42		408(57.46%)
	Lower mental wellbeing (0-41)		266(37.46%)
DQoL categorical	Higher QoL (> median 2.25)		103(14.51%)
	Lower QoL (≤ median 2.25)		493(69.43%)

WHO Region	African Region	8(1.13%)
	Eastern Mediterranean Region	5(0.70%)
	European Region	317(44.65%)
	Region of the Americas	241(33.94%)
	South-East Asia Region	29(4.08%)
	Western Pacific Region	110(15.49%)
World bank income categories	High-income economies	580(81.69%)
	Upper-middle economies	89(12.54%)
	Lower-middle economies	41(5.77%)

3.2 Reliability and Validity

The SIS and subscales (based on the original theoretical solution) had excellent internal consistency, with only minor improvements observed when two items were removed; therefore no items were removed based on the reliability statistics (see Table 3.2).

The convergent validity hypotheses were not supported, the Person's correlation statistics are presented in Table 3.2. The results of the convergent validity analysis were not as predicted and will be discussed in detail in the next session of this paper. A weak, significant, positive correlation was found between social isolation and WEMWBS scores, suggesting that as well-being increases, so does social isolation. Three of four correlation coefficients (albeit negligible strengths) were positive which was unexpected as inverse correlations were predicted between subjective well-being and stigma impact scale total and subscale scores. The only negative correlation coefficient was seen between the WEMWBS and the internalised shame subscale. All four correlation coefficients between the stigma impact scale total score and subscales and the DQol were weak, positive and significant, not as expected. These results suggest that as quality of life in dementia increases as the stigma impact increases.

Table 3.2. Psychometric Properties of the Stigma Impact Scale and subscales

		Theoretical Model				**EFA Proposed Model**			
Construct	**Sub-component**	**SIS Total**	**Social Rejection**	**Social Isolation**	**Internalised Shame**	**Total**	**F1**	**F2**	**F3**
Reliability	**Internal consistency**[1]	.943	.889	.883	.888	.953	.932	.898	.867
	Item if deleted	Minor increase if SIS1 (.948) or SIS17 (.944) were removed	Minor increase if SIS1 were removed .904	None	None	None	None	None	None
Convergent validity[2]	**WEMWBS**	.039	.028	.093*	-.012	-.016	-.069	.065	.011
	DQoL	.231**	.191**	.229**	.216**	.008	-.029	.061	.025

1Cronbach’s alpha; [2]Persons correlation coefficient; *p<.05; **p<.001

3.3 EFA

Barlett’s test of sphericity was significant (X^2 (190) = 4443.248 p<.001.) suggesting an EFA can be carried out and the Kaiser-Meyer-Olkin Measure of sampling adequacy (KMO = .946) was greater than 0.60 suggesting an adequate sample for an EFA.

Three components had eigenvalues over 1 (in line with Kaiser’s criterion, see Figure 3.1. Scree Plot for Exploratory Factor Analysis of the Stigma Impact Scale (N=357) and in combination explained 57.38% of the variance. Factor loadings from the pattern and structure matrix can be found in Table 3.4. Pattern Factor Loadings for Exploratory Factor Analysis of the Stigma Impact Scale (N=357) and Table 3.5. Structure Factor Loadings for Exploratory Factor Analysis of the Stigma Impact Scale (N=357) and reflect a similar three-factor structure of the theoretical model with some alterations.

Factor 1 contained nine items (SIS: 5, 7, 8, 9, 10, 11, 12, 16, 19) and was named ‘rejection and secrecy’. Factor 2 contained six items (SIS: 13, 14, 15, 17, 18, 20) and was named ‘loneliness and belonging’. Factor 3 contained four items (SIS: 2, 3, 4, 6) with the exclusion of SIS item 1 as the factor loading was below the cut off (< .50) across all factors and this final subscale was named ‘perceived social isolation’.

Post-hoc reliability analyses showed excellent to good internal consistency for all three factors (Cronbach’s alpha F1 = 0.95, F2 = .888 and F3 =.870). Factor correlations suggest dependence between factors (see

Table 3.3. EFA Model Factor Correlation Matrix).

Table 3.3. EFA Model Factor Correlation Matrix

Factor	1	2	3
1	-		
2	0.523	-	
3	0.674	0.649	-

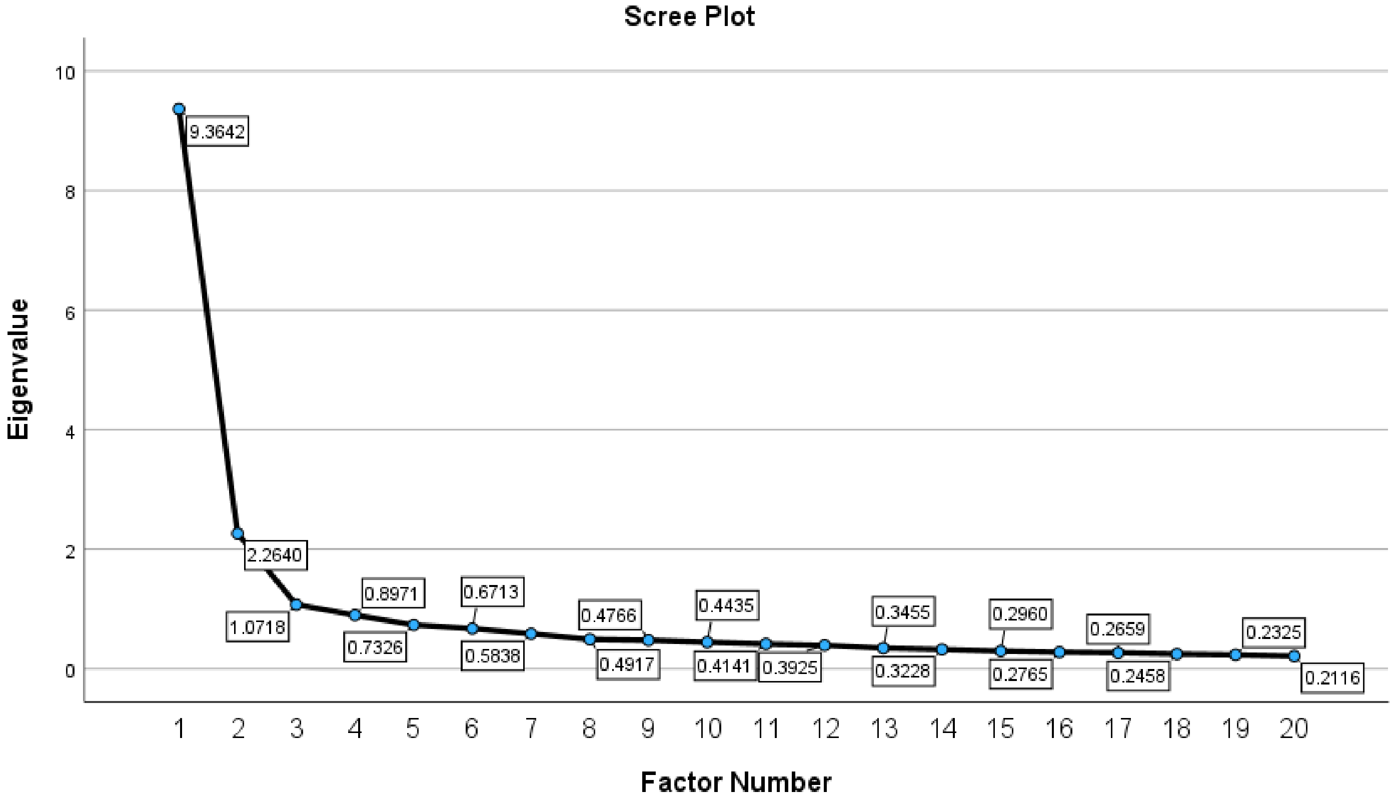


Figure 3.1. Scree Plot for Exploratory Factor Analysis of the Stigma Impact Scale (N=357)

Table 3.4. Pattern Factor Loadings for Exploratory Factor Analysis of the Stigma Impact Scale (N=357)

	Factor 1	**Factor 2**	**Factor 3**
SIS8: I feel others think I am to blame for my dementia	0.851	0.363	0.536
SIS7: Some family members have rejected me because of my dementia	0.780	0.334	0.625
SIS11: I feel a need to keep my dementia a secret	0.776	0.348	0.418
SIS5: I feel others are concerned they could catch my dementia through contact like a handshake or eating food I prepare	0.762	0.304	0.561
SIS12: I feel some friends have rejected me because of my dementia	0.726	0.540	0.636
SIS16: I feel I am at least partially to blame for my dementia	0.726	0.432	0.465
SIS19: Due to my dementia others seem to feel awkward and tense when they are around me	0.721	0.661	0.665
SIS10: I fear someone telling others about my dementia without my permission	0.704	0.475	0.466
SIS9: I do not feel I can be open with others about my dementia	0.674	0.498	0.503
SIS1: My employer/co-workers have discriminated against me because of my dementia	0.253	0.132	0.252
SIS13: I have a greater need than usual for reassurance that others care about me	0.436	0.817	0.509
SIS14: I feel lonely more often than usual	0.394	0.800	0.507
SIS15: Due to my impairment I have a sense of being unequal in my relationship with others	0.480	0.782	0.562
SIS20: Due to my dementia I sometimes feel useless	0.511	0.725	0.581
SIS17: I feel less competent than I did before my dementia	0.190	0.666	0.384
SIS18: I encounter embarrassing situations as a result of my dementia	0.472	0.619	0.518
SIS4: I feel set apart from others who do not have dementia	0.602	0.625	0.811
SIS3: I feel I have been treated with less respect than usual by others	0.579	0.601	0.806
SIS6: I feel others avoid me because of my dementia	0.708	0.513	0.787
SIS2: Some people act as though I am less competent than usual	0.415	0.588	0.760

Table 3.5. Structure Factor Loadings for Exploratory Factor Analysis of the Stigma Impact Scale (N=357)

	Factor 1	**Factor 2**	**Factor 3**
SIS8: I feel others think I am to blame for my dementia	0.916	-0.110	
SIS11: I feel a need to keep my dementia a secret	0.907		-0.192
SIS16: I feel I am at least partially to blame for my dementia	0.738	0.115	-0.106
SIS5: I feel others are concerned they could catch my dementia through contact like a handshake or eating food I prepare	0.737	-0.212	0.201
SIS7: Some family members have rejected me because of my dementia	0.693	-0.227	0.305
SIS10: I fear someone telling others about my dementia without my permission	0.685	0.197	-0.123
SIS9: I do not feel I can be open with others about my dementia	0.582	0.209	
SIS12: I feel some friends have rejected me because of my dementia	0.523	0.142	0.191
SIS19: Due to my dementia others seem to feel awkward and tense when they are around me	0.447	0.329	0.150
SIS13: I have a greater need than usual for reassurance that others care about me		0.835	
SIS14: I feel lonely more often than usual		0.818	
SIS17: I feel less competent than I did before my dementia	-0.246	0.757	
SIS15: Due to my impairment I have a sense of being unequal in my relationship with others		0.710	
SIS20: Due to my dementia I sometimes feel useless	0.128	0.581	0.118
SIS18: I encounter embarrassing situations as a result of my dementia	0.151	0.465	0.115
SIS2: Some people act as though I am less competent than usual	-0.210	0.195	0.775
SIS3: I feel I have been treated with less respect than usual by others		0.129	0.692
SIS4: I feel set apart from others who do not have dementia		0.159	0.657
SIS6: I feel others avoid me because of my dementia	0.333		0.593
SIS1: My employer/co-workers have discriminated against me because of my dementia	0.165		0.191

3.4 CFA

The three-factor model proposed by the EFA was submitted to a CFA and assessed using global fit indices (see Table 3.6. CFA Global fit indices for the Stigma Impact Scale (N = 353) and Figure 3.2). The Chi-squared test statistic was significant (X^2= 784.013), p>.05) suggesting poor model fit for the observed data. However, given the sample size the Chi-squared statistic was interpreted with caution alongside the global fit indices. The CFI value of 0.875 and the TLI (0.856) were below the specified cut offs, suggestive of poor model fit, and the RMSEA (0.110) was larger than the specified cut off again suggesting poor model fit.

Table 3.6. CFA Global fit indices for the Stigma Impact Scale (N = 353)

	X^2	df	CFI	TLI	RMSEA
Theoretical Model	867.168**	167	0.864	0.845	0.109
Proposed Model	784.013**	149	0.875	0.856	0.110

X^2= Chi-Square goodness of fit; *df*= degrees of freedom; CFI= comparative fit index; TLI= Tucker Lewis fit Index; RMSEA = root mean square error of approximation

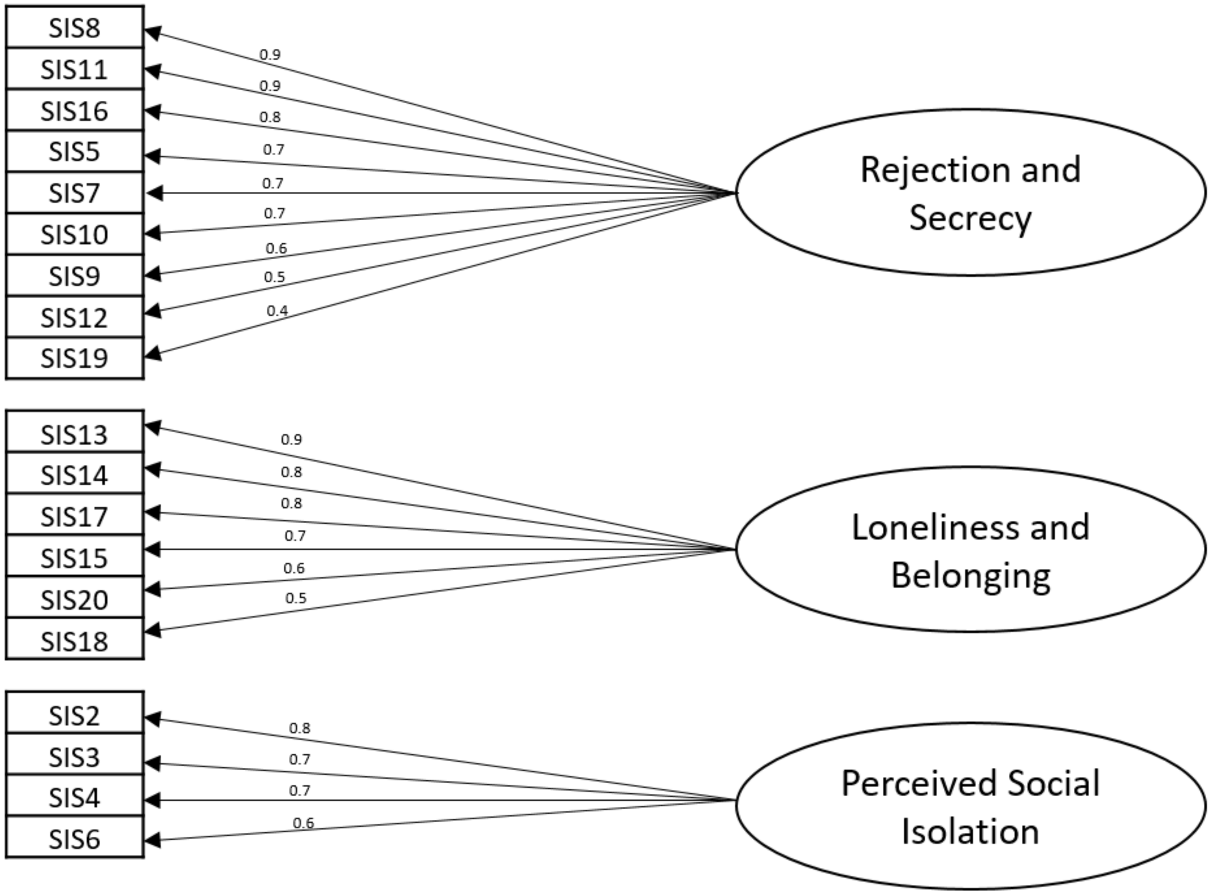


Figure 3.2. Factor Structure for Stigma Impact Scale based on a confirmatory factor analysis with the three-factor solution

3.5 Endorsement of the SIS

South East Asia (N=29) and Africa (N=8) were not included in the final endorsement table (See Table 3.7 for overall sample, and

Table 3.8 for WHO Region breakdown) due to low numbers. In the overall sample, seven items were endorsed by over half the participants. Some of the most commonly endorsed items included item17 (‘‘I feel less competent than I did before my dementia’; 63.52%), item18 (‘I encounter embarrassing situations as a result of my dementia’; 61.55%), item 20 (‘Due to my dementia I sometimes feel useless’; 56.48%). The least commonly endorsed items were item 1 (‘My employer/co-workers have discriminated against me because of my dementia’; 21.27%), item 5 (‘I feel others are concerned they could catch my dementia through contact like a handshake or eating food I prepare’; 28.03%) and Item 11 (‘I feel a need to keep my dementia a secret’; 32.68%).

A graphical representation of the SIS item level endorsement ratings can be found in Figure 3.3. Participants in the Western Pacific Region (WPR) and the Americas (AMR) endorsed items of the SIS in a similar pattern, the most highly endorsed item was 17 (‘I feel less competent than I did before my dementia’; WPR = 82.73%, AMR = 83.82%) and the least Item 5 (‘I feel others are concerned they could catch my dementia through contact like a handshake or eating food I prepare’ WPR = 10.00%, AMR = 6.64%). In Europe (EUR), the most highly endorsed item was Item 8 (‘I feel others think I am to blame for my dementia’; 58.04%) and the least endorsed (‘My employer/co-workers have discriminated against me because of my dementia; 22.71%)

Table 3.7. Item level responses to the Stigma Impact Scale in the Overall Sample (N=710)

	Item wording	**Not Applicable**		**Strongly Agree**		**Agree**		**Disagree**		**Strongly disagree**	
		N	%	N	%	N	%	N	%	N	%
1	My employer/co-workers have discriminated against me because of my dementia	402	56.62	51	7.18	100	14.08	119	16.76	38	5.35
2	Some people act as though I am less competent	113	15.92	74	10.42	303	42.68	178	25.07	42	5.92
3	I feel I have been treated with less respect than	101	14.23	74	10.42	242	34.08	246	34.65	47	6.62
4	I feel set apart from others who do not have	96	13.52	78	10.99	259	36.48	234	32.96	43	6.06
5	I feel others are concerned they could catch my dementia through contact like a handshake or	94	13.24	115	16.20	84	11.83	189	26.62	228	32.11
6	I feel others avoid me because of my dementia	93	13.10	81	11.41	209	29.44	232	32.68	95	13.38
7	Some family members have rejected me because of	109	15.35	103	14.51	160	22.54	195	27.46	143	20.14
8	I feel others think I am to blame for my dementia	97	13.66	94	13.24	170	23.94	188	26.48	161	22.68
9	I do not feel I can be open with others about my dementia	79	11.13	62	8.73	207	29.15	251	35.35	111	15.63
10	I fear someone telling others about my dementia without my permission	92	12.96	74	10.42	190	26.76	246	34.65	108	15.21
11	I feel a need to keep my dementia a secret	87	12.25	79	11.13	153	21.55	242	34.08	149	20.99
12	I feel some friends have rejected me because of my	103	14.51	101	14.23	190	26.76	229	32.25	87	12.25
13	I have a greater need than usual for reassurance that others care about me	80	11.27	78	10.99	301	42.39	205	28.87	46	6.48
14	I feel lonely more often than usual	78	10.99	92	12.96	283	39.86	207	29.15	50	7.04
15	Due to my impairment I have a sense of being unequal in my relationship with others	80	11.27	75	10.56	282	39.72	221	31.13	52	7.32
16	I feel I am at least partially to blame for my	79	11.13	99	13.94	197	27.75	185	26.06	150	21.13
17	I feel less competent than I did before my dementia	61	8.59	137	19.30	314	44.23	156	21.97	42	5.92
18	I encounter embarrassing situations as a result of	81	11.41	104	14.65	333	46.90	160	22.54	32	4.51
19	Due to my dementia others seem to feel awkward and tense when they are around me	86	12.11	63	8.87	266	37.46	245	34.51	50	7.04
20	Due to my dementia I sometimes feel useless	75	10.56	87	12.25	314	44.23	179	25.21	55	7.75

Table 3.8. Endorsement of the SIS across WHO regions and overall

	Item wording	**European Region (N= 317)**		**Region of the Americas (N= 241)**		**West Pacific Region (N=110)**		**Overall Sample (N=710)**	
		N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
17	I feel less competent than I did before my dementia	127	40.06	202	83.82	91	82.73	451	63.52
18	I encounter embarrassing situations as a result of my dementia	174	54.89	163	67.63	80	72.73	437	61.55
20	Due to my dementia I sometimes feel useless	163	51.42	140	58.09	73	66.36	401	56.48
13	I have a greater need than usual for reassurance that others care about me	140	44.16	135	56.02	72	65.45	379	53.38
2	Some people act as though I am less competent than usual	134	42.27	147	61	61	55.45	377	53.1
14	I feel lonely more often than usual	148	46.69	133	55.19	68	61.82	375	52.82
15	Due to my impairment I have a sense of being unequal in my relationship with others	155	48.9	127	52.7	52	47.27	357	50.28
4	I feel set apart from others who do not have dementia	161	50.79	115	47.72	43	39.09	337	47.46
19	Due to my dementia others seem to feel awkward and tense when they are around me	174	54.89	91	37.76	43	39.09	329	46.34
3	I feel I have been treated with less respect than usual by others	154	48.58	100	41.49	45	40.91	316	44.51
16	I feel I am at least partially to blame for my dementia	178	56.15	125	51.87	48	43.64	296	41.69
12	I feel some friends have rejected me because of my dementia	172	54.26	71	29.46	34	30.91	291	40.99
6	I feel others avoid me because of my dementia	161	50.79	155	64.32	36	32.73	290	40.85
9	I do not feel I can be open with others about my dementia	136	42.9	83	34.44	40	36.36	269	37.89
8	I feel others think I am to blame for my dementia	184	58.04	40	16.6	34	30.91	264	37.18
10	I fear someone telling others about my dementia without my permission	145	45.74	72	29.88	40	36.36	264	37.18
7	Some family members have rejected me because of my dementia	171	53.94	53	21.99	27	24.55	263	37.04

11	I feel a need to keep my dementia a secret	151	47.63	49	20.33	27	24.55	232	32.68
5	I feel others are concerned they could catch my dementia through contact like a handshake or eating food I prepare	169	53.31	16	6.64	11	10	199	28.03
1	My employer/co-workers have discriminated against me because of my dementia	72	22.71	38	15.77	30	27.27	151	21.27

[a] Endorsement was the proportion of participants who responded either “strongly agree” or “agree”

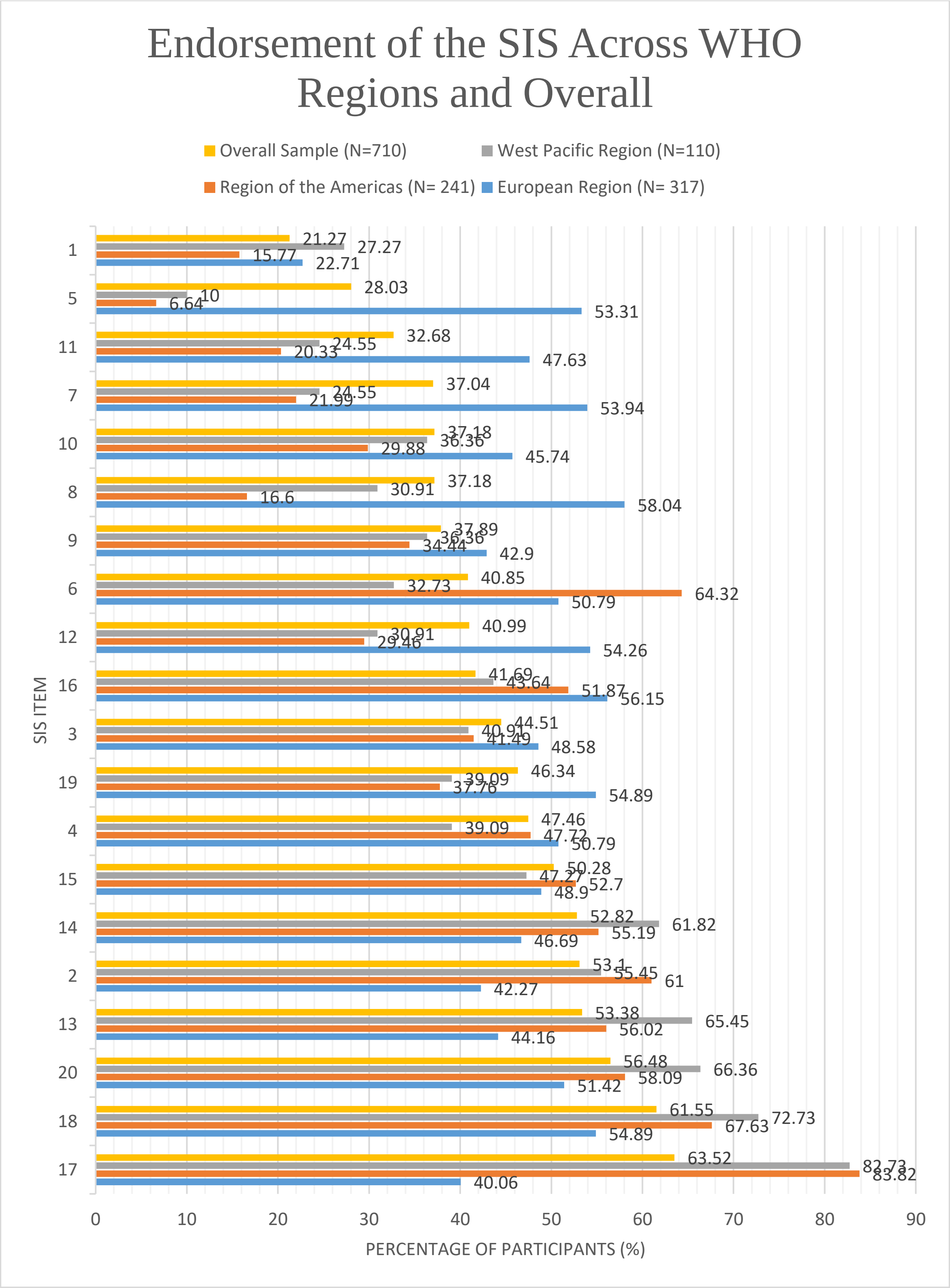


Figure 3.3. Endorsement of SIS items across four WHO Regions

4. Discussion

4.1 Summary of Findings

The overall aim of this study was to examine the psychometric properties of the SIS in a global sample of people living with dementia by examining the reliability, validity and factor structure of the measure as well as levels of endorsement of each item. Based on the aforementioned results the overall SIS and subscales had good to excellent internal consistency. There was a small improvement in the internal consistency overall from the theoretical to the EFA proposed model where the key difference was the removal of one item (SIS1).The validity analysis did not yield support for the hypotheses of convergent validity and therefore this psychometric property was not found in this study; reasons for this are discussed further below. Both the theoretical model and the EFA proposed model were evaluated and although there was a marginal improvement in some global fit indices, they were still below the recommended cut off points for 'good' model fit. Now I will explore these findings further.

4.1.1 SIS Factor Structure

The EFA proposed factor structure did not fully retain any of the original theoretical model subscales but rather reorganised items into new factors with one item completely removed (SIS1). For this reason I have renamed the factors and I will now explain my rationale for doing so by highlighting which theoretical model items made up the EFA proposed factor structure. Factor 1 contained nine items (SIS: 5, 7, 8, 9, 10, 11, 12, 16, 19) which were a combination of the theoretical model subscales of social rejection (SIS5, SIS7, SIS12, SIS19) and internalised shame (SIS8, SIS9, SIS10, SIS11, SIS16). Items within this factor focus on experiences of rejection, blame, secrecy and diagnostic disclosure. Therefore, this factor was renamed as the "rejection and secrecy" subscale to capture the contents of the items. In the theoretical model, items relating to rejection were in a separate subscale to those relating to diagnostic secrecy; however, it is plausible that experiences of rejection may exacerbate one's tendency to choose diagnostic secrecy, particularly as the scale instructions ask participants to recall experiences from the last two weeks. In the EFA model, items relating to rejection and secrecy were combined to create a new factor or subscale, which adds strength to the argument that perhaps the concepts are intertwined more strongly than originally suggested by the theoretical model hence the analyses of the current study support the creation of a combined rejection and secrecy subscale.

Factor 2 contained six items (SIS: 13, 14, 15, 17, 18, 20) which were a combination of the theoretical model's entire subscale of social isolation (SIS13, SIS 14, SIS 15, SIS 17+ SIS 20) with one addition from the social rejection subscale (SIS18). Items within this factor focussed on cognitions and affect such as lacking competence and usefulness, feeling unequal in relationships and experiencing loneliness, as well as the perceived sense of experiencing embarrassment because of having dementia. Therefore this factor was named "loneliness and belonging" as the items that referred to internal thoughts and feelings such as a sense of being unequal in relationships or feeling more lonely than usual, all related to an internal sense of loneliness and lack of belonging. Whilst feeling less competent, useless and embarrassed may contribute to one's sense of no longer belonging, this may not necessarily mean that one is socially isolated or experiencing physical or psychological social isolation, hence why the subscale and newly proposed factor was renamed.

Factor 3 contained four items (SIS: 2, 3, 4, 6) with the exclusion of SIS 1 as the factor loading was below the cut off. Items within this factor were a combination of the theoretical model subscales of social rejection (SIS2, SIS3, SIS6) and internalised shame (SIS4). Items within this factor focussed on feeling set apart from others, being treated with less respect, perceived avoidance and being perceived as less competent. As the items within this factor all relate to being perceived negatively and therefore set apart or avoided, this factor was named “perceived social isolation”.

Overall the EFA proposed model did improve goodness of fit as per the global fit indices however none of the indices met the required cut offs. This suggests that further work on the SIS is necessary in order to understand how to improve the measure. This may involve further changing subscales or looking at whether a bi-dimensional or unidimensional measure is more appropriate through dropping items or subscales. Future work should consider doing this with people living with dementia to ensure the validity of the procedure and relevance of a revised version of the SIS.

4.1.2 Stigma, Wellbeing and Quality of Life in Dementia

It was hypothesised that the more stigma one experiences the poorer one’s overall sense of wellbeing would be. However, the results of the validity analysis did not reveal a relationship between subjective wellbeing and the SIS. The results of this relationship may follow a similar pattern to those found between SIS and self-esteem where some research has noted an inverse relationship between self-esteem and internalised shame only (Burgener & Berger, 2008) and another has found significant negative relationships between all SIS subscales and self-esteem (Bhatt et al., 2021). Being able to subjectively share one’s sense of wellbeing reflects one’s ability to feel positive characteristics about oneself. This includes usefulness and confidence and the very act of participating in a survey to further the understanding of stigma research would be in line with more positive wellbeing, therefore perhaps due to sample characteristics the original more polarised view of stigma and well-being as conceptual opposites does not hold. Also it is important to consider that wellbeing is culturally sensitive, for example being able to make up one’s own mind about things may be a Western representation of positive wellbeing, but in other parts of the world which do not rely on individualistic ideas of decision-making and autonomy would not be seen as such (Wolfe, Greenhill, Butchard, & Day, 2021).

There was a significant positive relationship between stigma impact and quality of life which was not as predicted. One reason for this may be the conceptual understanding between stigma and quality of life as the relationship between the two constructs in dementia is not well documented. It may be that the more stigma one experiences, the more motivated one is to practice forms of stigma resistance and therefore rather than feel a reduced quality of life, one may actually feel more empowered to maintain a good quality life, such as engaging in activities that counteract low self-esteem or feelings of loneliness. Perhaps individuals who experience greater perceived stigma also have a greater tendency to reject this stigma such that it does not result in negative psychological consequences.

It is plausible that the relationship between stigma and the variables of well-being and quality of life could be explained through a moderation model. A moderation model would offer the opportunity to understand the way a third variable could strengthen or even change the direction of the relationship between two variables. For example, it could be hypothesised that the relationship between well-being or quality of life and stigma in dementia could be explained by self-esteem (Jemini Bhatt, Stoner, Scior, & Charlesworth, 2020), relationship quality with one’s carer (Chunga, Kim, Liu, & Zarit, 2021) or behavioural and psychological symptoms associated with dementia (Feast et al., 2016).

4.1.3 Endorsement of the SIS

The endorsement ratings were calculated for the overall sample and across three WHO regions (Europe, Americas and Western Pacific Region). To begin with the overall sample, all items of the SIS were endorsed by approximately 20% or more of people living with dementia which suggests the SIS items reflect relevant and identifiable constructs that resonate with the experience of living with dementia. The least endorsed item overall was SIS1 which reflects the pattern of the statistical analyses both in terms of the reliability analysis where the total score of the measure improved when this item was deleted and the factor analyses confirmed that it did not load above the cut off for any of the three factors.

In the overall sample, items that represented feeling less competent and encountering embarrassing situations were endorsed by the greatest proportion of participants (>60%) which is in line with commonly noted stereotypes of dementia which are even more heightened following the divisive and isolating impact of COVID-19 (J. D. R. Bacsu et al., 2024). Items that were endorsed by >50% included feeling useless, incompetence, inequality in relationships, loneliness and an increased need for reassurance from others. The latter can be understood through the former list whereby experiencing inequalities in relationships as well as loneliness and being perceived as less competent would understandably result in feeling an increased need for social feedback particularly as meaningful social participation in ones network in dementia is pertinent to manage the condition (Dröes et al., 2017).

In the overall sample, >40% of respondents endorsed items that represented a felt sense of rejection and avoidance by others, feeling partial blame for having dementia, being treated less respectfully and being set apart from their social surroundings. The themes of feeling avoided and rejected by others are commonplace narratives found in dementia related stigma literature (Rewerska-Juśko & Rejdak, 2020) and although not unsurprising, the endorsement of such items suggests that the SIS is capturing relevant concepts of stigma for people living with dementia. Items endorsed by 20-40% of participants were around secrecy and dementia, rejection from family members and perceived blame from others for the dementia diagnosis. Secrecy around dementia in particular is sensitive to cultural context as disclosure of a diagnosis of dementia may result in differing socio-cultural consequences. Although it is beyond the scope of this study to investigate these, the way in which disclosing a diagnosis of dementia is influenced by cultural context should be a research priority in the future, particularly given its strong connection to a lack of help-seeking behaviours (O’Connor, Mann, & Wiersma, 2018).

Other than SIS1, the least endorsed item overall was SIS5 “I feel others are concerned they could catch my dementia through contact like a handshake or eating the food I prepare” which was endorsed by 28.03% of participants. One reason for this may be that the item refers to a common myth of dementia that has been the target of awareness raising campaigns but these campaigns are not globally widespread. For example, initiatives like Dementia Friends are implemented worldwide but not necessarily in all WHO regions. Therefore this item being least endorsed may reflect disparities around awareness raising and knowledge about dementia in various countries. Interestingly, the region of Europe has the most dementia friendly initiatives and policies (Cahill, 2020) in comparison to other WHO regions such as the Americas (AMR) and Western Pacific Region (WPR), however in the sample of the current study Europe had the largest endorsement for this item (53.31%) in comparison to WPR (6.64%) and AMR (10%). Therefore it is plausible that knowing more about dementia does not change the stigma associated with it, contrary to the rationales behind awareness raising campaigns and initiatives that has been documented in mental health (Corrigan, 2018).

4.2 Strengths and Limitations

This empirical chapter is the first to report data for the SIS in a global sample of people living with dementia however there are some limitations of this work. A large amount of data was not missing at random and therefore systematically missing. Approximately, 700 participants were missing SIS items 12-20 which suggests an error in the survey equipment or presentation of questions to participants via Qualtrics. It is not possible to establish exactly why this technological difficulty arose but important learning for future research is to pilot test and review live results more vigorously. Although the EFA proposed model requires further improvement, the extent to which items were endorsed speaks volumes to their relevance for people living with dementia. For this reason it would add richness to the study if text responses were collected alongside the SIS as they were for another measure in the wider survey that is not discussed here (Bhatt et al., 2023).

The current study is unable to present findings around the influence of cultural background and stigma experience. The sample in this study was in many ways varied and diverse however due to the small number of participants in some WHO regions or countries, differences between groupings were not analysed as these tests would have been underpowered.

4.3 Implications

The SIS appears to be a reliable and well endorsed measure of stigma with people living with dementia. Further investigation of factor structure and validity is required and this has implications for future research use. The SIS clearly taps into relevant constructs for people living with dementia given the levels of endorsement for each item. This suggests that stigma is an ongoing experience of living with dementia for many. Using the SIS as a guide for clinical interviews or structured interviews to ask about stigma impact may be a fruitful way to understand how health and social care systems can better serve people living with dementia. It is beyond the scope of the current study to look into the ethnographic representations of stigma and cultural differences that give rise to and nurture these. Perhaps using the lens of culture, qualitative and quantitative research could generate some understandings as to how the stigma experience is shaped by various cultural backgrounds.

References

Abdalrahim, A., Alamoush, K. M., ALBashtawy, M., Hamaideh, S. H., Mohammad, K. I., Alkhawaldeh, A., … Albashtawy, B. (2023). Jordanian Community People\'s Knowledge of and Attitudes Toward Dementia. *SAGE OPEN NURSING*, *9*. https://doi.org/10.1177/23779608231201052

Aldridge, H., Fisher, P., & Laidlaw, K. (2019). Experiences of shame for people with dementia: An Interpretative Phenomenological Analysis. *Dementia*, *18*(5), 1896–1911. https://doi.org/10.1177/1471301217732430

Alzheimer's Disease International. (2019). Alzheimer's Disease International. 2019. World Alzheimer Report 2019: Attitudes to dementia. London: Alzheimer's Disease International., 311–329. https://doi.org/10.1007/978-3-030-10814-4_23

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Antonak, R. F., & Livneh, H. (1995). Direct and Indirect Methods to Measure Attitudes Toward Persons With Disabilities, With an Exegesis of the Error-Choice Test Method. *Rehabilitation Psychology*, *40*(1), 3–24. https://doi.org/10.1037/0090-5550.40.1.3

Bacsu, J. D., Johnson, S., O'Connell, M. E., Viger, M., Muhajarine, N., Hackett, P., … McIntosh, T. (2022). Stigma Reduction Interventions of Dementia: A Scoping Review. *Canadian Journal on Aging*, *41*(2), 203–213. https://doi.org/10.1017/S0714980821000192

Bacsu, J. D. R., Spiteri, R. J., Nanson, K., Rahemi, Z., Webster, C., Norman, M., & Stone, C. (2024). Understanding stigma of dementia during COVID-19: a scoping review. *Frontiers in Psychiatry*, *15*(March), 1–11. https://doi.org/10.3389/fpsyt.2024.1261113

Barker, Timothy H., Habibi, N., Aromataris, E., Stone, J. C., Leonardi-Bee, J., Sears, K., … Munn, Z. (2024). The revised JBI critical appraisal tool for the assessment of risk of bias for quasi-experimental studies. *JBI Evidence Synthesis*, *22*(3), 378–388. https://doi.org/10.11124/JBIES-23-00268

Barker, Timothy Hugh, Stone, J. C., Sears, K., Klugar, M., Tufanaru, C., Leonardi-Bee, J., … Munn, Z. (2023). The revised JBI critical appraisal tool for the assessment of risk of bias for randomized controlled trials. *JBI Evidence Synthesis*, *21*(3), 494–506. https://doi.org/10.11124/JBIES-22-00430

Berning, M. J., Parkinson, A., Tessier, K. M., Pejsa, L., McCarthy, T. C., & Ratner, E. R. (2023). Effect of a dementia friends information session on health professional students' attitudes and knowledge related to dementia. *GERONTOLOGY \& GERIATRICS EDUCATION*, *44*(2), 185–195. https://doi.org/10.1080/02701960.2022.2123319

Berwald, S., Roche, M. M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British Communities' perceptions of memory problems: "We don't do dementia." *PLoS ONE*, *11*(4), 1–15. https://doi.org/10.1371/journal.pone.0151878

Bhatt, Jem, Brohan, E., Blasco, D., Oliveira, D., Bakolis, I., Comas-Herrera, A., … Evans-Lacko, S. (2023). The development and validation of the Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia). *BJPsych Open*, *9*(5), 1–8. https://doi.org/10.1192/bjo.2023.551

Bhatt, Jemini, Stoner, C., Scior, K., & Charlesworth, G. (2020). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *Submitted to BMC Geriatrics*, 0–2. https://doi.org/10.21203/rs.3.rs-21719/v1

Bhatt, Jemini, Stoner, C., Scior, K., & Charlesworth, G. (2021). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *BMC Geriatrics*, 1–12. https://doi.org/10.21203/rs.3.rs-21719/v1

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health and Illness*, *39*(2), 199–211. https://doi.org/10.1111/1467-9566.12530

Blay, S. L., & Peluso, É. T. P. (2010). Public stigma: The community's tolerance of alzheimer disease. *American Journal of Geriatric Psychiatry*, *18*(2), 163–171. https://doi.org/10.1097/JGP.0b013e3181bea900

Breckler, S. (1984). Empirical validation of affect, behavior, and cognition as distinct components of attitude. Journal of Personality and Social Psychology, 47, 1191-1205. *Journal of Personality and Social Psychology*, *47*(6), 1191–1205.

Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *Gerontologist*, *39*(1), 25–35. https://doi.org/10.1093/geront/39.1.25

Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia*, *7*(1), 31–53. https://doi.org/10.1177/1471301207085366

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, *14*(5), 609–632. https://doi.org/10.1177/1471301213504202

Burnham, J. (2018). Developments in social GRRRAAACCEEESSS: Visible-invisible and voiced-unvoiced. *Culture and Reflexivity in Systemic Psychotherapy: Mutual*

Perspectives, 139–160. https://doi.org/10.4324/9780429473463-7

Cahill, S. (2020). WHO’s global action plan on the public health response to dementia: some challenges and opportunities. *Aging and Mental Health*, *24*(2), 197–199. https://doi.org/10.1080/13607863.2018.1544213

Canning, S. E., Gaetz, M., & Blakeborough, D. (2020). It takes time: Building relationships and understanding through an intergenerational ballet programme. *Dementia*, *19*(2), 270–284. https://doi.org/10.1177/1471301218772895

Cantrell, M. A., & Lupinacci, P. (2007). Methodological issues in online data collection. *Journal of Advanced Nursing*, *60*(5), 544–549. https://doi.org/10.1111/j.1365-2648.2007.04448.x

Cetingok, S., Irmak, H. S., & Gultekin, T. (2023). An Interactive Way to Understand Dementia: Multimodal Experiential Learning Approach in Gerontology Education. *MEDICAL JOURNAL OF BAKIRKOY*, *19*(1), 7–14. https://doi.org/10.4274/BMJ.galenos.2023.2023.2-4

Çetingök, S., Irmak, H. S., & Gültekin, T. (2023). An Interactive Way to Understand Dementia: Multimodal Experiential Learning Approach in Gerontology Education. *Medical Journal of Bakirkoy*, *19*(1), 7–14. https://doi.org/10.4274/BMJ.galenos.2023.2023.2-4

Chan, H. Y. L., Ho, F. K. Y., Chui, K. C. M., Hui, E. Y. S., Wong, B., Chong, Y., … Kwok, T. C. Y. (2020). Capacity building for dementia care in community care services: a mixed methods approach. *BMC GERIATRICS*, *20*(1). https://doi.org/10.1186/s12877-020-01517-8

Cheng, S. T., Lam, L. C. W., Chan, L. C. K., Law, A. C. B., Fung, A. W. T., Chan, W. M. C.,

… Chan, W. M. C. (2011). The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. *International Psychogeriatrics, 23*(9), 1433–1441. https://doi.org/10.1017/S1041610211000834

Cheung, D. S. K., Ho, L. Y. W., Kwok, R. K. H., Lai, D. L. L., & Lai, C. K. Y. (2022). The effects of involvement in training and volunteering with families of people with dementia on the knowledge and attitudes of volunteers towards dementia. *BMC PUBLIC HEALTH, 22*(1). https://doi.org/10.1186/s12889-022-12687-y

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and Society, 38*(4), 785–810. https://doi.org/10.1086/669608

Chunga, R. E., Kim, K., Liu, Y., & Zarit, S. H. (2021). Family caregivers' distress responses to daily behavioral and psychological symptoms of dementia: The moderating role of relationship quality. *International Journal of Geriatric Psychiatry, 36*(6), 822–830. https://doi.org/https://doi.org/10.1002/gps.5482

Clarke, C., Woods, B., Moniz-Cook, E., Mountain, G., Øksnebjerg, L., Chattat, R., … Wolverson, E. (2020). Measuring the well-being of people with dementia: a conceptual scoping review. *Health and Quality of Life Outcomes, 18*(1), 1–14. https://doi.org/10.1186/s12955-020-01440-x

Clement, S., Lassman, F., Barley, E., Evans-Lacko, S., Williams, P., Yamaguchi, S., … Thornicroft, G. (2013). Mass media interventions for reducing mental health-related stigma. *Cochrane Database of Systematic Reviews, 2013*(7). https://doi.org/10.1002/14651858.CD009453.pub2

CORRIGAN, P. W. (2018). *The Stigma Effect*. Columbia University Press. Retrieved from http://www.jstor.org/stable/10.7312/corr18356

Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J., & Rüsch, N. (2012). Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies. *Psychiatric Services*, *63*(10). https://doi.org/10.1176/appi.ps.005292011

Corrigan, Patrick W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, *54*(9), 765–776. https://doi.org/10.1037/0003-066X.54.9.765

Corrigan, Patrick W, & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*(1), 16–20. https://doi.org/10.1007/s00221-011-2870-1

Cowan, T. L. (2021). College students' and community members' attitudes toward dementia: The impact of dementia friends sessions. *Gerontology and Geriatrics Education*, *42*(1), 140–149. https://doi.org/10.1080/02701960.2019.1657859

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299.

Crenshaw, K. (1998). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics. In *Feminism And Politics*. Oxford: Oxford University Press.

D Szcześniak, A Kobyłko, I Wojciechowska, M Kłapciński, J. R. (2018). Internalized stigma and its correlates among patients with severe mental illness. *Neuropsychiatric Disease and Treatment*, 2599–2608.

Daley, S., Hebditch, M., Jones, C., Bremner, S., Feeney, Y., Towson, G., … Banerjee, S. (2023). Time for Dementia: Quantitative evaluation of a dementia education programme for healthcare students. *International Journal of Geriatric Psychiatry*, *38*(5), e5922.

https://doi.org/10.1002/gps.5922

Devlin, E., MacAskill, S., & Stead, M. (2006). 'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia. *International Journal of Nonprofit and Voluntary Sector Marketing*, *21*(July), 47–58. https://doi.org/10.1002/nvsm

Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., … Zuidema, S. (2017). Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging and Mental Health*, *21*(1), 4–17. https://doi.org/10.1080/13607863.2016.1254596

Duarte, Natalia, Alves, S., & Gomes, B. (2023). Evaluation of a dementia training course for staff of a center of dementia care. *DEMENTIA AND GERIATRIC COGNITIVE DISORDERS*, *52*(4), 205–213. https://doi.org/10.1159/000529856

Duarte, Natália, Alves, S., & Gomes, B. (2023). Evaluation of a Dementia Training Course for Staff of a Center of Dementia Care. *Dementia and Geriatric Cognitive Disorders*, *52*(4), 205–213. https://doi.org/10.1159/000529856

Dumesnil, H., & Verger, P. (2009). Public awareness campaigns about depression and suicide: A review. *Psychiatric Services*, *60*(9), 1203–1213. https://doi.org/10.1176/ps.2009.60.9.1203

Eekhout, I. (2015). *Don't Miss Out!: Incomplete data can contain valuable information.*

Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *British Journal of Psychiatry*, *208*(5), 429–434. https://doi.org/10.1192/bjp.bp.114.153684

Fife, B. L., & Wright, E. R. (2000). The Dimensionality of Stigma : A Comparison of Its Impact on the Self of Persons with HIV / AIDS and Cancer. *Journal of Health and Social Behavior*, *41*(1), 50–67.

Fraboni, M., Saltstone, R., & Hughes, S. (1990). The Fraboni Scale of Ageism (FSA): An Attempt at a More Precise Measure of Ageism. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *9*(1), 56–66. https://doi.org/10.1017/S0714980800016093

George, D. R., Stuckey, H. L., Dillon, C. F., & Whitehead, M. M. (2011). Impact of participation in timeslips, a creative group-based storytelling program, on medical student attitudes toward persons with dementia: A qualitative study. *Gerontologist*, *51*(5), 699–703. https://doi.org/10.1093/geront/gnr035

George, D. R., Stuckey, H. L., & Whitehead, M. M. (2014). How a creative storytelling intervention can improve medical student attitude towards persons with dementia: A mixed methods study. *DEMENTIA-INTERNATIONAL JOURNAL OF SOCIAL RESEARCH AND PRACTICE*, *13*(3), 318–329. https://doi.org/10.1177/1471301212468732

Gilbert, P. (2010). *The compassionate mind : a new approach to life's challenges*. Oakland, Calif. SE - xxvii, 513 pages : illustrations ; 23 cm: New Harbinger Publications. https://doi.org/LK - https://worldcat.org/title/436624753

Gove, D. M., Andrews, J., Capstick, A., Geoghegan, C., Georges, J., Libert, S., … Williamson, T. (2019). Dementia as a disability: Implications for ethics , policy and practice. A Discussion Paper., 0–61. Retrieved from http://hdl.handle.net/10454/14923

Gove, D., Small, N., Downs, M., & Vernooij-Dassen, M. (2017). General practitioners' perceptions of the stigma of dementia and the role of reciprocity. *Dementia*, *16*(7).

https://doi.org/10.1177/1471301215625657

Graham, J. W. (2009). Missing Data Analysis: Making It Work in the Real World. *Annual Review of Psychology*, *60*(1), 549–576. https://doi.org/10.1146/annurev.psych.58.110405.085530

Hailstone, J., Mukadam, N., Owen, T., Cooper, C., & Livingston, G. (2017). The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. *International Journal of Geriatric Psychiatry*, *32*(3), 288–296. https://doi.org/10.1002/gps.4462

Harrer, M., Cuijpers, P., A, F. T., & Ebert, D. D. (2021). *Doing Meta-Analysis With {R}: A Hands-On Guide* (1st ed.). Boca Raton, FL and London: Chapman & Hall/CRC Press.

Harris, P. B., & Caporella, C. A. (2014). An intergenerational choir formed to lessen alzheimer's disease stigma in college students and decrease the social isolation of people with alzheimer's disease and their family members: A pilot study. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(3), 270–281. https://doi.org/10.1177/1533317513517044

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? *American Journal of Geriatric Psychiatry*, *26*(3), 316–331. https://doi.org/10.1016/j.jagp.2017.09.006

Heuer, S., Douglas, N., Burney, T., & Willer, R. (2020). Service-Learning with older adults in care communities: Measures of attitude shifts in undergraduate students. *GERONTOLOGY \& GERIATRICS EDUCATION*, *41*(2), 186–199. https://doi.org/10.1080/02701960.2019.1596087

Higgins, J. P., & Green, S. E. (2008). *Cochrane Handbook for Systematic Reviews of Interventions: Cochrane Book Series*. https://doi.org/10.1109/ISIT.2017.8006970

Higgins, J. P. T., & Thompson, S. G. (2002). Quantifying heterogeneity in a meta-analysis. *Statistics in Medicine*, *21*(11), 1539–1558. https://doi.org/10.1002/sim.1186

Johnson, R., Harkins, K., Cary, M., Sankar, P., & Karlawish, J. (2015). The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. *Social Science and Medicine*, *143*, 117–127. https://doi.org/10.1016/j.socscimed.2015.08.031

Kafadar, A. H., Barrett, C., & Cheung, K. L. (2021). Knowledge and perceptions of Alzheimer's disease in three ethnic groups of younger adults in the United Kingdom. *BMC PUBLIC HEALTH*, *21*(1). https://doi.org/10.1186/s12889-021-11231-8

Kimzey, M., Mastel-Smith, B., & Alfred, D. (2016). The impact of educational experiences on nursing students' knowledge and attitudes toward people with Alzheimer's disease: A mixed method study. *NURSE EDUCATION TODAY*, *46*, 57–63. https://doi.org/10.1016/j.nedt.2016.08.031

Kogan, N. (1961). Attitudes toward old people: The development of a scale and an examination of correlates. *Journal of Abnormal and Social Psychology, 62*(1), 44–54. https://doi.org/10.1037/h0048053

Korkmaz Aslan, G., Kılınç İşleyen, E., & Kartal, A. (2023). Nursing students' knowledge and attitudes about dementia: A cross-sectional study. *Nurse Education in Practice, 72*(August). https://doi.org/10.1016/j.nepr.2023.103800

Krause, N. (2002). A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. *Journals of Gerontology - Series B Psychological Sciences* *and Social Sciences*, *57*(5). https://doi.org/10.1093/geronb/57.5.S263

Lefever, S., Dal, M., & Matthíasdóttir, Á. (2007). Online data collection in academic research: Advantages and limitations. *British Journal of Educational Technology*, *38*(4), 574–582. https://doi.org/10.1111/j.1467-8535.2006.00638.x

Link, B. G, & Phelan, J. C. (2006). Stigma and its public health implications. *Lancet*, *367*(9509), 528–529. https://doi.org/10.1016/S0140-6736(06)68184-1

Link, Bruce G, & Phelan, J. C. (2001). Conceptualizing stigma. *Annu. Rev. Sociol*, *27*(Lewis 1998), 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Lion, Katarzyna Małgorzata, Szcześniak, D., Bulińska, K., Evans, S. B., Evans, S. C., Saibene, F. L., … Rymaszewska, J. (2019). Do people with dementia and mild cognitive impairments experience stigma? A cross-cultural investigation between Italy, Poland and the UK. *Aging & Mental Health*, *0*(0), 1–9. https://doi.org/10.1080/13607863.2019.1577799

Lion, Katarzyna Malgorzata, Szczesniak, D., Bulinska, K., Mazurek, J., Evans, S. B., Evans, S. C., … Rymaszewska, J. (2021). Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits? *AGING \& MENTAL HEALTH*, *25*(1), 160–169. https://doi.org/10.1080/13607863.2019.1683815

Livingston, J. D., Milne, T., Fang, M. L., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: A systematic review. *Addiction*, *107*(1), 39–50. https://doi.org/10.1111/j.1360-0443.2011.03601.x

Lokon, E., Li, Y., & Parajuli, J. (2017). Using art in an intergenerational program to improve students’ attitudes toward people with dementia. *GERONTOLOGY \& GERIATRICS*

EDUCATION, *38*(4), 407–424. https://doi.org/10.1080/02701960.2017.1281804

Maio, G. R., Verplanken, B., & Haddock, G. (2018). The Psychology of Attitudes and Attitude Change. London: SAGE Publications Ltd. Retrieved from http://digital.casalini.it/9781526454126

Mangiaracina, F., Chattat, R., Farina, E., Saibene, F. L., Gamberini, G., Brooker, D., … Meiland, F. J. M. (2017). Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries. *Aging and Mental Health*, *21*(1), 40–48. https://doi.org/10.1080/13607863.2016.1258540

Marmara, J., Zarate, D., Vassallo, J., Patten, R., & Stavropoulos, V. (2022). Warwick Edinburgh Mental Well-Being Scale (WEMWBS): measurement invariance across genders and item response theory examination. *BMC Psychology*, *10*(1), 1–17. https://doi.org/10.1186/s40359-022-00720-z

Maskeliunas, R., Damasevicius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious Game iDO: Towards Better Education in Dementia Care. *INFORMATION*, *10*(11). https://doi.org/10.3390/info10110355

Maskeliunas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious game iDO: Towards better education in dementia care. *Information (Switzerland)*, *10*(11), 1–15. https://doi.org/10.3390/info10110355

Maskeliūnas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious Game iDO: Towards Better Education in Dementia Care. *Information (2078-2489)*, *10*(11), 355. Retrieved from https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=lls&AN=139863788&site=ehost-live&scope=site&custid=s8454451

McCall, L. (2005). The Complexity of Intersectionality, *38*(4), 811–845. Retrieved from http://www.jstor.org/stable/10.1086/426800

Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *BMJ Open*, *5*(9). https://doi.org/10.1136/bmjopen-2015-007990

Nguyen, T., & Li, X. (2018). Understanding public-stigma and self-stigma in the context of dementia : A systematic review of the global literature. *Dementia*. https://doi.org/10.1177/1471301218800122

O’Connor, D., Mann, J., & Wiersma, E. (2018a). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies, 44*(February), 45–51. https://doi.org/10.1016/j.jaging.2018.01.010

O’Connor, D., Mann, J., & Wiersma, E. (2018b). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies, 44*(October 2017), 45–51. https://doi.org/10.1016/j.jaging.2018.01.010

O’Connor, M. L., & McFadden, S. H. (2010). Development and psychometric validation of the dementia attitudes scale. *International Journal of Alzheimer’s Disease, 2010*. https://doi.org/10.4061/2010/454218

O’Connor, M. L., & McFadden, S. H. (2012). A Terror Management Perspective on Young Adults’ Ageism and Attitudes Toward Dementia. *Educational Gerontology, 38*(9), 627–643. https://doi.org/10.1080/03601277.2011.595335

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ, 372*. https://doi.org/10.1136/bmj.n71

Patel, I., Patel, J., Jindal, S. V., Desai, D., & Desai, S. (2021). Knowledge, Awareness, and Attitude Towards Dementia Amongst Medical Undergraduate Students: Can a Sensitization Program Help? *ANNALS OF INDIAN ACADEMY OF NEUROLOGY*, *24*(5), 754–758. https://doi.org/10.4103/aian.AIAN_874_20

Pescosolido, B. A., & Martin, J. K. (2015). The Stigma Complex. *Annual Review of Sociology*, *41*(1), 87–116. https://doi.org/10.1146/annurev-soc-071312-145702

Petscher, Y., Schatschneider, C., & Compton, D. L. (2013). *Applied quantitative analysis in education and the social sciences*. *Applied Quantitative Analysis in Education and the Social Sciences*. https://doi.org/10.4324/9780203108550

Phenwan, T., Sixsmith, J., McSwiggan, L., & Buchanan, D. (2021). A rapid review of internet mediated research methods with people with dementia: Practical, technical, and ethical considerations. *Qualitative Report*, *26*(11), 3318–3341. https://doi.org/10.46743/2160-3715/2021.5089

Piver, L. C., Nubukpo, P., Faure, A., Dumoitier, N., Couratier, P., & Clément, J. P. (2013). Describing perceived stigma against Alzheimer's disease in a general population in France: The STIG-MA survey. *International Journal of Geriatric Psychiatry*, *28*(9), 933–938. https://doi.org/10.1002/gps.3903

Price, E. (2010). Coming out to care: Gay and lesbian carers' experiences of dementia services. *Health and Social Care in the Community*, *18*(2), 160–168. https://doi.org/10.1111/j.1365-2524.2009.00884.x

Rewerska-Juśko, M., & Rejdak, K. (2020). Social Stigma of People with Dementia. *Journal of Alzheimer's Disease*, *78*(4), 1339–1343. https://doi.org/10.3233/JAD-201004

Roberts, H. J., & Noble Hannah J.; ORCID: https://orcid.org/0000-0003-2110-9542 AI -

Noble, James M.; ORCID: https://orcid.org/0000-0003-0648-6702, J. M. A. I.-R. (2015). Education Research: Changing medical student perceptions of dementia: An arts-centered experience. *Neurology*, *85*(8), 739–741. https://doi.org/https://dx.doi.org/10.1212/WNL.0000000000001867

Roberts, H. J., & Noble, J. M. (2015). Education Research: Changing medical student perceptions of dementia: An arts-centered experience. *Neurology*, *85*(8), 739–741. https://doi.org/10.1212/WNL.0000000000001867

Roes, M., Laporte Uribe, F., Peters-Nehrenheim, V., Smits, C., Johannessen, A., Charlesworth, G., … Tezcan-Güntekin, H. (2022). Intersectionality and its relevance for research in dementia care of people with a migration background. *Zeitschrift Fur Gerontologie Und Geriatrie*, *55*(4), 287–291. https://doi.org/10.1007/s00391-022-02058-y

Rosin, E. R., Blasco, D., Pilozzi, A. R., Yang, L. H., & Huang, X. (2020). A Narrative Review of Alzheimer's Disease Stigma. *Journal of Alzheimer's Disease*, *78*(2), 515–528. https://doi.org/10.3233/JAD-200932

Schneider, J., Schonstein, A., Teschauer, W., Kruse, A., & Teichmann, B. (2020). Hospital Staff's Attitudes Toward and Knowledge About Dementia Before and After a Two-Day Dementia Training Program. *JOURNAL OF ALZHEIMERS DISEASE*, *77*(1), 355–365. https://doi.org/10.3233/JAD-200268

Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior*, *15*(6), 1075–1087. https://doi.org/10.1007/s10461-010-9847-0

Stryker, S. (1987). The Vitalization of Symbolic Interactionism. *Social Psychology Quarterly*, *50*(1), 83–94.

Stryker, S. (2006). Traditional Symbolic Interactionism, Role Theory, and Structural Symbolic Interactionism: The Road to Identity Theory. *Handbook of Sociological Theory*, 211–231. https://doi.org/10.1007/0-387-36274-6_11

Swaffer, K. (2014). Dementia: Stigma, Language, and Dementia-friendly. *Dementia*, *13*(6), 709–716. https://doi.org/10.1177/1471301214548143

Szcześniak, D., Urbańska, K., Farina, E., Saibene, F. L., Chattat, R., Evans, S., … Rymaszewska, J. (2017). Does participation in the Meeting Centre Support Programme change the stigma experienced by people with dementia? *European Psychiatry*, *41*, S177. https://doi.org/10.1016/j.eurpsy.2017.01.2078

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., … Stewart-Brown, S. (2007). The Warwick-Dinburgh mental well-being scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes*, *5*, 1–13. https://doi.org/10.1186/1477-7525-5-63

Thomas, A., Palmer, J. K., Coker-Juneau, C. J., & Williams, D. J. (2003). Factor structure and construct validity of the interaction with disabled persons scale. *Educational and Psychological Measurement*, *63*(3), 465–483. https://doi.org/10.1177/0013164403063003008

Thornicroft, G. (2003, July 1). Shunned: Discrimination against people with mental illness. Oxford University Press. https://doi.org/10.1093/med/9780198570981.001.0001

Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: ignorance, prejudice or discrimination? *British Journal of Psychiatry*, *190*(MAR.), 1–3. https://doi.org/10.1192/bjp.bp.106.025791

Thornicroft, G., Sunkel, C., Alikhon Aliev, A., Baker, S., Brohan, E., el Chammay, R., …

Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet*, *400*(10361), 1438–1480. https://doi.org/10.1016/S0140-6736(22)01470-2

Tirado-Rafferty, A., Petrescu-Prahova, M., Belza, B., Berridge, C., Zhou, Y., & La Fazia, D. M. (2023). Implementation and impact of a Dementia Friends pilot. *DEMENTIA-INTERNATIONAL JOURNAL OF SOCIAL RESEARCH AND PRACTICE*, *22*(3), 493–513. https://doi.org/10.1177/14713012221147703

Wadley, V. G., & Haley, W. E. (2001). Diagnostic attributions versus labeling: Impact of Alzheimer's disease and major depression diagnoses on emotions, beliefs, and helping intentions of family members. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *56*(4), P244–P252. Retrieved from http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L32652704%5Cnhttp://sfx.metabib.ch/sfx_locater?sid=EMBASE&issn=10795014&id=doi:&atitle=Diagnostic+attributions+versus+labeling:+Impact+of+Alzheimer's+disease+and+major+depression+di

Walmsley, B., & McCormack, L. (2016). Shame, hope, intimacy and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*, *15*(6), 1666–1684. https://doi.org/10.1177/1471301215573676

Wang, S., Cheung, D. S. K., Leung, A. Y. M., & Davidson, P. M. (2021). Bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia: A pilot randomized controlled trial. *RESEARCH IN NURSING \& HEALTH*, *44*(4), 692–703. https://doi.org/10.1002/nur.22143

WHO. (2017). Global action plan on the public health response to dementia 2017 - 2025. *Geneva: World Health Organization*, 52. Retrieved from http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

Wolfe, S. E., Greenhill, B., Butchard, S., & Day, J. (2021). The meaning of autonomy when living with dementia: A Q-method investigation. *Dementia*, *20*(6), 1875–1890. https://doi.org/10.1177/1471301220973067

Woo, B. K. P. (2017). Family history and its relationship with dementia stigma beliefs among Chinese Americans. *Geriatrics and Gerontology International*, *17*(1), 122–125. https://doi.org/10.1111/ggi.12686

Woo, B. K. P., & Chung, J. O. . (2013). PUBLIC STIGMA ASSOCIATED WITH DEMENTIA IN A CHINESE-AMERICAN IMMIGRANT POPULATION. *Journal of American Geriatrics Society*, *22*(7), 1621-16–32.

World Health Organization. (2022). *A blueprint for dementia research*. Retrieved from https://www.who.int/publications/i/item/9789240058248

Yordy, B., Stuart Pope, W., & Wang, C. H. (2019). Canine Outreach Promoting Engagement: The Effect of Meaningful Activities on Students' Attitudes Toward Cognitively Impaired Older Adults. *Nurse Educator*, *44*(2), 102–105. https://doi.org/10.1097/NNE.0000000000000549

Zhu, L., Schall, A., Paulitsch, M., Pantel, J., & Tesky, V. A. (2023). Attitudes Toward People with Dementia in Germany and China A Questionnaire Validation. *GEROPSYCH-THE JOURNAL OF GERONTOPSYCHOLOGY AND GERIATRIC PSYCHIATRY*. https://doi.org/10.1024/1662-9647/a000327

Part 3: Critical Appraisal

1. Introduction

In this chapter I critically reflect on particular aspects of the research process such as the theoretical underpinnings of my empirical chapter and methodological choices I made. I will then move on to a critique of the methodology with a focus on the consequences and implications of web-based research methods.

2. Theoretical issues

2.1 The Multidimensional Model of Stigma Impact (MMSI)

As previously mentioned in Chapter 2 the MMSI (see Figure 1.2), draws together illness characteristics, facets of self-stigma and aspects of the Self to give an overall understanding of how the label of dementia is experienced (Burgener & Berger, 2008). More specifically, self-stigma is experienced by those with dementia through social rejection, social isolation and internalised shame which in turn has negative consequences for one's self-esteem, affect and self-efficacy (Burgener & Berger, 2008).

The MMSI was based on assumption that social positioning and social responses form the basis of one's sense of self and behaviour taken from the modified labelling theory (Bruce G Link & Phelan, 2001) and symbolic interactionism (Stryker, 1987, 2006). Using these ideas the MMSI was used to explain the impact of stigma on individuals with HIV/AIDS (Fife & Wright, 2000) leading to the earliest version of the Stigma Impact Scale (SIS). Following this Burgener & Berger, (2008) adapted the MMSI and the SIS to Parkinson's and Alzheimer's disease. Since this paper, the SIS has been used in dementia-research in several European countries (Jemini Bhatt et al., 2021; Katarzyna Małgorzata Lion et al., 2019; Mangiaracina et al., 2017; Szcześniak et al., 2017).

The body of cross-sectional and intervention research in dementia-related stigma is beginning to grow, but the field is still in its infancy in terms of theoretical models and frameworks and specifically the MMSI is the only available model for self-stigma in dementia. The difficulty with adapting existing models to different populations (e.g. people affected by HIV/AIDS to Parkinson's or Alzheimer 's disease), in this manner can be broken down to two main factors. First, the development of a model involves a systematic procedure ideally comprising of stages of consultation with experts, including lived experience experts, mixed methods testing and at the very least rigorous psychometric evaluation of any scale that is developed as a result of a model. This requires time and resources, which in reality researchers, particularly those conducting empirical studies for a training programme or a PhD, often do not have. Secondly, if adaptation of an existing model is the most fruitful way forward, the lack of systematic guidance on how to do this often forces researchers into deductive research methods, fitting models to the participant experience such that something observable can be recorded and presented in a scientific manner. When adapting theory from other populations to explain the stigma experience of people living with dementia, the motivational differences in epistemologies of positive realism and the relativist, phenomenological approaches are necessary to consider. I will articulate this further below.

In our attempts to align ourselves to a scientific line of enquiry we place importance on deductive, structured and pre-determined research designs. We use questionnaires and scales to capture participant experience and thus the numbers are taken to shed light on a novel area, as noted, in the empirical chapter where I present the first psychometric validation of the SIS as the only self-stigma measure in dementia, in the largest sample tested to date. There is an uncomfortable epistemological tension that has arisen in my attempt to quantify self-stigma in dementia both in this thesis and previously in my research career. I refer specifically to whether my approach may be seen as reductionist (using existing theory from other populations) by not properly constructing a grounded picture of self-stigma specifically in dementia using more inductive and flexible research designs. To some extent, this tension may even begin to explain why, even though items of the SIS were endorsed by people living with dementia globally, the factor structure was messy. To be more specific, item level concepts of the SIS clearly resonated with participants, but the overall three factor conceptual understanding did not hold after statistical analysis.

2.2 The Role of Shame

Shame is under-researched in dementia-related stigma. The SIS captures internalised shame but both social and psychological consequences of shame need to be considered. Shame is both a process that lives in relational and internal spaces. For example, shame is an emotion generated as a result of social response but also a by-product of one’s sense of self (Aldridge, Fisher, & Laidlaw, 2019).

In a recent study, one qualitative theme related to avoidance as a manifestation of shame in dementia where people living with dementia avoided social situations and concealed their difficulties (Aldridge et al., 2019). Concealment relates closely to the idea of social isolation discussed in the MMSI but is not reflected in the internalised shame subscale of the SIS tested in my empirical paper. Therefore perceived shame may manifest through behaviours whereby people living with dementia create emotional distance, maintain anonymity and identity and protect others from distress (Aldridge et al., 2019). In the way I have just described, shame is not encompassed in the MMSI but perhaps should be. This is also a point of discussion for stigma research.

It is plausible that shame in relation to the label of dementia is enacted socially and therefore potential scope for intervening may arise through a better understanding of shame, social response, power and stigma. It is also possible that psychological interventions already designed to tackle shame can be adapted or extended to cover stigma related concerns such as Compassion Focussed Therapy (Gilbert, 2010).

2.3 Intersectional Lens

A stigmatised attitude does not exist in a vacuum where other characteristics of a person are suspended or ignored. For example, I would argue that separating stigma relating to dementia from ageism is an on-going theoretical and methodological challenge. This line of inquiry asks the question "what are we actually measuring?" The methodology I presented in this thesis is not suited to answering this question and therefore I look to the study of intersectionality a term coined by Crenshaw (1991, 1998) who explored the ways in which gender and race interact to give shape to the experience of Black women in various contexts. This gives rise to conversations about intragroup differences rather than conflate such differences by discussing *women's rights* as one simplified concept. Drawing from Crenshaw's work, the study of intersectionality in dementia looks to understand how social identities and locations intersect in the presence or absence of power and privilege considering an array of approaches to labelling and naming categories through which classifications and intersections can be described (Roes et al., 2022). Dementia as a stigmatised syndrome intersects with age, however at this intersection additional factors shape the inequality and inequity that is experienced. These additional factors can be understood through Burnham's Social GGRRAAACCEEESS acronym which stands for: gender, geography, race, religion, age, ability, appearance, class, culture, ethnicity, education, employment, sexuality, sexual orientation, spirituality (Burnham, 2018). Together intersectional stigma is one approach to studying dementia requiring careful consideration around measurement and theoretical orientation.

Given the breadth of the global sample in my empirical chapter, the complexity of various intersections present in the dataset would have caused considerable methodological challenges. This brings me to discussing intersectional methodology where different approaches are understood through the way each method deals with categories (e.g. the characteristics we consider at intersections). There are three methodological approaches I will explore, the anticategorical, the intracategorical and the intercategorical approach which are reviewed in McCall (2005). I will define each of these approaches based on how they make use of categories such as the social graces I mentioned above.

The anticategorical approach in interesectionality is defined as methodology which eradicates the usefulness of categories by the very nature of them merely representing social constructions, more specifically "*just"* language that we have used to represent constructs which never have a correct answer with ever changing definitions (McCall, 2005). According to McCall, (2005), anticategorical researchers would advise that the crisis of 'representative research' is essentially epistemologically irresolvable and therefore not a limitation that is discussed. This approach sits uncomfortably with me as a means of studying dementia-related stigma as it negates differences that shape people's lives, which as researchers I believe we have a duty to capture. For example, a person living with dementia in inner city London who experienced privilege through generational wealth, owns their property, is a native English speaker, no familial support in comparison to a Bangladeshi person living with dementia in the same location but occupying social housing, with no familial wealth, English as a second language, fantastic familial support, will without doubt have different experiences.

The intracategorical approach lends itself to case study or single group designs whereby the focus is on a particular intersection that has been neglected such as a singular dimension of one category is used to understand the intersectional experience of a group of individuals. For example, in the case of Crenshaw's work the rationale for intersectional enquiry formed when women's rights research (with white women) and research about race (with Black men) could not be used to understand the experience and rights of Black women (McCall, 2005). For example, in my empirical chapter participants were too varied to represent only one dimension of each category. However, future work may look to understand, for example, the impact of stigma on working class Indian women living with dementia in inner city locations. In this example several categories are represented within a case (race-ethnicity, class, gender, georgraphy).

The final approach I will discuss is the intercategorical approach which is different from the previous two approaches as it can accommodate for larger numbers of participants and greater levels of complexity where the focus of the analysis is the actual relationship of inequality amongst a particular social group (McCall, 2005). Unlike the intracategorical approach, here several dimensions of one category can be broken down and analysed simultaneously. This creates several studies in their own right and can be thought of in statistical terms as a complex multilevel or hierarchal model. An example of this approach would be to analyse data from people living with dementia (men, women, other) from a south Asian background (Indian, Tamil, Pakistani, Nepalese) of varying class (working, middle and upper) and education (pre-high school, high-school, college, higher education). In this example the potential number of possible groups becomes 144 if we wanted to look at gender, race-ethnicity, class and education in shaping the experience of stigma in the backdrop of dementia. The statistical power and resource to conduct and analyse such a study is not commonplace hence the studies of each of the aforementioned categories have become exclusive and unique schools of thought in their own right, often with little sharing between fields.

3. Methodological Issues: Web Based Research

3.1 Advantages of Web Based Research

The advantages of online data collection have been noted for both researchers and participants (Lefever, Dal, & Matthíasdóttir, 2007; Phenwan, Sixsmith, McSwiggan, & Buchanan, 2021). For researchers, these include being able to reach a large number of participants across geographical boundaries with minimal expense of data collection and ease through which data is automatically inputted in a database (Lefever et al., 2007). In a review specific to data collection with people living with dementia, web based research was found to give this population a greater chance of being involved in research they would have otherwise not considered (Phenwan et al., 2021). Further web-based research allows participation to take place in one's home thereby offering a sense of comfort to participate in one's own time and at their pace (Phenwan et al., 2021).

3.2 Sample Bias

This said, limitations to online data collection should be considered. Generally speaking sampling in this way assumes all people living with dementia have access to the internet and a device (e.g laptop, computer, mobile) in order to participate in the study, and that they have access to the hardware they require to participate in the survey. Assumptions such as these bias a sample where often higher income households who can afford internet access and technology to use the internet have better access to the study. To some extent, the current study dealt with these issues by ensuring an offline data collection protocol was in place. However, this was supported by healthcare professionals and therefore limited to their availability and reach, particularly in more rural areas. Looking at the demographics of participants most were from Europe, well-educated and from higher income countries – which may be a direct result of the web-based approach used to collect data and perhaps demonstrates a failure to achieved a representative sample.

3.3 Technical Challenges

Due to an inexplicable glitch a large amount of data were systematically missing. This led to many participants being excluded from the analysis. Previous research has noted the importance of beta-testing and piloting global surveys, with an emphasis on regular attention being paid by web administrators to live results as they come in so that careful screening can monitor such glitches and correct these where needed (Cantrell & Lupinacci, 2007).

4. Conclusions and Personal Reflections

In light of the statistical results of my empirical chapter, the MMSI may not completely conceptualise self-stigma in dementia. However items of the SIS clearly resonated with participants and further testing and changes such as exploring the role of shame or conducting qualitative research to clarify the model may be necessary. I have discussed some limitations of adapting models from various populations to explain dementia related stigma, as well as the importance of shame in our conceptualisations. Intersectional methodology may hold the answer to better understanding what we are measuring through ‘stigma measurement’. Finally, there are limitations to web-based research as well as several advantages. In the face of society’s increasing dependence on technology, the usefulness and ethics of the web-based approach in dementia research should be closely monitored.

5. References

Abdalrahim, A., Alamoush, K. M., ALBashtawy, M., Hamaideh, S. H., Mohammad, K. I., Alkhawaldeh, A., … Albashtawy, B. (2023). Jordanian Community People\'s Knowledge of and Attitudes Toward Dementia. *SAGE OPEN NURSING*, *9*. https://doi.org/10.1177/23779608231201052

Aldridge, H., Fisher, P., & Laidlaw, K. (2019). Experiences of shame for people with dementia: An Interpretative Phenomenological Analysis. *Dementia*, *18*(5), 1896–1911. https://doi.org/10.1177/1471301217732430

Alzheimer’s Disease International. (2019). Alzheimer’s Disease International. 2019. World Alzheimer Report 2019: Attitudes to dementia. London: Alzheimer’s Disease International., 311–329. https://doi.org/10.1007/978-3-030-10814-4_23

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Pub.

Antonak, R. F., & Livneh, H. (1995). Direct and Indirect Methods to Measure Attitudes Toward Persons With Disabilities, With an Exegesis of the Error-Choice Test Method. *Rehabilitation Psychology*, *40*(1), 3–24. https://doi.org/10.1037/0090-5550.40.1.3

Bacsu, J. D., Johnson, S., O’Connell, M. E., Viger, M., Muhajarine, N., Hackett, P., … McIntosh, T. (2022). Stigma Reduction Interventions of Dementia: A Scoping Review. *Canadian Journal on Aging*, *41*(2), 203–213. https://doi.org/10.1017/S0714980821000192

Bacsu, J. D. R., Spiteri, R. J., Nanson, K., Rahemi, Z., Webster, C., Norman, M., & Stone, C. (2024). Understanding stigma of dementia during COVID-19: a scoping review. *Frontiers in Psychiatry*, *15*(March), 1–11. https://doi.org/10.3389/fpsyt.2024.1261113

Barker, Timothy H., Habibi, N., Aromataris, E., Stone, J. C., Leonardi-Bee, J., Sears, K., … Munn, Z. (2024). The revised JBI critical appraisal tool for the assessment of risk of bias for quasi-experimental studies. *JBI Evidence Synthesis*, *22*(3), 378–388. https://doi.org/10.11124/JBIES-23-00268

Barker, Timothy Hugh, Stone, J. C., Sears, K., Klugar, M., Tufanaru, C., Leonardi-Bee, J., … Munn, Z. (2023). The revised JBI critical appraisal tool for the assessment of risk of bias for randomized controlled trials. *JBI Evidence Synthesis*, *21*(3), 494–506. https://doi.org/10.11124/JBIES-22-00430

Berning, M. J., Parkinson, A., Tessier, K. M., Pejsa, L., McCarthy, T. C., & Ratner, E. R. (2023). Effect of a dementia friends information session on health professional students' attitudes and knowledge related to dementia. *GERONTOLOGY \& GERIATRICS EDUCATION*, *44*(2), 185–195. https://doi.org/10.1080/02701960.2022.2123319

Berwald, S., Roche, M. M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British Communities' perceptions of memory problems: "We don't do dementia." *PLoS ONE*, *11*(4), 1–15. https://doi.org/10.1371/journal.pone.0151878

Bhatt, Jem, Brohan, E., Blasco, D., Oliveira, D., Bakolis, I., Comas-Herrera, A., … Evans-Lacko, S. (2023). The development and validation of the Discrimination and Stigma Scale Ultra Short for People Living with Dementia (DISCUS-Dementia). *BJPsych Open*, *9*(5), 1–8. https://doi.org/10.1192/bjo.2023.551

Bhatt, Jemini, Stoner, C., Scior, K., & Charlesworth, G. (2020). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *Submitted to BMC Geriatrics*, 0–2. https://doi.org/10.21203/rs.3.rs-21719/v1

Bhatt, Jemini, Stoner, C., Scior, K., & Charlesworth, G. (2021). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *BMC Geriatrics,* 1–12. https://doi.org/10.21203/rs.3.rs-21719/v1

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health and Illness, 39*(2), 199–211. https://doi.org/10.1111/1467-9566.12530

Blay, S. L., & Peluso, É. T. P. (2010). Public stigma: The community's tolerance of alzheimer disease. *American Journal of Geriatric Psychiatry, 18*(2), 163–171. https://doi.org/10.1097/JGP.0b013e3181bea900

Breckler, S. (1984). Empirical validation of affect, behavior, and cognition as distinct components of attitude. Journal of Personality and Social Psychology, 47, 1191-1205. *Journal of Personality and Social Psychology, 47*(6), 1191–1205.

Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). *Gerontologist, 39*(1), 25–35. https://doi.org/10.1093/geront/39.1.25

Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia*, *7*(1), 31–53. https://doi.org/10.1177/1471301207085366

Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). The effects of perceived stigma on quality of life outcomes in persons with early-stage dementia: Longitudinal findings: Part 2. *Dementia*, *14*(5), 609–632. https://doi.org/10.1177/1471301213504202

Burnham, J. (2018). Developments in social GRRRAAACCEEESSS: Visible-invisible and voiced-unvoiced. *Culture and Reflexivity in Systemic Psychotherapy: Mutual*

Perspectives, 139–160. https://doi.org/10.4324/9780429473463-7

Cahill, S. (2020). WHO's global action plan on the public health response to dementia: some challenges and opportunities. *Aging and Mental Health*, *24*(2), 197–199. https://doi.org/10.1080/13607863.2018.1544213

Canning, S. E., Gaetz, M., & Blakeborough, D. (2020). It takes time: Building relationships and understanding through an intergenerational ballet programme. *Dementia*, *19*(2), 270–284. https://doi.org/10.1177/1471301218772895

Cantrell, M. A., & Lupinacci, P. (2007). Methodological issues in online data collection. *Journal of Advanced Nursing*, *60*(5), 544–549. https://doi.org/10.1111/j.1365-2648.2007.04448.x

Cetingok, S., Irmak, H. S., & Gultekin, T. (2023). An Interactive Way to Understand Dementia: Multimodal Experiential Learning Approach in Gerontology Education. *MEDICAL JOURNAL OF BAKIRKOY*, *19*(1), 7–14. https://doi.org/10.4274/BMJ.galenos.2023.2023.2-4

Çetingök, S., Irmak, H. S., & Gültekin, T. (2023). An Interactive Way to Understand Dementia: Multimodal Experiential Learning Approach in Gerontology Education. *Medical Journal of Bakirkoy*, *19*(1), 7–14. https://doi.org/10.4274/BMJ.galenos.2023.2023.2-4

Chan, H. Y. L., Ho, F. K. Y., Chui, K. C. M., Hui, E. Y. S., Wong, B., Chong, Y., … Kwok, T. C. Y. (2020). Capacity building for dementia care in community care services: a mixed methods approach. *BMC GERIATRICS*, *20*(1). https://doi.org/10.1186/s12877-020-01517-8

Cheng, S. T., Lam, L. C. W., Chan, L. C. K., Law, A. C. B., Fung, A. W. T., Chan, W. M. C.,

… Chan, W. M. C. (2011). The effects of exposure to scenarios about dementia on stigma and attitudes toward dementia care in a Chinese community. *International Psychogeriatrics, 23*(9), 1433–1441. https://doi.org/10.1017/S1041610211000834

Cheung, D. S. K., Ho, L. Y. W., Kwok, R. K. H., Lai, D. L. L., & Lai, C. K. Y. (2022). The effects of involvement in training and volunteering with families of people with dementia on the knowledge and attitudes of volunteers towards dementia. *BMC PUBLIC HEALTH, 22*(1). https://doi.org/10.1186/s12889-022-12687-y

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of Women in Culture and Society, 38*(4), 785–810. https://doi.org/10.1086/669608

Chunga, R. E., Kim, K., Liu, Y., & Zarit, S. H. (2021). Family caregivers' distress responses to daily behavioral and psychological symptoms of dementia: The moderating role of relationship quality. *International Journal of Geriatric Psychiatry, 36*(6), 822–830. https://doi.org/https://doi.org/10.1002/gps.5482

Clarke, C., Woods, B., Moniz-Cook, E., Mountain, G., Øksnebjerg, L., Chattat, R., … Wolverson, E. (2020). Measuring the well-being of people with dementia: a conceptual scoping review. *Health and Quality of Life Outcomes, 18*(1), 1–14. https://doi.org/10.1186/s12955-020-01440-x

Clement, S., Lassman, F., Barley, E., Evans-Lacko, S., Williams, P., Yamaguchi, S., … Thornicroft, G. (2013). Mass media interventions for reducing mental health-related stigma. *Cochrane Database of Systematic Reviews, 2013*(7). https://doi.org/10.1002/14651858.CD009453.pub2

CORRIGAN, P. W. (2018). *The Stigma Effect*. Columbia University Press. Retrieved from http://www.jstor.org/stable/10.7312/corr18356

Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J., & Rüsch, N. (2012). Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies. *Psychiatric Services*, *63*(10). https://doi.org/10.1176/appi.ps.005292011

Corrigan, Patrick W., & Penn, D. L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, *54*(9), 765–776. https://doi.org/10.1037/0003-066X.54.9.765

Corrigan, Patrick W, & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*(1), 16–20. https://doi.org/10.1007/s00221-011-2870-1

Cowan, T. L. (2021). College students' and community members' attitudes toward dementia: The impact of dementia friends sessions. *Gerontology and Geriatrics Education*, *42*(1), 140–149. https://doi.org/10.1080/02701960.2019.1657859

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review*, *43*(6), 1241–1299.

Crenshaw, K. (1998). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory, and Antiracist Politics. In *Feminism And Politics*. Oxford: Oxford University Press.

D Szcześniak, A Kobyłko, I Wojciechowska, M Kłapciński, J. R. (2018). Internalized stigma and its correlates among patients with severe mental illness. *Neuropsychiatric Disease and Treatment*, 2599–2608.

Daley, S., Hebditch, M., Jones, C., Bremner, S., Feeney, Y., Towson, G., … Banerjee, S. (2023). Time for Dementia: Quantitative evaluation of a dementia education programme for healthcare students. *International Journal of Geriatric Psychiatry*, *38*(5), e5922.

https://doi.org/10.1002/gps.5922

Devlin, E., MacAskill, S., & Stead, M. (2006). 'We're still the same people': developing a mass media campaign to raise awareness and challenge the stigma of dementia. *International Journal of Nonprofit and Voluntary Sector Marketing*, *21*(July), 47–58. https://doi.org/10.1002/nvsm

Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., … Zuidema, S. (2017). Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. *Aging and Mental Health*, *21*(1), 4–17. https://doi.org/10.1080/13607863.2016.1254596

Duarte, Natalia, Alves, S., & Gomes, B. (2023). Evaluation of a dementia training course for staff of a center of dementia care. *DEMENTIA AND GERIATRIC COGNITIVE DISORDERS*, *52*(4), 205–213. https://doi.org/10.1159/000529856

Duarte, Natália, Alves, S., & Gomes, B. (2023). Evaluation of a Dementia Training Course for Staff of a Center of Dementia Care. *Dementia and Geriatric Cognitive Disorders*, *52*(4), 205–213. https://doi.org/10.1159/000529856

Dumesnil, H., & Verger, P. (2009). Public awareness campaigns about depression and suicide: A review. *Psychiatric Services*, *60*(9), 1203–1213. https://doi.org/10.1176/ps.2009.60.9.1203

Eekhout, I. (2015). *Don't Miss Out!: Incomplete data can contain valuable information.*

Feast, A., Orrell, M., Charlesworth, G., Melunsky, N., Poland, F., & Moniz-Cook, E. (2016). Behavioural and psychological symptoms in dementia and the challenges for family carers: Systematic review. *British Journal of Psychiatry*, *208*(5), 429–434. https://doi.org/10.1192/bjp.bp.114.153684

Fife, B. L., & Wright, E. R. (2000). The Dimensionality of Stigma : A Comparison of Its Impact on the Self of Persons with HIV / AIDS and Cancer. *Journal of Health and Social Behavior*, *41*(1), 50–67.

Fraboni, M., Saltstone, R., & Hughes, S. (1990). The Fraboni Scale of Ageism (FSA): An Attempt at a More Precise Measure of Ageism. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *9*(1), 56–66. https://doi.org/10.1017/S0714980800016093

George, D. R., Stuckey, H. L., Dillon, C. F., & Whitehead, M. M. (2011). Impact of participation in timeslips, a creative group-based storytelling program, on medical student attitudes toward persons with dementia: A qualitative study. *Gerontologist*, *51*(5), 699–703. https://doi.org/10.1093/geront/gnr035

George, D. R., Stuckey, H. L., & Whitehead, M. M. (2014). How a creative storytelling intervention can improve medical student attitude towards persons with dementia: A mixed methods study. *DEMENTIA-INTERNATIONAL JOURNAL OF SOCIAL RESEARCH AND PRACTICE*, *13*(3), 318–329. https://doi.org/10.1177/1471301212468732

Gilbert, P. (2010). *The compassionate mind : a new approach to life's challenges*. Oakland, Calif. SE - xxvii, 513 pages : illustrations ; 23 cm: New Harbinger Publications. https://doi.org/LK - https://worldcat.org/title/436624753

Gove, D. M., Andrews, J., Capstick, A., Geoghegan, C., Georges, J., Libert, S., … Williamson, T. (2019). Dementia as a disability: Implications for ethics , policy and practice. A Discussion Paper., 0–61. Retrieved from http://hdl.handle.net/10454/14923

Gove, D., Small, N., Downs, M., & Vernooij-Dassen, M. (2017). General practitioners' perceptions of the stigma of dementia and the role of reciprocity. *Dementia*, *16*(7).

https://doi.org/10.1177/1471301215625657

Graham, J. W. (2009). Missing Data Analysis: Making It Work in the Real World. *Annual Review of Psychology*, *60*(1), 549–576. https://doi.org/10.1146/annurev.psych.58.110405.085530

Hailstone, J., Mukadam, N., Owen, T., Cooper, C., & Livingston, G. (2017). The development of Attitudes of People from Ethnic Minorities to Help-Seeking for Dementia (APEND): a questionnaire to measure attitudes to help-seeking for dementia in people from South Asian backgrounds in the UK. *International Journal of Geriatric Psychiatry*, *32*(3), 288–296. https://doi.org/10.1002/gps.4462

Harrer, M., Cuijpers, P., A, F. T., & Ebert, D. D. (2021). *Doing Meta-Analysis With {R}: A Hands-On Guide* (1st ed.). Boca Raton, FL and London: Chapman & Hall/CRC Press.

Harris, P. B., & Caporella, C. A. (2014). An intergenerational choir formed to lessen alzheimer's disease stigma in college students and decrease the social isolation of people with alzheimer's disease and their family members: A pilot study. *American Journal of Alzheimer's Disease and Other Dementias*, *29*(3), 270–281. https://doi.org/10.1177/1533317513517044

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2018). A Systematic Review of Dementia-related Stigma Research: Can We Move the Stigma Dial? *American Journal of Geriatric Psychiatry*, *26*(3), 316–331. https://doi.org/10.1016/j.jagp.2017.09.006

Heuer, S., Douglas, N., Burney, T., & Willer, R. (2020). Service-Learning with older adults in care communities: Measures of attitude shifts in undergraduate students. *GERONTOLOGY \& GERIATRICS EDUCATION*, *41*(2), 186–199. https://doi.org/10.1080/02701960.2019.1596087

Higgins, J. P., & Green, S. E. (2008). *Cochrane Handbook for Systematic Reviews of Interventions: Cochrane Book Series*. https://doi.org/10.1109/ISIT.2017.8006970

Higgins, J. P. T., & Thompson, S. G. (2002). Quantifying heterogeneity in a meta-analysis. *Statistics in Medicine*, *21*(11), 1539–1558. https://doi.org/10.1002/sim.1186

Johnson, R., Harkins, K., Cary, M., Sankar, P., & Karlawish, J. (2015). The relative contributions of disease label and disease prognosis to Alzheimer's stigma: A vignette-based experiment. *Social Science and Medicine*, *143*, 117–127. https://doi.org/10.1016/j.socscimed.2015.08.031

Kafadar, A. H., Barrett, C., & Cheung, K. L. (2021). Knowledge and perceptions of Alzheimer's disease in three ethnic groups of younger adults in the United Kingdom. *BMC PUBLIC HEALTH*, *21*(1). https://doi.org/10.1186/s12889-021-11231-8

Kimzey, M., Mastel-Smith, B., & Alfred, D. (2016). The impact of educational experiences on nursing students' knowledge and attitudes toward people with Alzheimer's disease: A mixed method study. *NURSE EDUCATION TODAY*, *46*, 57–63. https://doi.org/10.1016/j.nedt.2016.08.031

Kogan, N. (1961). Attitudes toward old people: The development of a scale and an examination of correlates. *Journal of Abnormal and Social Psychology, 62*(1), 44–54. https://doi.org/10.1037/h0048053

Korkmaz Aslan, G., Kılınç İşleyen, E., & Kartal, A. (2023). Nursing students' knowledge and attitudes about dementia: A cross-sectional study. *Nurse Education in Practice, 72*(August). https://doi.org/10.1016/j.nepr.2023.103800

Krause, N. (2002). A comprehensive strategy for developing closed-ended survey items for use in studies of older adults. *Journals of Gerontology - Series B Psychological Sciences* *and Social Sciences*, *57*(5). https://doi.org/10.1093/geronb/57.5.S263

Lefever, S., Dal, M., & Matthíasdóttir, Á. (2007). Online data collection in academic research: Advantages and limitations. *British Journal of Educational Technology*, *38*(4), 574–582. https://doi.org/10.1111/j.1467-8535.2006.00638.x

Link, B. G, & Phelan, J. C. (2006). Stigma and its public health implications. *Lancet*, *367*(9509), 528–529. https://doi.org/10.1016/S0140-6736(06)68184-1

Link, Bruce G, & Phelan, J. C. (2001). Conceptualizing stigma. *Annu. Rev. Sociol*, *27*(Lewis 1998), 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Lion, Katarzyna Małgorzata, Szcześniak, D., Bulińska, K., Evans, S. B., Evans, S. C., Saibene, F. L., … Rymaszewska, J. (2019). Do people with dementia and mild cognitive impairments experience stigma? A cross-cultural investigation between Italy, Poland and the UK. *Aging & Mental Health*, *0*(0), 1–9. https://doi.org/10.1080/13607863.2019.1577799

Lion, Katarzyna Malgorzata, Szczesniak, D., Bulinska, K., Mazurek, J., Evans, S. B., Evans, S. C., … Rymaszewska, J. (2021). Does the Meeting Centre Support Programme decrease the experience of stigmatisation among people with cognitive deficits? *AGING \& MENTAL HEALTH*, *25*(1), 160–169. https://doi.org/10.1080/13607863.2019.1683815

Livingston, J. D., Milne, T., Fang, M. L., & Amari, E. (2012). The effectiveness of interventions for reducing stigma related to substance use disorders: A systematic review. *Addiction*, *107*(1), 39–50. https://doi.org/10.1111/j.1360-0443.2011.03601.x

Lokon, E., Li, Y., & Parajuli, J. (2017). Using art in an intergenerational program to improve students’ attitudes toward people with dementia. *GERONTOLOGY \& GERIATRICS*

EDUCATION, *38*(4), 407–424. https://doi.org/10.1080/02701960.2017.1281804

Maio, G. R., Verplanken, B., & Haddock, G. (2018). The Psychology of Attitudes and Attitude Change. London: SAGE Publications Ltd. Retrieved from http://digital.casalini.it/9781526454126

Mangiaracina, F., Chattat, R., Farina, E., Saibene, F. L., Gamberini, G., Brooker, D., … Meiland, F. J. M. (2017). Not re-inventing the wheel: the adaptive implementation of the meeting centres support programme in four European countries. *Aging and Mental Health*, *21*(1), 40–48. https://doi.org/10.1080/13607863.2016.1258540

Marmara, J., Zarate, D., Vassallo, J., Patten, R., & Stavropoulos, V. (2022). Warwick Edinburgh Mental Well-Being Scale (WEMWBS): measurement invariance across genders and item response theory examination. *BMC Psychology*, *10*(1), 1–17. https://doi.org/10.1186/s40359-022-00720-z

Maskeliunas, R., Damasevicius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious Game iDO: Towards Better Education in Dementia Care. *INFORMATION*, *10*(11). https://doi.org/10.3390/info10110355

Maskeliunas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious game iDO: Towards better education in dementia care. *Information (Switzerland)*, *10*(11), 1–15. https://doi.org/10.3390/info10110355

Maskeliūnas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious Game iDO: Towards Better Education in Dementia Care. *Information (2078-2489)*, *10*(11), 355. Retrieved from https://search.ebscohost.com/login.aspx?direct=true&AuthType=ip,shib&db=lls&AN=139863788&site=ehost-live&scope=site&custid=s8454451

McCall, L. (2005). The Complexity of Intersectionality, *38*(4), 811–845. Retrieved from http://www.jstor.org/stable/10.1086/426800

Mukadam, N., Waugh, A., Cooper, C., & Livingston, G. (2015). What would encourage help-seeking for memory problems among UK-based South Asians? A qualitative study. *BMJ Open*, *5*(9). https://doi.org/10.1136/bmjopen-2015-007990

Nguyen, T., & Li, X. (2018). Understanding public-stigma and self-stigma in the context of dementia : A systematic review of the global literature. *Dementia*. https://doi.org/10.1177/1471301218800122

O'Connor, D., Mann, J., & Wiersma, E. (2018a). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies*, *44*(February), 45–51. https://doi.org/10.1016/j.jaging.2018.01.010

O'Connor, D., Mann, J., & Wiersma, E. (2018b). Stigma, discrimination and agency: Diagnostic disclosure as an everyday practice shaping social citizenship. *Journal of Aging Studies*, *44*(October 2017), 45–51. https://doi.org/10.1016/j.jaging.2018.01.010

O'Connor, M. L., & McFadden, S. H. (2010). Development and psychometric validation of the dementia attitudes scale. *International Journal of Alzheimer's Disease*, *2010*. https://doi.org/10.4061/2010/454218

O'Connor, M. L., & McFadden, S. H. (2012). A Terror Management Perspective on Young Adults' Ageism and Attitudes Toward Dementia. *Educational Gerontology*, *38*(9), 627–643. https://doi.org/10.1080/03601277.2011.595335

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *The BMJ*, *372*. https://doi.org/10.1136/bmj.n71

Patel, I., Patel, J., Jindal, S. V., Desai, D., & Desai, S. (2021). Knowledge, Awareness, and Attitude Towards Dementia Amongst Medical Undergraduate Students: Can a Sensitization Program Help? *ANNALS OF INDIAN ACADEMY OF NEUROLOGY*, *24*(5), 754–758. https://doi.org/10.4103/aian.AIAN_874_20

Pescosolido, B. A., & Martin, J. K. (2015). The Stigma Complex. *Annual Review of Sociology*, *41*(1), 87–116. https://doi.org/10.1146/annurev-soc-071312-145702

Petscher, Y., Schatschneider, C., & Compton, D. L. (2013). *Applied quantitative analysis in education and the social sciences*. *Applied Quantitative Analysis in Education and the Social Sciences*. https://doi.org/10.4324/9780203108550

Phenwan, T., Sixsmith, J., McSwiggan, L., & Buchanan, D. (2021). A rapid review of internet mediated research methods with people with dementia: Practical, technical, and ethical considerations. *Qualitative Report*, *26*(11), 3318–3341. https://doi.org/10.46743/2160-3715/2021.5089

Piver, L. C., Nubukpo, P., Faure, A., Dumoitier, N., Couratier, P., & Clément, J. P. (2013). Describing perceived stigma against Alzheimer's disease in a general population in France: The STIG-MA survey. *International Journal of Geriatric Psychiatry*, *28*(9), 933–938. https://doi.org/10.1002/gps.3903

Price, E. (2010). Coming out to care: Gay and lesbian carers' experiences of dementia services. *Health and Social Care in the Community*, *18*(2), 160–168. https://doi.org/10.1111/j.1365-2524.2009.00884.x

Rewerska-Juśko, M., & Rejdak, K. (2020). Social Stigma of People with Dementia. *Journal of Alzheimer's Disease*, *78*(4), 1339–1343. https://doi.org/10.3233/JAD-201004

Roberts, H. J., & Noble Hannah J.; ORCID: https://orcid.org/0000-0003-2110-9542 AI -

Noble, James M.; ORCID: https://orcid.org/0000-0003-0648-6702, J. M. A. I.-R. (2015). Education Research: Changing medical student perceptions of dementia: An arts-centered experience. *Neurology*, *85*(8), 739–741. https://doi.org/https://dx.doi.org/10.1212/WNL.0000000000001867

Roberts, H. J., & Noble, J. M. (2015). Education Research: Changing medical student perceptions of dementia: An arts-centered experience. *Neurology*, *85*(8), 739–741. https://doi.org/10.1212/WNL.0000000000001867

Roes, M., Laporte Uribe, F., Peters-Nehrenheim, V., Smits, C., Johannessen, A., Charlesworth, G., … Tezcan-Güntekin, H. (2022). Intersectionality and its relevance for research in dementia care of people with a migration background. *Zeitschrift Fur Gerontologie Und Geriatrie*, *55*(4), 287–291. https://doi.org/10.1007/s00391-022-02058-y

Rosin, E. R., Blasco, D., Pilozzi, A. R., Yang, L. H., & Huang, X. (2020). A Narrative Review of Alzheimer’s Disease Stigma. *Journal of Alzheimer’s Disease*, *78*(2), 515–528. https://doi.org/10.3233/JAD-200932

Schneider, J., Schonstein, A., Teschauer, W., Kruse, A., & Teichmann, B. (2020). Hospital Staff’s Attitudes Toward and Knowledge About Dementia Before and After a Two-Day Dementia Training Program. *JOURNAL OF ALZHEIMERS DISEASE*, *77*(1), 355–365. https://doi.org/10.3233/JAD-200268

Sengupta, S., Banks, B., Jonas, D., Miles, M. S., & Smith, G. C. (2011). HIV interventions to reduce HIV/AIDS stigma: A systematic review. *AIDS and Behavior*, *15*(6), 1075–1087. https://doi.org/10.1007/s10461-010-9847-0

Stryker, S. (1987). The Vitalization of Symbolic Interactionism. *Social Psychology Quarterly*, *50*(1), 83–94.

Stryker, S. (2006). Traditional Symbolic Interactionism, Role Theory, and Structural Symbolic Interactionism: The Road to Identity Theory. *Handbook of Sociological Theory*, 211–231. https://doi.org/10.1007/0-387-36274-6_11

Swaffer, K. (2014). Dementia: Stigma, Language, and Dementia-friendly. *Dementia*, *13*(6), 709–716. https://doi.org/10.1177/1471301214548143

Szcześniak, D., Urbańska, K., Farina, E., Saibene, F. L., Chattat, R., Evans, S., … Rymaszewska, J. (2017). Does participation in the Meeting Centre Support Programme change the stigma experienced by people with dementia? *European Psychiatry*, *41*, S177. https://doi.org/10.1016/j.eurpsy.2017.01.2078

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., … Stewart-Brown, S. (2007). The Warwick-Dinburgh mental well-being scale (WEMWBS): Development and UK validation. *Health and Quality of Life Outcomes*, *5*, 1–13. https://doi.org/10.1186/1477-7525-5-63

Thomas, A., Palmer, J. K., Coker-Juneau, C. J., & Williams, D. J. (2003). Factor structure and construct validity of the interaction with disabled persons scale. *Educational and Psychological Measurement*, *63*(3), 465–483. https://doi.org/10.1177/0013164403063003008

Thornicroft, G. (2003, July 1). Shunned: Discrimination against people with mental illness. Oxford University Press. https://doi.org/10.1093/med/9780198570981.001.0001

Thornicroft, G., Rose, D., Kassam, A., & Sartorius, N. (2007). Stigma: ignorance, prejudice or discrimination? *British Journal of Psychiatry*, *190*(MAR.), 1–3. https://doi.org/10.1192/bjp.bp.106.025791

Thornicroft, G., Sunkel, C., Alikhon Aliev, A., Baker, S., Brohan, E., el Chammay, R., …

Winkler, P. (2022). The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet*, *400*(10361), 1438–1480. https://doi.org/10.1016/S0140-6736(22)01470-2

Tirado-Rafferty, A., Petrescu-Prahova, M., Belza, B., Berridge, C., Zhou, Y., & La Fazia, D. M. (2023). Implementation and impact of a Dementia Friends pilot. *DEMENTIA-INTERNATIONAL JOURNAL OF SOCIAL RESEARCH AND PRACTICE*, *22*(3), 493–513. https://doi.org/10.1177/14713012221147703

Wadley, V. G., & Haley, W. E. (2001). Diagnostic attributions versus labeling: Impact of Alzheimer's disease and major depression diagnoses on emotions, beliefs, and helping intentions of family members. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *56*(4), P244–P252. Retrieved from http://www.embase.com/search/results?subaction=viewrecord&from=export&id=L32652704%5Cnhttp://sfx.metabib.ch/sfx_locater?sid=EMBASE&issn=10795014&id=doi:&atitle=Diagnostic+attributions+versus+labeling:+Impact+of+Alzheimer's+disease+and+major+depression+di

Walmsley, B., & McCormack, L. (2016). Shame, hope, intimacy and growth: Dementia distress and growth in families from the perspective of senior aged care professionals. *Dementia*, *15*(6), 1666–1684. https://doi.org/10.1177/1471301215573676

Wang, S., Cheung, D. S. K., Leung, A. Y. M., & Davidson, P. M. (2021). Bibliotherapy for improving caregiving appraisal of informal caregivers of people with dementia: A pilot randomized controlled trial. *RESEARCH IN NURSING \& HEALTH*, *44*(4), 692–703. https://doi.org/10.1002/nur.22143

WHO. (2017). Global action plan on the public health response to dementia 2017 - 2025. *Geneva: World Health Organization*, 52. Retrieved from http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

Wolfe, S. E., Greenhill, B., Butchard, S., & Day, J. (2021). The meaning of autonomy when living with dementia: A Q-method investigation. *Dementia*, *20*(6), 1875–1890. https://doi.org/10.1177/1471301220973067

Woo, B. K. P. (2017). Family history and its relationship with dementia stigma beliefs among Chinese Americans. *Geriatrics and Gerontology International*, *17*(1), 122–125. https://doi.org/10.1111/ggi.12686

Woo, B. K. P., & Chung, J. O. . (2013). PUBLIC STIGMA ASSOCIATED WITH DEMENTIA IN A CHINESE-AMERICAN IMMIGRANT POPULATION. *Journal of American Geriatrics Society*, *22*(7), 1621-16–32.

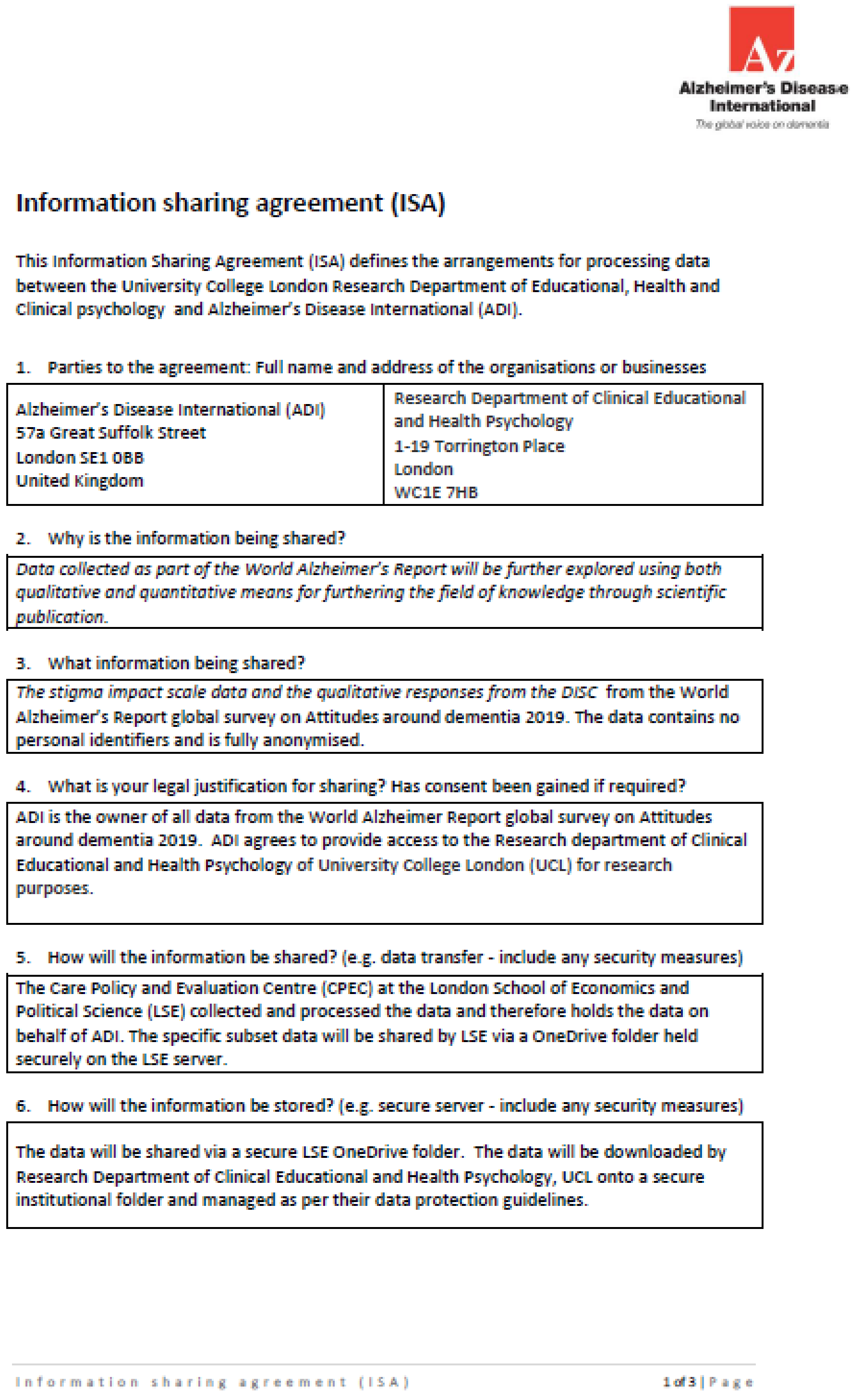
World Health Organization. (2022). *A blueprint for dementia research*. Retrieved from https://www.who.int/publications/i/item/9789240058248

Yordy, B., Stuart Pope, W., & Wang, C. H. (2019). Canine Outreach Promoting Engagement: The Effect of Meaningful Activities on Students' Attitudes Toward Cognitively Impaired Older Adults. *Nurse Educator*, *44*(2), 102–105. https://doi.org/10.1097/NNE.0000000000000549

Zhu, L., Schall, A., Paulitsch, M., Pantel, J., & Tesky, V. A. (2023). Attitudes Toward People with Dementia in Germany and China A Questionnaire Validation. *GEROPSYCH-THE JOURNAL OF GERONTOPSYCHOLOGY AND GERIATRIC PSYCHIATRY*. https://doi.org/10.1024/1662-9647/a000327

Appendix

Data Sharing Agreement



Alzheimer's Disease International
The global voice on dementia

Information sharing agreement (ISA)

This Information Sharing Agreement (ISA) defines the arrangements for processing data between the University College London Research Department of Educational, Health and Clinical psychology and Alzheimer's Disease International (ADI).

1. Parties to the agreement: Full name and address of the organisations or businesses

Alzheimer's Disease International (ADI) 57a Great Suffolk Street London SE1 0BB United Kingdom	Research Department of Clinical Educational and Health Psychology 1-19 Torrington Place London WC1E 7HB

2. Why is the information being shared?

Data collected as part of the World Alzheimer's Report will be further explored using both qualitative and quantitative means for furthering the field of knowledge through scientific publication.

3. What information being shared?

The stigma impact scale data and the qualitative responses from the DISC from the World Alzheimer's Report global survey on Attitudes around dementia 2019. The data contains no personal identifiers and is fully anonymised.

4. What is your legal justification for sharing? Has consent been gained if required?

ADI is the owner of all data from the World Alzheimer Report global survey on Attitudes around dementia 2019. ADI agrees to provide access to the Research department of Clinical Educational and Health Psychology of University College London (UCL) for research purposes.

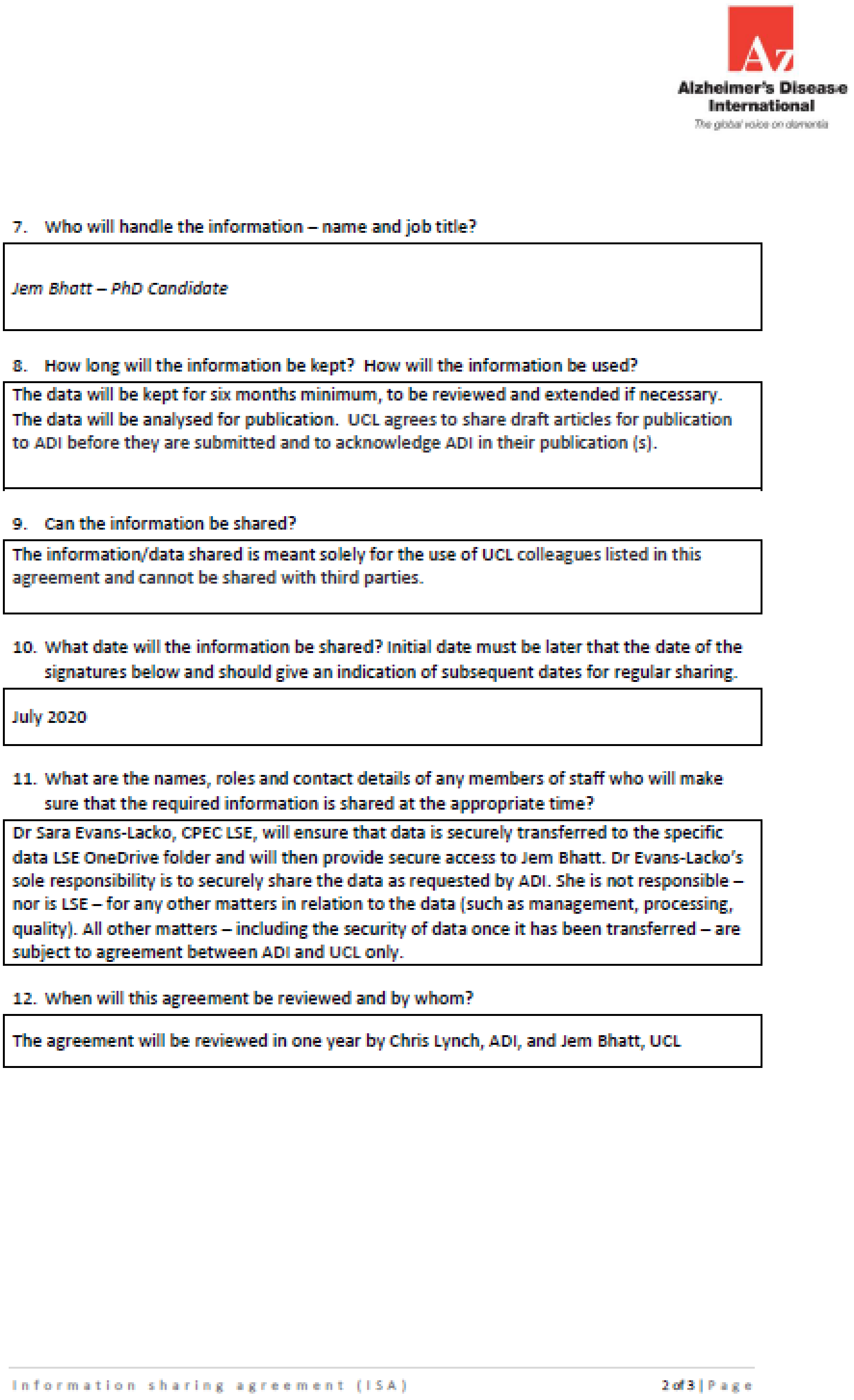
5. How will the information be shared? (e.g. data transfer - include any security measures)

The Care Policy and Evaluation Centre (CPEC) at the London School of Economics and Political Science (LSE) collected and processed the data and therefore holds the data on behalf of ADI. The specific subset data will be shared by LSE via a OneDrive folder held securely on the LSE server.

6. How will the information be stored? (e.g. secure server - include any security measures)

The data will be shared via a secure LSE OneDrive folder. The data will be downloaded by Research Department of Clinical Educational and Health Psychology, UCL onto a secure institutional folder and managed as per their data protection guidelines.

Information sharing agreement (ISA) 1 of 3 | Page



Alzheimer's Disease International
The global voice on dementia

7. Who will handle the information – name and job title?

Jem Bhatt – PhD Candidate

8. How long will the information be kept? How will the information be used?

The data will be kept for six months minimum, to be reviewed and extended if necessary. The data will be analysed for publication. UCL agrees to share draft articles for publication to ADI before they are submitted and to acknowledge ADI in their publication (s).

9. Can the information be shared?

The information/data shared is meant solely for the use of UCL colleagues listed in this agreement and cannot be shared with third parties.

10. What date will the information be shared? Initial date must be later that the date of the signatures below and should give an indication of subsequent dates for regular sharing.

July 2020

11. What are the names, roles and contact details of any members of staff who will make sure that the required information is shared at the appropriate time?

Dr Sara Evans-Lacko, CPEC LSE, will ensure that data is securely transferred to the specific data LSE OneDrive folder and will then provide secure access to Jem Bhatt. Dr Evans-Lacko's sole responsibility is to securely share the data as requested by ADI. She is not responsible – nor is LSE – for any other matters in relation to the data (such as management, processing, quality). All other matters – including the security of data once it has been transferred – are subject to agreement between ADI and UCL only.

12. When will this agreement be reviewed and by whom?

The agreement will be reviewed in one year by Chris Lynch, ADI, and Jem Bhatt, UCL

Information sharing agreement (ISA) 2 of 3 | Page

This agreement must be formally approved and signed by both parties before any information sharing takes place. Both parties will ensure that the ISA and any associated documents are known and understood by all staff involved in the process.

Originating organisation

Name of organisation: **Alzheimer's Disease International**

Name: **Chris Lynch**

Position: **Policy, Communications and Publications Director and Deputy CEO.**

Signature: …………………………………… Date: ……………

Partner organisation

Name of organisation: **Research Department of Clinical Educational and Health Psychology, UCL**

Name: **Dr Jem Bhatt**

Position: **PhD Candidate**

Signature: [redacted] Date: 08-07-2020

6. Participant demographics variables – full table

Variable	**N(%) or Mean(SD)**		Variable	**N(%)**	
Sex	Male	277(39.00)	Country	Argentina	2(0.28%)
	Female	433(61.00)		Australia	30(4.23%)
Age	N=710, Range: 24-92	64.81(11.71)		Belgium	12(1.69%)
Employment status	Full time paid employment	101(14.20)		Brazil	36(5.07%)
	Part time paid employment	26(3.70)		Canada	27(3.80%)
	Self-employed	50(7.00)		China	11(1.55%)
	Unpaid/voluntary work	55(7.70)		Colombia	4(0.56%)
	Unpaid carer	16(2.30)		Costa Rica	3(0.42%)
	Retired	391(55.10)		Croatia	2(0.28%)
	Student	4(0.60)		Dominican Republic	1(0.14%)
	Illness/sick-leave	43(6.10)			
	Looking for/other, unemployed	54(7.60)		France	2(0.28%)
				Germany	3(0.42%)
Education	Less than primary/elementary school	5(0. 70)		Greece	7(0.99%)
				Iceland	1(0.14%)
	Primary/elementary school	22(3.10)		India	14(1.97%)
	Secondary school/ High school (or equivalent)	163(23.00)		Indonesia	9(1.27%)
	Vocational training or apprenticeship	90(12.70)		Iran	2(0.28%)
				Ireland	1(0.14%)
				Italy	59(8.31%)

	College/pre-university/university		257(36.20)		Japan	9(%)
					Kenya	1(0.14%)
	Post graduate degree completed		173(24.40)		Lebanon	1(0.14%)
Area of residence	Urban		332(45.40)		Malaysia	7(0.99%)
	Suburban		162(22.80)		Mauritius	1(0.14%)
	Semi-rural		155(21.80)		Mexico	8(1.13%)
	Rural		59(8.30)		Netherlands	181(25.49%)
Stigma Impact Scale	N= 710	Range: 78.00	42.35(16.38)		New Zealand	15(2.11%)
					Norway	1(0.14%)
					Philippines	3(0.42%)
					Portugal	2(0.28%)
WEMWBS total	N= 681	Range: 1.70	44.40(11.28)		Puerto Rico	1(0.14%)
DEMQoL total	N= 596	Range :2.79	1.99(0.30)		Qatar	2(0.28%)
WEMWBS categorical	Higher mental wellbeing ≥42		408(57.46%)		Russia	3(0.42%)
	Lower mental wellbeing (0-41)		266(37.46%)		Singapore	1(0.14%)
DQoL categorical	Higher QoL (> median 2.25)		103(14.51%)		Slovenia	3(0.42%)
	Lower QoL (≤ median 2.25)		493(69.43%)		South Africa	6(0.85%)
WHO Region	African Region		8(1.13%)		Spain	2(0.28%)
	Eastern Mediterranean Region		5(0.70%)		Taiwan	20(2.82%)
	European Region		317(44.65%)		Thailand	6(0.85%)
	Region of the Americas		241(33.94%)		United Kingdom	38(5.35%)

	South-East Asia Region	29(4.08%)		United States	159(22.39%)
	Western Pacific Region	110(15.49%)		Vietnam	14(1.97%)
World bank income categories	High-income economies	580(81.69%)			
	Upper-middle economies	89(12.54%)			
	Lower-middle economies	41(5.77%)			

7. Quasi Experimental Study Quality Appraisal Tool

Internal Validity		Choice - Comments/Justification	Yes	No	Unclear	N/A
Bias related to temporal precedence						
1	Is it clear in the study what is the "cause" and what is the "effect" (i.e. there is no confusion about which variable comes first)?		☐	☐	☐	☐
Bias related to selection and allocation						
2	Was there a control group?		☐	☐	☐	☐
Bias related to confounding factors						
3	Were participants included in any comparisons similar?		☐	☐	☐	☐
Bias related to administration of intervention/exposure						
4	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?		☐	☐	☐	☐

Bias related to assessment, detection and measurement of the outcome						
5	Were there multiple measurements of the outcome, both pre and post the intervention/exposure?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐

6	Were the outcomes of participants included in any comparisons measured in the same way?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐

7	Were outcomes measured in a reliable way?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐

Bias related to participant retention

8	Was follow-up complete and if not, were differences between groups in terms of their follow-up adequately described and analyzed?					
	Outcome 1		Yes	No	Unclear	N/A
	Result 1		☐	☐	☐	☐

Statistical Conclusion Validity

9	Was appropriate statistical analysis used?					
	Outcome 1		**Yes**	**No**	**Unclear**	**N/A**

Overall appraisal: Include: ☐ Exclude: ☐ Seek Further Info: ☐

Comments:

8. RCT Quality Appraisal Tool

Internal Validity		Choice - Comments/Justification	Yes	No	Unclear	N/A
Bias related to selection and allocation						
1	Was true randomization used for assignment of participants to treatment groups?		☐	☐	☐	☐
2	Was allocation to treatment groups concealed?		☐	☐	☐	☐
3	Were treatment groups similar at the baseline?		☐	☐	☐	☐
Bias related to administration of intervention/exposure						
4	Were participants blind to treatment assignment?		☐	☐	☐	☐
5	Were those delivering the treatment blind to treatment assignment?		☐	☐	☐	☐

6	Were treatment groups treated identically other than the intervention of interest?		☐	☐	☐	☐

Bias related to assessment, detection and measurement of the outcome

7	Were outcome assessors blind to treatment assignment?		Yes	No	Unclear	N/A
	Outcome 1		☐	☐	☐	☐

8	Were outcomes measured in the same way for treatment groups?		Yes	No	Unclear	N/A

9	Were outcomes measured in a reliable way		Yes	No	Unclear	N/A

Bias related to participant retention

10	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?					
	Outcome 1		Yes	No	Unclear	N/A
	Result 1		☐	☐	☐	☐

Statistical Conclusion Validity

11	Were participants analysed in the groups to which they were randomized?		

	Outcome 1		Yes	No	Unclear	N/A
	Result 1		☐	☐	☐	☐

12	Was appropriate statistical analysis used?					
	Outcome 1		Yes	No	Unclear	N/A
	Result 1		☐	☐	☐	☐

			Yes	No	Unclear	N/A
13	Was the trial design appropriate and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?		☐	☐	☐	☐

Overall appraisal: Include: ☐ Exclude: ☐ Seek Further Info: ☐

Comments: