THE UNIVERSITY OF HULL

Measuring aspects of self in dementia and investigating the validity of a self-compassion scale

being a Thesis submitted in partial fulfilment
of the requirements for the degree of Doctor of Clinical Psychology

in the University of Hull

by

Jessica Baggaley, BSc (Hons) Psychology

May 2023

Acknowledgements

Firstly, I would like to say a big thank you to all of the participants for giving up their time to take part in the study, this research couldn't have happened without you.

Thank you to everyone who helped with sharing and advertising the study. I would like to give special thanks to everybody from the Butterflies Memory Loss Support Group and the DEEP East Riders for welcoming me into your groups and getting involved in the study.

To the Research and Development team at Humber Teaching NHS Foundation Trust and Tees Esk and Wear Valley NHS Foundation Trust thank you for all of your help with recruitment and sharing the study.

Thank you to my supervisors, Dr Emma Wolverson and Dr Chris Clarke, for the guidance and support you have given me across the many stages of putting together this thesis. I have learnt so much from you both that I will take forward with me into my career and future research.

Lastly, to my family and friends I am incredibly grateful for all of your encouragement, support and patience. Thank you for being there with me through the ups and downs over the past three years.

Overview

This portfolio thesis consists of three parts. Part one is a systematic literature review, part two is an empirical paper and part three forms the accompanying appendices. Overall, they aim to evaluate and to add to the existing literature in relation to measuring specific aspects of self with people living with dementia.

Part One: A systematic literature review that investigated what aspects of self have been measured using self-report instruments in evaluating psychosocial interventions for people with dementia. A narrative synthesis was conducted with 24 studies and included a variety of psychosocial interventions. The review identified seven aspects of self, which were measured using a range of self-report instruments, however the effectiveness of the interventions for these aspects of self were mixed. Limitations and methodological quality of the studies are discussed, alongside clinical implications and future considerations for research.

Part Two: An empirical study that investigated the validity, reliability, and factor structure of the SCS-SF for people with dementia, as well as exploring correlations with well-being and demographic differences in self-compassion. The SCS-SF subscale intercorrelations and correlational analyses with measures of well-being, self-esteem and depression were investigated to assess convergent and discriminant validity of the SCS-SF in dementia. Exploratory Factor Analysis was conducted to determine the factor structure of the SCS-SF in dementia and to further assess construct validity. Differences in self-compassion based on participant age, gender, dementia subtype and time since diagnosis were also analysed. The study findings, implications and future recommendations are discussed.

Part Three: Appendices for the systematic literature review and empirical paper.

Total word count: 19,814 (excluding appendices and contents)

Contents

List of Tables and Figures

Part One: Systematic Literature Review

List of Figures

List of Tables

Part Two: Empirical Paper

List of Tables

Part One – Systematic Literature Review

This paper is written in format ready for submission to Dementia.

(Please see Appendix C for submission guidelines)

Word Count: 5,372 (excluding abstract, figures, tables, and references**)**

Self-report instruments measuring aspects of self for people living with dementia: A systematic literature review of psychosocial interventions

Jessica A. Baggaley[a]*, Dr Emma Wolverson[a,b] and Dr Chris Clarke[c]

[a] School of Psychology and Social Work, Aire Building, University of Hull, Hull, United Kingdom; [b]Research and Publications Team. Dementia UK, London, United Kingdom; [c] Tees, Esk and Wear Valley NHS Foundation Trust, United Kingdom

*Corresponding author. Email: j.a.baggaley-2017@hull.ac.uk

Abstract

Objective: A positive sense of self may be a key domain of psychological well-being for people living with dementia and could be a legitimate target for psychosocial interventions in dementia care. Determining the effectiveness of such interventions, often requires self-report instruments. This review aims to investigate what aspects of self have been measured using self-report instruments in evaluating psychosocial interventions for people living with dementia and to explore the effectiveness of these interventions at demonstrating positive outcomes related to aspects of self.

Method: A systematic search of the literature using five electronic databases and one register (CENTRAL) was conducted. A narrative synthesis and methodological quality assessment was completed for the included studies.

Results: A total of 24 studies were included in the review and seven aspects of self were measured using a range of self-report instruments, many not validated for dementia; self-esteem, self-efficacy, self-compassion, self-growth, self-acceptance, self-management, and self-identity. Studies included a variety of interventions, however the effectiveness of these interventions for the aspects of self was mixed.

Conclusion: Psychosocial interventions demonstrate some evidence of supporting specific aspects of self in dementia, however further research to improve this evidence base is needed. Future research is also needed to investigate the validity and reliability of existing self-report instruments that aim to measure aspects of self in dementia. Limitations and implications of the review are discussed.

Keywords: aspects of self, dementia; interventions; measure; self

Introduction

Stigma is a widespread issue for people living with dementia (Nguyen & Li, 2020) due to the negative narratives surrounding the condition in terms of progressive 'loss of self' (Davis, 2004), competence and self-esteem (Nguyen & Li, 2020). Feeling uncertain about the possible impact on one's sense of self and identity is a key concern for people living with dementia (Caddell & Clare, 2011a; Steeman et al., 2007) and the internalisation of negative narratives may exacerbate this.

Construction of the 'loss of self' narrative can be understood within Sabat and Harre's (1992) theory of self in dementia which proposes that a person holds three 'selves'; (1) one's point of view and personal identity, (2) the attributes one holds along with beliefs about these, and (3) how one presents themselves to the world (Sabat, 2001). The model emphasises that people living with dementia are positioned by others as helpless and confused and that their behaviour is interpreted by others to confirm this (Sabat & Harre, 1992). This can lead to others perceiving a diminished self in people living with dementia even when self remains intact for the person with dementia. Therefore, the preservation of self in dementia is heavily influenced by the complex interplay between interpersonal, social, psychological, and embodied factors (Surr, 2006).

Alternate multi-dimensional theories of self have also been applied to dementia (e.g., Caddell & Clare, 2011b) such as Neisser's (1988) Five Factor Model of Self, which suggests that self consists of ecological, interpersonal, extended, private, and conceptual selves. However, this may be viewed as simplistic by suggesting that components of self are independent from each other and overlook the complexities of the concept of self. More recently, Bomilcar et al. (2021) proposed seven components of self in dementia and considered the interactions between these individual domains to a greater extent; embodied, agentic, implicit, critical, surrogate, extended, and emergent self. There remains no agreed

definition of self in dementia, and no agreement as to whether it is a unitary construct or consists of several different 'selves', self domains, or self-evaluations (Caddell & Clare, 2010, 2013b; Klein & Gangi, 2010; McConnell, 2011).

The lack of an agreed definition or model of self has resulted in a range of different qualitative and quantitative methods used to measure and understand self (Caddell & Clare, 2010). Quantitative measures may be particularly useful in showing the extent that aspects of self change over time (Caddell & Clare, 2010) and in response to psychosocial interventions in dementia care (Moniz-Cook et al., 2008; Schölzel-Dorenbos et al., 2007). However, a review by Caddell and Clare (2011b) found that for interventions aiming to support self and identity in dementia, very few studies used standardised self-report measures relating to aspects of self and instead relied on observational methods or well-being measures.

The use of observational, or proxy-based measures, may risk bias (Schölzel-Dorenbos et al., 2007) and be influenced by the proxies own experiences (Logsdon et al., 2002; Sands et al., 2004), resulting in inconsistencies. For example, people diagnosed with dementia self-report higher quality of life than carer completed measures (e.g., Griffiths et al., 2020; Hounsome et al., 2011; Logsdon et al., 2002; Moyle et al., 2012; Sands et al., 2004; Sheehan et al., 2012). Subsequently there has been a growing interest in the use of self-report outcome measures, reflecting the move to person-centred care and recognition of the varied and unique experiences of dementia (Kitwood & Bredin, 1992; Kitwood, 1997, 2019).

A previous scoping review of well-being self-report measures identified six self-related measures and proposed that a 'positive sense of self' was a key domain of psychological well-being for people living with dementia (Clarke et al., 2020). In addition, self-report measures of self-efficacy and self-identity have been identified as self-related positive psychology outcome measures in dementia (Stoner et al., 2019). A positive sense of

self can be dynamic and maintained whilst living with dementia (Caddell & Clare, 2010; Strikwerda-Brown et al., 2019) and may affect coping with the challenges that follow a dementia diagnosis (Caddell & Clare, 2011b). Therefore, aspects of self that may be quantifiable, such as self-esteem and self-efficacy, can be measured when evaluating psychosocial interventions aiming to improve well-being in dementia (Lamont et al., 2019). Whilst Clarke et al. (2020) and Stoner et al. (2019) did not specifically focus their reviews on measures of disparate aspects of self, their findings suggest that since Caddell and Clare's (2011b) review, a larger pool of self-report measures relating to aspects of self are being used with people living with dementia.

The aim of the current review was to extend previous reviews (Caddell & Clare, 2011b; Clarke et al., 2020; Stoner et al., 2019) to develop a clearer understanding of what aspects of self have been measured within evaluations of psychosocial interventions for people living with dementia and how effective these interventions have been in relation to these aspects of self.

The specific questions underpinning this review were:

1. What aspects of self have been measured using self-report instruments to evaluate psychosocial interventions for people living with dementia?
2. What is the effectiveness of psychosocial interventions in demonstrating positive outcomes related to aspects of self?

This review aimed to identify what aspects of self have been measured in psychosocial interventions for dementia, and so adopted the position that there are multiple specific domains of self, rather than a single unitary self.

Methods

Search Strategy

A systematic review of the literature was conducted in January 2023. The following electronic databases were searched via the platform EBSCOHost: Academic Search Premier, PsycINFO, PsycARTICLES, MEDLINE and CINAHL Complete to cover psychology, health, and medicine. The Cochrane Central Register of Controlled Trials (CENTRAL) was also searched to increase the likelihood of identifying all relevant literature relating to randomised control trials (RCT's). Preliminary searches prior to the database review helped to identify key search terms such as aspects of self that had been highlighted or discussed in existing dementia research.

The following search terms were used: (dement * or alzheimer*) AND (TI (intervention* or treat* or program* or counsel* or therap* or activit* or group* or support* or workshop or course)) AND ("sense of self" or "aspect of self" or selfhood or self-esteem or self-efficacy or self-compassion or self-identity or self-stigma or self-concept or self-worth or self-aware* or self-agency or self-acceptance or self-confidence or self-trust or self-image or self-respect or self-recognition or self-knowledge or self-determination or self-critic* or self-control).

Truncations (*) and the operators (OR/AND) were used to broaden the search. To increase the frequency of relevant articles the following search limiters were applied on the EBSCOHost search: academic journals, peer reviewed and English language. A date limiter of 1992-2023 was also used as this was when Sabat and Harre (1992) published their theory of self in dementia.

Article Screening

The search resulted in 1,251 studies after duplicates were removed. A total of 1,201 papers were rejected following title and abstract stages as were not relevant to the review. The remaining 50 papers were screened in full using the inclusion and exclusion criteria (Table 1). A total of 24 studies were identified as meeting the required criteria and were included in the review. References and citation searches using Google Scholar were screened for the 24 studies. Three further studies were identified; however, following screening these were excluded. Figure 1 shows the PRISMA (Page et al., 2021) flow diagram outlining the article selection process.

Following the data extraction process for the 24 included studies, the terms 'self-management' and 'self-growth' were also identified. An additional search using these terms was conducted to identify any papers that may have been missed. Seven full papers were screened; however, all were excluded. Appendix D outlines the search terms and process for the additional search.

Table 1.

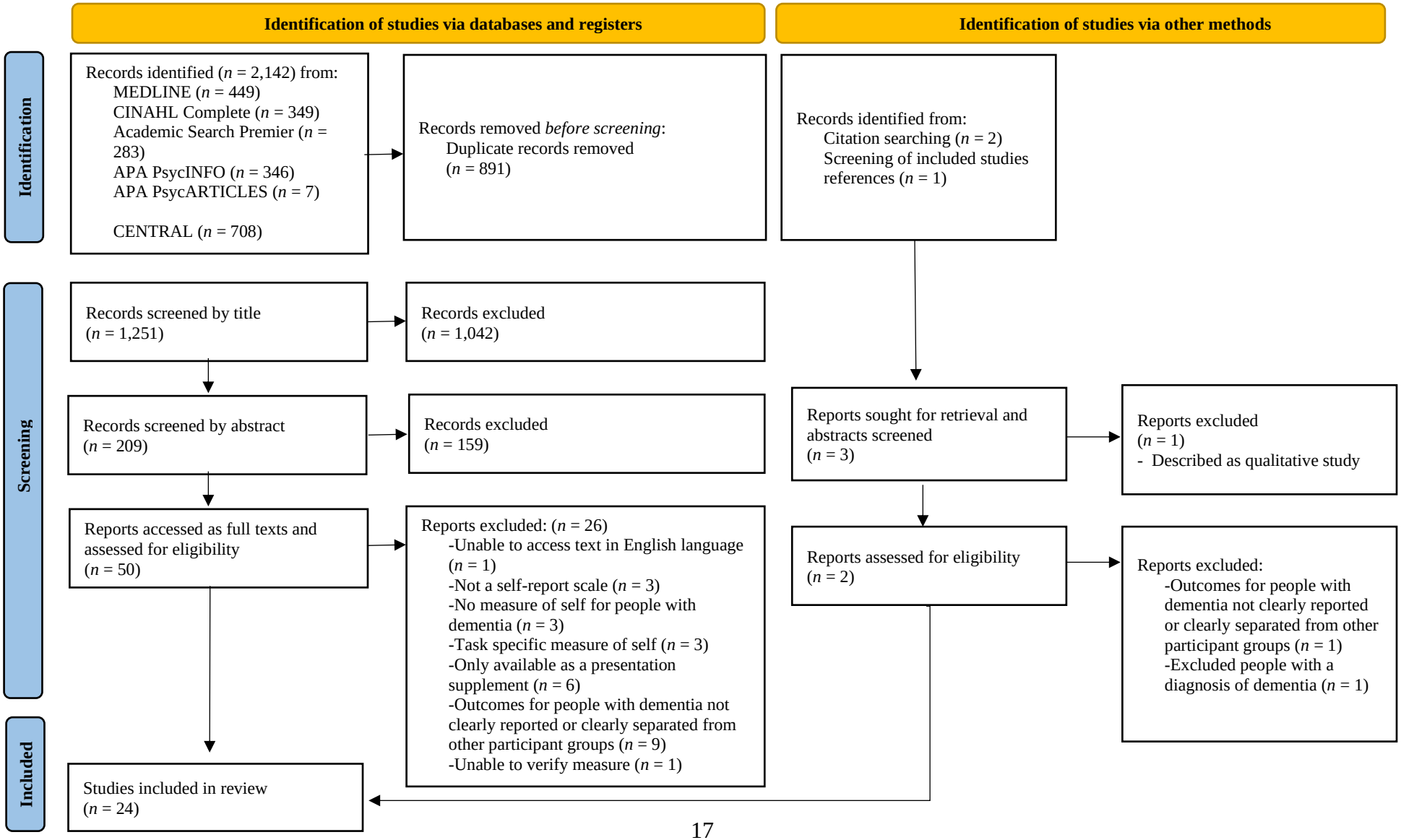
Inclusion and exclusion criteria for the review

	Inclusion Criteria	Exclusion Criteria
Intervention	The study evaluated a psychosocial intervention, in which activities/tasks/education were delivered.	The intervention was solely focussed on physical health or pharmacology.
Participants	To remain inclusive, participants were people with a diagnosis of dementia (any subtype), or probable dementia based on clear assessment criteria.	Studies that excluded people with a dementia diagnosis/participants did not include people with dementia/outcomes for participants with dementia were not clearly reported or separated from other

		participant groups (e.g., caregivers) as only people with dementia were under consideration in this review.
Outcomes	An aspect of self was measured pre and post intervention using a self-report instrument.	Studies that did not use a self-report instrument to measure self (e.g., reported only qualitative data) as it was not within the scope of this review to synthesise qualitative data.
	Studies that measured an aspect of self using a domain from a larger well-being instrument were included as long as the data relating to the self domain was reported separately from the scale as a whole.	Measure of self was not completed both pre and post intervention as it would not be possible to evaluate the effectiveness of the intervention.
	The measure of self had an explicit standardised approach or was freely available in order to verify the scale. Measures translated from English were included as long as the original instrument could be verified.	Measure of self was not self-reported by people with dementia. Measure only investigated a task specific aspect of self, which may be different from general aspects of self (Shelton, 1990; Siefer et al., 2021; Marsh et al., 2019). For example, general self-efficacy may be more closely related to self compared to task specific self-efficacy which is heavily based on previous experiences of the task (Shelton, 1990). As the current review examined aspects of self across contexts, task-specific measures of self were excluded.
Publication	The paper was published in a peer reviewed journal to ensure quality.	The paper was not available in the English language as the researchers would be unable to understand the analysis.

		Grey literature to ensure quality.
Design	Any primary research study design, including small *n* or *n*=1 studies were included in order to provide different levels of evidence and a balanced representation of the existing literature.	Reviews or discussion papers, as this review included only original studies/primary findings.

Figure 1. *PRISMA (Page et al., 2021) flow diagram of article selection process*



Quality Assessment

A quality assessment of the included studies was conducted using the Mixed Methods Appraisal Tool (MMAT, Hong et al., 2018), which is outlined in Appendix E. The assessment criteria for 'quantitative descriptive studies' (4.1-4.5) were removed as these were outside the scope of this review. Qualitative data was excluded from this review; however, for mixed method design studies the qualitative quality assessment items were completed to be able to respond to the overall mixed method assessment criteria. Quality assessment items were scored using the possible responses; yes, no or can't tell. The overall percentage score of 'yes' criteria is presented alongside descriptive summaries, therefore studies may score 20, 40, 60, 80 or 100 percent (Hong et al., 2020). Percentage score for mixed methods studies was determined by the percentage of 'yes' ratings in the lowest scoring component (Hong et al., 2020). Studies were rated 'yes' for the mixed methods criteria 5.5 (adherence to quality criteria for each component) if four or five out of the five assessment criteria for both the quantitative and qualitative components were rated 'yes'. Regarding complete outcome data and attrition (criteria 2.3), this review used a cut off of 20% for acceptable withdrawal rates (Van Tulder et al., 2003) and 80% for acceptable complete outcome data (Thomas et al., 2004). Studies were not excluded from this review based on quality scores or screening questions but are discussed during synthesis.

The MMAT advises a minimum of two independent reviewers (Hong et al., 2018), therefore inter-rater reliability was assessed by an independent reviewer who quality assessed five (20.8%) of the included studies; one from each percentage score band. Out of the 45 ratings possible from the five studies, four discrepancies were identified. The discrepancies were discussed before the ratings were mutually agreed.

Data Extraction and Analysis

Due to the heterogeneity of the included studies, a meta-analysis was not suitable and therefore a narrative synthesis was used to answer the research questions. Following the narrative synthesis guidance by Popay et al. (2006), a data extraction form was created (Appendix F). A preliminary synthesis of the data was conducted to identify patterns across the studies outcomes and designs, followed by an exploration of relationships between the studies and an assessment of the studies strengths and limitations. For mixed method studies, only the quantitative self-report components completed by people with dementia were synthesised. The term 'participants' used in this review therefore refers only to participants in the studies who had a diagnosis of dementia and does not include any participants from other population groups such as caregivers.

Results

Overview of Included Studies

In total, 24 studies met the inclusion criteria. Table 2 summarises their key characteristics and findings relevant to the research questions.

Included studies took place in the UK (*n*=8), USA (*n*=3), France (*n*=3), Spain (*n*=2), Netherlands (*n*=2), Hong Kong (*n*=1), Germany (*n*=1), South Korea (*n*=1), Australia (*n*=1), Canada (*n*=1), and one multi-national study took place in the UK, Italy, and Poland.

The majority of studies were randomised control trials (*n*=11), followed by mixed-methods (*n*=9), non-randomised repeated measures (*n*=8), case series (*n*=2), quasi-experimental (*n*=2) and one *n*=1 design.

The total number of included participants across all studies was 1,893 and the majority of interventions were delivered in a group format. Subtypes of dementia included

were Alzheimer's dementia, Vascular dementia, Mixed dementia, Parkinson's dementia, Lewy body dementia, and Frontotemporal dementia. Most studies (*n*=13) included a range of these subtypes but two included only individuals with Alzheimer's dementia (Gonzalez et al., 2015; Lee et al., 2008) and four did not report subtypes (Collins et al., 2022, Fitzsimmons & Buettner, 2003; Sprange et al., 2015; Werheid et al., 2021). Six studies included individuals with 'probable dementia'.

Most studies (*n*=11) included mainly participants in the early/mild stages of dementia. Eight studies included participants in the mild to moderate stages (Brooker et al., 2018; Clare et al., 2019; Cooke et al., 2010; Collins et al., 2022; Craig et al., 2018; Dodd et al., 2022; Richards et al., 2019; Werheid et al., 2021), one study included moderate to severe stages (Platel et al., 2021) and three included a range of stages of dementia (Dröes et al., 2019; Hindle et al., 2018; Pérez-Sáez et al., 2018). Foloppe et al's., (2018) single participant was described as being in the moderate stage of dementia.

Two studies explicitly stated that the measure of self was a primary outcome of the intervention (Richards et al., 2019; Quinn et al., 2016) and five studies reported the measure of self as a secondary outcome (Clare et al., 2019; Hindle et al., 2018; Marshall et al., 2015; Mountain et al., 2022; Pongan et al., 2017). The remaining studies did not differentiate between primary or secondary outcomes in relation to the chosen measures.

Quality of Included Studies

Appendix G shows study quality ratings. Two studies did not have clear research questions or aims therefore the research purpose was unclear (Richards et al., 2019; Werheid et al., 2021). The majority of studies were RCT's, the 'gold standard' of research designs (Rennie, 1996; Sibbald & Roland, 1998) although the quality of the studies varied, with only Clare et al. (2019) and Hindle et al. (2018) meeting all quality criteria for RCT's.

Common limitations for RCT's and non-randomised studies were high attrition rates and incomplete data, which can lead to a loss of statistical power and invalid conclusions (Kang, 2013). Lack of consideration of confounding factors (nine studies) may have limited internal validity. External validity may have been limited due to participants not matching target populations (five studies) and generalisability limited due to incomparable control and intervention groups at baseline (three RCT's). A relative strength regarding internal validity was that nine RCT's blinded outcome assessors to intervention groups which reduces the risk of detection bias.

Mixed method studies were generally lower quality and were often unclear on methodology rationales, suggesting that the purpose of a mixed method approach was often unclear. The quantitative components of these studies were mostly lower quality compared to qualitative components, although Mountain et al. (2022) and Quinn et al. (2016) met all criteria for both components. Werheid et al. (2021) and Fitzsimmons and Buettner (2003) were both lower quality studies due to not meeting any qualitative quality criteria, however their quantitative components, which were synthesised in this review, were of higher quality.

Table 2.
Summary of included studies characteristics

Author (publication year) & location	Aims	Participants (*n*)	Design & measure completion	Intervention	Measure of self (construct evaluated)	Key findings regarding self	Quality score
Berk et al. (2019) Netherlands	To explore the feasibility and effectiveness of an adapted Mindfulness Based Stress Reduction (MBSR) programme.	Seven people with early-stage Alzheimer's (4), Vascular (2) or Frontotemporal (1) dementia. Mean age 71.46, two females, five males.	Mixed methods pilot study Measures completed two weeks before and after the programme.	Eight weekly (2.5 hour) adjusted MBSR sessions covering topics such as acceptance, stress, and meditation. Daily homework tasks and a four-hour silent day.	SCS-SF (self-compassion)	Reduced self-compassion with a large effect size.	60
Brooker et al. (2018) Italy, Poland, and the UK	To transfer Meeting Centre Support Programmes (MCSP) to Italy, Poland, and the UK to evaluate the impact on social, behavioural, and emotional functioning.	159 people (89 females, 70 males) with mild to moderately severe dementia (85 in MCSP, 74 in usual care - control) of any subtype (sample demographic not reported). MCSP mean age 78.4 and control 78.5.	Quantitative non-randomised Measures completed within one month of starting the programme and repeated at six months.	MCSP included tailored post-diagnostic psychosocial interventions offered three days per week (UK/Poland) and 3.5-2 days per week (Italy).	DQoL (self-esteem) Polish and Italian versions back translated	Significant improvement in self-esteem for MCSP with a medium effect size.	60
Burgener et al. (2008)	To evaluate the feasibility and	42 people (24 intervention, 19	RCT	40 weeks of Tai Chi exercises (1 hour 3	RSES (self-esteem)	Significant difference in self-	40

USA	effects of a multimodal intervention on cognitive, physical, and behavioural outcomes.	control) in early to mid-stages of dementia (20 females, 23 males) including a range of subtypes (sample demographic not reported). Intervention mean age 77.9 and control 76.0.	Measures completed at baseline, 20 and 40 weeks.	times per week), group and individual Cognitive Behavioural Therapy (90 minutes biweekly), and a support group (90 minutes biweekly). Control group received attention-control education programs and were offered the intervention after 20 weeks.		esteem between the intervention and control group at 20-weeks. Increase in self-esteem post intervention not significant and stabilised from 20 to 40 weeks.	
Clare et al. (2019) England and Wales	To determine whether individual goal-oriented cognitive rehabilitation (CR) improves everyday functioning.	474 (226 females, 248 males) people with mild to moderate Alzheimer's (284), Vascular (74) or Mixed (116) dementia randomised to CR (238) or treatment as usual (TAU; 236). Mean age 78.56.	Multi-centre, single-blind RCT Measures completed at 3- and 9-months post randomisation.	Ten weekly one hour CR sessions that took a problem-solving approach to goals, followed by four one-hour maintenance sessions. TAU involved medication monitoring and psychosocial support.	GSES (self-efficacy)	No significant differences in self-efficacy found.	100

Collins et al. (2022) Canada	To explore the feasibility of Occupational Therapist delivered Cognitive Stimulation Therapy (CST) on the impact on self-efficacy and hope.	10 people (4 females, 6 males) with mild to moderate dementia (sample demographic not reported). Mean age 79.7.	Mixed methods Outcome measures completed before after the programme.	CST mirrored the 'Making a Difference' manual (Spector et al., 2006) delivered twice weekly for 14 one-hour group sessions.	GSES (self-efficacy)	Self-efficacy increased in five participants. GSES scores ranged from 21–37 pre intervention and 24–40 post intervention.	40
Cooke et al. (2010) Australia	To investigate the effect of a live music program on quality of life and depression.	47 people (33 females, 14 males) in early to mid-stages of dementia or probable dementia. Age range 75-94.	Cross over RCT Measures completed at baseline, mid-point, and post intervention.	Music group (intervention) involved song singing and the reading (control) group involved short stories, quizzes and local news for three mornings weekly over eight weeks.	DQoL (self-esteem)	Significant improvement in self-esteem over time, regardless of arm, specifically from mid-point to post intervention.	60
Craig et al. (2018) UK	To develop a Compassion Focused Therapy (CFT) intervention for people with dementia and depression and/or anxiety, and to assess its	Seven people (6 females, 1 male) with Alzheimer's (5), Vascular (1) or Mixed (1) dementia at mild to moderate cognitive impairment. Age range 53-88.	Mixed methods case series Measures completed pre, mid-point and post intervention.	CFT intervention involved topics such as developing self-compassion and managing difficult feelings over 10 sessions.	SCS-SF (self-compassion)	All participants showed improvements in self-compassion. Except for participant five, all completed the intervention in the moderate or high	20

	feasibility, acceptability, and utility.					self-compassion range.	
Dodd et al. (2022) UK	To develop an intervention based on nostalgia and assess whether couples could engage in nostalgic conversations.	Six people with Alzheimer's (3), Vascular (2) or Mixed (1) dementia at mild to moderate cognitive impairment level. Age range 72-84.	Mixed methods case series Measures completed at baseline and five week follow up.	Five-week nostalgic conversations intervention involved support from coaches via alternative weekly home visits and phone calls and the use of a workbook.	RSES (self-esteem) PWB (self-growth)	Self-esteem: Reliable change index showed improvement for one participant Clinically significant improvement found for two participants. Self-growth: Reliable change index showed improvements for four participants and one deteriorated. Clinically significant improvement shown for one participant.	20
Dröes et al. (2019) Netherlands	To evaluate the effectiveness of individualized Meeting Centers Support Program	29 Meeting Centers: 16 experimental iMCSP, 13 regular MCSP	The aspects of the study relating to people living with dementia used an	DemenTalent: people with dementia worked as volunteers in various settings aligning with their interests.	RSES (self-esteem) DQOL (self-esteem)	No differences were found in self-esteem between the groups.	20

	(iMCSP) compared to regular MCSP and no day care support.	282 people living with various subtypes of dementia across a range of stages of dementia: DemenTalent (39, mean age 76.54), Regular MCSP (54, mean age 80.67), no support (189, mean age 79.87)	explorative RCT. Measures completed at 0 and 6 months.	Regular MCSP control: a day club offering a range of recreational and creative activities.			
Fitzsimmons & Buettner (2003) USA	To evaluate an experiential college course for older adults with early-stage dementia.	Ten people (five females, two males) newly diagnosed with dementia signed up to participate (subtypes not reported), Mean age 77.9.	Mixed methods Measures completed in the first and final session.	Educational health promotion course involved experts providing information about dementia and healthy behaviours weekly for 10 weeks.	RSES (self-esteem) GSES (self-efficacy)	Self-esteem improved from a pre-test mean of 18.4 to a post-test of 22.0. Self-efficacy remained relatively stable from a pre-test mean of 33.17 to a post-test of 33.0.	0
Foloppe et al. (2018) France	To investigate whether it was possible to increase autonomy in cooking activities using	One participant (female, age 79) diagnosed with probable dementia at a moderate impairment.	Single n design Outcomes assessed at baseline, one day, one month and six	Four cooking tasks completed (one hour) for four days involving virtual cooking tasks on a computer (intervention) and a	French-Canadian RSES (self-esteem)	One day post-intervention self-esteem showed no change compared to baseline. Self-esteem scores decreased at the	80

	interventions based on errorless learning, vanishing cue, and virtual reality techniques.		months post intervention.	real condition (cooking tasks in a real kitchen).		one and six month follow up.	
Gonzalez et al. (2015) Spain	To examine the benefits of an integrative reminiscence programme in reducing depressive symptoms, increasing self-esteem and psychological well-being dimensions.	42 people with mild Alzheimer's dementia (23 reminiscence, 19 control). Mean age 80.24, 31% men, 69% women.	Quasi-experimental design Measures completed two weeks pre intervention and immediately after.	Reminiscence programme involved different topics focussed on life stages over 10, weekly, 60-minute sessions. Control group received usual day care whilst awaiting the intervention programme.	RSES (self-esteem) PWB (self-growth and self-acceptance)	Self-esteem: no significant time-group interaction and no significant differences between the groups at pre-intervention or over time. Time-group interaction was significant for self-acceptance (significantly increased) and self-growth post intervention.	80
Hindle et al. (2018) Wales	To examine the appropriateness and feasibility of cognitive rehabilitation (CR) for people with dementias	29 people (10 CR, 10 relaxation group, 9 TAU) living with Parkinson's dementia (25) or Lewy body dementia (4). Mean	Single blind RCT Measures completed at baseline, two- and six-months	Eight, weekly, one-hour sessions of either CR (involving compensatory and restorative cognitive strategies), relaxation therapy	GSES (self-efficacy)	Significant difference between CR and RT at the two month follow up.	100

	associated with Parkinson's.	age 76.34, females (6) and males (23)	post randomisation.	(RT; involving muscle relaxation and breathing exercises) or TAU.		No significant differences between CR or RT for self-efficacy at the six month follow up.	
Lee et al. (2008) South Korea	To evaluate the effects of a Life Review Programme (LRP) specific to Korean culture on emotional well-being.	17 older adults (65+) with mild Alzheimer's dementia (6 females and 4 males in Facility A, demographics not reported for Facility B).	Quasi-experimental Measures completed the week before, after and six months post intervention.	Four-week LRP for one hour twice weekly covering different activities representing life stages.	Korean translated RSES (self-esteem)	No significant effects on self-esteem overall, however found a significant increase post intervention followed by a significant decline at the six month follow up.	60
Marshall et al. (2015) UK	To report a pilot study in which recently diagnosed participants were randomised to either a 10-week intervention or waiting-list control.	58 people (28 intervention, 30 control) diagnosed with Alzheimer's (45), Vascular (7) Mixed (4) or Lewy body (2) dementia in the prior 18 months (33 females, 25 males). Intervention group mean age 74.6 and control group 76.6.	RCT (study was mixed methods, however qualitative component reported in a separate paper) Measures completed 2-4 weeks before intervention, up to 2 weeks	'Living well with dementia' group (intervention) incorporated elements of psychotherapy and psychoeducation for 10, weekly, 75-minute sessions.	RSES (self-esteem)	Self-esteem improved at the two week and 10 week follow up post intervention. Alongside quality of life, self-esteem showed the largest change for the intervention group compared to the control group.	60

			following intervention and at a 10 week follow up.				
Mountain et al. (2022) England	To determine the clinical and cost-effectiveness of an intervention to promote self-management, independence, and self-efficacy.	480 people (201 females, 279 males) with mild dementia of varying subtypes randomised to intervention (241) or usual care (239). Mean age of 77.	Mixed methods RCT Measures completed at baseline, eight- and 12-months post randomisation.	'Journeying through dementia' intervention involved topics such as keeping well, understanding dementia, and keeping connections over 12 weekly groups (two hours) and four one-to-one sessions.	GSES (self-efficacy) SMAS (self-management)	At the 8-month assessment, differences were in favour of the intervention group for self-efficacy and self-management, however the differences between the groups were not significant.	60
Pérez-Sáez et al. (2018) Spain	To assess the impact of a pottery workshop in relation to feelings of well-being, mood state and self-esteem.	30 people with varying subtypes and stages of dementia (22 females, 8 males). Mean age 79.97.	Quantitative non-randomised Measures completed in the first and final workshop.	Pottery workshop was held between 10am-2pm for 10, weekly, 45-minute sessions.	Spanish translated RSES (self-esteem)	Self-esteem significantly increased regardless of degree of cognitive impairment.	80

Platel et al. (2021) France	To examine the impact of repeated musical reminiscence workshops on recall of autobiographical memories and sense of identity.	20 people with probable Alzheimer's dementia with major cognitive impairment. Mean age 84.2. 20 matched controls	Quantitative non-randomised Measures completed on day one and 12 of the intervention.	Groups of musical reminiscence workshops using three popular songs as cues to promote autobiographical memory retrieval.	The IMAGE Test and the I-AM Test (self-identity)	No significant differences found in evaluations for the I-AM Test. IMAGE Test: No significant differences between mean global profiles for either group. Only three participants in the dementia group significantly modified the distribution of their answers.	60
Pongan et al. (2017) France	To determine the efficacy of choral singing versus painting sessions on chronic pain, mood, quality of life, and cognition.	59 people (39 females, 20 males) with mild probable Alzheimer's dementia. Mean age in singing group (31) was 78.8, and in painting group (28) was 80.2.	Multi-centre RCT Measures completed at baseline, 12 and 16 week follow ups.	12 weekly, two hour groups involving either singing songs or painting based on themes.	RSES (self-esteem)	Self-esteem improved over time in both groups but did not reach statistical significance.	40
Quinn et al. (2016) Wales	To evaluate the feasibility of a self-management intervention.	24 people (intervention 13, TAU 11) with early-stage Alzheimer's, Vascular or Mixed dementia	Mixed method single blind RCT	The self-management group involved eight, weekly, 90-minute group sessions	GSES (self-efficacy)	Small positive effect on self-efficacy found post intervention. Improvements in	80

		(sample subtype demographics not reported). Intervention mean age 75.2, females (3) and males (10). TAU mean age 76.1, females (3) and males (8).	Measures completed at baseline, three- and six-months post randomisation.	including psychoeducation, problem-solving and mindfulness.		self-efficacy found at three and six months compared to TAU.	
Richards et al. (2019) USA	Unclear aims but reported on a Visual Arts Education (VAE) programme.	27 people (15 VAE, 12 control) with mild to moderate 'Alzheimer's and related dementia' (sample demographic not reported). VAE mean age was 74.8, females (7) and males (8). Control mean age was 74.0, females (6) and males (6).	RCT Measures collected at baseline, after the programme and at a six month follow up.	VAE group ran once per week (1.5 hours) for two months involving hat decoration, embossing, painting, ceramics, and photography. Control condition involved 1.5-hour weekly painting sessions for 8 weeks.	RSES (self-esteem)	The improvement in self-esteem for the VAE group over time was not significant. Significant difference in self-esteem between the groups regardless of level of cognitive ability.	40
Sprange et al. (2015) UK	To examine the feasibility of a future population-based larger trial of a community based self-	10 people with mild dementia (5 females, 5 males). Sample subtype demographics not reported.	Mixed methods Measures completed at baseline and post intervention.	'Journeying through Dementia' involved topics such as keeping well memory and endings over 12-weeks for 2-hour weekly groups	GSES (self-efficacy)	Mean self-efficacy decreased slightly at post intervention follow up (25 from 27).	40

	management intervention.			and four one-to-one sessions.			
Werheid et al. (2021) Germany	Unclear study aims however reported on the adaption and translation of a Cognitive Stimulation Therapy (CST) manual into German following the FMAP model.	13 people (7 females, 6 males) with mild to moderate dementia (outpatient 6, residential 7). Subtypes not reported. Outpatient mean age 66.8 and residential 86.3.	Mixed methods pilot with parallel groups Outcomes were assessed pre and post intervention.	CST group ran twice a week for 7 weeks (14 sessions).	GSES (self-efficacy)	Self-efficacy scores significantly increased post CST.	0
Young et al. (2014) Hong Kong	To evaluate the positive effects of a support group.	Randomised 39 people (20 intervention, 19 control) with mild dementia (26) or probable dementia (13). Mean age 80.3, 17 females, 22 males.	Single blind RCT Measures completed pre and post intervention.	Weekly 90-minute support group for 10 sessions involved psychoeducation, coping skills, and emotional support. Control group received standardised educational written material about dementia.	Chinese RSES (self-esteem) Chinese GSES (self-efficacy)	No significant change in self-esteem or self-efficacy for either group.	60

Aspects of Self and their Measures

Table 3 shows the outcome measures used for each aspect of self for the included studies.

Table 3.

Aspects of self measured within the included studies

Aspect of self	Measure	Used in studies in the review
Self-esteem	Dementia Quality of Life Instrument (DQoL; Brod et al., 1999)	Brooker et al. (2018) Cooke et al. (2010) Dröes et al. (2019)
	Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965)	Burgener et al. (2008) Dodd et al. (2022) Dröes et al. (2019) Fitzsimmons & Buettner (2003) Gonzalez et al. (2015) Marshall et al. (2015) Pongan et al. (2017) Richards et al. (2019)
	French-Canadian Rosenberg Self-esteem Scale (Vallières & Vallerand, 1990)	Foloppe et al. (2018)
	Korean translated Rosenberg Self-esteem Scale (Jeon, 1974 as cited in Lee et al., 2008)	Lee et al. (2008)
	Spanish translated Rosenberg Self-esteem Scale (Martín-Albo et al., 2007)	Pérez-Sáez et al. (2018)
	Chinese version Rosenberg Self-esteem Scale (Leung & Wong, 2008)	Young et al. (2014)

Self-efficacy	Generalised self-efficacy scale (GSES; Schwarzer & Jerusalem, 1995)	Clare et al. (2019) Collins et al. (2022) Fitzsimmons & Buettner (2003) Hindle et al. (2018) Mountain et al. (2022) Quinn et al. (2016) Sprange et al. (2015) Werheid et al. (2021)
	Chinese version General Self-efficacy Scale (Schwarzer et al., 1997)	Young et al. (2014)
Self-compassion	Self-compassion scale short form (SCS-SF; Raes et al., 2011)	Berk et al. (2019) Craig et al. (2018)
Self-growth	Personal Growth subscale of the Psychological Well-being scale (PWB; Ryff, 1989)	Dodd et al. (2022) Gonzalez et al. (2015)
Self-acceptance	Self-acceptance subscale of the Psychological Well-Being scales (PWB; Ryff, 1989)	Gonzalez et al. (2015)
Self-management	Self-management ability scale (SMAS; Schuurmans et al., 2005)	Mountain et al. (2022)
Self-identity	The IMAGE Test (Eustache et al., 2013)	Platel et al. (2021)
	The I-AM Test (Eustache et al., 2013)	Platel et al. (2021)

Note. Descriptive summary of the rating scale for each measure outlined in Appendix H.

Only the DQoL (Brod et al., 1999) has been validated specifically for people living with dementia, however acceptable internal consistency reliability was found for the RSES (Rosenberg, 1965) in dementia (Burgener et al., 2008) and initial evidence supports the validity and reliability of the IMAGE test (Eustache et al., 2013).

Of the studies included in the review, only three reported on internal consistency reliability of the measures in their respective studies; the RSES (Rosenberg, 1965) demonstrated α=0.89 to α=0.92 across three assessment points (Burgener et al., 2008) and the Korean RSES (Jeon, 1974 as cited in Lee et al., 2008) demonstrated α=0.62 (Lee et al., 2008). Cooke et al. (2010) reported that Cronbach's alpha for the DQoL (Brod et al., 1999) subscales was between 0.62-0.87, however did not report on the exact reliability of the self-esteem subscale separately.

Intervention Effectiveness

Outcomes of psychosocial interventions in relation to aspects of self are described below, according to intervention type and grouped by construct.

Self-esteem

Multicomponent Psychoeducational and Social Interventions. Two studies found an increase in self-esteem following a psychoeducational group (Fitzsimmons & Buettner, 2003) and a psychoeducational psychotherapy group (Marshall et al., 2015), compared to one RCT which found no significant changes in self-esteem following a support group (Young et al., 2014). The participants in all three studies were mostly people recently diagnosed with dementia in the year (Marshall et al., 2015) or three years (Young et al., 2014) prior to the intervention. Fitzsimmons and Buettner (2003), stated only that participants were 'newly diagnosed' and did not conduct statistical analysis, therefore limiting the extent the studies can be compared. However, one key difference was that these studies used different language versions of the RSES (Rosenberg, 1965) within different countries, therefore the measures' translation or possible cultural differences in self-esteem and/or effectiveness of the interventions may have impacted the findings.

Meeting Centre Support Programme's (MCSP) which provide personalised post diagnostic support were measured in two studies (Brooker et al., 2018; Dröes et al., 2019) and found that MCSP's demonstrated significant increases in self-esteem after six months (Brooker et al., 2018). Updating MCSP to include supporting people with dementia to work as volunteers in the community did not show any significant differences in self-esteem when compared to the regular MCSP or those receiving no day services (Dröes et al., 2019), however findings may have been impacted by demographic differences between the groups such as participants in the volunteering group being younger, more often male and living independently. Furthermore, both studies (Brooker et al., 2018; Dröes et al., 2019) had high attrition rates, possibly impacting non-response bias, and due to the flexible nature of the programmes, participant attendance levels varied.

Reminiscence Interventions. Reminiscence groups using quasi-experimental designs did not demonstrate clear evidence for improving self-esteem; Gonzalez et al. (2015) found no significant improvement in self-esteem and Lee et al. (2008) found the initial significant improvements in self-esteem were not maintained long term at the six month follow up. Participants representativeness of the target population is unclear in Lee at al. (2008) who were unable to fully report on participant demographics, limiting external validity. On the other hand, reminiscence interventions may be more effective when delivered individually (Dodd et al., 2022), however the evidence is weak due to the small sample, therefore limiting generalisability.

Mindfulness and Third Wave Therapeutic Interventions. Group Tai Chi alongside Cognitive Behavioural Therapy demonstrated a slight improvement in self-esteem 20 weeks post intervention, which stabilised at the 40 week follow up (Burgener et al., 2008). However, the intervention and control group showed significant differences in self-esteem at 20 weeks due to a decrease in self-esteem for the control group; in addition, the randomisation

procedure was poorly explained. Considering the progressive nature of dementia, stabilisation (opposed to decline) was perceived as a positive outcome (Burgener et al., 2008), and could suggest that the intervention helped to protect against decline in self-esteem, albeit non-response bias may be an issue due to attrition (>20%).

Creative Interventions. Three RCT's (Cooke et al., 2010; Pongan et al., 2017; Richards et al., 2019) and one non-randomised design (Pérez-Sáez et al., 2018) found increases in self-esteem following creative interventions. Pottery workshops (Pérez-Sáez et al., 2018) and visual arts activities such as painting, ceramics, and photography (Richards et al., 2019) may be beneficial for self-esteem regardless of cognitive impairment or stage of dementia. However, the increase in self-esteem was not significant (Richards et al., 2019) and the findings of Pérez-Sáez et al. (2018) should be interpreted with caution due to the exclusion of eight participant data sets as a result of incomplete responses or participants receiving 'excessive help' to complete the questionnaire.

Participant attendance may impact the benefits of creative interventions as Cooke et al. (2010) found that only participants who attended over 50% of the music or reading groups demonstrated significant increases in self-esteem. However approximately half of the participants attended over 50% of sessions, therefore adherence to the intervention was an issue. On the other hand, Pongan et al. (2017) did not find a significant increase in self-esteem for participants with at least 50% attendance but did find that the painting group showed a greater increase in mean self-esteem scores across time. However, the lack of a non-intervention control group as a comparison and insufficient explanation of randomisation procedure is a limitation.

Technologies. Foloppe et al. (2018) investigated the use of virtual reality-based training on autonomy in cooking activities and found no benefits to self-esteem for a 79-year-

old woman with probable Alzheimer's dementia, however generalisability of these findings is limited by the *n*=1 design.

Self-efficacy

Multicomponent Psychoeducational and Social Interventions. Five studies conducting interventions which included social and educational components measured self-efficacy (Fitzsimmons & Buettner., 2003; Mountain et al., 2022; Quinn et al., 2016; Sprange et al., 2015; Young et al., 2014), two of which investigated the 'Journeying Through Dementia' self-management programme (Mountain et al., 2022; Sprange et al., 2015). Only one study found improvements in self-efficacy with small effect sizes at three- and six-months post intervention compared to treatment as usual (Quinn et al., 2016). However, whilst the study scored highly during quality assessment, statistical analysis of the data was not possible due to lack of power (Quinn et al., 2016), limiting the study's conclusions. Mostly self-efficacy remained stable or showed no significant improvement following the interventions (Fitzsimmons & Buettner., 2003; Mountain et al., 2022; Sprange et al., 2015; Young et al., 2014).

Cognitive Based Interventions. Cognitive based interventions showed some evidence for improving self-efficacy, specifically Cognitive Stimulation Therapy, (CST; Collins et al., 2022; Werheid et al., 2021) which may be influenced by participants recognising a stabilisation in their cognitive abilities (Werheid et al., 2021). However due to the studies small sample sizes and Collins et al. (2022) not conducting statistical analysis, the evidence supporting this assertion is weak.

Two RCT's conducted Cognitive Rehabilitation (CR) interventions and found no significant changes in self-efficacy (Clare et al., 2019; Hindle et al., 2018). Whilst Hindle et al. (2018) did find a significant difference in self-efficacy between the CR and relaxation

control group at two months post-intervention, there was no significant difference between the groups at the six month follow up or with the TAU group at any time point. Both studies were rated as high quality due to meeting all quality assessment criteria.

Self-compassion

Mindfulness and Third Wave Therapeutic Interventions. Two studies showed contrasting findings for self-compassion following a mindfulness-based intervention (Berk et al., 2019) and a Compassion Focussed Therapy (CFT) intervention (Craig et al., 2018). Both studies were limited due to no statistical analysis. Although Berk et al. (2019) found a reduction in self-compassion post intervention, 71% of participants received help completing the self-compassion measure and therefore the findings should be interpreted with caution. Furthermore, generalisability was low for the self-compassion improvements found by Craig et al. (2018) due to the case series design.

Self-acceptance and Self-growth

Reminiscence Interventions. Two reminiscence interventions showed positive outcomes in relation to self-growth when delivered in group (Gonzalez et al., 2015) or couples format (Dodd et al., 2022), however Dodd et al's (2022) case series design limits generalisability. Gonzalez et al. (2015) also found a significant time and group interaction for self-acceptance, however due to lack of a follow up it was unclear whether the significant increase in self-acceptance post intervention was maintained longer term (Gonzalez et al., 2015).

Self-identity

Reminiscence Intervention. Only one study (Platel et al., 2021) measured changes in self-identity following a musical reminiscence programme using songs to promote autobiographical memory retrieval. Participant inclusion and exclusion criteria was unclear;

therefore, sample representativeness was uncertain, limiting external validity. Overall, no significant differences were detected for either the IMAGE test or I-AM test (Eustache et al., 2013), suggesting that musical reminiscence did not affect self-identity.

Self-management

Multicomponent Intervention. Mountain et al. (2022) was the only study to measure self-management in their intervention, which comprised self-management elements and engagement in meaningful activity, even though an additional two studies were described as 'self-management' interventions (Quinn et al., 2016; Sprange et al., 2015). Much the same as the findings for self-efficacy, at eight months post intervention, self-management outcomes were in favour of the intervention group compared to the control, however differences between the groups were not significant and self-management remained stable pre and post intervention (Mountain et al., 2022).

Discussion

The aims of this review were to (1) explore what aspects of self have been measured in psychosocial interventions for people living with dementia and (2) to evaluate the effectiveness of the interventions in achieving positive outcomes for aspects of self in dementia. The included studies demonstrated considerable heterogeneity in relation to study design, country, and intervention type, therefore study outcomes were also heterogeneous. Nevertheless, this review was able to constructively synthesise the relationships and patterns between the studies based on aspects of self and interventions to discuss the key aims.

Aspects and Measures of Self

An increase in the use of self-report instruments to measure aspects of self in interventions was evident due to the majority of studies included in this review being published following that of Caddell and Clare (2011b). Whilst current conceptualisations

highlight the existence of multiple domains of self in dementia (Bomilcar et al., 2021; Neisser; 1988) encompassing a variety of specific aspects of self, this review found that the majority of included studies measured self-esteem or self-efficacy. One reason for this may be that at present there are limited validated self-report instruments that measure different aspects of self for people living with dementia. This is also reflected in the wider literature outside the scope of this review, for example; self-stigma scales have tentatively demonstrated validity in dementia (Bhatt et al., 2021; Burgener & Berger, 2008), and the Tennessee Self-Concept Scale (TSCS-II; Fitts & Warren, 1996) and Self-Identity in Dementia Questionnaire (SID-Q; Cohen-Mansfield et al., 2000) have been used with people with dementia in non-intervention studies (e.g., Addis & Tippett, 2004; Caddell & Clare, 2013a;), however all have limited psychometric information regarding use in dementia. This highlights the need for future research to investigate the validity of a range of self-related measures for people living with dementia.

There may be accessibility issues for some measures, such as the SCS-SF (Raes et al., 2011) and the Spanish RSES (Martín-Albo et al., 2007), considering the additional support that some participants required to complete the scales. Further concerns regarding the soundness of the findings and possible bias against non-western cultures are raised due to translation issues of the RSES (Rosenberg, 1965) into Chinese (Leung & Wong, 2008) and the Korean RSES (Jeon, 1974 as cited in Lee et al., 2008) which shows limited validity with older adults (Lee, 2022). This may be due to differences in how self-esteem is self-evaluated in individualistic or collectivist cultures (Cai et al., 2007; Schmitt & Allik, 2005). Given these issues, the use of measures of self that have not demonstrated validity with people with dementia is concerning if they are being used as evidence to determine what people living with dementia may find helpful as interventions.

Effectiveness of Interventions

The effectiveness of interventions on the aspects of self varied in relation to the type of intervention and aspect of self which was measured. Multicomponent interventions that incorporate psychoeducational elements, followed by reminiscence interventions, were the most frequent interventions conducted and tested.

Whilst CST showed consistent evidence for improving self-efficacy, which may be influenced by a perceived improvement in memory and cognitive abilities (Hall et al., 2013), other psychosocial interventions did not have significant positive outcomes in relation to self-efficacy or self-management in dementia. The wider literature regarding people with chronic diseases, suggests that the mixed findings in relation to self-efficacy outcomes following interventions such as self-management programmes, may be influenced by barriers such as feeling overwhelmed by the amount of information presented about a condition in a short period of time (Farley, 2020). Considering this, interventions which include elements of psychoeducation may not demonstrate positive outcomes regarding self-efficacy for people with dementia when the education is not appropriately broken down into smaller, less overwhelming components.

Findings were stronger for self-esteem but also mixed. Creative interventions demonstrated the most consistent improvements in self-esteem across differing stages of dementia which is reflective of the wider literature showing that art therapy programmes improve self-esteem for older adults (Ching-Teng et al., 2019; Kim, 2013). The improvements seen for self-esteem may relate to the increased sense of control, mastery and accomplishment that follow creative interventions, alongside providing an opportunity for self-exploration (Ching-Teng et al., 2019; Kim, 2013, Richards et al., 2019). A sense of

accomplishment relating to the possible perceived improvements in cognitive abilities (Hall et al., 2013) may also explain the improvements in self-efficacy following CST.

Group interventions appeared to demonstrate more positive outcomes for aspects of self compared to interventions delivered to participants individually. This supports previous research that has identified social connectedness as a key facilitator of self-efficacy during interventions for people with chronic diseases (Farley, 2020) as well as suggestions that for people with dementia, social connections are a key factor for improving aspects of self/the interpersonal self within interventions (Baird & Thompson, 2018). The benefits of group interventions for aspects of self may be explained by qualitative research which has found that group interventions provide opportunities for people with dementia to share experiences, information, and understandings of dementia to help others, which appeared to improve self-esteem (Mason et al., 2005). However, it is likely that the finding in the current review is biased as the majority of included studies were group interventions, therefore comparisons with one-to-one interventions were limited. Future research may wish to further explore the differences in outcomes for aspects of self between group versus individual interventions.

Differences in intervention outcomes between demographic characteristics were not necessarily a focus of the studies; however, may be a possible explanation for the varied findings. For example, differences in the proportion of male and female participants may have impacted the contrasting findings regarding the impact of mindfulness/CFT on self-compassion as previous research suggests that masculine stereotypes are associated with lower self-compassion (Reilly et al., 2014). On the other hand, amongst older adults, self-compassion may be greater in males compared to females (Bratt & Fagerström, 2020). An alternate explanation may be that CFT interventions support all three self-compassion components (Neff, 2003), self-kindness, common humanity, and mindfulness, whereas mindfulness-based interventions only align with the mindfulness component. This raises

questions as to what specific components of interventions may positively impact aspects of self. Future research should build upon Farley's (2020) review relating to people with a chronic disease, by exploring what other factors (e.g., attendance rates, social connections, dementia subtypes and level of cognitive impairment) may be associated with outcomes for aspects of self specifically for people living with dementia.

Limitations

Whilst a range of databases and search terms were used in this review, as well as the additional search for terms that arose post data extraction, it is possible that other measures of self were missed due to the complexities surrounding definitions of self. For example, Clarke et al. (2020) included 'dignity' as a measure of 'positive sense of self', which was not considered as an aspect of self in this review. Excluding specific task focussed measures of self and only including peer reviewed studies may have limited this review. Similarly, only studies in the English language were included therefore this review may not capture all relevant evidence. Lastly, the heterogeneity of the studies resulted in challenges synthesising and comparing findings, however, the MMAT (Hong et al., 2018) allowed the quality of these studies to be evaluated effectively and the range of methodological designs is a strength as provides differing levels of evidence and demonstrates the breadth of existing research.

Implications and Recommendations

The issues raised regarding the validity of the measures of self for dementia included in this review have important implications for how these instruments are used in research and clinical settings with people living with dementia. Clinicians and researchers should take caution when interpreting unvalidated measures of self for people living with dementia and further research is needed to investigate the psychometric properties of these measures in dementia. Future research should explore whether there are differences in the outcomes for

aspects of self following psychosocial interventions in relation to demographic variables such as gender, culture, stage and subtype of dementia. Due to the heterogeneity of the studies, it was not possible to draw conclusions regarding the effectiveness of interventions on the different aspects of self. Future psychosocial interventions that measure self-reported outcomes relating to aspects of self using high quality methodological designs such as RCT's are needed and will help to add to the quality and expansion of the existing evidence base.

Conclusions

Research with people living with dementia is increasingly considering the effectiveness of psychosocial interventions at providing positive outcomes related to aspects of self, however the effectiveness of these interventions appears mixed and the paucity of validated measures of self in dementia a major limitation. This review highlights the need for further research in order to improve the evidence base of self-report measures of aspects of self in dementia.

References

Addis, R. D., & Tippett, L. (2004). Memory of myself: Autobiographical memory and identity in Alzheimer's disease. *Memory*, 12(1), 56-74. https://doi.org/10.1080/09658210244000423

Baird, A., & Thompson, W. F. (2018). The impact of music on the self in dementia. *Journal of Alzheimer's Disease*, 61(3), 827-841. https://doi.org/ 10.3233/JAD-170737

Berk, L., Warmenhoven, F., Stiekema, A. P., Van Oorsouw, K., Van Os, J., de Vugt, M., & Van Boxtel, M. (2019). Mindfulness-based intervention for people with dementia and their partners: results of a mixed-methods study. *Frontiers in Aging Neuroscience*, 11, Article 92. https://doi.org/10.3389/fnagi.2019.00092

Bhatt, J., Stoner, C. R., Scior, K., & Charlesworth, G. (2021). Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia. *BMC Geriatrics*, 21(1), 1-12. https://doi.org/10.21203/rs.3.rs-21719/v2

Bomilcar, I., Bertrand, E., Morris, R. G., & Mograbi, D. C. (2021). The seven selves of dementia. *Frontiers in Psychiatry*, 12, Article 646050. https://doi.org/10.3389/fpsyt.2021.646050

Bratt, A., & Fagerström, C. (2020). Self-compassion in old age: confirmatory factor analysis of the 6-factor model and the internal consistency of the Self-compassion scale-short form. *Aging & Mental Health*, 24(4), 642-648. https://doi.org/10.1080/13607863.2019.1569588

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

Brooker, D., Evans, S., Evans, S., Bray, J., Saibene, F. L., Scorolli, C., Szcześniak, D., d'Arma, A., Urbańska, K. M., Atkinson, T., Farina, E., Rymaszewska, J., Chattat, R., Henderson, C., Rehill, A., Hendriks, I., Meiland, F., & Dröes, R. M. (2018). Evaluation of the implementation of the Meeting Centres Support Program in Italy, Poland, and the UK; exploration of the effects on people with dementia. *International Journal of Geriatric Psychiatry*, 33(7), 883-892. https://doi.org/10.1002/gps.4865

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., Yang, Y., Gilbert, R., & Marsh-Yant, S. (2008). The effects of a multimodal intervention on outcomes of persons with early-stage dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 23(4), 382-394. https://doi.org/ 10.1177/1533317508317527

Caddell, L. S., & Clare, L. (2010). The impact of dementia on self and identity: A systematic review. *Clinical Psychology Review*, 30(1), 113-126. https://doi.org/10.1016/j.cpr.2009.10.003

Caddell, L. S., & Clare, L. (2011a). I'm still the same person: The impact of early-stage dementia on identity. *Dementia*, 10(3), 379-398. https://doi.org/10.1177/1471301211408255

Caddell, L. S., & Clare, L. (2011b). Interventions supporting self and identity in people with dementia: A systematic review. *Aging & Mental Health*, 15(7), 797-810. https://doi.org/10.1080/13607863.2011.575352

Caddell, L. S., & Clare, L. (2013a). How does identity relate to cognition and functional abilities in early-stage dementia?. *Aging, Neuropsychology, and Cognition*, 20(1), 1-21. https://doi.org/10.1080/13825585.2012.656575

Caddell, L., & Clare, L. (2013b). Studying the self in people with dementia: How might we proceed? *Dementia*, 12(2), 192-209. https://doi.org/10.1177/1471301211418486

Cai, H., Brown, J. D., Deng, C., & Oakes, M. A. (2007). Self-esteem and culture: Differences in cognitive self-evaluations or affective self-regard?. *Asian Journal of Social Psychology*, 10(3), 162-170. https://doi.org/10.1111/j.1467-839X.2007.00222.x

Ching-Teng, Y., Ya-Ping, Y., & Yu-Chia, C. (2019). Positive effects of art therapy on depression and self-esteem of older adults in nursing homes. *Social Work in Health Care*, 58(3), 324-338. https://doi.org/10.1080/00981389.2018.1564108

Clare, L., Kudlicka, A., Oyebode, J. R., Jones, R. W., Bayer, A., Leroi, I., Kopelman, M., James, I. A., Culverwell, A., Pool, J., Brand, A., Henderson, C., Hoare, Z., Knapp, M., & Woods, B. (2019). Individual goal-oriented cognitive rehabilitation to improve everyday functioning for people with early-stage dementia: A multicentre randomised controlled trial (the GREAT trial). *International Journal of Geriatric Psychiatry*, 34(5), 709-721. https://doi.org/10.1002/gps.5076

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

Cohen-Mansfield, J., Golander, H., & Arnheim, G. (2000). Self-identity in older persons suffering from dementia: preliminary results. *Social Science & Medicine*, *51*(3), 381–394. https://doi.org/10.1016/s0277-9536(99)00471-2

Collins, K., Hanna, M., Makarski, J., & Kastner, M. (2023). Occupational Therapist Led Cognitive Stimulation Therapy: Feasibility of Implementation. *Canadian Journal of Occupational Therapy,* 90(1), 68-78. https://doi.org/10.1177/00084174221115284

Cooke, M., Moyle, W., Shum, D., Harrison, S., & Murfield, J. (2010). A randomized controlled trial exploring the effect of music on quality of life and depression in older people with dementia. *Journal of Health Psychology*, 15(5), 765-776. https://doi.org/10.1177/1359105310368188

Craig, C., Hiskey, S., Royan, L., Poz, R., & Spector, A. (2018). Compassion focused therapy for people with dementia: A feasibility study. *International Journal of Geriatric Psychiatry,* 33(12), 1727-1735. https://doi.org/10.1002/gps.4977

Davis, D. H. (2004). Dementia: Sociological and philosophical constructions. *Social Science & Medicine*, 58(2), 369–378 https://doi.org/10.1016/S0277-9536(03)00202-8

Dodd, E., Ismail, S., Christopher, G., Wildschut, T., Sedikides, C., & Cheston, R. (2022). Nostalgic conversations: The co-production of an intervention package for people living with dementia and their spouse. *Dementia*, 21(2), 489-502. https://doi.org/10.1177/14713012211047350

Dröes, R. M., van Rijn, A., Rus, E., Dacier, S., & Meiland, F. (2019). Utilization, effect, and benefit of the individualized meeting centers support program for people with dementia and caregivers. *Clinical Interventions in Aging*, 1527-1553. http://doi.org/10.2147/CIA.S212852

Eustache, M. L., Laisney, M., Juskenaite, A., Letortu, O., Platel, H., Eustache, F., Desgranges, B. (2013). Sense of identity in advanced Alzheimer's dementia: a cognitive dissociation between sameness and selfhood. *Conscious and Cognition*, 22(4), 1456–1467. https://doi.org/10.1016/j.concog.2013.09.009

Farley, H. (2020). Promoting self-efficacy in patients with chronic disease beyond traditional education: A literature review. *Nursing Open*, 7(1), 30-41. https://doi.org/10.1002/nop2.382

Fitts, W. H. & Warren, W. L. (1996). *Tennessee Self-Concept Scale 2nd Edition*. Western Psychological Services.

Fitzsimmons, S., & Buettner, L. L. (2003). Health promotion for the mind, body, and spirit: a college course for older adults with dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 18(5), 282-290. https://doi.org/10.1177/153331750301800504

Foloppe, D. A., Richard, P., Yamaguchi, T., Etcharry-Bouyx, F., & Allain, P. (2018). The potential of virtual reality-based training to enhance the functional autonomy of Alzheimer's disease patients in cooking activities: A single case study. *Neuropsychological Rehabilitation*, 28(5), 709-733. https://doi.org/10.1080/09602011.2015.1094394

Gonzalez, J., Mayordomo, T., Torres, M., Sales, A., & Meléndez, J. C. (2015). Reminiscence and dementia: a therapeutic intervention. *International Psychogeriatrics*, 27(10), 1731-1737. https://doi.org/10.1017/S1041610215000344

Griffiths, A. W., Smith, S. J., Martin, A., Meads, D., Kelley, R., & Surr, C. A. (2020). Exploring self-report and proxy-report quality-of-life measures for people living with dementia in care homes. *Quality of Life Research*, 29, 463-472. https://doi.org/10.1007/s11136-019-02333-3

Hall, L., Orrell, M., Stott, J., & Spector, A. (2013). Cognitive stimulation therapy (CST): neuropsychological mechanisms of change. *International Psychogeriatrics*, 25(3), 479-489. https://doi.org/10.1017/S1041610212001822

Hindle, J. V., Watermeyer, T. J., Roberts, J., Brand, A., Hoare, Z., Martyr, A., & Clare, L. (2018). Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease-A pilot randomised controlled trial. *International Journal of Geriatric Psychiatry*, 33(5), 718-728. https://doi.org/10.1002/gps.4845

Hong, Q. N., (2020, December 9). *Reporting the results of the MMAT (version 2018)* [Information Sheet]. http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/140056890/Reporting%20the%20results%20of%20the%20MMAT.pdf

Hong, Q. N., Pluye, P., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., Gagnon, M.P., Griffiths, F., Nicolau, B., & O'Cathain, A. (2018). *Mixed methods appraisal tool (MMAT), version 2018*. McGill University. http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMA

Hounsome, N., Orrell, M., & Edwards, R. T. (2011). EQ-5D as a quality of life measure in people with dementia and their carers: evidence and key issues. *Value in Health*, 14(2), 390-399. https://doi.org/10.1016/j.jval.2010.08.002

Kang, H. (2013). The prevention and handling of the missing data. *Korean Journal of Anesthesiology,* 64(5), 402-406. https://doi.org/10.4097/kjae.2013.64.5.402

Kim, S. K. (2013). A randomized, controlled study of the effects of art therapy on older Korean-Americans' healthy aging. *The Arts in Psychotherapy*, 40(1), 158-164. https://doi.org/10.1016/j.aip.2012.11.002

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open university press.

Kitwood, T. (2019). In Brooker D. (Ed.*), Dementia reconsidered, revisited: The person still comes first* (Second ed.). Open University Press.

Kitwood, T., & Bredin, K. (1992). Towards a Theory of Dementia Care: Personhood and Well-being. *Ageing and Society*, 12(3), 269-287. https://doi.org/10.1017/S0144686X0000502X

Klein, S. B., & Gangi, C. E. (2010). The multiplicity of self: neuropsychological evidence and its implications for the self as a construct in psychological research. *Annals of the New York Academy of Sciences*, 1191, 1–15. https://doi.org/10.1111/j.1749-6632.2010.05441.x

Lamont, R. A., Nelis, S. M., Quinn, C., Martyr, A., Rippon, I., Kopelman, M. D., Hindle, J. V., Jones, R. W., Litherland, R., & Clare, L. (2010). Psychological predictors of 'living well' with dementia: findings from the IDEAL study. *Aging & Mental Health*, 24(6), 956-964. https://doi.org/10.1080/13607863.2019.1566811

Lee, K. (2022). An item response theory analysis of Rosenberg Self-Esteem among older Korean adults. *Current Psychology*, 1-10. https://doi.org/10.1007/s12144-022-03946-7

Lee, Y., Tabourne, C. E., & Yoon, J. (2008). Effects of life review program on emotional well-being of Korean elderly with Alzheimer's disease. *American Journal of Recreation Therapy*, 7(2), 35-45. https://doi.org/10.5055/ajrt.2008.0014

Leung, S. O., Wong, P. M. (2008) Validity and reliability of Chinese Rosenberg Self-Esteem Scale. *New Horizons in Education*, 56(1), 62–69. https://www.researchgate.net/publication/306203283_Validity_and_reliability_of_Chinese_Rosenberg_Self-Esteem_Scale

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine*, 64(3), 510-519. https://doi.org/10.1097/00006842-200205000-00016

Marsh, H. W., Pekrun, R., Parker, P. D., Murayama, K., Guo, J., Dicke, T., & Arens, A. K. (2019). The murky distinction between self-concept and self-efficacy: Beware of lurking jingle-jangle fallacies. *Journal of Educational Psychology*, 111(2), 331–353. https://doi.org/10.1037/edu0000281

Martín-Albo, J., Núñez, J. L., Navarro, J. G., & Grijalvo, F. (2007). The Rosenberg Self-Esteem Scale: translation and validation in university students. *The Spanish Journal of Psychology,* 10(2), 458-467. https://doi.org/10.1017/S1138741600006727

Mason, E., Clare, L., & Pistrang, N. (2005). Processes and experiences of mutual support in professionally-led support groups for people with early-stage dementia. *Dementia*, 4(1), 87-112. https://doi.org/10.1177/1471301205049192

McConnell, A. R. (2011). The Multiple Self-Aspects Framework: Self-Concept Representation and Its Implications. *Personality and Social Psychology Review,* 15(1), 3–27. https://doi.org/10.1177/1088868310371101

Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., Vugt, M. D., Mountain, G., O'connell, M., Harrison, J., Vasse, E., Dröes, R, M., & Orrell, M, For The Interdem* Group. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging and Mental Health,* 12(1), 14-29. https://doi.org/10.1080/13607860801919850

Mountain, G., Wright, J., Cooper, C. L., Lee, E., Sprange, K., Beresford-Dent, J., Young, T., Walters, S., Berry, K., Dening, T., Loban, A., Turton, E., Thomas, B. D., Young, E. L., Thompson, B, J., Crawford, B., Craig, C., Bowie, P., Moniz-Cook, E., & Foster, A. (2022). An intervention to promote self-management, independence and self-efficacy in people with early-stage dementia: the Journeying through Dementia RCT. *Health Technology Assessment*, 26(24), 1-152. https://doi.org/10.3310/KHHA0861

Moyle, W., Murfield, J. E., Griffiths, S. G., & Venturato, L. (2012). Assessing quality of life of older people with dementia: A comparison of quantitative self-report and proxy accounts. *Journal of Advanced Nursing*, 68(10), 2237-2246. https://doi.org/10.1111/j.1365-2648.2011.05912.x

Neff, K. D. (2003). Self-compassion: An alternative conceptualization of a healthy attitude toward oneself. *Self and identity*, 2(2), 85-101. https://doi.org/10.1080/15298860309032

Neisser, U. (1988). Five kinds of self-knowledge. *Philosophical Psychology*, 1(1), 35–59. https://doi.org/10.1080/09515088808572924

Nguyen, T., & Li, X. (2020). Understanding public-stigma and self-stigma in the context of dementia: A systematic review of the global literature. *Dementia*, 19(2), 148-181. https://doi.org/10.1177/1471301218800122

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., Stewart, L. A., Thomas, J., Tricco, A. C., Welch, V. A., Whiting, P., & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *The British Medical Journal*, 372:71. https://doi.org/10.1136/bmj.n71

Pérez-Sáez, E., Cabrero-Montes, E. M., Llorente-Cano, M., & González-Ingelmo, E. (2020). A pilot study on the impact of a pottery workshop on the well-being of people with dementia. *Dementia*, 19(6), 2056-2072. https://doi.org/10.1177/1471301218814634

Platel, H., Eustache, M. L., Coppalle, R., Viard, A., Eustache, F., Groussard, M., & Desgranges, B. (2021). Boosting Autobiographical Memory and the Sense of Identity

of Alzheimer Patients Through Repeated Reminiscence Workshops?. *Frontiers in Psychology*, 12, Article 636028. https://doi.org/10.3389/fpsyg.2021.636028

Pongan, E., Tillmann, B., Leveque, Y., Trombert, B., Getenet, J. C., Auguste, N., Dauphinot, V., El Haouari, H., Navez, M., Doret, J., Krolak-Salmon, P., The LACMé Group., Laurent, B., & Rouch, I. (2017). Can musical or painting interventions improve chronic pain, mood, quality of life, and cognition in patients with mild Alzheimer's disease? Evidence from a randomized controlled trial. Journal of Alzheimer's Disease, 60(2), 663-677. https://doi.org/10.3233/JAD-170410

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K., & Duffy, S. (2006). *Guidance on the conduct of narrative synthesis in systematic reviews.* https://www.lancaster.ac.uk/media/lancaster-university/content-assets/documents/fhm/dhr/chir/NSsynthesisguidanceVersion1-April2006.pdf

Quinn, C., Toms, G., Jones, C., Brand, A., Edwards, R. T., Sanders, F., & Clare, L. (2016). A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). *International Psychogeriatrics*, 28(5), 787-800. https://doi.org/10.1017/S1041610215002094

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the self-compassion scale. *Clinical Psychology & Psychotherapy*, 18(3), 250-255. https://doi.org/10.1002/cpp.702

Reilly, E. D., Rochlen, A. B., & Awad, G. H. (2014). Men's self-compassion and self-esteem: the moderating roles of shame and masculine norm adherence. *Psychology of Men & Masculinity*, 15(1), 22-28. https://doi.org/10.1037/a0031028

Rennie, D. (1996). How to report randomized controlled trials: the CONSORT statement. *Jama*, 276(8), 649-649. https://doi.org/10.1001/jama.1996.03540080071033

Richards, A. G., Tietyen, A. C., Jicha, G. A., Bardach, S. H., Schmitt, F. A., Fardo, D. W., Kryscio, R. J., & Abner, E. L. (2019). Visual Arts Education improves self-esteem for persons with dementia and reduces caregiver burden: A randomized controlled trial. *Dementia,* 18(7-8), 3130-3142. https://doi.org/10.1177/1471301218769071

Rosenberg, M. (1965). *Society and the Adolescent Self-Image*. Princeton University Press

Ryff, C. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological wellbeing. *Journal of Personality and Social Psychology*, 57(6), 1069-1081. https://doi.org/10.1037/0022-3514.57.6.1069

Sabat, S. R. (2001). *The Experience of Alzheimer's Disease: Life Through a Tangled Veil*. Blackwell Publishers.

Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing & Society*, 12(4), 443-461. https://doi.org/10.1017/S0144686X00005262

Sands, L. P., Ferreira, P., Stewart, A. L., Brod, M., & Yaffe, K. (2004). What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life?. *The American Journal of Geriatric Psychiatry*, 12(3), 272-280. https://doi.org/10.1097/00019442-200405000-00006

Schmitt, D. P., & Allik, J. (2005). Simultaneous administration of the Rosenberg Self-Esteem Scale in 53 nations: exploring the universal and culture-specific features of global self-esteem. *Journal of Personality and Social Psychology*, 89(4), 623-642. https://doi.org/10.1037/0022-3514.89.4.623

Schölzel-Dorenbos, C. J., Ettema, T. P., Bos, J., Boelens-van der Knoop, E., Gerritsen, D. L., Hoogeveen, F., de Lange, J., Meihuizen, L., & Dröes, R. M. (2007). Evaluating the

outcome of interventions on quality of life in dementia: selection of the appropriate scale. *International Journal of Geriatric Psychiatry*, 22(6), 511-519. https://doi.org/10.1002/gps.1719

Schuurmans, H., Steverink, N., Frieswijk, N., Buunk, B. P., Slaets, J. P., Lindenberg, S. (2005). How to measure self-management abilities in older people by self-report. The development of the SMAS-30. *Quality of Life Research,* 14, 2215–2228. https://doi.org/10.1007/s11136-005-8166-9

Schwarzer, R., Bäßler, J., Kwiatek, P., Schröder, K., Zhang, J. X. (1997). The assessment of optimistic self-beliefs: comparison of the German, Spanish, and Chinese versions of the General Self-Efficacy Scale. *Applied Psychology: An International Review*, 46(1), 69–88. https://doi.org/10.1111/j.1464-0597.1997.tb01096.x

Schwarzer, R., Jerusalem, M. (1995). Generalized Self-Efficacy Scale. In J. Weinman, S. Wright, & M. Johnston (Eds.), *Measures in Health Psychology: A User's Portfolio*. (pp. 35-37). NFER-Nelson.

Sheehan, B. D., Lall, R., Stinton, C., Mitchell, K., Gage, H., Holland, C., & Katz, J. (2012). Patient and proxy measurement of quality of life among general hospital in-patients with dementia. *Aging & Mental Health*, 16(5), 603-607. https://doi.org/10.1080/13607863.2011.653955

Shelton, S. H. (1990). Developing the construct of general self-efficacy. *Psychological Reports*, *66*(3), 987-994. https://doi.org/10.1177/003329419006600301

Sibbald, B., & Roland, M. (1998). Understanding controlled trials. Why are randomised controlled trials important?. *British Medical Journal*, 316, Article 201. https://doi.org/10.1136/bmj.316.7126.201

Siefer, K., Leuders, T., & Obersteiner, A. (2021). Which Task Characteristics Do Students Rely on When They Evaluate Their Abilities to Solve Linear Function Tasks? A Task-Specific Assessment of Self-Efficacy. *Frontiers in Psychology*, 12, Article 596901. https://doi.org/10.3389/fpsyg.2021.596901

Spector, A., Thorgrimsen, L., Woods, B., & Orrell, M. (2006). *Making a difference: An evidence-based group programme to offer cognitive stimulation therapy (CST) to people with dementia.* Hawker Publications.

Sprange, K., Mountain, G. A., Shortland, K., Craig, C., Blackburn, D., Bowie, P., Harkness, K., & Spencer, M. (2015). Journeying through Dementia, a community-based self-management intervention for people aged 65 years and over: a feasibility study to inform a future trial. *Pilot and Feasibility Studies*, 1(1), 1-14. https://doi.org/10.1186/s40814-015-0039-6

Steeman, E., Godderis, J., Grypdonck, M., De Bal, N., & De Casterlé, B. D. (2007). Living with dementia from the perspective of older people: is it a positive story?. *Aging & Mental Health*, 11(2), 119-130. https://doi.org/10.1080/13607860600963364

Stoner, C. R., Stansfeld, J., Orrell, M., & Spector, A. (2019). The development of positive psychology outcome measures and their uses in dementia research: a systematic review. *Dementia*, 18(6), 2085-2106. https://doi.org/10.1177/1471301217740288

Strikwerda-Brown, C., Grilli, M. D., Andrews-Hanna, J., & Irish, M. (2019). "All is not lost" Rethinking the nature of memory and the self in dementia. *Ageing Research Reviews*, 54. https://doi.org/10.1016/j.arr.2019.100932

Surr, C. A. (2006). Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science & Medicine*, 62(7), 1720-1730. https://doi.org/10.1016/j.socscimed.2005.08.025

Thomas, B. H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: Providing the research evidence for public health nursing interventions. *Worldviews on Evidence-Based Nursing*, 1(3), 176-184. https://doi.org/10.1111/j.1524-475X.2004.04006.x

Vallières, E. F., & Vallerand, R. J. (1990). Traduction et validation canadienne-française de l'échelle de l'estime de soi de Rosenberg [French-Canadian translation and validation of Rosenberg's self-esteem scale]. *International Journal of Psychology*, 25(2), 305–316. https://doi.org/10.1080/00207599008247865

Van Tulder, M., Furlan, A., Bombardier, C., Bouter, L., & Editorial Board of the Cochrane Collaboration Back Review Group. (2003). Updated method guidelines for systematic reviews in the Cochrane Collaboration Back Review Group. *Spine*, 28(12), 1290-1299. https://doi.org/10.1097/01.BRS.0000065484.95996.AF

Werheid, K., Schaubs, B., Aguirre, E., & Spector, A. (2021). Cognitive stimulation therapy: Model-based cultural adaptation and manual translation of an evidence-based psychosocial group therapy for people with dementia. *The Journal of Gerontopsychology and Geriatric Psychiatry*, 34(3), 117–124. https://doi.org/10.1024/1662-9647/a000244

Young, D. K., Kwok, T. C., & Ng, P. Y. (2014). A single blind randomized control trial on support groups for Chinese persons with mild dementia. *Clinical Interventions in Aging*, 9, 2105-2112. http://dx.doi.org/10.2147/CIA.S68687

Part Two – Empirical Paper

This paper is written in format ready for submission to Aging and Mental Health.

(Please see Appendix J for submission guidelines)

Word Count: 7, 258 (excluding abstract**)**

Measuring self-compassion in people living with dementia: investigating the validity of the Self-compassion Scale-Short Form (SCS-SF)

Jessica A. Baggaley[a]*, Dr Emma Wolverson[b] and Dr Chris Clarke[c]

[a]*School of Psychology and Social Work, Aire Building, University of Hull, Hull, United Kingdom;* [b]*Research and Publications Team. Dementia UK, London, United Kingdom;* [c] *Tees, Esk and Wear Valley NHS Foundation Trust, United Kingdom*

*Corresponding author. Email: j.a.baggaley-2017@hull.ac.uk

Abstract

Objective: Self-compassion may be a psychological resource for living well with dementia, but research is limited by the lack of a validated self-compassion measure for people with dementia. This study aimed to explore how the SCS-SF performs for people with dementia in relation to the scale's validity, reliability, underlying dimensions, correlations with well-being and demographic differences in self-compassion.

Method: A total of 207 people with dementia took part and 193 participant data sets were analysed. Participants completed the SCS-SF and measures of well-being, self-esteem, and depression. Data analysis included internal consistency reliability, correlational analyses to investigate construct validity, Exploratory Factor Analysis (EFA), plus ANOVAs and t-tests regarding demographic differences in self-compassion.

Results: Self-compassion significantly correlated positively with well-being and self-esteem, and negatively with depression. Reliability and preliminary construct validity of the SCS-SF was supported. EFA suggested two underlying factors formed by the positive and negative components of self-compassion. Self-compassion significantly differed based on participant age but not gender, dementia subtype or time since diagnosis.

Conclusion: The SCS-SF may be a valid and reliable measure of self-compassion for people with dementia, but more research is needed to confirm this. The SCS-SF may measure two distinct constructs, which possibly play different roles in relation to well-being in dementia: self-compassion and self-criticism. Clinicians and researchers may wish to interpret the factors separately.

Keywords: dementia, measure, self-compassion, short-form, reliability, validity, well-being

Introduction

Compassion flows in three directions; towards others, from others and towards the self (Gilbert, 2009). Self-compassion can be understood as a positive attitude of kindness and non-judgement directed towards the self (Neff, 2003b), and has been associated with well-being across a range of populations (Zessin et al., 2015), including older adults (Brown et al., 2019; Tavares et al., 2023). Neff (2003b) conceptualises self-compassion as consisting of three main elements: self-kindness, common humanity, and mindfulness.

Research has found that self-compassion is involved in positive ageing (Allen & Leary, 2013; Phillips & Ferguson, 2013) and therefore may be an important part of the life-review process (Erikson & Erikson, 1998) when considering personal inadequacies and difficult life situations outside of our control (Neff, 2003b). In older adults, males may report greater self-compassion compared to females (Bratt & Fagerström, 2020) and self-compassion has been found to increase with age (Homan, 2016). It may be that self-compassion has a role in establishing ego integrity (Erikson & Erikson, 1998), which also has been found to increase with age and be predicted by self-compassion, suggesting that older adults with high ego integrity are able to be kinder towards themselves and accepting of past adverse experiences (Phillips & Ferguson, 2013). However, Phillips & Ferguson (2013) did not find a significant correlation between self-compassion and age, or any significant differences between males and females, therefore evidence supporting this is currently equivocal. Withstanding the potential differences across demographic variables, overall, research has suggested that interventions which promote self-compassion may benefit well-being in older populations (e.g., Allen et al., 2012; Homan, 2016; Kim & Ko, 2018).

If self-compassion does have a role in maintaining well-being in later life during adversity, it may be of value for older people living with dementia, who encounter many challenges (Read et al., 2017). Research has shown that other psychological resources

relating to the self, such as self-esteem and self-efficacy are associated with the capacity to live well with dementia and identify these as targets for intervention (Lamont et al., 2019). However, to date, research on self-compassion and dementia is extremely limited.

It is unclear whether self-compassion does have a role in improving well-being in dementia as existing research shows mixed findings. Whilst interventions that include components of self-compassion, such as mindfulness-based interventions (Berk et al., 2018; Hoffman et al., 2020) and Compassion Focussed Therapy (Collins et al., 2017), have demonstrated positive outcomes relating to well-being in dementia, the role of self-compassion is unclear due to many studies not measuring this. Research that has measured self-compassion in dementia is scarce. Craig et al. (2018) found improvements in self-compassion, mood and anxiety in dementia following Compassion Focussed Therapy and concluded that self-compassion may be a protective factor as dementia progresses. On the other hand, a mindfulness intervention did not find improvements in self-compassion or quality of life for people with dementia (Berk et al., 2019) and self-compassion was not considered to mediate improvements in mood following a meditation programme (Innes et al., 2012), although the finding was not limited to dementia as participants included caregivers and people with mild cognitive impairment.

There is the possibility that the scarcity of research and mixed findings regarding the role of self-compassion in improving well-being in dementia is a result of measurement error, as a major limitation of existing studies (Berk et al., 2019; Craig et al., 2018; Innes et al., 2012) is the lack of a self-compassion measure that has been validated for people with dementia. In addition, 71% of participants in Berk et al. (2019) received help to complete the Self-compassion Scale Short Form (SCS-SF; Raes et al., 2011). The SCS-SF is a 12-item adaptation of the 26-item Self-compassion Scale (Neff, 2003a), which has demonstrated good psychometric properties when using the total score and has been proposed as a reliable and

valid alternative to the SCS in other populations (Neff, 2003a; Raes et al., 2011). Whilst outcome measurement is a topic of interest in dementia research (Clarke et al., 2020), as measures can be useful tools to evaluate interventions, measures often require adapting for varying levels of cognitive impairment (Schölzel-Dorenbos et al., 2007) and therefore the SCS-SF may not be accessible and psychometrically robust for all stages of dementia, however Berk et al's. (2019) participants were in the early stages of dementia. It is therefore uncertain whether the SCS-SF is a valid and reliable measure of self-compassion for people with dementia.

Furthermore, the construct validity and factor structure of the SCS-SF in dementia has yet to be investigated. Within other populations, a first order factor (self-compassion) with six second order factors based on the subscales self-kindness (SK), common humanity (CG), mindfulness (MI), self-judgement (SJ), isolation (IS) and overidentification (OI) has been supported for the SCS-SF; (Castilho et al., 2015; Raes et al., 2011). Uršič et al., 2019 found a six-factor model based on the six subscales but were unable to replicate the higher order factor. A bifactor model (Rocha et al., 2022), a two factor (positive and negative factor) model (Babenko & Guo, 2019; Bratt & Fagerström, 2020; Hayes et al., 2016; Kotera & Sheffield, 2020; Lluch-Sanz et al., 2022) and a three-factor model (one positive, two negative factors) with 10 items (Meng et al., 2019) have shown a better fit across a range of populations with English or translated SCS-SF versions. However, Bratt & Fagerström (2020) were unable to confirm the proposed two factor structure for older adults in Sweden as during Confirmatory Factor Analysis (CFA) the two-factor structure did not show acceptable fit. In summary, it is uncertain how the SCS-SF may perform psychometrically for people with dementia, particularly with reference to its construct validity and underlying structure.

Research Aims

The key aim of this study is to understand how the SCS-SF performs for people with dementia by investigating the validity and reliability of the scale. The study also aims to explore the underlying dimensions of the SCS-SF, the correlation between self-compassion and well-being, and whether self-compassion differs based on demographic variables. This study may help to support further research into self-compassion for people with dementia by potentially removing the barrier of not having a validated self-compassion measure for dementia. Ultimately, this may inform the development and evaluation of interventions that are most appropriate and beneficial for supporting the well-being of people with dementia. In relation to the aims, the study sought to answer the following questions:

Primary Question

- Is the SCS-SF a reliable and valid measure of self-compassion for people living with dementia?

Secondary Questions

- What is the factor structure of the SCS-SF for people with dementia?
- Does self-compassion measured using the SCS-SF correlate with well-being for people with dementia?
- Does self-compassion in people with dementia, measured using the SCS-SF, differ based on gender, age, dementia subtype or time since diagnosis?

Regarding the SCS-SF validity (primary question) and the correlation between self-compassion and well-being (secondary question); based on previous research (Homan, 2016; Hwang et al, 2016) the study proposed the hypothesis (H1) that self-compassion (SCS-SF) would positively correlate with measures of well-being and self-esteem, and negatively correlate with a measure of depression. Hypotheses were not proposed for the remaining research questions due to the exploratory aims.

Materials and Methods

Design and Participants

A quantitative cross-sectional design was utilised with a volunteer sample of people with dementia who took part in the research by completing a set of measures. In order to enhance accessibility, prior to recruitment, the study advertisement poster and participant information documents were reviewed by people living with dementia at a PPI group and changes to the documents to improve accessibility were made following this. Participants were recruited from Join Dementia Research (JDR), an online UK service that allows people with dementia to register their interest in research and be matched to studies, as well as regional and national dementia charities via posters, social media, and word of mouth. Two National Health Service (NHS) Trusts also supported study promotion and recruitment amongst people with dementia using their services.

Inclusion criteria specified that participants had a diagnosis of dementia and able to read English; however, to remain inclusive and maximise recruitment this included any subtype of dementia, any length of time since diagnosis and all ages.

Procedure

Study recruitment ran from October 2022 to March 2023. Participants accessed the measures online via the QR code or direct link within the advert (Appendix K). Upon opening the link, a short summary of the study information was presented, and participants were advised to follow a link to access the full information document (Appendix L). After reading the information, participants could proceed to a consent page before being able to access the measures (Appendix M). On completion, participants were presented with an ‘opt in’ question where they were able to input an email address if they wanted to be contacted by the researcher to hear about the study results. Finally, participants were presented with a debrief page and sources for support (Appendix N).

A paper option was available by request and was posted to the participant's home address. Paper measures were posted along with an information sheet, debrief sheet and a pre-paid envelope to return.

Measures

Self-compassion

The 12-item Self-compassion Scale (SCS-SF; Raes et al., 2011) asks participants to rate how often they behave in the manner stated in each item using a five-point scale (almost never to almost always). The scale contains the subscales self-kindness (SK), mindfulness (MI), common humanity (CH), self-judgement (SJ), isolation (IS), over-identified (OI). Negative items (1, 4, 8, 9, 11, 12) are reversed scored and, since development, the authors recommend calculating the total mean SCS-SF rather than the sum (Neff, n.d.). Due to low Cronbach's alpha for the SCS-SF subscales individually, Raes et al. (2011) recommend using the total score, which demonstrated validity and adequate internal consistency reliability (Cronbach's alpha ≥ 0.86). Scores range from 1 to 5 and high scores indicate higher self-compassion.

Well-being

The adapted 12-item Control, Autonomy, Self-realisation, and Pleasure Scale (CASP-12 v2; Wiggins et al., 2008) was utilised (with permission). This instrument is based on the original 19-item version (CASP-19; Hyde et al., 2003) but shows stronger psychometric properties and may be more robust for people with dementia (Stoner et al., 2019). Unlike previous shortened versions (Börsch-Supan et al., 2005), the CASP-12 v2 combines the control and autonomy subscales into one subscale. Participants rate the extent that items apply to them using a four-point scale (often to never), four items are reverse scored and a higher total score indicates greater well-being (scores range from 12 to 48). Whilst the scale is defined as a quality of life (QoL) measure, previous research has used the CASP-12 to

measure well-being (Okely et al., 2016), as QoL is often used interchangeably with well-being, and demonstrated an internal reliability of $\alpha = 0.82$ for people over the age of 50 (Okely et al., 2016).

Self-esteem

The Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965) was utilised to measure participants' beliefs and attitudes towards themselves across 10 items using a five-point scale. Five items are reverse scored and higher total scores indicate greater self-esteem (scores range from 10 to 40). The RSES has demonstrated good internal reliability ($\alpha = .82$ and $\alpha = .83$) and face validity in dementia (Burgener & Berger, 2008; Lamont et al., 2019) and has been used in research to examine construct validity for a self-stigma scale in dementia (Burgener & Berger, 2008).

Depression

The 15-item item Geriatric Depression Scale (GDS-15; Sheikh & Yesavage, 1986) was used to assess symptoms of depression. Participants respond 'yes' or 'no' to items; ratings that are indicative of depression score one point. Scores range from 0 to 15 and a higher total score suggests greater levels of depression. The scale has demonstrated alpha reliability ($\alpha = .87$; Lach et al., 2010) and validity for people with dementia (e.g., Burgener & Berger, 2008; Lach et al., 2010).

Demographics

Participants were asked their age, gender, subtype of dementia and time since diagnosis.

Data Analysis

Data were analysed using SPSS. Convergent and discriminant validity of the SCS-SF was analysed using Pearson's correlational analysis for the intercorrelations between the original subscales on the SCS-SF and the SCS-SF correlations with the RSES, GDS-15 and

CASP-12 v2. Internal consistency reliabilities for each measure were calculated. Power analysis for correlations between the SCS-SF and measures of well-being, self-esteem and depression suggested a priori minimum sample size of 139 (Appendix O).

An Exploratory Factor Analysis (EFA) using Principal Axis Factoring (PAF) and oblique rotation for the SCS-SF was conducted to determine the possible underlying dimensions of the scale for people with dementia and to further assess construct validity. EFA was chosen, rather than CFA due to the differing factor structures proposed in other populations and therefore it was unclear what the factor structure may be for people with dementia. Oblique rotation was selected as this allows the factors to be correlated (Field, 2018) and previous research suggests that correlations between self-compassion factors and variables are likely (Raes et al., 2011). Whilst there are no strict rules for EFA sample size, the prevalent 10:1 participant to item ratio rule-of-thumb (Costello & Osborne, 2005) suggested a priori minimum sample size of 120.

In addition, ANOVA and t-tests were conducted to determine whether there were any differences in self-compassion based on age, gender, dementia subtype or time since diagnosis.

Ethics

This research was granted ethical approval by the University of Hull and the Yorkshire and Humber Sheffield Full Research Ethics Committee (Appendix P). All participant data was anonymised as no identifiable data was collected within the measures and random numbers automatically assigned to each data set as they were submitted. The information sheet informed participants they had the right to withdraw their informed consent and data up until submitting their responses as after this point the data was anonymous and therefore not possible to identify.

Results

A total of 207 participants attempted the measures and 179 of the participants completed the measures online. However, 14 participants' data sets were excluded (6.76%) due to missing data on the SCS-SF, therefore 193 participant data sets were analysed. Of these 193 data sets, two participants completed <50% of the CASP-12 v2 and one participant completed <50% of the GDS-15, therefore these three participants were excluded from analyses. Of the remaining participant data sets, seven responses were missing on the CASP-12 v2, 12 on the RSES and 11 on the GDS-15. No single participant missed more than two items in any one measure. Little's (1988) Missing Completely at Random (MCAR) test was non-significant (>.05); therefore, the data were assumed to be MCAR. These 30 missing responses were replaced using Multiple Imputation (see Schafer & Graham, 2002).

Skew and kurtosis of participant data for each measure, t-test and ANOVA group were reviewed (Appendix Q) and except for the time since diagnosis group '6 months – 1 year' (flagged as leptokurtic, kurtosis 2.1), all values were in the acceptable range of -2 to 2 (George & Mallery, 2022). No extreme outliers (>2 standard deviations away from the mean) were identified from box plots (Appendix R). Assuming central limit theorem (Field, 2018); normality tests were not utilised for the measures/t-tests, however, were for the ANOVA's due to smaller group sizes. Shapiro-Wilks test only showed a significant departure from normality for '5-10 years'; $W(41) = .926$, $p = 0.01$. Homogeneity of variances was demonstrated by Levene's test for gender (p=.509), age (p=.950), and diagnosis subtype (p=.704). Levene's test rejected the null hypothesis of equal variances for time since diagnosis, $F(4, 187) = 3.50$, $p = .009$. Considering this and the normality violation, the non-parametric Kruskal-Wallis test was conducted for time since diagnosis.

Participant demographic information is displayed in Table 1. A total of 51 participants (26.4%) reported receiving help to complete the measures from their partner (41), child (5), grandchild (1), care worker (1) or the researcher (3).

Table 1.

Summary of participant demographics, total mean score and standard deviation (SD) on the SCS-SF

Demographic	Number of Participants (%)	Total mean SCS-SF score (SD)
Gender		
Male	119 (61.7)	3.21 (.758)
Female	73 (37.8)	3.06 (.703)
Missing	1 (0.52)	3.33
Age		
50-64 years old	42 (21.8)	2.83 (.731)
65 or over	150 (77.7)	3.25 (.717)
Missing	1 (0.52)	3.08
Diagnosis subtype		
Alzheimer's dementia	108 (60.0)	3.25 (.755)
Vascular dementia	20 (10.4)	2.95 (.624)
Mixed dementia	31 (16.1)	3.02 (.754)
Mixed Alzheimer's and Vascular	10	2.825 (.872)
Other mixed dementia	6	2.83 (.447)
Mixed subtypes not reported	15	3.23 (.753)
Frontotemporal dementia (FTD)	19 (9.84)	3.17 (.707)
Dementia with Lewy Bodies (DLB)	8 (4.15)	3.18 (.884)
Posterior Cortical Atrophy (PCA)	2 (1.04)	2.17 (.236)
Not known	5 (2.59)	3.17 (.257)
Time since diagnosis		
Less than 6 months	19 (9.84)	3.11 (.502)
6 months – 1 year	31 (16.1)	3.11 (.635)
1-5 years	93 (48.2)	3.16 (.792)

5-10 years	41 (21.2)	3.21 (.830)
Over 10 years	8 (4.15)	3.29 (.452)
Not known	1 (0.52)	2.25

Reliability Analysis

Table 2 demonstrates the internal consistency reliability for the SCS-SF subscales. Only the removal of item 10 (*when I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people*) resulted in an increase in alpha, but this change was marginal (from .796 to .800). Cronbach's alpha for the present sample was α=.830 for CASP-12 v2, α=.884 for RSES and for GDS-15 α=.871.

Table 2.

Internal consistency reliability, means and standard deviation (SD) of the full SCS-SF and original subscales

Subscales	Cronbach's Alpha	Mean	SD
Total	.796	3.16	.738
SK	.483	2.96	1.02
SJ	.762	3.07	1.23
CH	.411	3.22	1.04
IS	.582	3.06	1.19
MI	.643	3.42	1.04
OI	.566	3.21	1.16

Note. n=193

Exploratory Factor Analysis

Suitability for EFA of the SCS-SF was confirmed as multicollinearity screening (Appendix S) showed that the *R*-matrix (0.022) determinant was greater than 0.00001 and inter-item correlations were below the cut off *r*=0.9 (Field, 2018). Also, Bartlett's test of sphericity was significant (χ 2 (66) = 714.846, P < 0.001) and Kaiser-Meyer-Olkin (KMO)

measure of sampling adequacy was 0.819, which is considered ‘meritorious’ for EFA (Kaiser & Rice, 1974). All KMO values for individual items were >0.7; therefore, above the acceptable limit of 0.5 (Kaiser & Rice, 1974).

A preliminary analysis to obtain eigenvalues for factors revealed a potential three-factor model. Three factors had eigenvalues over Kaiser’s criterion of 1, although factor 3’s eigenvalue (1.012) just met this cut off (Field, 2018). Appendix T presents the factor loadings for the three-factor model. In combination, the three factors explained 59.7% of the variance. Two items loaded onto factor 3 (item 6 and 10) and except for item 10 (.423) all factor loadings in the pattern matrix were >.45 which is considered an acceptable factor loading for sample sizes above 150 (Hair et al, 2010). The scree plot (Appendix U) demonstrated inflexions that would justify retaining two or three factors. However, the structure matrix (item and factor correlations), showed items cross-loading between factor 2 and 3. Extraction communalities were low to moderate, between .40 and .70 (Costello & Osborne, 2005), for eight items and <.40 for four items. As factors with less than three items may be unstable (Costello & Osborne, 2005), the scree plot showing the potential for two factors, heavy cross-loading, and factor 3’s relatively low eigenvalue; the factor analysis was repeated as a two-factor solution.

The subsequent two-factor model explained 51.4% of the variance (31.9% negative factor, 19.6% positive factor) and only item 6 cross-loaded. Table 3 presents the pattern and structure coefficients after rotation. Similar to the three-factor model, extraction communalities (Appendix V) were low to moderate, between .40 and .70 (Costello & Osborne, 2005), for eight items and <.40 for four items thus indicating that the proportion of each items variance that can be explained by the factors is limited. The two-factor model was retained because aside from item 6, the items that clustered on the same factors suggested that factor 1 represents negative indicators of self-compassion and factor 2 represents positive

indicators, with minimal cross loadings. Cronbach's alpha was calculated for both factors and did not improve if any items were deleted.

Table 3.

EFA summary of the two-factor solution for the SCS-SF

Item	Rotated Factor Loadings (Pattern Coefficients)		Structure Coefficients	
	Factor 1	Factor 2	Factor 1	Factor 2
11. I'm disapproving and judgmental about my own flaws and inadequacies.	.838		.820	
8. When I fail at something that's important to me, I tend to feel alone in my failure.	.698		.671	
12. I'm intolerant and impatient towards those aspects of my personality I don't like.	.663		.669	
1. When I fail at something important to me I become consumed by feelings of inadequacy.	.654		.675	
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	.648		.647	
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	.614		.620	
3. When something painful happens I try to take a balanced view of the situation.		.769		.763
2. I try to be understanding and patient towards those aspects of my personality I don't like.		.707		.686
5. I try to see my failings as part of the human condition.		.660		.644
7. When something upsets me I try to keep my emotions in balance.		.535		.559
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.		.371		.373

6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	.322	.362	.409	.439
Eigenvalues	3.82	2.35		
% of variance	31.9	19.6		
α	.839	.746		
Note. n=193, only coefficients above 0.3 are shown				

Correlational Analysis

Bivariate correlations for the SCS-SF subscales (Table 4) show that correlations between the positive (SK, CH, MI) and negative (SJ, IS, OI) subscales were small (Cohen, 1988) and indicative of discriminant validity.

Table 4.

SCS-SF original subscale intercorrelations

Subscale	Subscale					
SK	SJ	CH	IS	MI	OI	Total
SK	.223**	.484***	.208**	.493***	.253***	.646***
SJ		.057	.620***	.182*	.632***	.718***
CH			.038	.469***	.142*	.522***
IS				.116	.643***	.694***
MI					.243***	.606***
OI						.760***
Note. ***p<.001, **p<.01, *p<.05, *n*=193						

Table 5 presents correlations between the CASP-12 v2, RSES and GDS-15 with the SCS-SF total mean and the positive (*M* = 3.20, *SD* = .838) and negative (*M* = 3.11, *SD* = 1.04) factors. The SCS-SF demonstrated significant positive correlations with the CASP-12 v2 and RSES, and significant negative correlations with the GDS-15 with large (>.5) effect sizes (Cohen 1988).

Table 5.

Correlations between SCS-SF total mean (plus sub-factors identified through EFA) and CASP-12 v2, RSES, and GDS-15 total scores

Scales	SCS-SF Total Mean	SCS-SF Negative Factor (Factor 1)	SCS-SF Positive Factor (Factor 2)
CASP[a]	.550**	.512**	.341**
CA	.522**	.486**	.322**
PL	.425**	.404**	.252**
SR	.421**	.382**	.273**
RSES[b]	.680**	.660**	.381**
GDS-15[c]	-.541**	-.554**	-.268**
SCS-SF Total Mean[b]		.833**	.730**
SCS-SF Negative Factor (Factor 1)[b]			.230*

Note. **p<.001, * p<.01 Sample size: [a]*n*=191, [b]*n*=193, [c]*n*=192

Demographic group differences in self-compassion

Results from the independent t-tests, one-way ANOVA and Kruskal-Wallis for group differences in total mean SCS-SF (Table 6) found a significant difference only between the two age groups, with a large (>.5) effect size (Cohen, 1988).

Table 6.

ANOVA, Kruskal-Wallis, and t-test statistics for demographic group differences in total mean SCS-SF

Demographic Group	Test	*P* value	Cohens d	Eta-squared
Gender[a] *(t-test; male, female)*	*t*=1.41	.161	.203	
Age[a] *(t-test; 50-64 years old, 65 or over)*	*t*=3.37	<.001*	.569	
Diagnosis subtype[b] *(ANOVA; Alzheimer's, Vascular, Mixed dementia, 'Other' dementia's)*	*F*=1.42	.239		.0226
Time since diagnosis[a] *(Kruskal-Wallis; less than 6 months, 6 months-1 year, 1-5 years, 5-10 years, over 10 years)*	*H*=.866	.929		.0275

Note. *p<.001, Sample size: [a]192, [b]188, Diagnosis subtype; *'Other' dementia* group comprised FTD, DLB and PCA.

Discussion

The absence of a validated measure of self-compassion in dementia has been a major limitation of existing studies and a barrier for further research. This is the first study to investigate how the SCS-SF performs for people with dementia. The primary aim of this study was to investigate the validity and reliability of the SCS-SF for people with dementia. The study also aimed to explore the underlying dimensions of the SCS-SF, correlations with well-being and whether self-compassion differed depending on age, gender, dementia subtype or time since diagnosis.

Correlational analyses between the total mean SCS-SF with the CASP-12 v2, RSES and GDS-15 supports the convergent validity of the SCS-SF for people with dementia and the proposed hypothesis that self-compassion would correlate positively with well-being and

self-esteem, and negatively with depression. These findings are consistent with existing literature in older adults (e.g., Homan, 2016) and other populations (e.g., Hwang et al., 2016; Neff 2003a), however future research is needed to clarify the causal direction of these relationships in dementia. Given that treating oneself with kindness and common humanity are components of self-compassion (Neff, 2003b), it may be that self-compassion helps to maintain sense of identity and connection with others (Homan, 2016). Therefore, if self-compassion facilitates important psychological needs in dementia such as identity and inclusion (Kitwood, 1997), future research should consider the potential role of self-compassion as a mediator for improving well-being.

EFA indicated that the underlying dimensions of the SCS-SF consisted of a positive and negative factor that explained 51.4% of variance, which does not fit the hierarchical structure proposed by Raes et al. (2011). The finding is consistent with several other studies which confirmed (using CFA) a similar two factor structure amongst students (Kotera & Sheffield, 2020), nurses (Lluch-Sanz et al., 2022) and psychotherapy clients (Hayes et al., 2016). In addition, these studies found the two factors explained similar levels of variance to that found in the present study, including the negative factor explaining more variance than the positive factor. Whilst a similar two factor structure, which explained 39.7% of variance, was initially demonstrated for older adults; further analysis (CFA) found the two-factor structure was not an acceptable fit (Bratt & Fagerström, 2020). Considering this, there may be an alternative factor structure which explains more variance but was not detected based on the existing scale and current sample, therefore further research (e.g., CFA) is needed to confirm this factor structure (and variance explained) for people with dementia.

The two factors demonstrated some evidence of discriminant validity due to minimal cross-loading; however, this is limited due to the issues with items 6 (*when I'm going through a very hard time, I give myself the caring and tenderness I need*) and 10 (*when I feel inadequate*

in some way, I try to remind myself that feelings of inadequacy are shared by most people). These items also demonstrated cross-loading and/or low factor loadings in Bratt and Fagerström (2020) using a Swedish translation, suggesting that for people with dementia and older adults these items may be ambiguous and may not measure self-compassion as they do for other populations/age groups. Alternatively, these are two of the longer items on the measure which may have impacted accessibility for people with dementia. Future research with older people and/or people with dementia could focus on adapting these items or investigate removing them from the scale.

The weak (<.3) positive correlation (Cohen, 1988) found between the negative (reverse scored) and positive factor contradicts suggestions that they may represent opposing poles of self-compassion (Lluch-Sanz, et al., 2022) as a strong correlation would be expected. Instead, the negative factor may represent self-criticism (Hayes et al., 2016; Kotera & Sheffield, 2020; López et al., 2015) which is inversely associated with self-compassion (Zhang et al., 2019) and posited as a distinct construct from self-compassion (Neff, 2011, p. 165) with different neural activity (Lutz et al., 2020). As well as explaining more variance in self-compassion, the negative factor (higher scores indicate lower self-criticism) showed relatively stronger correlations with total self-compassion, well-being, self-esteem, and depression compared to the positive factor (self-compassion), supporting the distinction between the factors. Considering this, whilst the total SCS-SF score showed acceptable internal consistency reliability (George & Mallery, 2022), it may not be appropriate to combine the two factors together under the label of 'self-compassion'. Instead, it may be more appropriate to measure the two factors separately for people with dementia as they showed acceptable (positive factor) and good (negative factor) internal consistency reliability separately (George & Mallery, 2022).

A pertinent implication from these findings is that for people with dementia the relative absence of self-criticism may be more important for well-being than the presence of self-compassion. It may be that people with dementia find self-compassion more difficult, possibly moderated by ageing, or, due to the impact of negativity bias, which may be heightened in dementia (Fleming et al., 2003), are more likely to attend to changes in self-criticism compared to self-compassion and therefore hold greater weight towards the impact of self-criticism on well-being. Furthermore, self-compassion may originate in care seeking/giving behaviours developed from childhood (Gilbert, 2009) and therefore may be a more stable self to self relating process compared to self-criticism, which is influenced by social and environmental factors daily (Veilleux et al., 2023). Further research is needed to investigate the predictive capabilities of self-compassion and self-criticism for well-being in dementia.

The potential stability of self-compassion may also explain the finding that SCS-SF scores did not differ depending on time since diagnosis. Alternatively, rather than time since diagnosis, it may be that self-compassion differs between stages of dementia as people navigate challenges relating to expectations and reality of dementia progression (e.g., Read et al., 2017). Considering the variation in dementia progression and delays in diagnosis and help-seeking (Parker et al., 2020); time since diagnosis may not be an accurate reflection of a person's stage of dementia or cognitive ability. Cognitive impairment or stage of dementia was not measured in this study but may be factors future research can consider. Consistent with Phillips & Ferguson (2013), no differences in gender were found suggesting that the SCS-SF measures self-compassion similarly for men and women. This was the first study to explore differences in self-compassion based on dementia subtype, and whilst no differences were found, future research may wish to explore this with a larger sample size.

The significant difference in self-compassion for participants aged 50 to 64 compared to over 65, is consistent with previous findings that self-compassion may increase with age (Hwang et al., 2016) including for older adults (Homan, 2016). Therefore, if self-compassion is involved in establishing ego integrity in older age (Erikson & Erikson, 1998; Phillips & Ferguson, 2013), it is possible that dementia does not impact this process. The association between self-criticism and age over time in dementia may be different and potentially be confounded by cognitive impairment; therefore, future research could investigate this.

Limitations

Several limitations should be considered. Firstly, whilst the a priori sample size was achieved, a larger sample (>300) may have provided a more stable factor solution in the EFA (Field, 2018). Secondly, the opportunity sampling of the participants limits generalisability of the findings; whilst attempts were taken to be inclusive via a range of advertisement approaches, it may have been less likely that individuals outside of the regional area with limited access to technology were aware of the study. In addition, as most participants completed the self-report measures online independently, it cannot be confirmed that all participants did have diagnoses of dementia and did not receive excessive help to complete the measures. Furthermore, although significant differences in self-compassion were not found for gender or dementia subtype, a larger proportion of males and individuals with Alzheimer's dementia were involved in the study. Also, the measures were only offered in English, even though translated versions of the SCS-SF are available, again limiting generalisability.

Lastly, an outcome measure which would be expected to be completely uncorrelated with self-compassion (to evidence discriminant validity), such as social desirability (Crowne & Marlowe, 1960), was not included, therefore limiting conclusions regarding the overall construct validity. The addition of another measure was decided against at the design and PPI

stage as people living with dementia advised that this would create participant burden. Future research should therefore aim to further establish discriminant validity of the SCS-SF.

Recommendations and Conclusions

In terms of recommendations for clinicians, given the possibility that a two-factor structure of the SCS-SF measures two distinct concepts, it is recommended that when using the SCS-SF with people living with dementia in clinical or research settings, caution is taken when interpreting the total score. Instead, clinicians may wish to assess the positive and negative factors separately. If future research also suggests that self-compassion is predictive of well-being for people living with dementia, it may be beneficial for interventions aiming to support well-being with people with dementia to cultivate self-compassion and reduce self-criticism. For example, people with low self-compassion may benefit from self-compassion techniques within Compassion Focussed Therapy and mindfulness. In addition, people with high self-criticism may also benefit from Cognitive Behavioural Therapy techniques such as thought challenging.

To conclude, the SCS-SF shows evidence of reliability and construct validity for people with dementia. However, the scale may comprise a positive and negative factor that measure distinct concepts in dementia, and these may be subject to age. Further exploration of the structure and suitability of the SCS-SF to measure self-compassion for people living with dementia is warranted.

References

Allen, A. B., Goldwasser, E. R., & Leary, M. R. (2012). Self-Compassion and Well-being among Older Adults. *Self and Identity*, 11(4), 428-452. https://doi.org/10.1080/15298868.2011.595082

Allen, A. B., & Leary, M. R. (2013). Self-compassionate Responses to Aging. *The Gerontologist*, 54(2), 190-200. https://doi.org/10.1093/geront/gns204

Babenko, O., & Guo, Q. (2019). Measuring self-compassion in medical students: Factorial validation of the Self-Compassion Scale–Short Form (SCS-SF). *Academic Psychiatry*, 43(6), 590-594. https://doi.org/10.1007/s40596-019-01095-x

Berk, L., Warmenhoven, F., Stiekema, A. P., Van Oorsouw, K., Van Os, J., de Vugt, M., & Van Boxtel, M. (2019). Mindfulness-based intervention for people with dementia and their partners: Results of a mixed-methods study. *Frontiers in Aging Neuroscience*, 11, Article 92. https://doi.org/10.3389/fnagi.2019.00092

Berk, L., Warmenhoven, F., van Os, J., & van Boxtel, M. (2018). Mindfulness training for people with dementia and their caregivers: rationale, current research, and future directions. *Frontiers in Psychology*, 9, Article 982. https://doi.org/10.3389/fpsyg.2018.00982

Börsch-Supan, A., Brugiavini, A., Jürges, H., Makenbach, J., Siegrist, J., & Weber, G. (Eds). (2005). *Health, Ageing and Retirement in Europe. First Results from the Survey of Health, Ageing and retirement in Europe (SHARE).* Mannheim Research Institute for the Economics of Aging (MEA).

Bratt, A., & Fagerström, C. (2020). Self-compassion in old age: confirmatory factor analysis of the 6-factor model and the internal consistency of the Self-compassion scale-short form. *Aging & Mental Health*, 24(4), 642-648. https://doi.org/10.1080/13607863.2019.1569588

Brown, L., Huffman, J. C., & Bryant, C. (2019). Self-compassionate aging: A systematic review. *The Gerontologist*, 59(4), 311-324. https://doi.org/10.1093/geront/gny108

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

Castilho, P., Pinto-Gouveia, J., & Duarte, J. (2015). Evaluating the multifactor structure of the long and short versions of the self-compassion scale in a clinical sample. *Journal of Clinical Psychology*, 71(9), 856-870. https://doi.org/10.1002/jclp.22187

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

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). Lawrence Erlbaum Associates.

Collins, R. N., Gilligan, L. J., Poz, R. (2017). The Evaluation of a Compassion-Focused Therapy Group for Couples Experiencing a Dementia Diagnosis. *Clinical Gerontologist,* 41(5), 474-486. https://doi.org/10.1080/07317115.2017.1397830

Costello, A. B., & Osborne, J. (2005). Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Practical Assessment, Research, and Evaluation*, 10, Article 7. https://doi.org/10.7275/jyj1-4868

Craig, C., Hiskey, S., Royan, L., Poz, R., & Spector, A. (2018). Compassion Focused Therapy for People with Dementia: A Feasibility Study. *International Journal of Geriatric Psychiatry*, 33(12), 1727-1735. https://doi.org/10.1002/gps.4977

Crowne, D. P., & Marlowe, D. (1960). A new scale of social desirability independent of psychopathology. *Journal of Consulting Psychology*, 24, 349-354. https://doi.org/10.1037/h0047358

Erikson, E., & Erikson, J. (1998). *The life cycle completed: Extended version*. W. W. Norton & Company

Field, A. (2018). *Discovering statistics using IBM SPSS Statistics*. SAGE edge.

Fleming, K., Kim, S. H., Doo, M., Maguire, G., & Potkin, S. G. (2003). Memory for emotional stimuli in patients with Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias®*, 18(6), 340-342. https://doi.org/10.1177/153331750301800604

George, D., & Mallery, P. (2022). *IBM SPSS statistics 27 step by step: A simple guide and reference* (Seventeenth ed.). Routledge

Gilbert, P. (2009). *The Compassionate Mind.* Robinson

Hair, J. F., Black, W. C., Babin, B. J., & Anderson, R. E. (2010). *Multivariate data analys*is (7th ed.). Prentice Hall

Hayes, J. A., Lockard, A. J., Janis, R. A., & Locke, B. D. (2016). Construct validity of the Self-Compassion Scale-Short Form among psychotherapy clients. *Counselling Psychology Quarterly*, 29(4), 405-422. https://doi.org/10.1080/09515070.2016.1138397

Hoffman, L., Hutt, R., Yi Tsui, C. K., Zorokong, K., & Marfeo, E. (2020). Meditation-based interventions for adults with dementia: A scoping review. *The American Journal of Occupational Therapy*, 74(3), 1-14. https://doi.org/10.5014/ajot.2020.037820

Homan, K. J. (2016). Self-compassion and psychological well-being in older adults. *Journal of Adult Development*, 23(2), 111–119. https://doi.org/10.1007/s10804-016-9227-8

Hwang, S., Kim, G., Yang, J. W., & Yang, E. (2016). The moderating effects of age on the relationships of self-compassion, self-esteem, and mental health. *Japanese Psychological Research*, 58(2), 194-205. https://doi.org/10.1111/jpr.12109

Hyde, M., Wiggins, R., Higgs, P., & Blane, D. (2003). A measure of quality of life in early old age: The theory, development and properties of a needs satisfaction model (CASP-19). *Aging & Mental Health*, 7(3), 186-194. https://doi.org/10.1080/1360786031000101157

Innes, K. E., Selfe, T. K., Brown, C. J., Rose, K. M., & Thompson-Heisterman, A. (2012). The effects of meditation on perceived stress and related indices of psychological status and sympathetic activation in persons with Alzheimer's disease and their caregivers: a pilot study. *Evidence-Based Complementary and Alternative Medicine*, Article 927509. https://doi.org/10.1155/2012/927509

Kaiser, H. F., & Rice, J. (1974). Little jiffy, mark 4. *Educational and Psychological Measurement*, 34(1), 111-117. https://doi.org/10.1177/001316447403400115

Kim, C., & Ko, H. (2018). The impact of self-compassion on mental health, sleep, quality of life and life satisfaction among older adults. *Geriatric Nursing*, 39(6), 623-628. https://doi.org/10.1016/j.gerinurse.2018.06.005

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open university press.

Kotera, Y., & Sheffield, D. (2020). Revisiting the self-compassion scale-short form: Stronger associations with self-inadequacy and resilience. *SN Comprehensive Clinical Medicine*, 2(6), 761-769. https://doi.org/10.1007/s42399-020-00309-w

Lach, H. W., Chang, Y. P., & Edwards, D. (2010). Can older adults with dementia accurately report depression using brief forms? Reliability and validity of the Geriatric Depression Scale. *Journal of Gerontological Nursing*, 36(5), 30-37. https://doi.org/10.3928/00989134-20100303-01

Lamont, R. A., Nelis, S. M., Quinn, C., Martyr, A., Rippon, I., Kopelman, M. D., Hindle, J., Jones, R., Litherland, R., & Clare, L. (2019). Psychological predictors of 'living well' with dementia: findings from the IDEAL study. *Aging & Mental Health,* 24(6), 956-964. https://doi.org/10.1080/13607863.2019.1566811

Little, R. J. A. (1988). A Test of Missing Completely at Random for Multivariate Data with Missing Values. *Journal of the American Statistical Association,* 83 (404), 1198-1202. https://doi.org/10.2307/2290157

Lluch-Sanz, C., Galiana, L., Vidal-Blanco, G., & Sansó, N. (2022). Psychometric properties of the self-compassion scale—Short form: Study of its role as a protector of Spanish nurses professional quality of life and well-being during the COVID-19 pandemic. *Nursing Reports*, 12(1), 65-76. https://doi.org/10.3390/nursrep12010008

López, A., Sanderman, R., Smink, A., Zhang, Y., Van Sonderen, E., Ranchor, A., & Schroevers, M. J. (2015). A reconsideration of the Self-Compassion Scale's total score: self-compassion versus self-criticism. *Plos One,* 10(7), Article 0132940. https://doi.org/10.1371/journal.pone.0132940

Lutz, J., Berry, M. P., Napadow, V., Germer, C., Pollak, S., Gardiner, P., ... & Schuman-Olivier, Z. (2020). Neural activations during self-related processing in patients with chronic pain and effects of a brief self-compassion training–a pilot study. *Psychiatry Research: Neuroimaging,* 304, Article 111155. https://doi.org/10.1016/j.pscychresns.2020.111155

Meng, R., Yu, Y., Chai, S., Luo, X., Gong, B., Liu, B., Hu, Y., Luo, Y., & Yu, C. (2019). Examining psychometric properties and measurement invariance of a Chinese version of the Self-Compassion Scale–Short Form (SCS-SF) in nursing students and medical workers. *Psychology Research and Behavior Management*, 12, 793-809. https://doi.org/10.2147/PRBM.S216411

Neff, K. D. (2003a). Development and validation of a scale to measure self-compassion. *Self and Identity*, 2, 223-250. https://doi.org/10.1080/15298860309027

Neff, K. D. (2003b). Self-compassion: An alternative conceptualization of a healthy attitude toward oneself. *Self and identity*, 2(2), 85-101. https://doi.org/10.1080/15298860309032

Neff, K. D. (2011). *Self-compassion: The Proven Power of Being Kind to Yourself.* Yellow Kite

Neff, K. D. (n.d.). *Topics to be covered in self-compassion research seminar* [Information Sheet]. https://self-compassion.org/wp-content/uploads/2021/03/SCS-SF-information.pdf

Okely, J. A., Cooper, C., & Gale, C. R. (2016). Wellbeing and arthritis incidence: the survey of health, ageing and retirement in Europe. *Annals of Behavioral Medicine*, 50(3), 419-426. https://doi.org/10.1007/s12160-015-9764-6

Parker, M., Barlow, S., Hoe, J., & Aitken, L. (2020). Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia. *International Psychogeriatrics*, 32(5), 611-634. https://doi.org/10.1017/S1041610219002229

Phillips, W. J., & Ferguson, S. J. (2013). Self-compassion: a resource for positive aging. *Journals of Gerontology*, 68(4), 529-539. https://doi.org/10.1093/geronb/gbs091

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the self-compassion scale. *Clinical Psychology & Psychotherapy*, 18(3), 250-255. https://doi.org/10.1002/cpp.702

Read, S. T., Toye, C., & Wynaden, D. (2017). Experiences and expectations of living with dementia: A qualitative study. *Collegian*, 24(5), 427-432. https://doi.org/10.1016/j.colegn.2016.09.003

Rocha, L., Pereira, L. B., & Peluso, M. L. (2022). Self-Compassion Scale-Short Form (SCS-SF): initial evidence of validity in Brazil. *Revista Psicologia em Pesquisa*, 16(2), 1-20. https://doi.org/10.34019/1982-1247.2022.v16.31549

Rosenberg, M. (1965). *Society and the Adolescent Self-Image*. Princeton University Press

Schafer, J. L., & Graham, J. W. (2002). Missing data: our view of the state of the art. *Psychological Methods*, 7(2), Article 147. https://doi.org/10.1037/1082-989X.7.2.147

Schölzel-Dorenbos, C. J., Ettema, T. P., Bos, J., Boelens-van der Knoop, E., Gerritsen, D. L., Hoogeveen, F., De Lange, J., Meihuizen, L., & Dröes, R. M. (2007). Evaluating the outcome of interventions on quality of life in dementia: selection of the appropriate scale. *International Journal of Geriatric Psychiatry*, 22(6), 511-519. https://doi.org/10.1002/gps.1719

Sheikh, J. I., & Yesavage, J. A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 5(1-2), 165–173. https://doi.org/10.1300/J018v05n01_09

Stoner, C. R., Orrell, M., & Spector, A. (2019). The psychometric properties of the control, autonomy, self-realisation and pleasure scale (CASP-19) for older adults with dementia. *Aging & Mental Health*, 23(5), 643–649. https://doi.org/10.1080/13607863.2018.1428940

Tavares, L. R., Vagos, P., & Xavier, A. (2023). The role of self-compassion in the psychological (mal) adjustment of older adults: a scoping review. *International Psychogeriatrics*, 35(4), 179-192. https://doi.org/10.1017/S1041610220001222

Uršič, N., Kocjančič, D., & Žvelc, G. (2019). Psychometric properties of the Slovenian long and short version of the self-compassion scale. *Psihologija*, 52(2), 107-125. https://doi.org/10.2298/PSI180408029U

Veilleux, J., Clift, J. B., Brott, K. H., Warner, E., Schreiber, r., Henderson, H., & Shelton, D. (2023). “I’m so dumb and worthless right now”: Factors associated with heightened momentary self-criticism in daily life. *Preprints*. Advance online publication. https://doi.org/10.31234/osf.io/2dcvf

Wiggins, R. D., Netuveli, G., Hyde, M., Higgs, P., & Blane, D. (2008). The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: A combination of exploratory and confirmatory approaches. *Social Indicators Research*, 89(1), 61-77. https://doi.org/10.1007/s11205-007-9220-5

Zessin, U., Dickhäuser, O., & Garbade, S. (2015). The relationship between self-compassion and well-being: A meta-analysis. *Applied Psychology: Health and Well-Being*, 7(3), 340-364. https://doi.org/10.1111/aphw.12051

Zhang, H., Watson-Singleton, N. N., Pollard, S. E., Pittman, D. M., Lamis, D. A., Fischer, N. L., Patterson, B., & Kaslow, N. J. (2019). Self-Criticism and Depressive Symptoms: mediating Role of Self-Compassion. *Omega,* 80, 202–223. https://doi.org/10.1177/0030222817729609

Part Three: Appendices

Appendix A: Reflective statement

I eagerly anticipated the prospect of conducting and completing this thesis from the start of my three years on the Doctorate. I developed a strong interest in research during my undergraduate dissertation investigating post-traumatic growth following bereavement. I recall being asked in my Doctorate interview what I may be interested in researching in the future and why. I remember this was a question that I had spent time contemplating in preparation for the interview, with lots of ideas for possible projects running through my mind. However, the area I settled on each time was research surrounding older adults and dementia. When it came to choosing research supervisors and selecting a research area, older adults and dementia continued to be the path I navigated towards.

I have always felt most comfortable around older generations, perhaps from my close relationship with my Nanna growing up. My Nanna passed away when I was in college and my experience of grief, alongside my experiences volunteering at an end-of-life hospice, influenced my interest in researching growth and bereavement for my undergraduate dissertation. Being a ward volunteer at the hospice, which offered end of life and respite care was an eye-opening experience for me, where I learnt about experiences relating to life, ageing, health, and death. Many individuals on the ward were older adults, with a range of multiple health conditions, including people living with dementia. It was here that I first began to understand the impact that dementia can have on those who are diagnosed and their loved ones in both the earlier and later stages of dementia progression. I believe that it was these experiences that led to my desire to research, and work clinically, with older adults and people living with dementia.

Whilst I knew that I wanted to conduct my research in the area of dementia, I wasn't sure on the specifics of the research. From spending time speaking with those on the ward I had noticed that many people experienced grief and frustrations surrounding changes in their

abilities and self-identities. This led me to begin considering concepts such as self-identity, self-efficacy, and self-esteem in dementia. During the Doctorate course I became interested in Compassion Focussed Therapy and the flows of compassion. As someone who has tended to take the position of wanting to complete tasks 'right' or 'perfectly', I came to realise that my own levels of self-compassion could often be low. Thinking back to the frustrations and self-criticisms raised on the ward, I began to wonder about self-compassion in people living with dementia. I was shocked by the lack of literature surrounding this for people living with dementia, even though the research on self-compassion in other populations appeared to be vastly growing. It was evident that there was a clear gap in the literature that aligned with my interests and therefore I settled on the area of dementia and self-compassion.

I was very fortunate to have the opportunity to be supervised by both Dr Emma Wolverson and Dr Chris Clarke, who have a wealth of knowledge and experience working with older adults and in dementia care. I have learnt so much from them throughout this thesis.

Empirical

Having decided on the area of self-compassion and dementia, the next decision was selecting a research design and methodology. Comparing my undergraduate experiences of quantitative and qualitative research, I felt a greater pull towards quantitative research. I find statistical analysis complex, and whilst maths was never a strong subject for me, I always enjoyed the challenge of working out answers to mathematical questions, trying to understand how the numbers might fit together. Therefore, whilst I was aware that statistical analysis would challenge me, I knew that I was likely to enjoy a quantitative approach. The limitations highlighted within the existing literature on self-compassion in dementia, also supported the use of a quantitative approach due to the need for a self-compassion measure to be validated for people living with dementia.

Gaining feedback from people living with dementia on my drafts of the study advertisement poster, information sheets and measures was incredibly useful. I recall feeling nervous taking these drafts to the dementia advisory board, questioning whether people would consider the research to be useful and relevant. However, the interest that board members shared regarding the study was reassuring. Amongst other feedback, one member of the board suggested that the definition of self-compassion used on the advertisement poster should be short and simple and suggested 'being kind and understanding to ourselves'. I liked this and subsequently used this as the definition on the poster and when I would be explaining the concept of self-compassion to others in person. My experience with the dementia advisory board really demonstrated to me the value of Patient and Public Involvement in research and I am thankful for the time and advice that the board members gave me.

One of the major challenges during the empirical project was the process of NHS ethics. After long discussions with Emma and Chris about the pros and cons of NHS ethics, I decided to follow this process with the hope that this would help me to achieve my sample size goal. At this point I was dubious that I would be able to meet a goal of 150 to 200 participants. Completing the IRAS forms and going through the many different stages felt like a never-ending complicated procedure. I recall feelings of frustration and anxiety as others in my cohort began recruitment whilst I continued down the NHS ethics process. However, having gone through this process and attending an ethics review panel (which was nowhere near as daunting as I had imagined), I developed a greater understanding of research ethics and built my confidence in explaining how this had been considered in my own research.

Prior to recruitment, Emma and Chris recommended forming relationships with local dementia charities and groups. Following this, I contacted Butterflies Memory Loss Support Group. The Butterflies group kindly welcomed me in as a volunteer whereby I was able to

build connections and get to know group members. I thoroughly enjoyed my time volunteering at Butterflies, and this allowed me to gain a deeper understanding of some of the unique experiences people have whilst living with dementia. I was also welcomed into the East Riders DEEP group and made new contacts with people living with dementia online who were interested in the project across the country. I recall learning about the impact dementia can have on sensory experiences, relationships and day to day living. I saw the positive impact of music, food, humour and social connections and it makes me wonder what else would be beneficial for research with people living with dementia to investigate. When I eventually reached 200 participants, I felt ecstatic and whilst I believe achieving this sample size (which was greater than the a priori sample size required) was a strength of the study, I could not have reached this without all of the support from the local and national dementia charities, Join Dementia Research, the two NHS trusts and all of the people who participated.

Even though I achieved my sample size goal, upon data analysis some participant data was missing. Deciding what to do with the missing data was a challenge as I found myself weighing up the ethical dilemma of wanting to use as much participant data as possible, as people had given up their time to complete the measures, however also being aware that substituting data for the SCS-SF (Raes et al., 2011) was statistically an issue as I would be including data that I never had during validation. After discussions with my supervisors, a statistician who offered me advice regarding statistical analysis, and further research on missing data methods I decided to exclude participants who had missing data on the SCS-SF (Raes et al., 2011) but use multiple imputation for any missing data on the other three measures that the scale was to be validated against. This felt like a balance of using as much participant data as possible whilst also remaining as statistically sound as possible. Arguably if I had formatted the online questionnaire so that participants had to submit a response to every question, the issue of missing data would not have occurred. I did consider this before

starting recruitment, however at the time I decided against it as felt that allowing participants to miss items would help the measures to be more accessible.

The statistical analysis of the data was another challenge. Having never conducted a factor analysis before, I read into the analysis, trying to understand the process. I initially found this stressful as believed there to be a 'right' way of conducting a factor analysis and wanted to ensure I followed this but was overwhelmed by the range of information during my reading. Speaking with a statistician in addition to the reading helped me to realise that there was no singular 'right' way to conduct a factor analysis (or any of the statistical analyses) and instead it was more important to be able to justify the decisions made such as the type of factor analysis and rotation method chosen. Breaking the factor analysis process down into these different stages helped me to better understand each aspect and be able to decide on the most appropriate options for my data.

Systematic Literature Review

Starting the literature review was a struggle. This was mostly due to my indecisiveness choosing a review question. For weeks I scoured the literature and drafted several review proposals, either finding that the question was too broad or too specific and therefore it seemed that there would be too much or too little literature to review. At one point I even ended up considering a more qualitative, experience focussed question which would not have aligned with the post-positivist epistemological position I had taken for my empirical. Emma and Chris gave me lots of helpful feedback on the proposals I had created, and I realised that I just had to run with a question and then see what studies arose. I learnt that there is only a certain amount of preparation you can do before you just have to give things a go. Meeting with the university library team was incredibly helpful as they confirmed that I was on the right path with my question/search terms and helped me to refine the search terms to reduce

the number of articles. Dropping the term ‘self’ made a huge difference to the numbers, along with having the intervention terms limited to title only which was justified given that all of the articles that I had flagged at this stage included the intervention terms in the title.

I liked the structured approach of the literature review process, however found the quality assessment stage stressful. I attempted to hold a consistent approach to rating the studies but at times found myself doubting my initial ratings and questioning whether I had been too harsh or kind. This probably linked to the perfectionist tendencies such as a belief that there was only one ‘correct’ rating possible rather than reminding myself that it was the justifications for the ratings that were most important. This indecisiveness led to the assessment process taking a long time, probably longer than it should have. However, I was reassured that my approach had been consistent after receiving the secondary reviewer’s ratings, who rated the majority of studies the same.

The literature review highlighted the need for a self-compassion measure to be validated for people with dementia and therefore directly linked to and built into the rationale for my empirical project, which aimed to fill this gap. Although I misjudged the amount of time that the literature review would require, it was satisfying to see this narrative form between my literature review and empirical as I came to writing up both studies.

Summary

Writing both the literature review and the empirical project was perhaps my favourite part of the process, as well as the most stressful time due to the impending deadline that approached. Seeing my work be pulled together and refined over time was rewarding however I often found myself holding onto drafts, not quite happy with them and wanting to get them to a better standard before sending them to Emma and Chris for feedback. It was clear to me that these perfectionist tendencies were holding me back, leaving me feeling stuck on a particular

draft for a period of time and feeling unmotivated. Even though my research focussed on self-compassion, it was easy to fall into being self-critical with these drafts. Over time, I learnt to be content with drafts being 'good enough' and to accept that drafts are just that – drafts. Emma and Chris' feedback would always help me to become 'unstuck' and find new ways forward. I am very grateful to them for the knowledge and advice they shared with me throughout the whole process.

The last three years working towards finalising this thesis has tested my ability to maintain a work life balance and has been the cause of a lot of stress, however, has been incredibly rewarding and I look forward to being part of many more research projects in the future. The process has pushed me out of my comfort zone, helped me to meet new people, learn new research skills, an array of knowledge and develop my own self-compassion. It feels fulfilling coming to the end of this thesis and I am proud of the work I have accomplished.

References

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the self-compassion scale. *Clinical Psychology & Psychotherapy,* 18(3), 250-255. https://doi.org/10.1002/cpp.702

Appendix B: Epistemological statement

This statement aims to present the ontological and epistemological positions taken within the Systematic Literature Review and Empirical Paper within this thesis.

Ontology can be defined as the assumptions that are made about the nature of reality (Easterby-Smith et al., 2012), such as the notion of a single or multiple reality (Bahari, 2010). Quantitative research, which is often concerned with objectivity and the idea of there been one truth, would therefore align with the realist ontological position (Dieronitou, 2014; Slevitch, 2011). On the other hand, qualitative research which is often concerned with subjective experiences would follow the assumption of multiple realities and therefore assume a relativist ontology (Dieronitou, 2014).

Epistemology can be understood as the "general set of assumptions about the ways of inquiring into the nature of the world" (Easterby-Smith et al., 2012, p.18) and therefore relates to what is considered as 'acceptable' knowledge and the methods that such knowledge is formed from (Bahari, 2010). Positivism, an epistemological positioned aligning with the realist oncology, assumes social facts have an objective reality/truth and research can be conducted in a value-free way (Bahari, 2010). On the other hand, interpretivism/constructivism considers humans as having roles as social actors (Saunders et al., 2007) and how the researchers own values and perspectives influence the findings of studies (Bahari, 2010) meaning that there is no single truth as findings are based on interpretations. Consequently, qualitative research which does not seek to be objective or generalisable often aligns with interpretivism/constructivism (Slevitch, 2011). Quantitative research interested in validity, generalisability and causal effects often aligns with positivism (Slevitch, 2011).

The Systematic Literature Review in this thesis focussed on outcome measures relating to aspects of self and the effects of interventions on these specific constructs and therefore may be considered as an investigation of causal relationships. Moreover, the review excluded qualitative studies and therefore aligned with a positivist realist position. Investigating the validity of outcome measure is commonly associated with the positivist realist position (Park et al., 2020). The Empirical Paper conducted statistical analysis to investigate the validity of an outcome measure and therefore also aligned with the positivist realist position.

However, the positivist position is limited as does not acknowledge the complexities of reality, ignores the impact of context, and can be viewed as reductionist (Ryan, 2006). Instead, a post-positivist position can be viewed as similar to positivism due to adhering to the assumption that there can be an objective reality, however it also acknowledges that an absolute truth is not possible and therefore realities and theories can be disproven (Moon & Blackman, 2014). The researcher aligned with this perspective and therefore held a post-positivist stance throughout this thesis.

References

Bahari, S. F. (2010). Qualitative versus quantitative research strategies: contrasting epistemological and ontological assumptions. *Sains Humanika*, 52(1). https://doi.org/10.11113/sh.v52n1.256

Dieronitou, I. (2014). The ontological and epistemological foundations of qualitative and quantitative approaches to research. *International Journal of Economics, Commerce and Management*, 2(10), 1-17. https://citeseerx.ist.psu.edu/document?repid=rep1&type=pdf&doi=0d0d7ff7b01e4daed1fc14b54191964076d6581f

Easterby-Smith, M., Thorpe, R., & Jackson, P. R. (2012). *Management research*. Sage.

Moon, K., & Blackman, D. (2014). A guide to understanding social science research for natural scientists. *Conservation Biology*, *28*(5), 1167-1177. https://doi.org/10.1111/cobi.12326

Park, Y., Konge, L., & Artino, A. R. (2020). The Positivism Paradigm of Research. *Academic Medicin*e, 95 (5). http://dx.doi.org/10.1097/ACM.0000000000003093

Ryan, A. B. (2006). Post-Positivist Approaches to Research. In M. Antonesa., H. Fallon., A.B. Ryan., A. Ryan & T. Walsh (Eds.), *Researching and Writing your thesis: a guide for postgraduate students.* (pp. 12-26.). Maynooth Adult and Community Education.

Saunders, M., Lewis, P., & Thornhill, A. (2007). *Research Methods for Business Students.* Prentice Hall

Slevitch, L. (2011). Qualitative and quantitative methodologies compared: Ontological and epistemological perspectives. *Journal of Quality Assurance in Hospitality & Tourism,* 12(1), 73-81. https://doi.org/10.1080/1528008X.2011.541810

Appendix C: Submission Guidelines for Journal Dementia

Manuscript Submission Guidelines:
This Journal is a member of the Committee on Publication Ethics.

Please read the guidelines below then visit the Journal's submission site http://mc.manuscriptcentral.com/dementia to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of Dementia will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere. Please see our guidelines on prior publication and note that ***Dementia*** **may accept submissions of papers that have been posted on pre-print servers;** please alert the Editorial Office when submitting (contact details are at the end of these guidelines) and include the DOI for the preprint in the designated field in the manuscript submission system. Authors should not post an updated version of their paper on the preprint server while it is being peer reviewed for possible publication in the journal. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your paper is accepted, you must include a link on your preprint to the final version of your paper.

1. What do we publish?

1.1 Aims & Scope

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

1.2 Article Types

Dementia welcomes original research or original contributions to the existing literature on social research and dementia. Biomedical and overly clinical research articles will not be accepted.

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

The journal also publishes book reviews. We send out a list of books to review twice a year in September and March.

If you would like to receive this list please e-mail Sarah Campbell, Book Review Editor at Sarah.Campbell@MMU.ac.uk and you will be added to our reviewer list. We welcome suggestions of books to review at any time. Also, if you have read a book that you think would be of interest to the journal and would like to review it, we also welcome unsolicited contributions.

Book reviews are usually around 1000 words in length but it will vary depending on the book. Providing a book review is not a guarantee of publication.

1.3 Writing your paper

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

1.3.1 Make your article discoverable

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

Back to top

2. Editorial policies

2.1 Peer review policy

Dementia operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible.

As part of the submission process you will be asked to provide the names of peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of

interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

- The reviewer should have no prior knowledge of your submission,
- The reviewer should not have recently collaborated with any of the authors,
- Reviewer nominees from the same institution as any of the authors are not permitted.

Please note that the Editors are not obliged to invite any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

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

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should be placed on the title page. Your main text should include a Declaration of Conflicting Interests (if applicable), any notes and your References but should be completely anonymized.

2.3.1 Third party submissions

Where an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statements must:

- Disclose this type of editorial assistance – including the individual's name, company and level of input
- Identify any entities that paid for this assistance
- Confirm that the listed authors have authorized the submission of their

manuscript via third party and approved any statements or declarations, e.g. conflicting interests, funding, etc.

Where appropriate, SAGE reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

2.4 Funding

Dementia requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

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

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

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki.

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative. Please do not submit the patient's actual written informed consent with your article, as this in itself breaches the patient's confidentiality. The Journal requests that you confirm to us, in writing, that you have obtained written informed consent but the written consent itself should be held by the authors/investigators themselves, for example in a patient's hospital record. The confirmatory letter may be uploaded with your submission as a separate file.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants.

2.7 Research data

The journal is committed to facilitating openness, transparency and reproducibility of research, and has the following research data sharing policy. For more information, including FAQs please visit the SAGE Research Data policy pages.

Subject to appropriate ethical and legal considerations, authors are encouraged to:

- share your research data in a relevant public data repository
- include a data availability statement linking to your data. If it is not possible to share your data, we encourage you to consider using the statement to explain why it cannot be shared.
- cite this data in your research

Back to top

3. Publishing Policies

3.1 Publication ethics

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

3.1.1 Plagiarism

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

3.1.2 Prior publication

If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the SAGE Author Gateway or if in doubt, contact the Editor at the address given below.

3.2 Contributor's publishing agreement

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

3.3 Open access and author archiving

Dementia offers offers optional open access publishing via the SAGE Choice programme. For more information on Open Access publishing options at SAGE please visit SAGE Open Access. For information on funding body compliance, and depositing your article in repositories, please visit SAGE's Author Archiving and Re-Use Guidelines and Publishing Policies.

Back to top

4. Preparing your manuscript for submission

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

4.2 Language

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

Please also consider how you are using abbreviations in your submission. Whilst QoL (for quality of life) and MMSE (for Mini-mental State Examination) may have common usage, please try to avoid unnecessary abbreviations in the submission of your manuscript, such as PWD (for people with dementia) and abbreviations that detract from the overall flow of the manuscript.

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

Useful websites to refer to for guidance

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

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

4.3 Artwork, figures and other graphics

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

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

4.4 Supplemental material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.5 Reference style

Dementia adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

Back to top

5. Submitting your manuscript

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

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

Book reviews must be submitted via the online system. If you would like to discuss your paper prior to submission, please email Sarah Campbell Sarah.Campbell@MMU.ac.uk

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

The collection of ORCID iDs from corresponding authors is now part of the submission process of this journal. If you already have an ORCID iD you will be asked to associate that to your submission during the online submission process. We also strongly encourage all co-authors to link their ORCID ID to their accounts in our online peer review platforms. It takes seconds to do: click the link when prompted, sign into your ORCID account and our systems are automatically updated. Your ORCID iD will become part of your accepted publication's metadata, making your work attributable to you and only you. Your ORCID iD is published with your article so that fellow researchers reading your work can link to your ORCID profile and from there link to your other publications.

If you do not already have an ORCID iD please follow this link to create one or visit our ORCID homepage to learn more.

5.2 Information required for completing your submission

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

Dementia requires authors to submit a short author biography. You will be asked to upload this as a seperate file.

5.3 Permissions

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

Back to top

6. On acceptance and publication

6.1 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the corresponding author via our editing portal SAGE Edit or by email, and corrections should be made directly or notified to us promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate.

6.2 Online First publication

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the SAGE Journals help page for more details, including how to cite Online First articles.

6.3 Access to your published article

SAGE provides authors with online access to their final article.

6.4 Promoting your article

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the Promote Your Article page on the Gateway for tips and advice.

Back to top

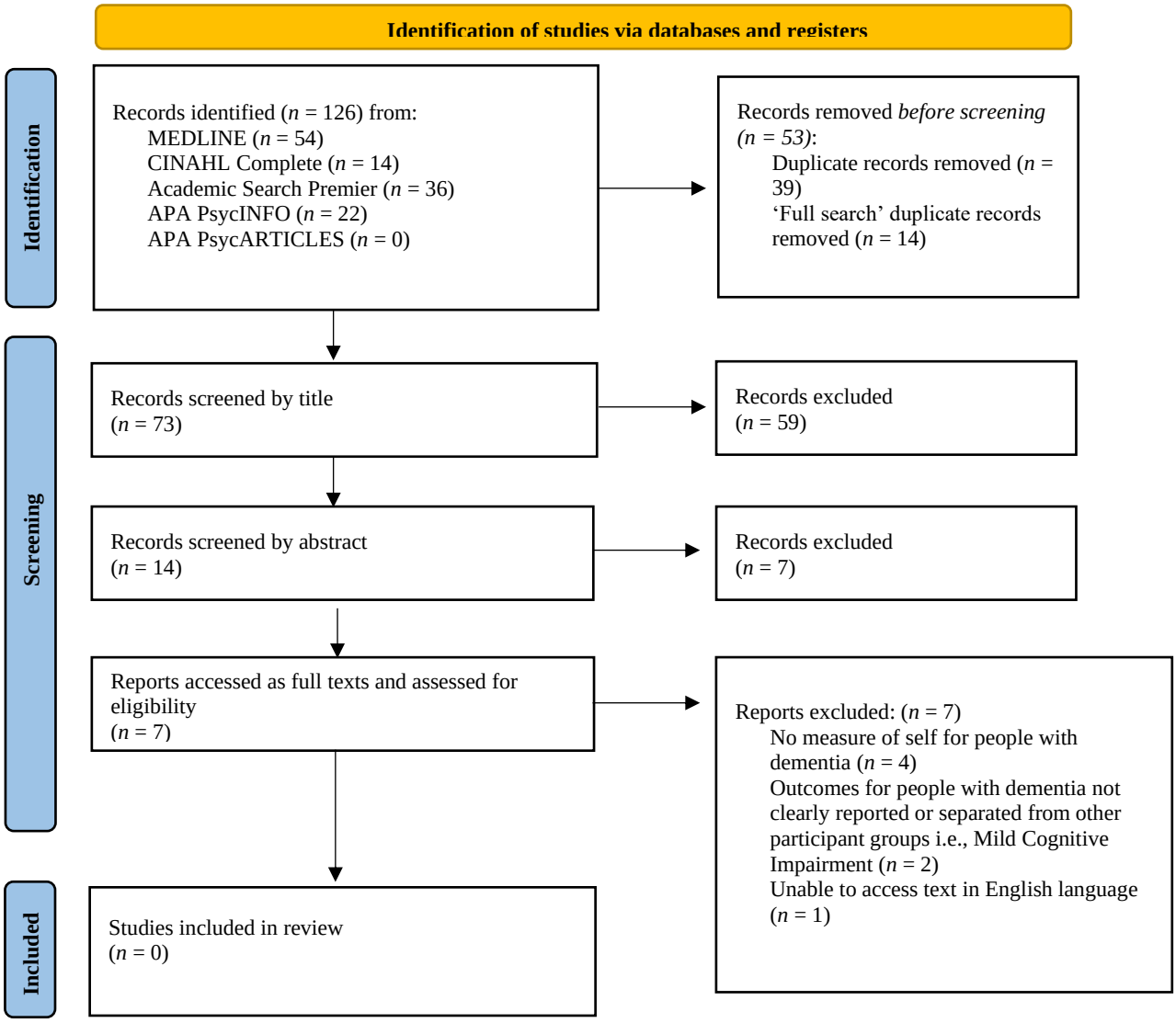
7. Further information

Any correspondence, queries or additional requests for information on the manuscript submission process should be sent to the Dementia editorial office as follows:

dem.pra@sagepub.com

Appendix D: Search terms and process for the additional literature search

The following databases on EBSCOHost were searched: Academic Search Premier, PsycINFO, PsycArticles, MEDLINE and CINAHL Complete. The search terms (dement * or alzheimer*) AND (TI (intervention* or treat* or program* or counsel* or therap* or activit* or group* or support* or workshop or course)) AND (self-management or self-growth) were used, alongside the same limiters used in the initial full search, to identify any papers that may have been missed. The search resulted in 73 studies after duplicates were removed and 66 studies were rejected by title and abstract screening. The remaining seven full texts were screened using the inclusion and exclusion criteria; however, all were excluded. The PRISMA (Page et al., 2021) flow diagram below outlines this process.



Appendix E: Reviewed studies that were excluded

	Study	Reason for exclusion
1	Amrani, L. E., Benard, C., Plourde, M., Giguere-Rancourt, A., Racine, E., & Simard, M. (2019). Cognitive rehabilitation of instrumental activities of daily living in Alzheimer's disease. *Alzheimer's Association International Conference*, 15(7), 1587-1587. https://doi.org/10.1016/j.jalz.2019.09.033	Presentation supplement only, unable to access a full text.
2	Blokland, M., Van Asch, I., Doornaar, M., Pot, A. M. (2015). Development and evaluation of a Dutch version of share: an intervention for community dwelling people with dementia and their caregivers. *International Psychogeriatrics*, 27(4), 113. https://doi.org/10.1017/S1041610215002161	Self-efficacy measured only for caregivers and only study poster was able to be accessed.
3	Buettner, L. L., & Fitzsimmons, S. (2009). Promoting health in early-stage dementia: evaluation of a 12-week course. *Journal of Gerontological Nursing*, 35(3), 39-49. https://doi.org/10.3928/00989134-20090301-02	Unclear whether all participants had a diagnosis of dementia due to 57 participants reported as 'unspecified/at risk of dementia'.
4	Charras, K., Mabire, J. B., Bouaziz, N., Deschamps, P., Froget, B., de Malherbe, A., Rosa, S., & Aquino, J. P. (2020). Dance intervention for people with dementia: Lessons learned from a small-sample crossover explorative study. *The Arts in Psychotherapy*, 70, Article 101676. https://doi.org/10.1016/j.aip.2020.101676	Task specific self scale – balance self-confidence
5	Choi, J., & Fiszdon, J. (2012). Self-efficacy for cognitive remediation in Alzheimer's disease. *Alzheimer's Association International Conference*, 8(4), 235-235. https://doi.org/10.1016/j.jalz.2012.05.623	Presentation supplement only, full article not available.
6	Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006). Utilization of self-identity roles for designing interventions for persons with dementia. The Journals of Gerontology Series B: *Psychological Sciences and Social Sciences*, 61(4), 202-212. https://doi.org/10.1093/geronb/61.4.P202	Self data that was analysed was not self-report for people living with dementia.
7	Cox, K. L., Flicker, L., Almeida, O. P., Xiao, J., Greenop, K. R., Hendriks, J., Phillips, M., & Lautenschlager, N. T. (2013). The FABS trial: a randomised control trial of the effects of a 6-month physical activity intervention on adherence and long-term physical activity and self-efficacy in older adults with memory complaints. *Preventive Medicine*, 57(6), 824-830. https://doi.org/10.1016/j.ypmed.2013.09.010	Task specific self scale (physical activity self-efficacy) and participants not people living with dementia.
8	Fane, M., Lysaker, P., Fiszdon, J., Twamley, E., Gooding, A., Baginski, C., & Choi, J. (2013). Cognitive behavioral therapy to enhance cognitive rehabilitation efficacy in Alzheimer's disease. *Alzheimer's Association*	Presentation supplement only, unable to access a full text.

	International Conference, 9(4), 495-495. https://doi.org/10.1016/j.jalz.2013.05.1019	
9	García-Alberca, J. M. (2017). Cognitive-behavioral treatment for depressed patients with Alzheimer's disease. An open trial. *Archives of Gerontology and Geriatrics*, 71, 1-8. https://doi.org/10.1016/j.archger.2017.02.008	No measure of self used.
10	Guseva, E. (2018). Bridging art therapy and neuroscience: Emotional expression and communication in an individual with late-stage Alzheimer's. *Art Therapy*, 35(3), 138-147. https://doi.org/10.1080/07421656.2018.1524260	Self scale not completed by people living with dementia.
11	Hamm, S., Sudres, J. L., Menouer, L., & Brandibas, G. (2019). Alzheimer's disease and singing: an application in mediated therapy. *Soins. Gerontologie*, 24(140), 15-19. https://doi.org/10.1016/j.sger.2019.09.004	Unable to access full article in English language.
12	Helcer, J., Santorelli, G., & Choi, J. (2012). Cognitive behavioral therapy to combat hopelessness and low self-efficacy in Alzheimer's disease. *Alzheimer's Association International Conference*, 8(4), 376-376. https://doi.org/10.1016/j.jalz.2012.05.1034	Presentation supplement only, unable to access a full text.
13	Kelly, M. E., Lawlor, B. A., Coen, R. F., Robertson, I. H., & Brennan, S. (2019). Cognitive rehabilitation for early stage Alzheimer's disease: a pilot study with an Irish population. *Irish Journal of Psychological Medicine*, 36(2), 105-119. https://doi.org/10.1017/ipm.2017.23	Task specific self scale – memory self-efficacy
14	Killen, A., Flynn, D., O'Brien, N., & Taylor, J. P. (2022). The feasibility and acceptability of a psychosocial intervention to support people with dementia with Lewy bodies and family care partners. *Dementia*, 21(1), 77-93. https://doi.org/10.1177/14713012211028501	Data for people living with dementia not clearly reported.
15	Lee, H., Kim, E., & Yoon, J. Y. (2022). Effects of a multimodal approach to food art therapy on people with mild cognitive impairment and mild dementia. *Psychogeriatrics*, 22(3), 360-372. https://doi.org/10.1111/psyg.12822	Data for people living with dementia not clearly separated from mild cognitive impairment participants.
16	Logsdon, R. G., Pike, K. C., McCurry, S. M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: outcomes from a randomized controlled clinical trial. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65(6), 691-697. https://doi.org/10.1093/geronb/gbq054	Data from people living with dementia not clearly separated from caregivers data.
17	Martinez, N., Stutzman, S. E., & Olson, D. M. (2021). Electronic interventions aimed at increasing self-worth in mild dementia may not be feasible. *Journal of the American Association of Nurse Practitioners*, 33(1), 5-10. https://doi.org/10.1097/JXX.0000000000000280	People living with dementia data not clearly separated from other participant groups.

18	Regan, K., White, F., Harvey, D., & Middleton, L. E. (2019). Effects of an exercise and mental activity program for people with dementia and their care partners. *Journal of Aging and Physical Activity,* 27(2), 276-283. https://doi.org/10.1123/japa.2017-0300	Data for people living with dementia not clearly separated from caregivers data.
19	Richeson, N. E., Boyne, S., & Brady, E. M. (2007). Education for older adults with early-stage dementia: Health promotion for the mind, body, and spirit. *Educational Gerontology*, 33(9), 723-736. https://doi.org/10.1080/03601270701364438	Data for people living with dementia not clearly separated from other participant groups (MCI).
20	Roberts, J. S., & Silverio, E. (2009). Evaluation of an education and support program for early-stage Alzheimer's disease. *Journal of Applied Gerontology,* 28(4), 419-435. https://doi.org/10.1177/0733464809333883	Data completed by people living with dementia not clearly reported.
21	Rymaszewska, J., Szczesniak, D., Urbanska, K., Brooker, D., Evans, S., Bray, J., Chattat, R., Farina, E., d'Arma, A., Saibene, F., Hendriks, I., Meiland, F., & Droes, R. M. (2018). Effectiveness of a psychosocial intervention in dementia: The meeting centre support programme for people with dementia and their carers in Poland, Italy and the UK. *European Psychiatry*, 48(1), 255-255. https://doi.org/ 10.1016/j.eurpsy.2017.12.016	Presentation supplement only, unable to access a full text.
22	Schall, A., Tesky, V. A., Adams, A. K., & Pantel, J. (2018). Art museum-based intervention to promote emotional well-being and improve quality of life in people with dementia: The ARTEMIS project. *Dementia*, 17(6), 728-743. https://doi.org/10.1177/1471301217730451	No measure of self used completed by people living with dementia.
23	Seifert, K., Spottke, A., & Fliessbach, K. (2017). Effects of sculpture based art therapy in dementia patients—A pilot study. *Heliyon*, 3(11), Article e00460. https://doi.org/10.1016/j.heliyon.2017.e00460	Unable to verify questionnaire as was custom designed.
24	Stockwell-Smith, G., Moyle, W., & Kellett, U. (2018). The impact of early psychosocial intervention on self-efficacy of care recipient/carer dyads living with early-stage dementia—A mixed-methods study. *Journal of Advanced Nursing*, 74(9), 2167-2180. https://doi.org/10.1111/jan.13710	Task specific measure of self - Symptom management and support service self-efficacy
25	Tabourne, C. E. (1995). The effects of a life review program on disorientation, social interaction and self-esteem of nursing home residents. *The International Journal of Aging and Human Development*, 41(3), 251-266. https://doi.org/10.2190/EG53-878E-MGRK-BCPP	Data for people living with dementia not clearly separated from other participant samples (depression with cognitive impairment).
26	Teti, A., M., Fiszdon, J. M., Taylor, B., Twamley, E. W., Pearlson, G. D., & Choi, J. (2018). Cognitive behavioural therapy to enhance memory training efficacy in people with dementia – 1 year follow up.	Presentation supplement only, unable to access a full text.

	Alzheimer's Association International Conference, 14(7), 285-285. https://doi.org/10.1016/j.jalz.2018.06.048	
27	Windle, G., Joling, K. J., Howson-Griffiths, T., Woods, B., Jones, C. H., Van de Ven, P. M., Newman, A., & Parkinson, C. (2018). The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: a mixed-methods longitudinal investigation. *International Psychogeriatrics*, 30(3), 409-423. https://doi.org/10.1017/S1041610217002162	Self scale not completed by people living with dementia.
27	Young, D. K. W. (2020). Multicomponent intervention combining a cognitive stimulation group and tai chi to reduce cognitive decline among community-dwelling older adults with probable dementia: A multi-center, randomized controlled trial. *Dementia*, 19(6), 2073-2089. https://doi.org/10.1177/1471301218814637	Excluded people with a diagnosis of dementia and was looking at reducing the risk of dementia.
Studies excluded from second database search:		
28	Ávila, A., De-Rosende-Celeiro, I., Torres, G., Vizcaíno, M., Peralbo, M., & Durán, M. (2018). Promoting functional independence in people with Alzheimer's disease: Outcomes of a home-based occupational therapy intervention in Spain. *Health & Social Care in the Community,* 26(5), 734-743. https://doi.org/10.1111/hsc.12594	No measure of self used for people living with dementia.
29	Beentjes, K. M., Neal, D. P., Kerkhof, Y. J., Broeder, C., Moeridjan, Z. D., Ettema, T. P., Pelkmans, W., Muller, M. M., Graff, M. J. L., & Dröes, R. M. (2020). Impact of the FindMyApps program on people with mild cognitive impairment or dementia and their caregivers; an exploratory pilot randomised controlled trial. *Disability and Rehabilitation: Assistive Technology,* 18(3), 253-265. https://doi.org/10.1080/17483107.2020.1842918	Data for people living with dementia not clearly separated from other participant sample (MCI).
30	Hirsch, C. (2013). A 12-month, in-home exercise program delayed functional deterioration in Alzheimer disease. *Annals of Internal Medicine,* 159(4). https://doi.org/10.7326/0003-4819-159-4-201308200-02010	No measure of self used for people living with dementia.
31	Hokkanen, L., Rantala, L., Remes, A. M., Härkönen, B., Viramo, P., & Winblad, I. (2008). Dance and movement therapeutic methods in management of dementia: a randomized, controlled study. *Journal of the American Geriatrics Society*, 56(4), 771-772. https://doi.org/10.1111/j.1532-5415.2008.01611.x	No measure of self used for people living with dementia.
32	Kerkhof, Y., Kohl, G., Veijer, M., Mangiaracina, F., Bergsma, A., Graff, M., & Dröes, R. M. (2022). Randomized controlled feasibility study of FindMyApps: first evaluation of a tablet-based intervention to promote self-management and meaningful activities in people with mild dementia. *Disability and Rehabilitation: Assistive Technology,*	Data for people living with dementia not clearly separated from other participant sample (MCI).

	17(1), 85-99. https://doi.org/10.1080/17483107.2020.1765420	
33	Lancioni, G. E., Singh, N. N., O'Reilly, M. F., Sigafoos, J., D'Amico, F., Laporta, D., Cattaneo, M. G., Scordamaglia, A., & Pinto, K. (2018). Technology-based behavioral interventions for daily activities and supported ambulation in people with Alzheimer's disease. *American Journal of Alzheimer's Disease & Other Dementias*, 33(5), 318-326. https://doi.org/10.1177/1533317518775038	No measure of self used for people living with dementia
34	Romero, B. (2004). Selbsterhaltungstherapie: Konzept, klinische Praxis und bisherige Ergebnisse [Self-Maintenance Therapy: Concept, Clinical Implementation, and Outcomes]. *Zeitschrift für Gerontopsychologie &-Psychiatrie,* 17(2), 119-134. https://doi.org/10.1024/1011-6877.17.2.119	Unable to access full article in English language

Appendix F: Mixed Method Appraisal Tool (Hong et al., 2018)

Category of study designs	**Methodological quality criteria**	**Responses**			
Screening questions (for all types)	S1. Are there clear research questions or aims?	Yes	No	Can't tell	Comments
	S2. Do the collected data allow to address the research questions?				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomised controlled trials	2.1. Is randomisation appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5. Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomised	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are the differences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Appendix G: Data extraction form

Study Characteristics	
Title of Paper	
Authors	
Year of Publication	
Country of Origin	
Study Aims	
Participant Characteristics	
Sample Size	
Age Range and Mean	
Gender	
Dementia Subtype	
Stage of dementia	
Method	
Study Design	
Intervention	
Measure of Self	
Key Findings	
Strengths/Limitations	

Appendix H: Quality ratings of the included studies

MMAT (Hong et al., 2018) criteria scores for included studies

Author and Year	Screening		Qualitative					Quantitative RCT					Quantitative Non-Randomised					Mixed Methods					Quality Score
	S1	S2	1.1	1.2	1.3	1.4	1.5	2.1	2.2	2.3	2.4	2.5	3.1	3.2	3.3	3.4	3.5	5.1	5.2	5.3	5.4	5.5	(%)
Berk et al. (2019)	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	Y	Y	Y	N	N	60
Brooker et al. (2018)	Y	Y	-	-	-	-	-	-	-	-	-	-	N	Y	N	Y	Y	-	-	-	-	-	60
Burgener et al. (2008)	Y	Y	-	-	-	-	-	CT	Y	N	CT	Y	-	-	-	-	-	-	-	-	-	-	40
Clare et al. (2019)*	Y	Y	-	-	-	-	-	Y	Y	Y	Y	Y	-	-	-	-	-	-	-	-	-	-	100
Collins et al. (2022)	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	Y	Y	N	N	N	N	Y	Y	Y	N	40
Cooke et al. (2010)	Y	Y	-	-	-	-	-	Y	Y	CT	Y	N	-	-	-	-	-	-	-	-	-	-	60
Craig et al. (2018)	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	Y	Y	N	N	N	N	N	N	Y	N	20
Dodd et al. (2022)	Y	Y	Y	Y	CT	N	N	-	-	-	-	-	N	Y	Y	N	Y	N	N	N	Y	N	20
Dröes et al. (2019)	Y	Y	-	-	-	-	-	Y	N	N	CT	CT	-	-	-	-	-	-	-	-	-	-	20
Fitzsimmons & Buettner (2003)	Y	Y	CT	CT	CT	N	N	-	-	-	-	-	Y	Y	N	CT	Y	CT	N	N	Y	N	0
Foloppe et al. (2018)	Y	Y	-	-	-	-	-	-	-	-	-	-	Y	Y	Y	CT	Y	-	-	-	-	-	80

Gonzalez et al. (2015)	Y	Y	-	-	-	-	-	-	-	-	-	-	Y	Y	CT	Y	Y	-	-	-	-	-	80
Hindle et al. (2018)	Y	Y	-	-	-	-	-	Y	Y	Y	Y	Y	-	-	-	-	-	-	-	-	-	-	100
Lee et al. (2008)	Y	Y	-	-	-	-	-	-	-	-	-	-	CT	Y	Y	CT	Y	-	-	-	-	-	60
Marshall et al. (2015)	Y	Y	-	-	-	-	-	CT	N	Y	Y	Y	-	-	-	-	-	-	-	-	-	-	60
Mountain et al. (2022)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	Y	N	N	Y	Y	60
Pérez-Sáez et al. (2018)	Y	Y	-	-	-	-	-	-	-	-	-	-	Y	Y	N	Y	Y	-	-	-	-	-	80
Platel et al. (2021)	Y	Y	-	-	-	-	-	-	-	-	-	-	N	Y	CT	Y	Y	-	-	-	-	-	60
Pongan et al. (2017)	Y	Y	-	-	-	-	-	CT	CT	N	Y	Y	-	-	-	-	-	-	-	-	-	-	40
Quinn et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	N	Y	Y	Y	Y	80
Richards et al. (2019)	N	CT	-	-	-	-	-	CT	Y	N	Y	CT	-	-	-	-	-	-	-	-	-	-	40
Sprange et al. (2015)	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	N	Y	N	N	Y	Y	Y	Y	N	N	40
Werheid et al. (2021)	N	CT	CT	CT	CT	N	CT	-	-	-	-	-	Y	Y	Y	N	Y	N	N	CT	Y	N	0
Young et al. (2014)	Y	Y	-	-	-	-	-	CT	Y	Y	Y	CT	-	-	-	-	-	-	-	-	-	-	60
*whilst this study was mixed methods, only rated as quantitative as the qualitative component was reported in a separate paper																							

Appendix I: Descriptive summary of the measures rating scales

Measure	Description
Dementia Quality of Life Instrument (DQoL; Brod et al., 1999)	The self-esteem subscale of the DQoL consists of four items scored on five-point rating scale (never to very often). Higher scores indicate greater self-esteem.
Rosenberg Self-esteem Scale (RSES; Rosenberg, 1965) and translated versions (Jeon, 1974; Leung & Wong, 2008; Martín-Albo et al., 2007; Vallières & Vallerand, 1990)	10 items scored on a four- or five-point scale (strongly agree to strongly disagree). Higher scores indicate greater self-esteem.
Generalised self-efficacy scale (GSES; Schwarzer & Jerusalem, 1995) and Chinese translated version (Schwarzer et al., 1997)	10 items measured on a four-point rating scale (not true at all to exactly true). Higher scores indicate greater self-efficacy.
Self-compassion scale short form (SCS-SF; Raes et al., 2011)	12 items scored on a five-point rating scale (almost never to almost always). Higher scores indicate greater self-compassion.
Personal Growth subscale of the Psychological Well-being scale (PWB; Ryff, 1989)	Seven items scored on a seven-point rating scale (strongly agree to strongly disagree). Higher scores indicate greater self-growth.
Self-acceptance subscale of the Psychological Well-Being scales (PWB; Ryff, 1989)	Seven items scored on a seven-point rating scale (strongly agree to strongly disagree). Higher scores indicate greater self-acceptance.
Self-management ability scale (SMAS; Schuurmans et al., 2005)	30-item measure with six subscales scored on five and six-point rating scales; never to very often, none to more than six, strongly disagree to strongly agree, and I'm certain that I can not to I'm certain that I can.
The IMAGE Test (Eustache et al., 2013)	24 self-descriptive items scored on a four-point rating scale (totally false to totally true) and the total score indicates overall sense of identity (generally positive or negative self-view).
The I-AM Test (Eustache et al., 2013)	Participants complete 10 statements beginning with "I am…". Scores are calculated based on the number of statements formed, the number of statements belonging to each category (idiocentric, small group, large group or allocentric) or subcategory (physical feature, personality trait or preference), number of categories and subcategories and emotional valence.

Appendix J: Submission guidelines for journal Aging and Mental Health

Instructions for Authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

AUTHOR SERVICES
Supporting Taylor & Francis authors

For general guidance on every stage of the publication process, please visit our Author Services website.

EDITING SERVICES
Supporting Taylor & Francis authors

For editing support, including translation and language polishing, explore our Editing Services website

Contents

- Publication Charges
- Copyright Options
- Complying with Funding Agencies
- My Authored Works

About the Journal

Aging & Mental Health is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Aging & Mental Health accepts the following types of article: Review, Original Article.

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 95% more citations* and over 7 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.

Please visit our Author Services website if you would like more information about our Open Select Program.

*Citations received up to 9th June 2021 for articles published in 2016-2020 in journals listed in Web of Science®. Data obtained on 9th June 2021, from Digital Science's Dimensions platform, available at https://app.dimensions.ai
**Usage in 2018-2020 for articles published in 2016-2020.

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. If you have shared an earlier version of your Author's Original Manuscript on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper.

A typical paper for this journal should be no more than 7,000 words for quantitative papers and 8,000 words for qualitative papers inclusive of

- figures
- tables
- references
- tables

Appendix excluded.

All revised papers could have extra 500 words allowance.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'.

Please note that long quotations should be indented without quotation marks.

All revised papers should have a clean version.

If there is more than one corresponding author, please unsubmit the paper and visit here.

If there is more than one first author, unsubmit the paper.

All papers should include a statement on ethical approval (with blinded affiliate information). All clinical trials must have been registered in a public repository and trial registration numbers should be included in the abstract, with full details in the methods section.

If the manuscript does not follow the required reference style, please unsubmit the paper and visit AMH reference format guideline.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact us here.

References

Please use this reference guide when preparing your paper. An EndNote output style is also available to assist you.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling

and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: What to Include

1. **Author details.** Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.
2. Should contain a structured abstract of 200 words.

   Objectives, Methods, Results, Conclusion.

3. **Graphical abstract** (optional). This is an image to give readers a clear idea of the content of your article. It should be a maximum width of 525 pixels. If your image is narrower than 525 pixels, please place it on a white background 525 pixels wide to ensure the dimensions are maintained. Save the graphical abstract as a .jpg, .png, or .tiff. Please do not embed it in the manuscript file but save it as a separate file, labelled GraphicalAbstract1.
4. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
5. Between 5 and 7 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
6. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   For single agency grants
   This work was supported by the [Funding Agency] under Grant [number xxxx].
   For multiple agency grants
   This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

7. **Disclosure statement.** This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare.* Further guidance on what is a conflict of interest and how to disclose it.
8. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
9. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, TIFF, or Microsoft Word (DOC or DOCX) files are acceptable for figures that have been drawn in Word. For information relating to other file types, please consult our Submission of electronic artwork document.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
13. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

Using Third-Party Material

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this

informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Clinical Trials Registry

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. However, for clinical trials that have not been registered prospectively, Taylor & Francis journals requires retrospective registration to ensure the transparent and complete dissemination of all clinical trial results which ultimately impact human health. Authors of retrospectively registered trials must be prepared to provide further information to the journal editorial office if requested. The clinical trial registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying With Ethics of Experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the Declaration of Helsinki. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this. In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed

guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on Research Ethics.

Consent

All authors are required to follow the ICMJE requirements and Taylor & Francis Editorial Policies on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is published. Authors should familiarise themselves with our policy on participant/patient privacy and informed consent. They may also use the Consent to Publish Form, which can be downloaded from the same Author Services page.

Health and Safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting Your Paper

This journal uses Routledge's Submission Portal to manage the submission process. The Submission Portal allows you to see your submissions across Routledge's journal portfolio in one place. To submit your manuscript please click here.

Please note that *Aging & Mental Health* uses Crossref™ to screen papers for unoriginal material. By submitting your paper to *Aging & Mental Health* you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer-reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication Charges

There are no submission fees, publication fees or page charges for this journal.

Colour figures will be reproduced in colour in your online article free of charge. If it is necessary for the figures to be reproduced in colour in the print version, a charge will apply.

Charges for colour figures in print are £300 per figure ($400 US Dollars; $500 Australian Dollars; €350). For more than 4 colour figures, figures 5 and above will be charged at £50 per figure ($75 US Dollars; $100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

Copyright Options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Complying with Funding Agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' open access policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Queries

Should you have any queries, please visit our Author Services website or contact us here.

Updated 5th of April 2023

Appendix K: Study advertisement poster

IRAS ID: 311460
V2.4 – 09.09.2022

UNIVERSITY OF HULL

NHS Humber Teaching

NHS Tees, Esk and Wear Valleys

Are you living with dementia?

I am looking for people living with dementia to take part in my research on self-compassion

Self-compassion is being kind and understanding towards ourselves

What would I have to do?

Complete a questionnaire asking questions about your experiences relating to self-compassion, wellbeing, depression and self-esteem.

If you are interested in taking part in this research please visit the website link or scan the QR code below to read the information sheet.

https://hull.onlinesurveys.ac.uk/scdementia

For more information or to request a paper version of the questionnaire please contact:
Jessica Baggaley:
Email: j.a.baggaley-2017@hull.ac.uk
Telephone: 07733081214
Planned end date of study is April 2023

Appendix L: Study information sheet

IRAS ID: 311460
V.1.7 – 09.09.2022

UNIVERSITY OF HULL | NHS Humber Teaching NHS Foundation Trust | NHS Tees, Esk and Wear Valleys NHS Foundation Trust

Full Information Sheet for Participants

Title of study: Measuring self-compassion in dementia

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being carried out and what taking part will involve. Please read the information carefully, you can talk about it with others if you wish.

If anything is not clear or you would like more information, please contact the researcher using the contact information below.

What is the purpose of the study?

Self-compassion is being kinder and less judgemental or critical towards ourselves, such as treating ourselves like we would treat other people that we care about.

The aim of this study is:

1. To understand whether a questionnaire can measure how much self-compassion someone might have whilst living with dementia.

2. To explore the relationship between self-compassion and wellbeing in dementia.

People that are kinder towards themselves (have more self-compassion) might be more likely to continue living well with dementia. A questionnaire could help to measure how much self-compassion someone has. This could help future research to explore self-compassion and help us to learn more about how people can be supported to live well with dementia.

Why have I been invited to take part?

You are being invited to take part because you have a diagnosis of dementia (this can be any type of dementia). To take part must be able to read and understand English.

Do I have to take part?

No. It is up to you if you wish to take part. By submitting your completed online questionnaire (or returning your completed paper questionnaire) you are consenting that you are happy to take part in the study. You can change your mind and stop the questionnaire at any time, up until you submit the questionnaire, without giving a reason. If you decide not to take part, your care and support will not be affected in any way.

What will I have to do?

You will complete a questionnaire asking you about your experiences related to:

- Self-compassion
- Wellbeing
- Depression
- Self-esteem

This questionnaire can be completed online (or if you would prefer, you may request a paper version to be posted to your address). You can complete the questionnaire by yourself, with help from others or with telephone support from the researcher which you can request via the telephone or email. The questionnaire will take between 15-30 minutes to complete. You do not have to complete the questionnaire in one sitting. You can complete the questionnaire over more than one session by pressing the 'finish later' button on the online questionnaire. The research stops once you have completed the questionnaire.

What are the possible risks of taking part?

The questionnaire will ask you to think about your wellbeing, mood, self-esteem, and self-compassion. If you feel that this may be upsetting you do not have to take part. If at any point when you are filling in the questionnaire you feel uncomfortable, you can close the questionnaire without submitting and your answers will not be saved. Once you have submitted your answers, we will not be able to remove them as all questionnaires are completed anonymously. If you feel that you need further support, please see the sources for support provided within the debrief sheet and at the end of the questionnaire.

This study has been reviewed and given a favourable opinion by the University of Hull Faculty of Health Sciences Ethics Committee and by an NHS Research and Ethics Committee.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for the people that take part, we hope that the information we get from this study might help to understand how people can be better supported to live well with dementia.

How will we use information about you?

We will need to use information from you for this research project. This information will include only the information that you provide within the questionnaire. We will not ask your name or address unless you request a paper copy of the questionnaire. The questionnaire data will not include your name or any other identifiable information therefore we will not know who has completed each data set as it will be anonymised.

We will keep all information about you safe and secure. The only people who will have access to your data will be the research team.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

The data will only be used for this study and will be safely stored for 10 years on secure network drives at the University of Hull. Your data will be processed in accordance with the UK-GDPR and the Data Protection Act 2018.

***If you complete a paper version of the questionnaire*:** your completed questionnaire will be scanned and saved onto the University of Hull approved secure storage service and the paper copies will be shredded.

What are your choices about how your information is used?

You can stop being part of the study at any time, up until you submit the questionnaire, without giving a reason.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

What will happen to the results of the study?

The results of the study will be written in a thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository (https://hydra.hull.ac.uk). The research will also be submitted

for publication in an academic journal or presented at conferences. You will not be personally identified in any report or publication. You will be able to 'opt in' to hear about the study results at the end of the questionnaire.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team
- by sending an email to dataprotection@hull.ac.uk, or
- by ringing the University of Hull's Data Protection Officer on 01482 466594

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the researcher using the following contact details:

Jessica Baggaley
Clinical Psychology, Aire Building
The University of Hull, Cottingham Road
Hull, HU6 7RX
Tel: 07733081214 / E-mail: j.a.baggaley-2017@hull.ac.uk

What if I have further questions, or if something goes wrong?

This research is sponsored by the University of Hull. If you wish to make a complaint about the study, you can contact the University of Hull using the details below for further advice and information:

Dr Emma Wolverson
Clinical Psychology, Aire Building
The University of Hull, Cottingham Road
Hull, HU6 7RX
Tel: 07809415107 / E-mail: E.Wolverson@hull.ac.uk

Alternatively, please contact coo@hull.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix M: Consent page and the set of measures

Consent

Please read these statements carefully and answer as appropriate. Your consent is required before you can take part in the study.

- I have read the study information.
- I understand what the study is about.
- I have had the opportunity to ask any questions.
- I understand that taking part is my choice and that I am free to stop at any point and just close the questionnaire.
- I agree to take part in this study

1. Please tick the box below if you agree with the statement

☐ I understand that by completing and submitting this questionnaire (or posting a paper copy) I am consenting to take part in the research

2. Are you:

- ○ Under 50 years old
- ○ 50-64 years old
- ○ 65 or over

3. What best describes your gender?

- ○ Male
- ○ Female
- ○ Prefer not to say
- ○ Prefer to self-describe

3.a. If you selected 'prefer to self-describe', please use this space:

4. If you know what subtype of dementia you were diagnosed with, please select it here.

- ☐ Alzheimer's
- ☐ Vascular Dementia
- ☐ Dementia with Lewy Bodies (DLB)
- ☐ Frontotemporal Dementia (FTD)
- ☐ Mixed Dementia
- ☐ Parkinson's Disease Dementia
- ☐ Not listed
- ☐ Not known

4.a. If you selected Not listed, please specify:

4.b. Please select how long it has been since you were first diagnosed.

- Less than 6 months
- 6 months - 1 year
- 1-5 years
- 5-10 years
- More than 10 years
- Not known

[Measures removed for publication]

9. Did you recieve any help to complete this questionnaire?

- ○ Yes
- ○ No

9.a. If you answered 'yes', please state what your relationship is to the person who helped you

10. **Optional: If you would like to receive a summary of the study findings in the future, please use this space to leave your email address before pressing 'finish'.** All email addresses will be stored in a separate password protected excel document on the secure storage service which only the researchers will be able to access. All email addresses will be immediately deleted after the summary of study results have been sent.

Appendix N: Study debrief sheet and sources for support

IRAS ID: 311460
V.1.3 - 17.02.2022

UNIVERSITY OF HULL | NHS Humber Teaching NHS Foundation Trust | NHS Tees, Esk and Wear Valleys NHS Foundation Trust

Debrief Information and Sources for Support for Participants

Thank you for taking part in this study.

Should you require any support before, during or after taking part in this research, please find below a list of possible contacts for support.

The Alzheimer's Society: offer support for people living with dementia, caregivers, and family	https://www.alzheimers.org.uk/ 0333 150 3456 (Dementia Connect support line)
Dementia UK: offer support and advice for people living with dementia. More information can be found at:	https://www.dementiauk.org/home/ 0800 888 66 78 Email: direct@dementiauk.org
Age UK	https://www.ageuk.org.uk/ 0800 169 2081
MIND: offer advice and support to anyone experiencing a mental health difficulty	0300 123 3393 Email: info@mind.org.uk
Samaritans: offer 24/7 free support for anyone wanting to talk about their worries	116 123 Email: jo@samaritans.org
You can also seek advice from your GP or local NHS mental health service	

If you would like any further information about the study, please contact the researcher whose details are given below.

Jessica Baggaley
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: 07733081214 Email: j.a.baggaley-2017@hull.ac.uk

Thank you for your time

Appendix O: Power analysis for correlations

Power analysis suggested that in order to achieve 80% power to find a correlation of 0.5, using a null of a 0.3 correlation, between the SCS-SF and the measures of well-being, self-esteem, and depression, a sample size of 139 would be needed. A null of 0.3 was chosen as correlations below this are considered a small effect size (Cohen, 1988) and therefore would not demonstrate convergent validity. An actual correlation of 0.5 was chosen as this aligned with the correlations found in existing literature (Hwang et al., 2016), and is commonly used as a cut off for convergent validity (Abma et al., 2016) as reflects a large effect (Cohen, 1988).

Power Analysis Table

				Test Assumptions		
	N	Actual Power[b]	Power	Null	Alternative	Sig.
Pearson Correlation[a]	139	.801	.8	.3	.5	.05

a. Two-sided test.

b. Based on Fisher's z-transformation and normal approximation with bias adjustment.

References

Abma, I. L., Rovers, M., & van der Wees, P. J. (2016). Appraising convergent validity of patient-reported outcome measures in systematic reviews: constructing hypotheses and interpreting outcomes. *BMC Research Notes,* 9(1), 1-5. https://doi.org/10.1186/s13104-016-2034-2

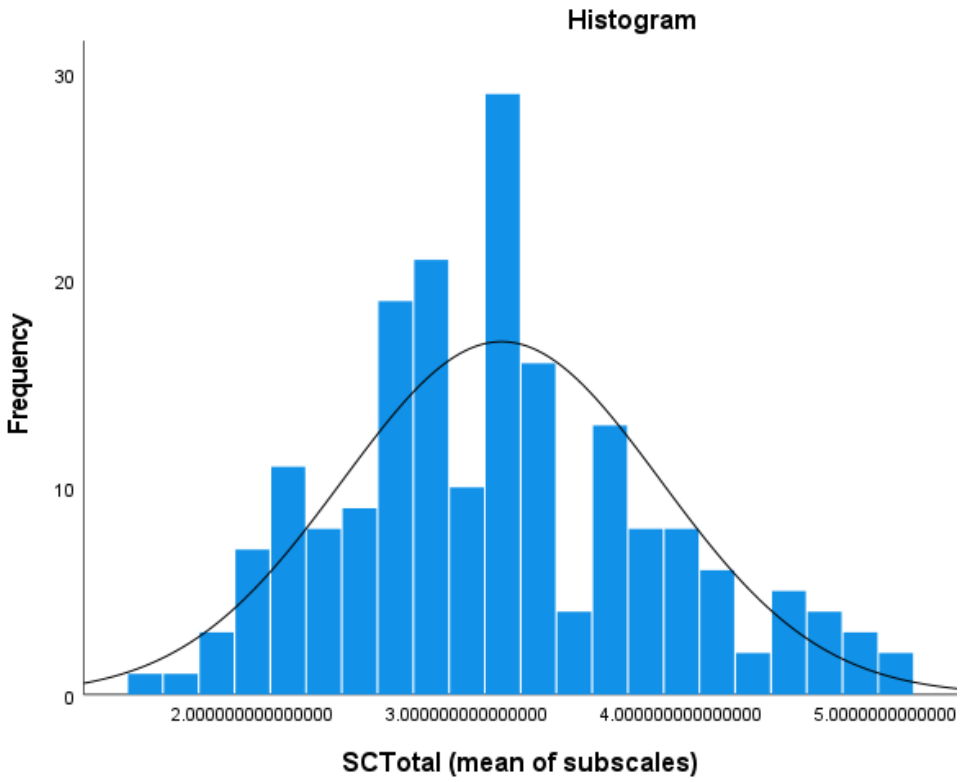
Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Science*s (2nd ed.). Lawrence Erlbaum Associates.

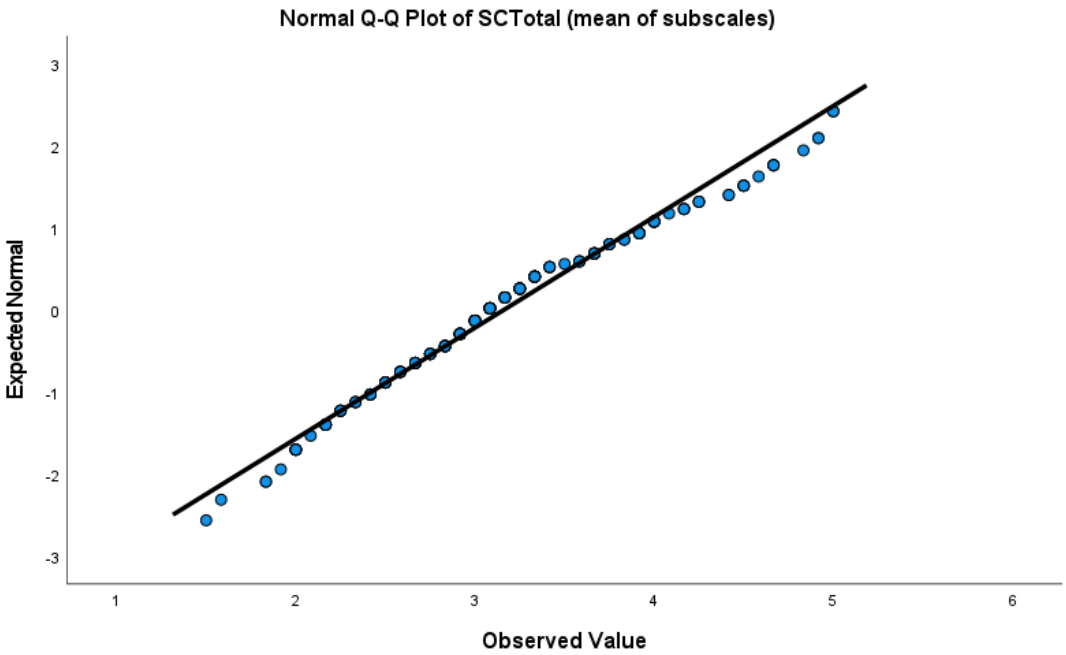
Hwang, S., Kim, G., Yang, J. W., & Yang, E. (2016). The moderating effects of age on the relationships of self-compassion, self-esteem, and mental health. *Japanese Psychological Research*, 58(2), 194-205. https://doi.org/10.1111/jpr.12109

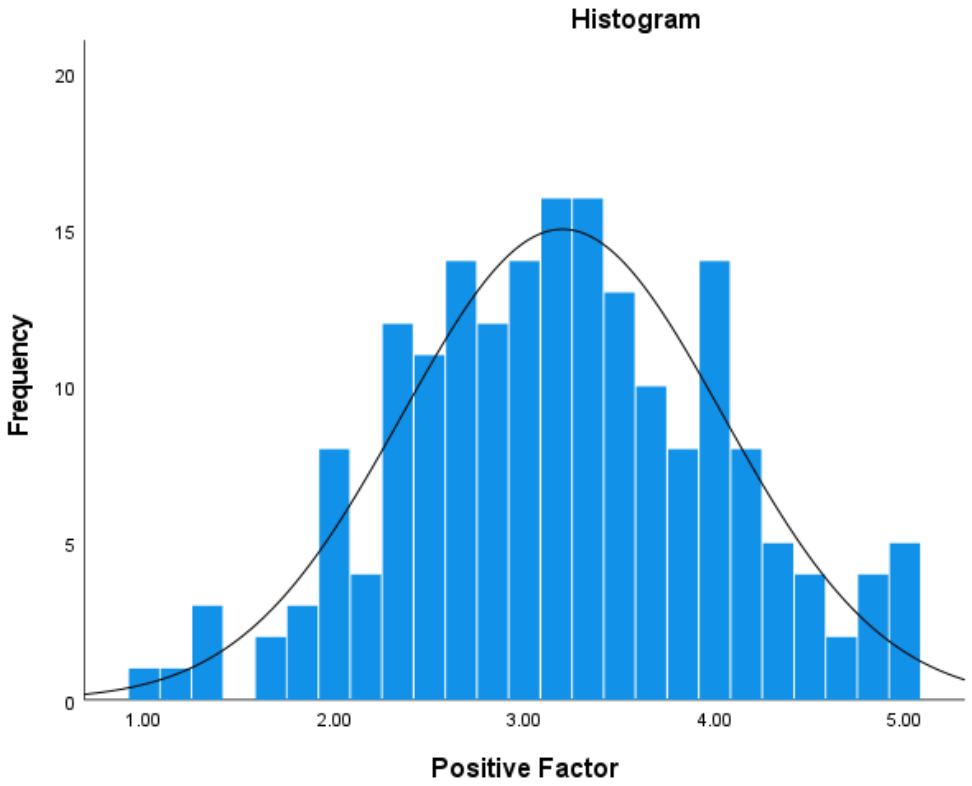
Appendix P: Ethics approvals – Removed for publication (University and HRA approvals)

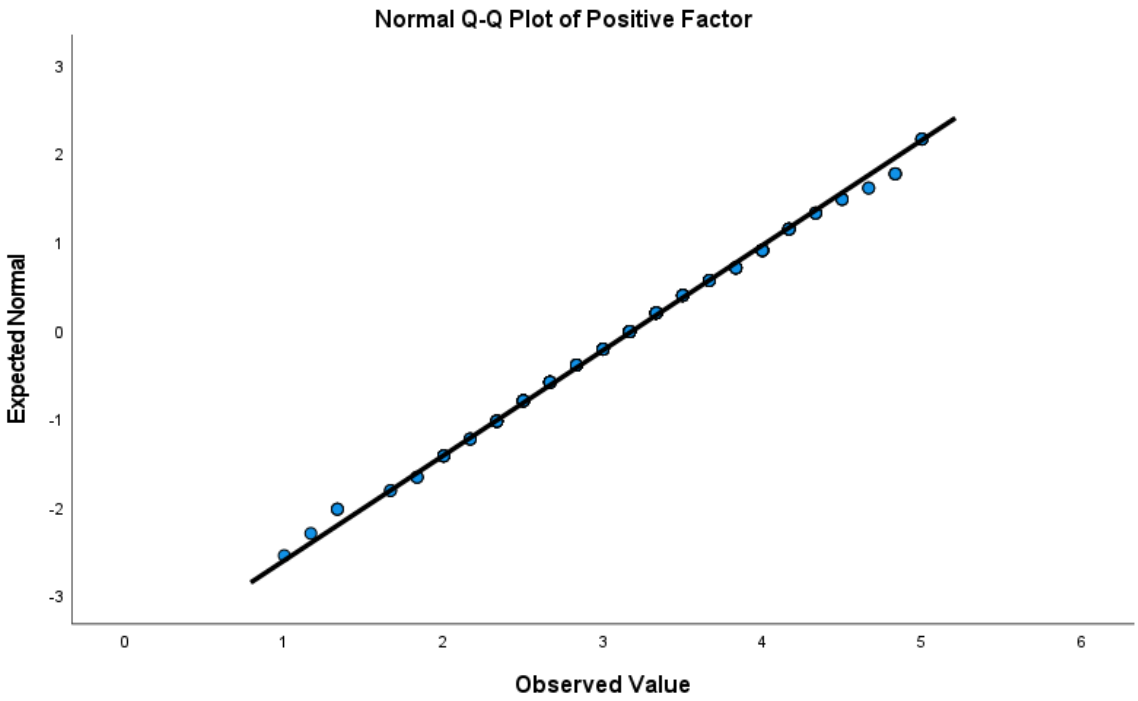
Appendix Q: Skew and kurtosis

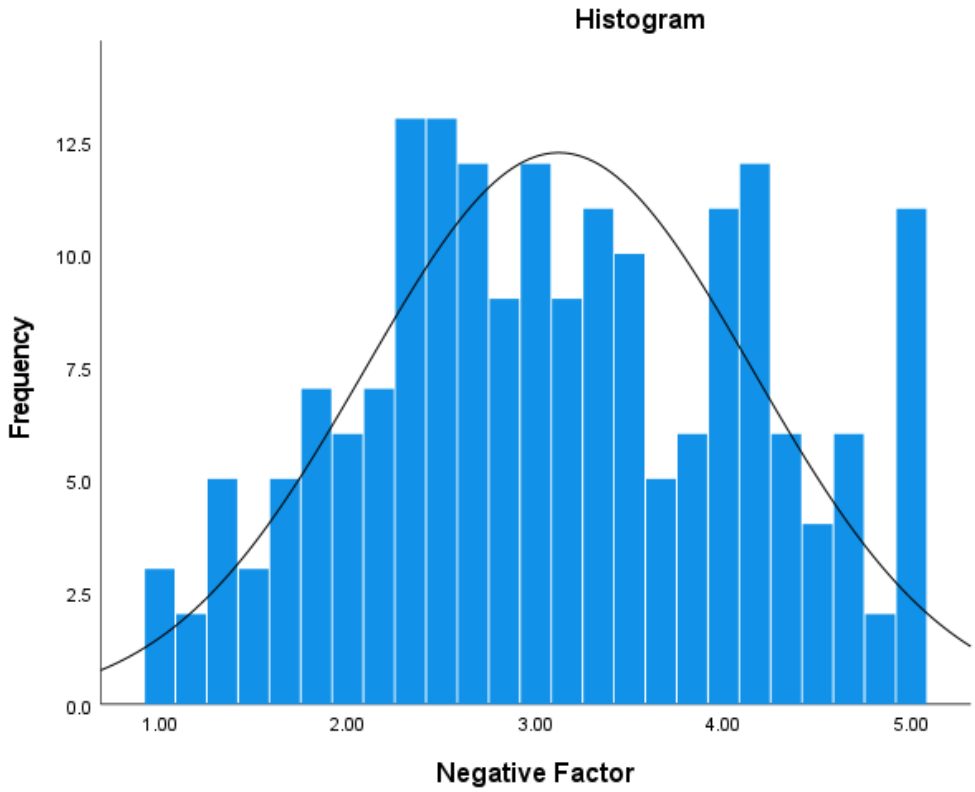
Measure/group	N	Skew (SE)	Kurtosis (SE)
SCS-SF Total	193	.403 (.176)	-.205(.351)
Positive factor	193	.006 (.176)	-.268 (.351)
Negative factor	193	.046 (.176)	-.805 (.351)
CASP-12 v2	191	-.231 (.176)	-.576 (.351)
RSES	193	-.049 (.176)	-.495 (.351)
GDS-15	192	.742 (.176)	-.483 (.351)
SCS-SF t-test groups			
Female	73	.200 (.281)	-.254 (.555)
Male	119	.511 (.222)	-.261 (.440)
50-65 years old	42	.978 (.365)	.720 (.717)
65 and over	150	.348 (.198)	-.105 (.394)
SCS-SF ANOVA groups			
6 months	19	.964 (.524)	1.344 (1.014)
6 months -1 year	31	.177 (.421)	2.100 (.821)
1-5 years	93	.310 (.250)	-.540 (.495)
5-10 years	41	.606 (.369)	-.690 (.724)
Over 10 years	8	.100 (.752)	-.508 (1.481)
Alzheimer's	108	.300 (.233)	-.310 (.461)
Vascular	20	.954 (.512)	.572 (.992)
Mixed	31	.358 (.421)	.022 (.821)
Other	29	.681 (.434)	.145 (.845)
Note. the normality of residuals were the same values as normality of participant data for the two ANOVAS; time since diagnosis and dementia subtype.			

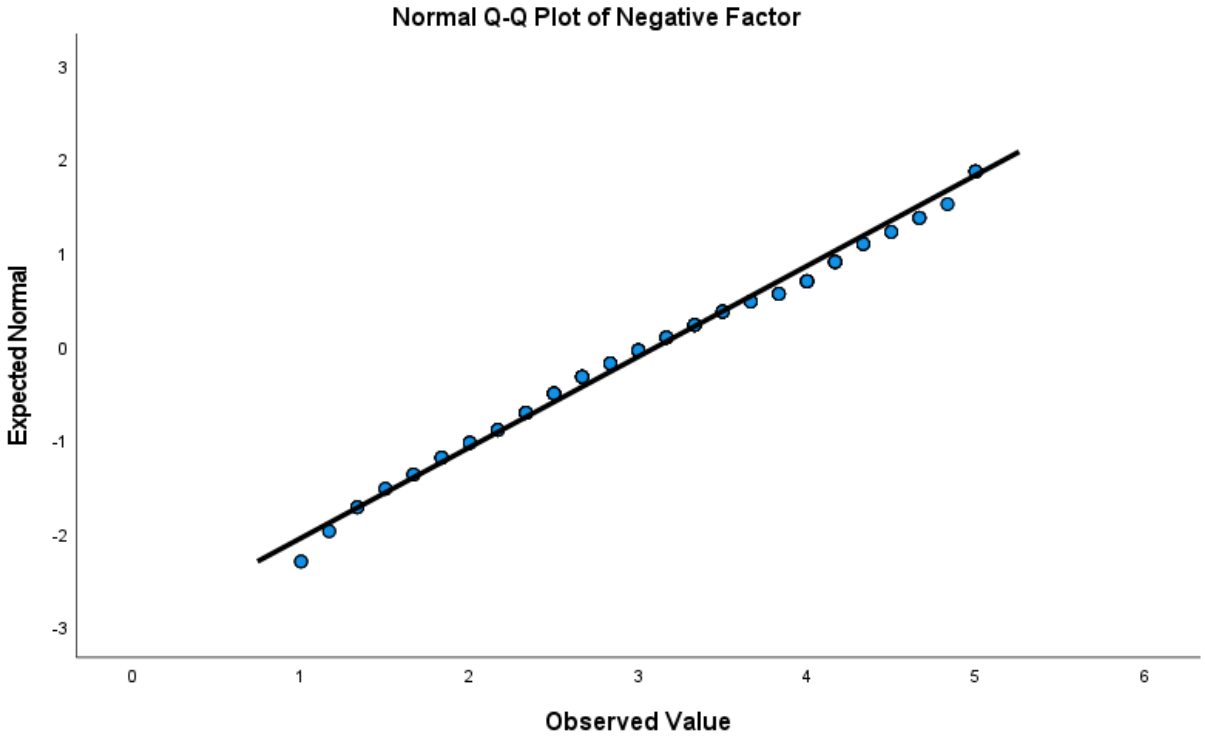

Histogram
Frequency
30
20
10
0
2.000000000000000
3.000000000000000
4.000000000000000
5.000000000000000
SCTotal (mean of subscales)


Normal Q-Q Plot of SCTotal (mean of subscales)
Expected Normal
3
2
1
0
-1
-2
-3
1
2
3
4
5
6
Observed Value

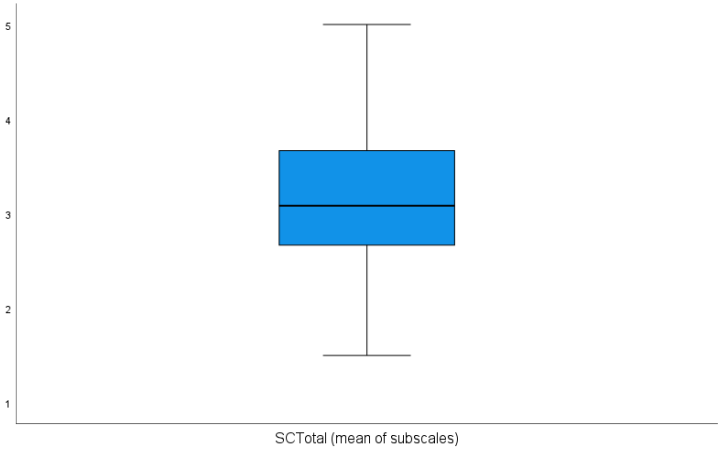

Histogram
Frequency
20
15
10
5
0
1.00
2.00
3.00
4.00
5.00
Positive Factor

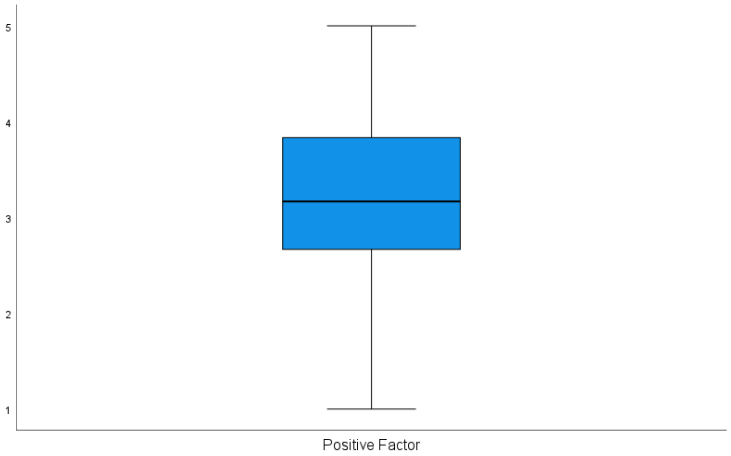

Normal Q-Q Plot of Positive Factor
Expected Normal
3
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value

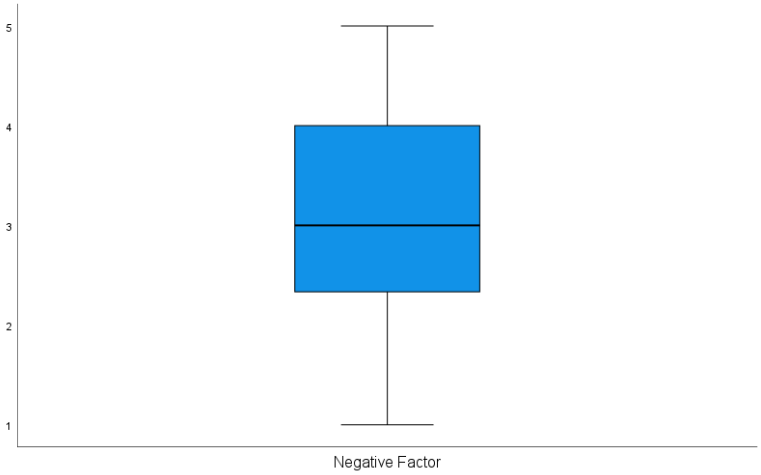

Histogram
Frequency
12.5
10.0
7.5
5.0
2.5
0.0
1.00
2.00
3.00
4.00
5.00
Negative Factor

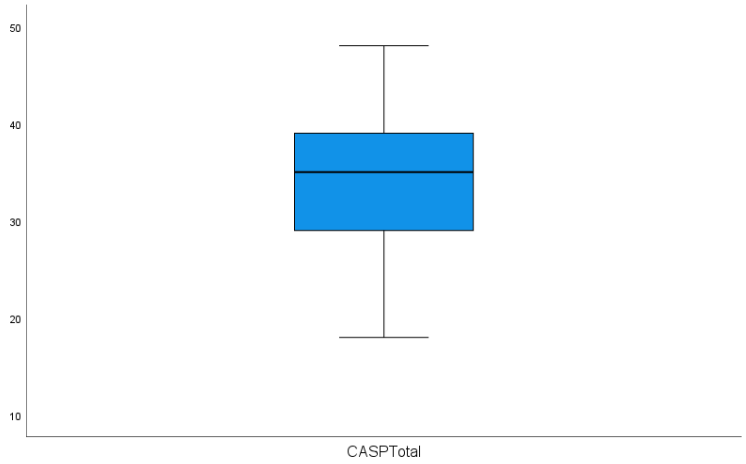

Normal Q-Q Plot of Negative Factor
Expected Normal
3
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value

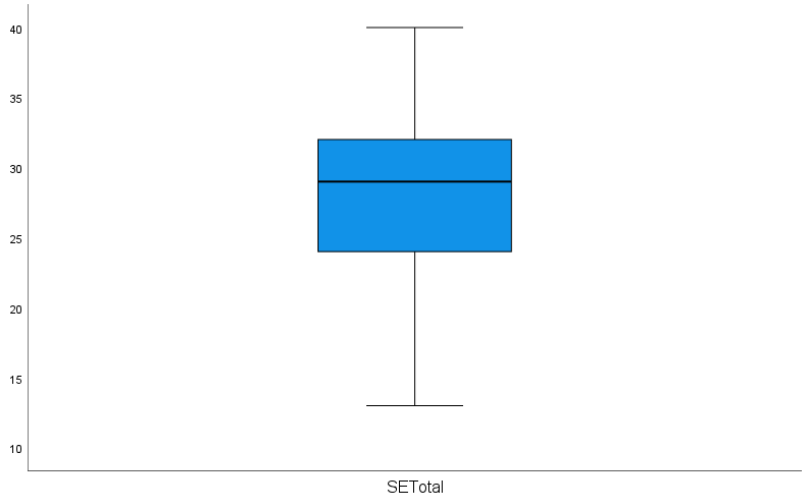
Appendix R: Box Plots

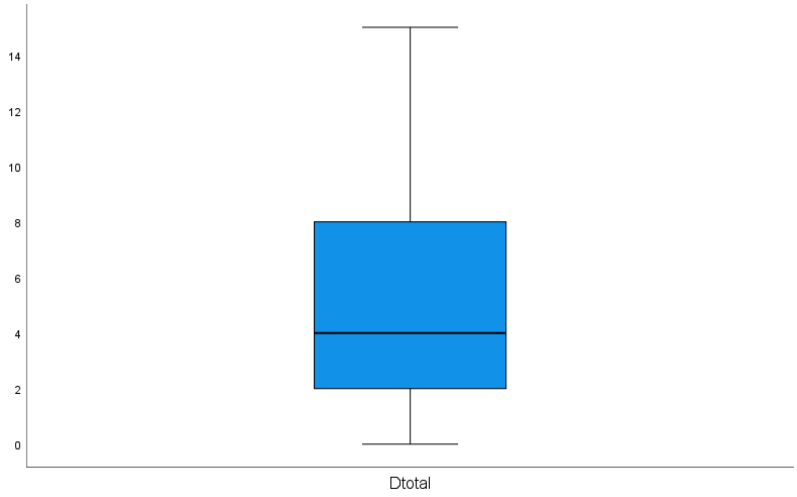







50
40
30
20
10
CASPTotal


40
35
30
25
20
15
10
SETotal


14
12
10
8
6
4
2
0
Dtotal

Appendix S: EFA correlation matrix

Correlation Matrix[a]

		SC1	SC2	SC3	SC4	SC5	SC6	SC7	SC8	SC9	SC10	SC11	SC12
Correlation	SC1	1.000	.039	.138	.417	.129	.404	.244	.459	.395	.134	.534	.437
	SC2	.039	1.000	.567	.099	.457	.319	.315	-.004	.029	.209	.010	.120
	SC3	.138	.567	1.000	.174	.504	.222	.474	.035	.117	.222	.072	.132
	SC4	.417	.099	.174	1.000	.014	.241	.143	.410	.418	.032	.525	.398
	SC5	.129	.457	.504	.014	1.000	.252	.332	.053	.059	.259	.021	.073
	SC6	.404	.319	.222	.241	.252	1.000	.261	.246	.233	.328	.320	.215
	SC7	.244	.315	.474	.143	.332	.261	1.000	-.017	.193	.224	.149	.207
	SC8	.459	-.004	.035	.410	.053	.246	-.017	1.000	.512	.003	.521	.427
	SC9	.395	.029	.117	.418	.059	.233	.193	.512	1.000	.052	.492	.433
	SC10	.134	.209	.222	.032	.259	.328	.224	.003	.052	1.000	.065	.005
	SC11	.534	.010	.072	.525	.021	.320	.149	.521	.492	.065	1.000	.616
	SC12	.437	.120	.132	.398	.073	.215	.207	.427	.433	.005	.616	1.000
Sig. (1-tailed)	SC1		.295	.028	<.001	.037	<.001	<.001	<.001	<.001	.032	<.001	<.001
	SC2	.295		.000	.085	.000	.000	.000	.477	.343	.002	.443	.048
	SC3	.028	.000		.008	.000	.001	.000	.314	.052	.001	.160	.033
	SC4	.000	.085	.008		.422	.000	.024	.000	.000	.332	.000	.000
	SC5	.037	.000	.000	.422		.000	.000	.232	.207	.000	.386	.158
	SC6	.000	.000	.001	.000	.000		.000	.000	.001	.000	.000	.001
	SC7	.000	.000	.000	.024	.000	.000		.406	.004	.001	.019	.002
	SC8	.000	.477	.314	.000	.232	.000	.406		.000	.484	.000	.000
	SC9	.000	.343	.052	.000	.207	.001	.004	.000		.238	.000	.000
	SC10	.032	.002	.001	.332	.000	.000	.001	.484	.238		.185	.472
	SC11	.000	.443	.160	.000	.386	.000	.019	.000	.000	.185		.000
	SC12	.000	.048	.033	.000	.158	.001	.002	.000	.000	.472	.000	

[a] Determinant = .022

Appendix T: EFA factor loadings and SPSS outputs for the three-factor model

EFA summary of the three-factor solution for the SCS-SF

Item	Rotated Factor Loadings (Pattern Coefficients)			Structure Coefficients		
	Factor 1	Factor 2	Factor 3	Factor 1	Factor 2	Factor 3
11. I'm disapproving and judgmental about my own flaws and inadequacies.	.815			.818		
12. I'm intolerant and impatient towards those aspects of my personality I don't like.	.693			.685		
8. When I fail at something that's important to me, I tend to feel alone in my failure.	.679			.672		
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	.652			.651		
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	.625			.626		
1. When I fail at something important to me I become consumed by feelings of inadequacy.	.598			.658		.392
3. When something painful happens I try to take a balanced view of the situation.		.922			.860	
2. I try to be understanding and patient towards those aspects of my personality I don't like.		.641			.672	.361
5. I try to see my failings as part of the human condition.		.564			.618	.378
7. When something upsets me I try to keep my emotions in balance.		.485			.539	.330
6. When I'm going through a very hard time, I give myself the caring and tenderness I need.			.679	.374	.352	.738

10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.			.423	.317	.466
Eigenvalues	3.82	2.35	1.012		
% of variance	31.9	19.6	8.43		
α	.839	.758	.493		

Note. *n*=193, only coefficients above 0.3 are shown

Communalities

	Initial	Extraction
SC1	.428	.488
SC2	.419	.459
SC3	.477	.758
SC4	.358	.396
SC5	.340	.397
SC6	.332	.582
SC7	.325	.313
SC8	.431	.459
SC9	.381	.426
SC10	.164	.237
SC11	.563	.673
SC12	.441	.480

Extraction Method: Principal Axis Factoring.

Total Variance Explained

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings[a]
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	3.823	31.857	31.857	3.325	27.705	27.705	3.052
2	2.350	19.581	51.438	1.852	15.437	43.141	2.185
3	1.012	8.430	59.868	.490	4.084	47.225	1.512
4	.784	6.536	66.404				
5	.684	5.701	72.105				
6	.656	5.466	77.571				
7	.611	5.091	82.661				
8	.569	4.738	87.399				
9	.447	3.722	91.121				
10	.390	3.250	94.371				
11	.358	2.986	97.357				
12	.317	2.643	100.000				

Extraction Method: Principal Axis Factoring.

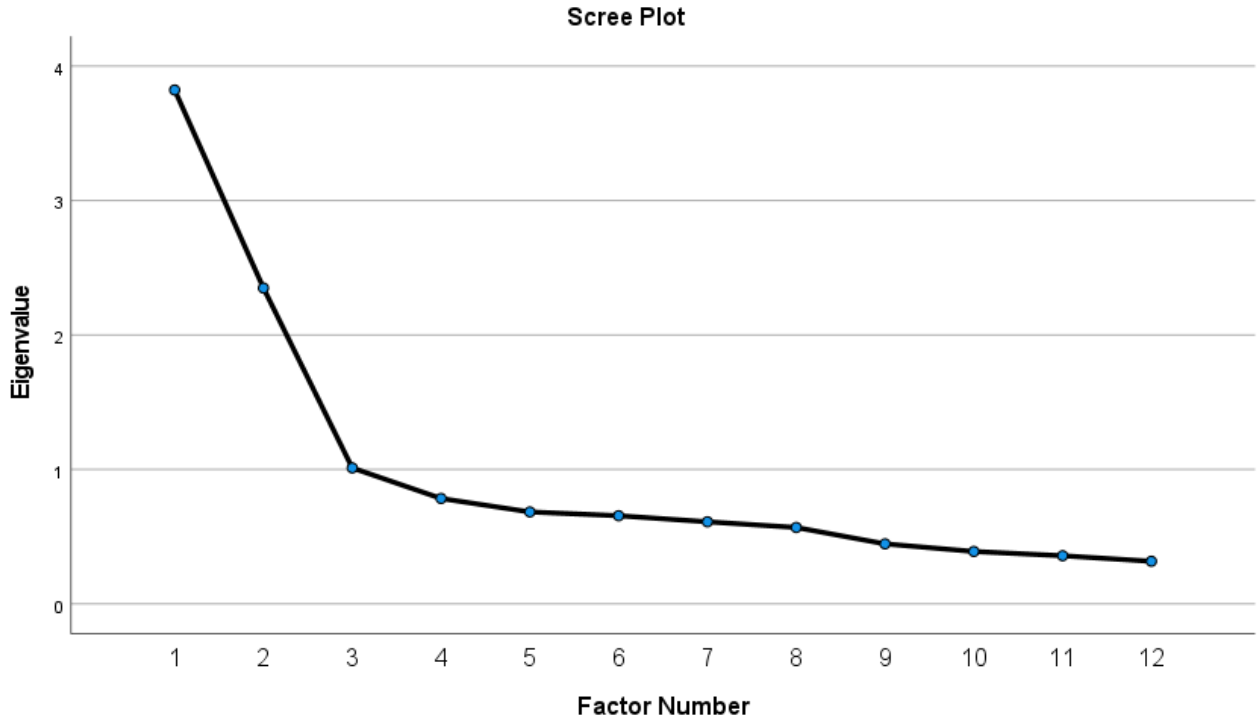
[a]. When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.

Anti-image Matrices

		SC1	SC2	SC3	SC4	SC5	SC6	SC7	SC8	SC9	SC10	SC11	SC12
Anti-image Covariance	SC1	.572	.079	-.007	-.075	-.036	-.147	-.087	-.108	-.014	-.021	-.088	-.063
	SC2	.079	.581	-.216	-.035	-.130	-.157	-.009	.013	.033	-.009	.043	-.072
	SC3	-.007	-.216	.523	-.075	-.165	.045	-.180	-.001	-.012	-.031	.011	.009
	SC4	-.075	-.035	-.075	.642	.078	-.012	.008	-.060	-.085	.026	-.132	-.017
	SC5	-.036	-.130	-.165	.078	.660	-.037	-.060	-.048	.007	-.086	.019	.006
	SC6	-.147	-.157	.045	-.012	-.037	.668	-.050	-.036	-.014	-.179	-.068	.044
	SC7	-.087	-.009	-.180	.008	-.060	-.050	.675	.137	-.089	-.057	-.002	-.063
	SC8	-.108	.013	-.001	-.060	-.048	-.036	.137	.569	-.181	.033	-.080	-.054
	SC9	-.014	.033	-.012	-.085	.007	-.014	-.089	-.181	.619	-.006	-.062	-.066
	SC10	-.021	-.009	-.031	.026	-.086	-.179	-.057	.033	-.006	.836	-.020	.054
	SC11	-.088	.043	.011	-.132	.019	-.068	-.002	-.080	-.062	-.020	.437	-.198
	SC12	-.063	-.072	.009	-.017	.006	.044	-.063	-.054	-.066	.054	-.198	.559
Anti-image Correlation	SC1	.869[a]	.137	-.013	-.124	-.058	-.237	-.140	-.190	-.024	-.031	-.176	-.111
	SC2	.137	.721[a]	-.393	-.057	-.209	-.252	-.015	.022	.055	-.013	.085	-.127
	SC3	-.013	-.393	.738[a]	-.130	-.281	.076	-.303	-.001	-.021	-.048	.023	.017
	SC4	-.124	-.057	-.130	.882[a]	.119	-.019	.012	-.100	-.135	.035	-.250	-.029
	SC5	-.058	-.209	-.281	.119	.810[a]	-.056	-.090	-.079	.011	-.116	.036	.009
	SC6	-.237	-.252	.076	-.019	-.056	.802[a]	-.075	-.058	-.022	-.239	-.125	.072
	SC7	-.140	-.015	-.303	.012	-.090	-.075	.778[a]	.221	-.137	-.076	-.004	-.102
	SC8	-.190	.022	-.001	-.100	-.079	-.058	.221	.832[a]	-.305	.048	-.160	-.095
	SC9	-.024	.055	-.021	-.135	.011	-.022	-.137	-.305	.875[a]	-.008	-.120	-.113
	SC10	-.031	-.013	-.048	.035	-.116	-.239	-.076	.048	-.008	.791[a]	-.033	.079
	SC11	-.176	.085	.023	-.250	.036	-.125	-.004	-.160	-.120	-.033	.833[a]	-.401
	SC12	-.111	-.127	.017	-.029	.009	.072	-.102	-.095	-.113	.079	-.401	.840[a]

[a]. Measures of Sampling Adequacy(MSA)

Appendix U: EFA scree plot



Appendix V: SPSS outputs for the EFA two factor solution

Anti-image Matrices

		SC1	SC2	SC3	SC4	SC5	SC6	SC7	SC8	SC9	SC10	SC11	SC12
Anti-image Covariance	SC1	.572	.079	-.007	-.075	-.036	-.147	-.087	-.108	-.014	-.021	-.088	-.063
	SC2	.079	.581	-.216	-.035	-.130	-.157	-.009	.013	.033	-.009	.043	-.072
	SC3	-.007	-.216	.523	-.075	-.165	.045	-.180	-.001	-.012	-.031	.011	.009
	SC4	-.075	-.035	-.075	.642	.078	-.012	.008	-.060	-.085	.026	-.132	-.017
	SC5	-.036	-.130	-.165	.078	.660	-.037	-.060	-.048	.007	-.086	.019	.006
	SC6	-.147	-.157	.045	-.012	-.037	.668	-.050	-.036	-.014	-.179	-.068	.044
	SC7	-.087	-.009	-.180	.008	-.060	-.050	.675	.137	-.089	-.057	-.002	-.063
	SC8	-.108	.013	-.001	-.060	-.048	-.036	.137	.569	-.181	.033	-.080	-.054
	SC9	-.014	.033	-.012	-.085	.007	-.014	-.089	-.181	.619	-.006	-.062	-.066
	SC10	-.021	-.009	-.031	.026	-.086	-.179	-.057	.033	-.006	.836	-.020	.054
	SC11	-.088	.043	.011	-.132	.019	-.068	-.002	-.080	-.062	-.020	.437	-.198
	SC12	-.063	-.072	.009	-.017	.006	.044	-.063	-.054	-.066	.054	-.198	.559
Anti-image Correlation	SC1	.869[a]	.137	-.013	-.124	-.058	-.237	-.140	-.190	-.024	-.031	-.176	-.111
	SC2	.137	.721[a]	-.393	-.057	-.209	-.252	-.015	.022	.055	-.013	.085	-.127
	SC3	-.013	-.393	.738[a]	-.130	-.281	.076	-.303	-.001	-.021	-.048	.023	.017
	SC4	-.124	-.057	-.130	.882[a]	.119	-.019	.012	-.100	-.135	.035	-.250	-.029
	SC5	-.058	-.209	-.281	.119	.810[a]	-.056	-.090	-.079	.011	-.116	.036	.009
	SC6	-.237	-.252	.076	-.019	-.056	.802[a]	-.075	-.058	-.022	-.239	-.125	.072
	SC7	-.140	-.015	-.303	.012	-.090	-.075	.778[a]	.221	-.137	-.076	-.004	-.102
	SC8	-.190	.022	-.001	-.100	-.079	-.058	.221	.832[a]	-.305	.048	-.160	-.095
	SC9	-.024	.055	-.021	-.135	.011	-.022	-.137	-.305	.875[a]	-.008	-.120	-.113
	SC10	-.031	-.013	-.048	.035	-.116	-.239	-.076	.048	-.008	.791[a]	-.033	.079
	SC11	-.176	.085	.023	-.250	.036	-.125	-.004	-.160	-.120	-.033	.833[a]	-.401
	SC12	-.111	-.127	.017	-.029	.009	.072	-.102	-.095	-.113	.079	-.401	.840[a]

[a]. Measures of Sampling Adequacy(MSA)

Communalities

	Initial	Extraction
SC1	.428	.464
SC2	.419	.478
SC3	.477	.583
SC4	.358	.385
SC5	.340	.419
SC6	.332	.291
SC7	.325	.322
SC8	.431	.462
SC9	.381	.419
SC10	.164	.139
SC11	.563	.678
SC12	.441	.449

Extraction Method: Principal Axis Factoring.

Total Variance Explained

	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings[a]
Factor	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	3.823	31.857	31.857	3.283	27.357	27.357	3.099
2	2.350	19.581	51.438	1.806	15.053	42.410	2.279
3	1.012	8.430	59.868				
4	.784	6.536	66.404				
5	.684	5.701	72.105				
6	.656	5.466	77.571				
7	.611	5.091	82.661				
8	.569	4.738	87.399				
9	.447	3.722	91.121				
10	.390	3.250	94.371				
11	.358	2.986	97.357				
12	.317	2.643	100.000				

Extraction Method: Principal Axis Factoring.

[a]. When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.