Adaptation and preliminary psychometric properties of three self-stigma outcome measures for people living with dementia

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Abstract

Background: A diagnosis of dementia presents individuals with both social and psychological challenges but research on self-stigma in dementia has been largely confined to qualitative approaches due to a lack of robust outcome measures that assess change. The Stigma Impact Scale is the most commonly used measure of self-stigma in dementia but its suitability as a tool to assess change in a diverse UK population is unclear. Thus, the aim of this study was to identify, adapt and evaluate the acceptability and psychometric properties of self-stigma measures for people with dementia for use as measures of change.

Method: A four-stage approach was used to identify, adapt and test self-stigma measures in a UK population who had received a diagnosis of dementia: 1) psychometric outcome measures were extracted based on the evidence base of an anti-stigma intervention that guided the current work, 2) identified measures were assessed for psychometric quality according to Terwee criteria, 3) modifications were made for culture (UK) and condition (dementia rather than mental health) through stakeholder consultations (researchers in fields of dementia and stigma; experts by experience in living with, or caring for persons with dementia), and 4) modified measures were pilot tested in a small sample of people living with dementia (N=40) for acceptability, and preliminary psychometric properties (internal consistency, test-retest, concurrent and convergent validity).

Results: Seven measures were identified but most were of low quality (Terwee range: 0-4). Three measures were considered and modifiable by stakeholders. Pilot testing indicated data were normally distributed. Almost all measures demonstrated acceptable internal consistency (except the Stigma Stress Scale total and internalized shame subscale), test retest reliability, concurrent validity and convergent validity, with some exceptions.

Conclusion: The Secrecy subscale, Stigma Impact Scale and Stigma Stress Scale were acceptable for use in a UK population of people living with dementia. However, further psychometric analysis is required before such measures can be implemented in psychosocial research.

Keywords: stigma, Alzheimer’s, cognition, outcomes, reliability, validity.
Background
Receiving a diagnosis of dementia presents individuals with both social and psychological challenges where stigma can be a pivotal and powerful negative force shaping people’s experiences (1). The recent World Alzheimer Report on Attitudes to Dementia concluded that people living with dementia are stigmatised across many different domains, such as social life, finances, housing, healthcare, intimate relationships, making or keeping friends and being treated unfairly by children or family (2).

Self-stigma and its impact
Self-stigma, also referred to as internalised stigma, is a cognitive process whereby an individual internalises negative stereotypes and prejudice related to their stigmatised identity (3). There is a well evidenced connection between mental health difficulties and the experience of self-stigma which in turn was associated with lower levels of empowerment, self-esteem, hope, self-efficacy, symptom severity, treatment adherence, social support and quality of life (4,5). Self-stigma has also been linked to negative consequences of concealing a diagnosis (e.g. anxiety and depression) and withdrawal from health services (4,6,7).

People with dementia have also been found to be at risk of self-stigma. A recent systematic review found self-stigma to be associated with anxiety and depression, personal control, self-esteem, social support and activity participation (8–10). More specifically, self-stigma has lasting negative consequences for people living with dementia such as withdrawing from everyday activities or interactions, delays in help-seeking, loss of confidence or feeling inferior (11–15).

Quantifying self-stigma
The measurement of self-stigma in mental health is complex, with a recent review of 57 empirical papers documenting five self-stigma outcome measures for people with a mental health diagnosis (16). Authors of the five self-stigma measures reported content validity, however no or little detail was given on other important psychometric properties including internal consistency and convergent validity. A further systematic review examining the efficacy of psychosocial self-stigma interventions for people with schizophrenia-spectrum diagnoses identified six self-stigma measures from 12 studies but, again, these measures were subject to limitations including no of sensitivity to change in seven randomised controlled trials (RCTs). Collectively, both systematic reviews concluded that further refinement of self-
stigma measures in line with reliability and validity criteria, careful cultural considerations and condition-specific adaptation with those who have lived experience of the condition are necessary avenues for future research (17–19).

**Rationale for study**

The intervention that informed present work, Honest, Open, Proud (HOP) is a group-based psychosocial intervention delivered over three sessions to help people with mental health difficulties consider disclosing stigmatised identities (e.g. a diagnosis of schizophrenia) across settings (20,21). HOP has recently undergone adaptation to support people living with dementia, however, there are currently no ‘gold standard’ outcome measures available to evaluate the effectiveness of psychosocial stigma reduction interventions in dementia, with previous studies criticised for not reporting psychometric properties of measures used or using non-standardised outcomes (10,22). As such, there is a need for standardised and psychometrically robust outcome measures developed specifically to evaluate self-stigma for people with dementia. The aim of the current study was to identify, modify and test the feasibility and psychometric properties of existing stigma instruments used in mental health research for use with people living with dementia.

**Methods**

**Stage 1: Review of HOP Outcome Measures**

A review of Honest Open Proud (HOP) intervention studies was conducted to identify instruments that have been previously used in peer reviewed journal articles up until December 2018. Instruments were only included if: the focus of the measure was self-stigma as defined by (23); the instrument had been used as an outcome measure in the evaluation of a HOP intervention; intervention studies were published in peer reviewed academic journals. Instruments were excluded if the focus of the measure was on constructs not applicable to dementia, for example symptomatic recovery.

**Stage 2: Measure Selection**

Measures were selected using a combination of psychometric quality and research team appraisal.

**Psychometric Quality Appraisal**
The instruments identified were appraised for psychometric quality using guidance by (24), which has been used in previous research to establish the quality of psychometric instruments (25–27). A focussed search for journal articles describing the development of each identified measure was conducted and each was appraised across seven domains: a) content validity, b) internal consistency, c) construct validity, d) reproducibility (in two parts: agreement and reliability), e) responsiveness, f) floor and ceiling effects and g) interpretability.

Any instrument could score a maximum of 2 per domain and a minimum of 0. Further details of scoring procedures are described in (25). Overall quality appraisal scores were calculated by summing the scores for each domain, with a potential score range between 0 and 18. Labels were assigned to interpret the quality of the instruments based on (25) where instruments that scored 0-4 were categorised as ‘poor’ quality, 5-9 as ‘moderate’ quality, 10-14 as ‘good’ quality, and 15-18 as ‘very good’ quality.

Research Team Appraisal

In addition to the quality appraisal criteria, two experts also appraised instruments, one an expert in stigma and disability (KS), the other an older adult’s expert with specialist knowledge in the measurement of psychological constructs (GC). Collectively, decisions were made to include instruments if all three of the following criteria were satisfied:

1. Instrument did not require significant changes to language that might invalidate previous psychometric findings (e.g. stereotypes and language used would be similar for a UK population);
2. The instrument was deemed acceptable and relevant for a person living with dementia;
3. The instrument could serve as a feasible outcome measure for an anti-stigma intervention for people living with dementia (“Who to tell, how and when?”)

Stage 3: Adaptation and Modification

Consultation with Experts

Research Experts. Five expert researchers in the field of dementia research (1- dementia prevention assessment and intervention, 2- behaviour change and intervention fidelity, 3 - positive psychological outcomes and psychometrics, 4 - mixed methods research understanding the impact of chronic health conditions, 5- psychological support for people living with dementia and family carers) were asked to review the instruments on an item by
item basis. The items were sent to each expert in a word document with instructions to indicate which items were relevant to people living with dementia based on their suitability and acceptability. Once all research experts indicated their views, they were collated in an excel spreadsheet.

*Lived Experience Experts.* A second expert group was made up of lived experience experts (people living with dementia and carers) involved in a patient and public involvement (PPI) capacity. PPI members were split into three sub-groups of approximately 2-3, with each group supported by one researcher. The instructions were to perform a card-sorting task where all items of the selected instruments were presented on strips of paper in no particular order and had to be sorted into two envelopes labelled “acceptable” and “not acceptable”. PPI members were informed that, in order for an item to be deemed acceptable, they must feel that it is understandable, relevant and that a person living with dementia would be able to answer the question. A round-robin technique was used to elicit thoughts and discussions on items from each member of the sub-groups. This methodology outlined by (28) allows for all group members to communicate a position rather than the acceptability of items being determined by a dominant personality. The card-sorting task was designed so that each item was reviewed at least twice by two different groups.

*Measure Modification Framework*

A measure modification framework (29) was used to incorporate modifications from consultation with two expert groups (Delbecq & VandeVen, 1971; Dening, Jones, & Sampson, 2012). In the event that expert groups had conflicting feedback about the instruments, discussions between authors were used to resolve this until a conclusion was reached. The Modification Framework described by (29)) increased the likelihood that adaptations to the psychometric measures would lead to items with comparable meanings, reliability and validity to that of the original measures. Three types of modifications were used based on the above expert consultation: (1) drop dimension (a dimension (subscale) is omitted), (2) drop items (items are removed from an existing scale and, (3) modify items (substituting a term or modifying wording without changing meaning).

**Stage 4: Pilot Testing**

**Participants**
Participants were included if they: (1) were an adult over the age of 18, and (2) had a primary progressive diagnosis of dementia. Participants were excluded if: (1) they had a chronic, terminal medical condition of which they were in the later stages, (2) they had a significant sensory impairment that could not be compensated for and precluded participation, and (3) they lacked capacity to consent to the study. Ethical approval for this research was granted by the University College London Research Ethics Committee (Project: 11501/002).

Participants were recruited via three avenues: (1) researchers contacted participants who declared an interest or were matched to the study criteria on the Join Dementia Research (JDR) database, (2) self-identification where participants had heard about the research and expressed an interest in taking part (e.g. via social media and advertisements placed in local community buildings and shops), and (3) through outreach activities carried out by the researchers such as attending dementia groups (e.g. Alzheimer’s Society localities).

Measures

Stigma Impact Scale (SIS). All 21 items were rated from 1 (‘strongly disagree’) to 4 (‘strongly agree’) with the addition of 0 for ‘not applicable’ items across four subscales, namely, social rejection (9 items, e.g. “I feel others avoid me because of my impairment”), internalised shame (5 items, e.g. “I feel others think I am to blame for my impairment”) and social isolation (7 items e.g. “I feel set apart from others who are well”). As per previous research, the financial insecurity subscale was excluded (31–33).

Rosenberg Self-Esteem Scale (RSES). This (34) consists of 10 items rated from 1 (‘strongly disagree’) to 4 (‘strongly agree’) measuring an individual’s beliefs and attitudes of themselves (e.g. “On the whole, I am satisfied with myself”).

Procedure

Potential participants were given a study information sheet and at least 24 hours to consider participating before consent was sought. Participation methods were either independently online or face-to-face data with the lead author assisted by three MSc students. Qualtrics (Qualtrics, Provo, UT) was used for online data collection, where a participant accessed the participant information sheet, screening questions, consent form and study measures through a survey link. During face-to-face data collection, these documents were presented to participants.
A subsample of participants were asked to complete the study instruments one to two weeks later (T2) in the same format in which they had completed them initially (T1).

**Analysis**

**Acceptability and Suitability.** Acceptability and suitability were ascertained using completion rates, time taken to complete T1 and floor and ceiling effects. This was due to the premise that a more acceptable and suitable instrument would yield high completion rates, have similar times of completion across measures and no floor or ceiling effects would be present. If 15% of participants achieved the highest or lowest possible scores, floor and ceiling effects were considered significant. Researchers who conducted home visits took field notes on their experience of completing the instruments to understand the acceptability and suitability of the instruments.

**Reliability**

**Internal consistency.** The internal consistency for each scale and subscales was assessed using Cronbach’s Alpha. A value for alpha ≥ 0.7 is considered acceptable (35)

**Test Retest.** Stability was assessed through an Intraclass Correlation Coefficient (ICC) analysis using a two-way random effect model. ICC figures ≥.70 or above indicate stability (24,36).

**Validity**

**Concurrent Validity.** A Pearson Product-Moment Correlation Coefficient (Person’s r) was used to assess concurrent validity against the SIS. A correlation of ≥.70 was considered an indication of good concurrent validity (24).

**Convergent Validity:** The RSES was used to assess convergent validity as self-esteem has been previously negatively correlated with stigma experience (e.g. application of self-stigma and secrecy). It was hypothesised that a low to moderate positive, correlation between self-stigma and self-esteem would be documented as per previous research (37). If at least 75% of the results are in accordance with this hypothesis, this demonstrates adequate convergent validity (24).

**Results**

**Stage 1: Review of HOP Outcome Measures**
Seven stigma instruments were identified from three HOP intervention studies: Perceived Devaluation Discrimination Questionnaire (38); Coming Out With Mental Illness Scale (39); Stigma Stress Scale (40); Self-Stigma Of Mental Illness Scale (41); Stigma Coping Orientation Scale (42); Internalised Stigma Of Mental Illness (43); Disclosure Related Distress Scale (44,45).

Stage 2: Measure Selection

Quality Appraisal

None of the identified measures reported information on reproducibility-agreement and responsiveness (see table 1). Internal consistency findings using Cronbach’s alpha (between >0.70 or < 0.95) in the absence of a factor analysis was reported for all measures apart from the SCOS. Criterion validity and floor and ceiling effecters were only reported for the ISMIS (43). Content validity was adequately reported only for the COMIS, SSMIS, ISMI and SIS with a clear description of the measurement aim, target population, concepts being measures, item selection. The SCOS did not report any target population involvement in item selection. Construct validity was adequately reported for the ISMI but not for the SSMIS and all other measures only partially met the criterion (as less than 75% of hypotheses were confirmed despite adequate design and methods). Information on reproducibility reliability was adequately reported for only the SSMIS and ISMI. Interpretability was adequately reported for the PDDQ and SCOS however, only partially reported for COMIS, SSS, ISMI and SIS (no definition of minimal important change or absence of at least four subgroups). No interpretability findings were reported for SCOS. It was not possible to appraise the psychometric quality of the Disclosure Related Distress Scale (DRDS, Mulfinger et al., 2018; Rüs et al., 2014) as the scale is an unvalidated measure previously used as a screening tool for HOP (Mulfinger et al., 2018). The DRDS was included for pilot testing to ascertain suitability and acceptability for people living with dementia rather than preliminary psychometric properties.

Expert Appraisal

The SSS, SSMIS and SIS met all expert appraisal criteria (see table 1). The PDDQ, ISMI, COMIS, SCOS would have required significant changes that would invalidate previous psychometric findings, such as mentions of symptomatic recovery throughout (‘going back to work after recovery’) and item stems across subscales that were not deemed relevant or acceptable for a UK population of people living with dementia (“I came out of the closet”); “I
1 stayed in the closet”; “I will come out of the closet”; “I stay in the closet”) and the lack of
transference of stereotypes from mental health to dementia. The COMIS was appraised as
being the only measure that would not be accessible and relevant for people living with
dementia. The COMIS, SCOS and ISMI were deemed unsuitable to serve as feasible
outcome measures for a disclosure decision-making intervention for people living with
dementia. This was because the COMIS dichotomised disclosure between ‘coming out’ and
‘staying in’ the closet rather than acknowledging the stages in-between (e.g. selective
disclosure). The SCOS had only one subscale containing relevant concepts to disclosure,
whilst the others were psychiatric treatment based.

Stage 3: Results of adaptation and modification

Lack of appropriate or relevant language for people living with dementia, cognitive burden of
completion and the inclusion of items around recovery were the main issues with the
identified measures. It was necessary to drop all dimensions on the SSMIS and four subscales
on the SCOS to leave only the secrecy subscale of the SCOS (SsSCOS). All dimensions on
the SIS and SSS were retained. Item removal was necessary for the SsSCOS where two items
were not relevant for people living with dementia “In order to get a job a former mental
patient will have to hide his or her history of hospitalisation” and “you believe that a person
who has recovered from mental illness earlier in life should not tell other people about it”.
Item removal was necessary for the DRDS where the second item of the scale referring to
employer/teacher disclosure was deemed irrelevant and removed. Consequently, the first item
was divided in two, where the first item asked about disclosure to friends and the second to
family. The DRDS items read as follows “In general how comfortable would you feel talking
to [item one: a friend; item two: a family member] about dementia, for example, telling them
you have a dementia diagnosis and how it affects you?”. Item modifications were made on
the SSS, SsSCOS and DRDS to remove “mental illness” references to “dementia”. In the
SSS, the term “prejudice” was replaced with “stigma” on the premise that prejudice and
stigma are interchangeable terms yet stigma is the most colloquially appropriate. For the SIS,
the term “dementia” was inserted into the instructions to be used interchangeably with
“impairment”. See table 2 for modification and adaptation summary.

Stage 4: Pilot Testing

Sample Characteristics
Forty-One people living with dementia met the eligibility criteria and provided informed consent to take part in this study. One participant who took part online was excluded due to large amounts of incomplete data. Eighteen participants took part online and 22 participants completed the study during face-to-face visits. Sample characteristics are summarised in Table 3. Three participants were unable to remember the nature of their diagnosis. The majority of participants were native English speakers of ‘white’ ethnic background with one participant declining to complete this question.

Acceptability and Suitability

The reported scores on the SSS, SIS and SsSCOS were normally distributed, with low levels of missing data. A Little’s Missing Completely At Random (MCAR) was non-significant for each measure \( (p = 1.00) \) indicating data were missing completely at random (MCAR) and therefore mean imputation at an item level was appropriate to deal with missing data \( (46,47) \).

Time taken was recorded for a small sample of face-to-face participants who took a mean of 43 minutes \( (n = 7) \) to complete the measures at T1. The time taken for completion ranged from 15- 60 minutes. No floor or ceiling effects were identified as the percentage of participants scoring the lowest or highest possible scores on an instrument was lower than 15%.

Field notes were collected during 14 of the 22 home visits carried out for face-to-face data collection. Three participants found the response categories of the SsSCOS challenging for items that were a double negative (item 1 and 4) but also because often the response was dependent on who the participant had in mind \( (e.g. \text{ item 7 of SsSCOS}) \). For items that required more thought, participants read aloud items as questions for themselves with each response category \( (e.g. \text{ Do I agree that [item wording]} \) or included the item in a sentence with response categories \( (e.g. \text{ I agree that [item wording]} \), to establish a level of agreement and disagreement and whether it was strong or not. The scales were presented in tables with items on each row and response categories on each column. One participant found it difficult to align the column and rows to tick the appropriate response box.

Two participants found the phrase ‘stigma against people living with dementia’ \( (\text{SSS}) \) confusing due to being unsure whether the item was referring to themselves as a person living with dementia, to others with dementia but not themselves, or to people living with dementia more generally. One participant found item 21 of the SIS \( (\text{“changes in my appearance have affected my social life”}) \) difficult to relate to dementia.
Reliability

The SIS (α = .906) and SsSCOS (α = .864) had acceptable internal consistency but the SSS (α = .643) did not. The Cronbach’s alpha values for all subscales were acceptable with the exception of the SIS subscale of internalised shame (α = .614) which fell below the cut-off for acceptability and the internal consistency was not improved through item removal. ICC agreement estimates and their 95% confidence intervals were calculated using data from 25 participants who completed both T1 and T2. Reliability of all measures between T1 and T2 was moderate (see table 4). Validity

The SSS total was positively correlated with the SIS, however, the correlation coefficient was below the necessary cut-off to demonstrate satisfactory concurrent validity SIS (r = .525, p < .001). The perceived harm subscale of the SSS and the SIS total were positively correlated but the ability to cope subscale of the SSS did not correlate with the SIS total. This may be because they quantify conceptually different components (ability to cope vs social and psychological impact of stigma). The perceived harm subscale of the SSS was positively correlated with the social rejection and social isolation subscales of the SIS but not the internalised shame subscale. The ability to cope subscale of the SSS did not significantly correlate with the SIS subscales of social rejection, internalised shame or social isolation. The SsSCOS and the SIS total (r = -.001, p > .05), social rejection and social isolation subscales were not significantly correlated. The SsSCOS was positively correlated with the internalised shame subscale of the SIS. In line with predictions, the overall SSS (r = -.475, p < .05) and SIS (r = -.587, p < .001), including all subscales with the exception of ability to cope subscale, were negatively correlated with the RSES. Correlations were within the predicted range of low-moderate with the exception of the perceived harm subscale. The SsSCOS (r = -.32, p > .05) did not correlate with the RSES, which was not in line with predictions or previous research.

Discussion

This is, to our knowledge, the first study to report the acceptability, suitability and psychometric properties of self-stigma measures for people living with dementia. The results of the small-scale pilot suggest that the subscales of the SSS, SsSCOS, and SIS are acceptable for use in a UK population of people living with dementia. All measures had moderate test-retest reliability, suggesting they may be suitable for use as outcomes measures (baseline versus follow-up), and all measures except the SSS total, and the internalised shame
subscale, had good internal consistency. Concurrent and convergent validity for measure
totals was found for the SSS but not the SsSCOS. The latter was not as predicted however, as
the SsSCOS was positively correlated with internalized shame.

Findings in the context of existing research

The link between the appraisal of stigma as harmful (perceived harm subscale of the SSS)
and social rejection and isolation was supported in the current study. However, the absence of
a correlation between perceived harm and internalised shame was not predicted as previous
mental health literature has found that internalised shame plays an integral role in shaping
stigma experiences (40,48). In addition, the SSS total and the ability to cope subscales did not
show correlations with internalised shame. It is possible that the formation of the SSS may
have contributed to this as the harm caused by stigma in dementia may affect one’s ability to
cope in a non-linear fashion, contrary to findings from mental health (40). Therefore the SSS
may not adequately measure the stigma stress appraisal process for people living with
dementia in the same way as in mental health. Further, the internal consistency of the SSS
was improved when the subscales were treated differently rather than as one overall score. As
the two subscales aim to operationalise conceptually opposite phenomena and no items were
identified as improving the overall internal consistency if removed, treating the subscales
separately may be more useful.

The SsSCOS only correlated with the internalised shame subscale of the SIS, which was not
as predicted but may indicate that an individual does not have to have had overt experiences
of stigma to experience negative consequences. To be more specific, secrecy may be
associated more with cognitive components of self-stigmatisation than the more social and
overt aspects (social rejection and isolation). Measuring levels of secrecy, therefore, may be a
way of operationalising internalised shame rather than measuring the appraisal of stigma
(SSS).

The current study found significant negative correlations between the SIS, all three subscales
and the RSES, whereas previous work was only able to find this for the internalised shame
subscale (37). The relationship between self-stigma and self-esteem is well documented in
mental health stigma research, but less so in dementia. The current study, therefore,
evidences the similarly important role of self-esteem in self-stigma for people living with
dementia
The internalised stigma of mental illness scale (ISMI) was excluded at the stakeholder consultation stage of the current study however it has been a popular measure for use in stigma reduction interventions for mental health (for a review see Wood et al., 2016). Although the ISMI had the highest quality rating of all identified measures, the content would have required significant changes for use in a population of people living with dementia. This speaks to the importance of acknowledging the nuances in the experience of self-stigma between clinical populations. With this in mind, the current study has begun to clarify the potential use of stigma measures in dementia, but efforts to establish specific frameworks (e.g. stress appraisal process in dementia) and theories should underpin the modification process as some measures may perform well in certain clinical populations and not others.

In line with recent guidance, the effectiveness of complex interventions, such as stigma reduction for people living with dementia, relies on robust design and development, along with feasible outcome measures to observe mechanisms of change (49,50). Self-stigma in dementia is under-defined and poorly operationalised ((51). The present study directly addresses this by developing outcomes measures that can be used in self-stigma research to evaluate interventions aimed at reducing stigma to address the lack of suitable outcome measures.

**Methodological problems and limitations**

The format of participation (online versus face-to-face) may have affected the results as participants may have been more likely to answer in a socially desirable manner if participation took place in person rather than online. In addition to this, four different researchers were involved in administering the instruments during face-to-face participation, potentially affecting inter-rater reliability. However, all researchers were trained in administration of the outcome measures and all had prior experience of working with people with dementia.

Although overall acceptability was satisfied, some participants felt that response categories were too absolute, where the answer would depend on whom the participant was thinking about at the time. For example, “how comfortable do you feel when talking to a friend about dementia?” depended on the “friend” in question, with some participants noting they had told some but not all of their “friends”. Thus, who the participant chose as the referent may have influenced the responses given. However, this feedback can be used to improve measures in the future.
The SIS was the only instrument available that had an existing evidence base for people living with dementia and was therefore used as the ‘gold standard’ measure to assess concurrent validity. However, the SIS may not truly offer a ‘gold standard’ measure as defined by (24). For this reason, concurrent validity of the SSS and SsSCOS should be interpreted with caution.

The current study has begun to address the criticisms of previous work, namely the lack of reporting on psychometric properties. However, as preliminary psychometrics here were based on a small sample size, further large-scale, quantitative studies are needed to confirm the psychometric properties of the SSS, SsSCOS and SIS.

**Future research**

As this study only provided tentative psychometric properties for three self-stigma measures, the next stage is to confirm these properties in a large-scale study and conduct further psychometric analysis to understand each measure’s sensitivity to change. Further, the various components of self-stigma and how they relate to each other and other mental and physical health concepts should be explored.

Currently, there are no models or frameworks to underpin the investigation of self-stigma in dementia, with little quantitative and qualitative work conceptualizing self-stigma. Work such as this should be established as it will form the basis of quantifying stigma experiences for people living with dementia.

Some participants were recruited through community groups (e.g. peer support) and others through the JDR database. Although the current study did not aim to quantify the experiences of people living with dementia, rather test the acceptability of doing so, it is important to note that those participants embedded in social groups that have shared experiences of dementia presented very different narratives regarding stigma and dementia to those not embedded in such groups. This may have a significant impact on wellbeing for people with dementia and the relationship between social connectedness, isolation and self-stigma which warrants further attention in future research.

**Conclusion**

Three self-stigma measures were identified and adapted using a robust four-stage process. The SsSCOS, SIS and SSS were acceptable for use in a UK population of people living with dementia. However, the psychometric properties were established on a small sample and
further psychometric analysis is required before such measures can be implemented in psychosocial research.

**Declarations**

**Ethics approval and consent to participate**

University College London Research Ethics Committee granted permission for this research to take place where all participants gave informed consent to take part.

**Consent for publication**

Not applicable

**Availability of data and materials**

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

**Competing interests**

The authors declare that they have no competing interests

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**Author’s contributions**

JB undertook data collection, data analysis and writing of the manuscript. CS commented on drafts of the manuscript, provided methodological support and second rated the psychometric quality of identified self-stigma measures. KS and GC designed the study in collaboration with JB, commented on drafts of the manuscript, and provided methodological and supervisory support. All authors read and approved the final manuscript

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