The psychometric properties of the Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19) for older adults with dementia.

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Abstract

Introduction: Asset based approaches to dementia research and measurement

emphasise the need to also assess the strengths and capabilities that people with

dementia retain, rather than assessing only losses or deficits. The CASP-19 proposes

wellbeing as the satisfaction of four 'needs' (control, autonomy, self-realisation and

pleasure). The CASP-19 may reflect the asses-based approach and has been validated

in over 20 countries. The aim of this study was to evaluate the CASP-19's

psychometric properties in older adults with dementia. Methods: An observational

study was conducted at five NHS trusts across England. Participants were asked to

either complete the CASP-19 by interview or self-report, alongside four other

measures to assess psychometric properties. Results: Internal consistency overall was

good (α =.856) but the autonomy subscale fell below the acceptable. The CASP-19

was significantly correlated in the expected direction with measures of quality of life

(r=.707), depression (r=-.707) and additional measures. It also remained moderately

stable over a one-week period but factor analyses indicated a 12-item measure may be

more robust. **Conclusions:** Despite some variations, the CASP-19 appears to have

adequate psychometric properties for older adults with dementia and can be used in

future research and practice.

Keywords: CASP-19, Psychometric, Dementia, Quality of Life, Reliability, Validity.

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Introduction

Whilst quality of life is now widely accepted as a central outcome for older adults with dementia, there are growing concerns that it may focus unduly on health (Smith, et al., 2005) without proper consideration of positive psychology principles.

The Control, Autonomy, Self-realisation and Pleasure (CASP-19) outcome measure builds on humanist psychology (Maslow, 1968), to emphasise wellbeing as the satisfaction of the four domains in its title. In this way, it assesses positive dimensions of ageing, which also helps to consider the increasing numbers of older adults who aim to pursue active and healthy lifestyles and many working beyond traditional retirement age (Institute for Economic Affairs, 2013).

Since its inception, the CASP-19 has been used successfully in older adults with a range of chronic conditions including insomnia (Abell, Shipley, Ferrie, Kivimäki, & Kumari, 2016), urinary incontinence (Adamczuk, et al., 2015), and those with a physical disability (Connolly, Garvey, & McKee, 2017). Furthermore, the CASP-19 has been used in over 20 countries and has been cross-culturally validated in places as diverse as Brazil (Lima, et al., 2014), Ethiopia (Hamren, Chungkham, & Hyde, 2015) and Spain (Pérez-Rojo, Martín, Noriega, & López, 2017).

More recently, there has been increased recognition of the role of positive psychology for people with dementia including a study on hope in early stage dementia (Wolverson, Clarke, & Moniz-Cook, 2010). A systematic review on positive outcome measures identified the CASP-19 as a well-developed, asset based measure that could

be of use for people with dementia (Stoner, Orrell, & Spector, 2015), although little is known of its psychometric properties for this population.

The aim of this study was to conduct and in-depth psychometric analysis for the CASP-19 in a sample of people with dementia to assess whether it is suitable for use in this population.

Methods

Design

Data for the current was collected as part of a larger, observational study on positive psychology measures at five NHS trusts across England. The study consisted of one baseline assessment and one re-test assessment within a one-week period on a subsample of participants. Participants either completed the assessments by interview or by self-report, depending on their preference.

Participants

Participants were primarily recruited through the Join Dementia Research (JDR) register, memory clinics, existing support groups and from previous research. The JDR is a joint initiative between the National Institute for Health Research (NIHR), Alzheimer Scotland, Alzheimer's Research UK and the Alzheimer's Society that enables people with dementia to sign up to a website to view and participate in research across the UK. Research assistants within each NHS trust identified individuals who were potentially eligible for inclusion if they had a formal diagnosis of dementia according to DSM-IV-TR criteria (American Psychiatric Association, 2000) and had the capacity to give informed consent.

Procedure

Research assistants and clinical support officers were responsible for identifying potential participants within their own NHS trust. Eligible participants were contacted to ascertain interest in the study and to establish capacity to give consent, via an informal capacity assessment. Informal capacity assessments were conducted in accordance to established guidelines (The British Psychological Society, 2010; Department of Health, 2005). All research staff were Good Clinical Practice (GCP) certified and had been trained in the Mental Capacity Act (2005). All participants were provided with a full information sheet, an abbreviated and accessible information sheet and a consent form prior to data collection. Following consent procedures, participants were asked their preference for manner of completion.

Participants were informed that the booklet could be sent to their address by post or email with a freepost return envelope, or that a research assistant could visit them at a place and time of their convenience to assist them with completion.

Measures

Participants were asked to provide demographic and clinical information consisting of age, sex, ethnicity, sub-type of dementia diagnosis, diagnosis date, co-morbid major physical or mental health conditions and current medication.

The Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19; Hyde, Wiggins, Higgs, & Blane, 2003)

The CASP-19 was developed in a sample of 286 people aged 65 – 75 years and is measured on a four-point Likert scale (0- never, 3 often). Possible scores range from 0

– 57 (mean 42.2), with higher scores reflect higher levels of wellbeing. Internal consistency across the subscales is acceptable (control: α = .59; autonomy: α = .65; pleasure: α = .74; self-realisation: α = .77) and factor analyses provided evidence for a second order, latent quality of life factor.

The Quality of Life in Alzheimer's Disease (QoL-AD; Logsdon, Gibbons, McCurry, & Teri, 1999).

The QoL-AD is a brief 13-item measure on a 4-point Likert scale, with scores ranging from 13 to 52. Higher scores indicate a better quality of life across domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. It has an acceptable reported level of internal consistency (0.77-0.84) and has demonstrated convergent validity with other quality of life and health related measures (Wolak-Thierry, et al., 2015). It was designed to be self-report and the scale can be completed even for those with more severe dementia (Thorgrimsen, et al., 2003).

The Geriatric Depression Scale Short Form (GDS-15; Yesavage, Brink, Rose, & Adey, 1983)

The GDS-15 is a 15-item measure with yes and no questions and designed to be self-administered, although questions may be read out if required. A score of 10 or higher indicates depression with a sensitivity/ specificity ratio of 84%/95% (Yesavage, Brink, Rose, & Adey, 1983). The GDS-15 has been validated for people with dementia (Lesher & Berryhill, 1994) and is sensitive to change in older adults (Vinkers, Gussekloo, Stek, Westendorp, & van der Mast, 2004).

The Engagement and Independence in Dementia Questionnaire (EID-Q; Stoner, Orrell, Long, Csipke, & Spector, 2017)

The EID-Q assesses the degree to which a person with dementia feels independent and is engaged socially with those around them. It is measured on a five-point Likert scale (0- not true at all, 4- true nearly all the time) and was developed in a sample of older adults with dementia. The EID-Q (Stoner, 2017) has excellent internal consistency (α =.91) and established correlations with the QoL-AD (r = .68) and the GDS-15 (r = -.74).

The Positive Psychology Outcome Measure (PPOM; Stoner, Orrell, Long, Csipke, & Spector, 2017)

The PPOM assesses hope and resilience for people with dementia and consists of an adapted version of the Herth Hope Index (Herth, 1992) and a resilience scale developed in a qualitative study of older adults with dementia. It is measured on a five-point Likert scale (0- not true at all, 4- true nearly all the time), has excellent internal consistency (α = .94) and established convergent validity with quality of life and depression (Stoner, 2017).

Analysis

Previous studies of the CASP-19 have suggested dealing with missing data by mean imputation at the 10% level (Kim, et al., 2015). Therefore, if a case had two or less instances of missing data, the mean of remaining items was imputed within the current study. Following this, multiple imputation (Rubin, 1987) was applied at a measure level using 20 imputations as 'possible' alternatives. Floor and ceiling effects were examined using visual inspections of histograms. If less than 15% of

respondents achieved the highest or lowest possible sores, ceiling and floor effects were not considered significant (Terwee, et al., 2007). Stability of the measures was assessed using intraclass correlation coefficient (ICC) between baseline and re-test. The CASP-19 was also assessed for internal consistency using a Cronbach alpha analysis at a subscale and measure level.

To assess the convergent validity of the CASP-19 a Pearson's r correlation was conducted between the CASP-19 and PPOM, EID-Q and GDS-15. It was a hypothesised that a positive correlation would be observed between the CASP-19 and the PPOM and EID-Q and a negative correlation would be observed between the CASP-19 and the GDS-15. Concurrent validity of the CASP-19 was established through an additional Pearson's r correlation analysis of the relationship between the measure and the Quality of Life in Alzheimer's Disease (QoL-AD). As both are proposed to measure quality of life, a positive correlation was hypothesised.

To further evidence the content validity of the CASP-19, an exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) was undertaken. Consistent with the original study, it was hypothesised that one second order 'quality of life' latent factor would emerge. To accomplish this, data was randomly halved and imported into MPlus and an EFA was run. Factors were then extracted using Kaiser's criterion (Kaiser, 1960). Following this, the remaining random half of the data was imported into MPlus and the factor structure identified within the EFA was applied as confirmatory within the CFA. To test the fit of this factor structure, a number of fit indices were used including chi-squared statistics, comparative fit index (CFI), standardised room mean square residuals (SRMR) and root mean square error of

approximation (RMSEA). Following completion of the CFA, all data was integrated and the CFA was performed again to ensure the measurement model proposed was a good fit for all the data. Finally, models were compared with other established factor solutions (Vanhoutte, 2012; Wiggins et al., 2008).

Results

Participants

Participants consisted of 129 (57.3%) men and 96 (42.7%) women (n=225) with an average age of 77.1 (SD = 9.4). Demographic and clinical information can be found in Tables 1 and 2.

[Insert Table 1 around here]

Clinically, a large proportion had diagnosed with Alzheimer's disease or dementia of mixed aetiology. Sixteen participants were not aware as to their specific sub-type diagnosis. Reasons for non-disclosure were variable with some participants indicating that they had not been informed as to the specific type, could not remember the sub-type and information being unavailable at respective research sites (Table 2).

[Insert Table 2 around here]

To ensure that the subsample of participants who consented to be retested were representative of the sample in full, a series of independent samples t-tests were conducted for each of the demographic variables. None were significant, indicating the subsample was representative of the sample in full.

Floor and Ceiling Effects.

Inspection of a histogram suggested that the CASP-19 followed a relatively normal distribution, with a very slight negative skew. The possible range of the CASP-19 was 0 - 57 and the observed range was 15 - 57. Mean scores were 40.57 with a standard deviation of 9.08 and did not differ according to whether participants completed the study by self-report or by interview. No participants scored zero, whilst only two participants achieved the highest possible score of 57, indicating floor and ceiling effects were not significant (Figure 1).

[Insert Figure 1 here]

Internal Consistency

The internal consistency of the CASP-19 was α =.856, which was considered adequate. The control subscale alpha was α =.645, the autonomy subscale was α =.505, the pleasure subscale was α =.718 and the self-realisation subscale had an internal consistency of α =.781. The subscale alphas were comparable to those originally reported for the CASP-19 (control: α = 0.59, autonomy: α = 0.65, pleasure: α = 0.74 and self-realisation: α = 0.77), with the exception of the autonomy subscale. However, items six and nine within this subscale were identified as only very marginally improving the consistency of the measure if removed ('family responsibilities prevent me from doing what I want to do': α =.859 and 'shortage of money stops me from doing the things I want to do': α =.863).

Test-retest reliability

Using a subsample of 48 participants, the CASP-19 showed good consistency within a one-week period (ICC=.859; 95%CI = .760 - .919) The control subscale demonstrated moderate consistency (ICC= .682; 95%CI = .495 - .809) as did the autonomy subscale (ICC= .703; 95%CI= .524 - .822). The pleasure subscale also demonstrated moderate consistency, although this was lower than both the autonomy and control subscales (ICC= .616; 95%CI= .401– 767). Self-realisation scores between baseline and retest were again moderately stable (ICC=.74; 95%CI = .578 - .846).

Convergent and concurrent validity

All Pearson's r correlations were significant and within the expected direction, indicating convergent validity of the CASP-19 with the GDS-15 (r = -.707), EID-Q (r = .75) and PPOM (r = .73). The QoL-AD was also significantly correlated with the CASP-19 (r = 707), indicating concurrent validity (Table 3). An independent samples t-test indicated that participants who scored 10 or above on the GDS-15, and therefore are more likely to have significant depressive symptoms, were more likely to score lower on the CASP-19 (M= 26.58), than those who scored below 5 on the GDS-15, indicating little or no depressive symptomology (M= 43.91; t (175) = 10.498, p < .001).

[Insert Table 3 around here]

Factor Structure

An EFA indicated the potential presence of six factors, with eigenvalues all above one (5.046, 2.056, 1.709, 1.148, 1.072, 1.045). However, an examination of item loadings

indicated the presence of four factors, consistent with that originally reported by the measure authors. Using a second order confirmatory factor analysis, consistent with the original study, fit indices were inadequate (Table 4) but all subscales significantly loaded onto the latent factor (control = 1.00, autonomy = 1.042, pleasure = 0.846 and self-realisation = 1.102). Item loadings for each subscale ranged from a low of .376 for item six and a high of 1.264 for item eight.

However, model fit here was not adequate and, therefore, other factor solutions were examined. Other authors (Vanhoutte, 2012; Wiggins et al., 2008) have proposed a shortened CASP-12, omitting item 3 from the control subscale, item 6 and 8 from the autonomy subscale, 13 and 14 from the pleasure subscale and items 16 and 17 from the self-realisation subscale. Two versions of this model were tested using a CFA, the first keeping the control and autonomy subscales separate and the second combing these two subscales (Table 4).

[Insert Table 4 around here]

Model fit here was much improved and marginally better for retaining all four subscales in a second order solution. However, when the internal consistency analysis was re-run using the 12-item solution, the internal consistency of the autonomy subscale was α =.34. Combing the control and autonomy subscale led to an alpha of .65. Therefore, the model in which these subscales was combined was accepted as superior. Standardised factor loadings for the three subscales are presented in Figure 2 and ranged from a low of .175 for item 9 to a high of .756 for item 10.

Whilst item 9 had a lower factor loading it, removing it from the model caused all fit indices to worsen (CFI= .938, RMSEA= .059, SRMR= .057).

[Insert Figure 2 around here].

Discussion

The evidence from this study indicates that the CASP-19 maintains adequate psychometric properties when used with people with dementia. Assessments of convergent and concurrent validity indicated a statistically significant relationship between the CASP-19, depression and quality of life as measured by the GDS-15 and QoL-AD respectively. However, analysis of the CASP-19 within the EFA stage, indicated the underlying latent factor reported by Hyde, Wiggins, Higgs and Blane (2003) was not adequate in a dementia population. Whilst all 19 items significantly loaded onto their respective factor, some fit indices fell below or above standard guidelines. As such, other factor solutions as reported by Vanhoutte (2012) and Wiggins et al., (2008) were examined and found to be more robust, suggesting this fit may be preferred for certain studies.

Implications

Results here indicate that the CASP-19 is a suitable positive psychology measure for people with dementia. The statistically significant correlation between the CASP-19, the QoL-AD and GDS-15 indicates that domains within the CASP-19 have important implications for both quality of life and depression for this population. All correlations were above r = .40 and, whilst harder to define, can be considered

clinically significant (Dunn, 2000; Evans, 1996). In particular, the independent samples t-test indicated that those who were more likely to have significant depressive symptomology scored on average 17 points lower on the CASP-19.

Both quality of life and depression are well established as valuable outcomes and measures of these concepts are systematically included in a number of psychosocial research programmes (e.g. Orrell, et al., 2017; Wenborn et al., 2016; Whitaker, et al., 2014). Based on evidence here, it is reasonable to suggest that positive concepts, such as those measured by the CASP-19 may be very closely related to these well etablished outcomes and further work is needed to explore whether it is possible to act on quality of life and depression vicariously, by intervening upon positive concepts.

Much of the qualitative literature suggests that dementia impacts, often negatively, upon every aspect of a person's life (e.g. Aminzadeh, Byszewski, Molnar, & Eisner, 2007; Robinson, Clare, & Evans, 2005). However, average scores on the CASP-19 here were largely similar to that of an older adult population (Hyde, Wiggins, Higgs & Blane, 2003). This suggests that positive concepts may be ingrained in identity or selfhood, and as such, largely unaffected by dementia (Caddell & Clare, 2010).

Future research

Psychometric properties reported here were adequate for people with dementia.

Therefore, the measure should be considered appropriate for people with dementia, who retain capacity, and can be used in future research. The current study underlies the need for researchers to consider the psychometric implications of adopting measures for populations that they were not originally intended for. Content validity

is often established within one specific population and there is the need to consider whether this remains stable across participant groups.

An important aspect of psychometric testing is that of responsiveness or, more simply, whether a measure can detect change as a result of an intervention. Whilst this could not be established here, the CASP-19 has been adopted for use in the Promoting Independence in Dementia (PRIDE) research programme in which a social intervention aimed at improving independence and wellbeing for people with dementia is being evaluated. Within the randomised controlled trial of this intervention, an analysis of responsiveness will be conducted to ensure that the CASP-19 is an adequate tool to measure change in this population.

Methodological problems

Obtaining demographic information could sometimes be challenging. Most commonly, participants were aware that they had 'memory problems' but were unable to recall whether they had been given a formal diagnosis or what this diagnosis was. Whilst this information was largely available for those who took part via the JDR, information for participants from other avenues was more difficult to obtain and could only be accomplished, with permission, through carer involvement or by accessing healthcare records. However, on a few occasions, this information could not be obtained and this is recognised as a limitation of the current work.

Informal feedback from a carer indicated a potential issue in that a carer assisted a person with dementia to complete the measures in the guise of a conversation. This was not standard procedure for participants, due to potential bias, who were informed

they could either complete the study independently or with the assistance of a trained researcher. Future studies may wish to address this by using explicit instructions detailing completion procedures.

Limitations

Participants here were predominantly White-British, with Black, Asian and Minority Ethnic (BAME) groups accounting for only eight participants. Consequently, psychometric properties reported here are primarily for White-British older adults with dementia and, as such, inferences cannot be drawn as to the cross-cultural validity of the CASP-19 for older adults with dementia.

The sample here primarily consisted of older adults with dementia. Whilst the inclusion criteria were purposively wide, participants under the age of 65 only accounted for 10.9% of the sample. It is likely that experiences of domains measured by the CASP-19 may differ for younger people with dementia who are often still in employment, have significant financial commitments and have dependent children or parents to care for (Roach, Keady, Bee & Hope, 2008). Future researchers may wish to conduct purposeful sampling to ensure younger people with dementia are represented within research. In relation to this, researchers may wish to consider more extensive testing of the CASP-19 within a larger and more varied sample.

Conclusion

Psychometric testing indicated adequate psychometric properties of the CASP-19 in a sample of people with dementia. Expected correlations were observed between

quality of life and depression. Of note, the factor structure of the CASP-12 appeared to be more robust than the CASP-19 suggesting it may be preferred for future studies.

Ethical Approval and Content to Participate

Ethical approval for the current study was granted by the East of England Research Ethics Committee, as part of an individual PhD study (15/EE/0443). All participants involved in the study were deemed capable of providing informed consent and were required to complete a consent form.

Consent for publication

Not applicable

Availability of data and material

The dataset used and analysed during the current study is available from the corresponding author on request.

Competing interests

The authors declare no competing interests.

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Authors Contributions

CS oversaw recruitment at NHS sites, analysed the data set and wrote the manuscript.

AS acted as Chief Investigator, providing oversight and supervision to CS. AS also assisted in the writing of the manuscript. MO provided supervisory and statistical support. MO also commented on drafts of the manuscript.

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Table 1 Participant demographics

| | Total Sample | Subsample | |
|------------------------|------------------|--------------------|--|
| | (n = 225) | (n = 48) | |
| Sex n (%) | | | |
| Male | 129 (57.3) | 29 (60.4) | |
| Female | 96 (42.7) | 19 (39.6) | |
| Age M (SD) Range | 77.1 (9.4) 50-99 | 76.63 (10.2) 59-99 | |
| Marital status n (%) | | | |
| Single | 9 (4) | 5 (10.4) | |
| Married | 147 (65.3) | 30 (62.5) | |
| Widowed | 51 (22.7) | 9 (18.8) | |
| Divorced | 13 (5.8) | 2 (4.2) | |
| Other | 5 (2.2) | 2 (4.2) | |
| Ethnicity <i>n</i> (%) | | | |
| White (British) | 201 (89.3) | 44 (91.7) | |
| White (other) | 10 (4.4) | 3 (6.3) | |
| Black | 4 (1.8) | 1 (2.1) | |
| Asian | 3 (1.3) | 0 (0) | |
| Mixed | 1 (0.4) | 0 (0) | |
| Unknown (missing) | 6 (2.7) | 0 (0) | |

Table 2 Participant clinical information

| | Total Sample | Subsample |
|------------------------------|--------------|-----------|
| | (n = 225) | (n = 48) |
| Dementia diagnosis n (%) | | |
| Alzheimer's disease | 109 (48.4) | 25 (52.1) |
| Vascular dementia | 40 (17.8) | 8 (16.7) |
| Dementia of mixed aetiology | 47 (20.9) | 8 (16.7) |
| Parkinson's related dementia | 4 (1.8) | 3 (6.3) |
| Other | 9 (3.9) | 3 (6.3) |
| Dementia (variant unknown) | 19 (8) | 1 (2.1) |
| Time since diagnosis n (%) | | |
| <1 year | 73 (32.4) | 17 (35.4) |
| 1-3 years | 92 (40.9) | 19 (39.6) |
| 3> years | 42 (18.6) | 9 (18.8) |
| Unknown | 18 (8) | 3 (6.3) |
| | | |

| Acetylcholinesterase inhibitor n (%) | | | |
|---|------------|-----------|--|
| None | 88 (39.1) | 18 (37.5) | |
| Donepezil | 90 (40) | 17 (35.4) | |
| Other | 47 (20.9) | 13 (27.1) | |
| Other major mental or physical health problem n (%) | | | |
| None | 167 (74.2) | 34 (70.8) | |
| Depression | 17 (7.6) | 2 (4.2) | |
| Other | 41 (18.2) | 10 (25) | |
| Other psychotropic medication n (%) | | | |
| None | 186 (82.7) | 41 (85.4) | |
| Antidepressant | 26 (11.6) | 4 (8.3) | |
| Other | 13 (5.7) | 3 (6.3) | |

Table 3 Convergent and concurrent validity of the CASP-19

| | Control | Autonomy | Self-realisation | Pleasure | CASP-19 |
|--------|---------|----------|------------------|----------|---------|
| GDS-15 | 614 | 537 | 646 | 571 | 707 |
| EID-Q | .592 | .525 | .638 | .501 | .750 |
| PPOM | .552 | .444 | .689 | .571 | .730 |
| QoL-AD | .594 | .560 | .655 | .441 | .707 |

All significant to p<.01 level.

Table 4 Model fit indices for the CASP-19 and CASP-12

| | CFI | RMSEA | SRMR |
|---------------------------------|------|-------|------|
| CASP 19: Four Subscales | .812 | .081 | .073 |
| CASP 12: Four Subscales | .947 | .055 | .045 |
| CASP 12: Three Subscales | .944 | .056 | .046 |

Figure 1 Distribution of the CASP-19

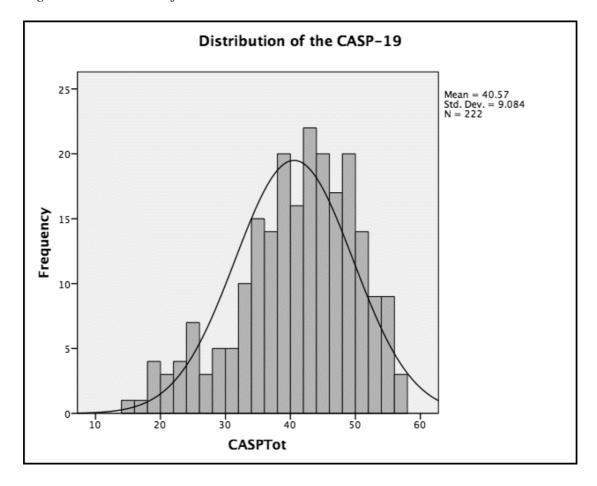


Figure 2 Standardised Factor Loadings for the CASP-12

