Psychometric properties of the ICECAP-O quality of life measurement tool when self-reported by community-dwelling older people with mild and moderate dementia

Abstract

To evaluate interventions designed to improve the quality of life of people with dementia (PWD), there is a need for psychometrically validated instruments. We tested the psychometric properties of the ICEpop CAPability measure for Older people (ICECAP-O) as a self-report measure of quality of life with PWD. We used data from a randomised controlled trial of Tai Chi with 83 community-dwelling older people with mild and moderate dementia. The ICECAP-O was found to be valid with correlations in the expected directions for fear of falls (r = -0.36, p = 0.001) and age (r = 0.12, p = 0.29), sensitive to change (mean difference = 0.051, p = 0.04, d = 0.51), and have an adequate factorial structure. The ICECAP-O is a valid, generic measure of quality of life for use with PWD without a proxy.

Keywords

Dementia; psychometric; quality of life; validity; wellbeing

Introduction

Current policy emphasises the importance of 'living well' with dementia [1]. To evaluate interventions designed to improve the quality of life of people with dementia (PWD), there is a need for psychometrically validated instruments. For PWD, quality of life has often been measured through observation or proxy reports [2]. Such approaches are limited because carers have different perspectives to PWD and often provide conflicting scores [3]. Of the previous studies that have used a self-report measure of quality of life among PWD, these mostly use a dementia-specific scale. Such dementia-specific scales can be highly sensitive to the needs of PWD. However, they are limited because their scores cannot be compared with adults without dementia. A previous study that used a generic measure of quality of life (EQ-5D) and dementia specific scales (DEMQoL and QoL-AD) found the scales were highly correlated [4]. This suggests that generic scales can be a valid alternative for measuring quality of life among PWD. However, the EQ-5D is a health-related measure, which does not capture many important psychosocial aspects that influence quality of life. While dementia-specific scales can overcome this limitation of the EQ-5D, a relatively new generic measure of quality of life is the ICEpop CAPability measure for Older people (ICECAP-O) [5]. The ICECAP-O uses a broader scope of attributes identified by older people as important to wellbeing (attachment, security, role, enjoyment, and control) [5]. It has been validated with the general healthy older population and for PWD when completed by a proxy [6]. In this study, we aimed to test for the first time, the psychometric properties of the ICECAP-O as a self-report measure with older people with mild and moderate dementia.

Method

Design

This study used data from a randomised controlled trial that investigated the effectiveness of Tai Chi to improve postural balance among community-dwelling PWD [7]. The study was approved by the West of Scotland Research Ethics Committee 4 (reference: 16/WS/0139) and Health Research Authority (IRAS project ID: 209193). Prior to the trial, we conducted a pilot study with five community-dwelling PWD aged 60+. The pilot was conducted as a structured interview on university campus and was approved by the university research ethics committee. As each participant was able to understand and complete all five items of the ICECAP-O, we proceeded to include the ICECAP-O in the trial described below.

Participants

The study was conducted in three locations across the South of England. Participants were recruited via various sources such as National Health Service memory clinics, local charities and self-referral. The intervention group received a Tai Chi exercise intervention for 20 weeks in addition to usual care, while the control group received usual care only. See Table 1 for participant eligibility criteria.

Measures

At baseline and the six-month follow-up post-baseline, all data were collected in a home visit. A researcher was trained to conduct data collection in a uniform manner and was blind to randomisation group. At baseline, after providing informed consent, PWD provided information by structured interview. This began with the Mini Addenbrooke's Cognitive Examination to assess global cognitive functioning to confirm eligibility [8]. PWD then provided demographic data and completed further scales by structured interview. PWD completed the ICECAP-O [5], a 5-item scale that is assigned weights and summed for a total score (minimum to maximum possible scores of 0 – 1), with a higher score indicating greater

capability. PWD completed a measure of fear of falling, the Iconographical Falls Efficacy Scale short-form [9]. Responses to this 10-item scale are summed (minimum to maximum possible scores of 10 – 40), with higher scores indicating greater fear.

Statistical analysis

After checking the univariate normality of the data (absolute values of skewness and kurtosis did not exceed 2 or 7 respectively), we tested convergent validity with a Pearson correlation between ICECAP-O total weighted scores and fear of falls (both at baseline). Based on a systematic review [10], we hypothesised that quality of life would be significantly negatively correlated with fear of falls. We tested discriminant validity with a Pearson correlation between ICECAP-O total weighted scores and age (both at baseline). Based on a systematic review [1], we hypothesised that age would not be significantly correlated with quality of life. We tested sensitivity to change with the 6-month post-baseline follow-up data from the trial. Participants were analysed in the group they were randomised to on an intention-to-treat basis (Tai Chi or control group). Total weighted ICECAP-O scores were compared between the two trial arms using a mixed (multi-level) model approach to take into account clustering within Tai Chi classes, baseline scores, treatment site, and 12-month falls history. We hypothesised that the Tai Chi group would have significantly higher quality of life than the control group. Lastly, we tested the ICECAP-O factorial structure with its five weighted items at baseline. For this, we conducted confirmatory factor analysis using the maximum likelihood method of estimation and a covariance matrix in AMOS 25 (see Table 2 for model fit indices).

Results

Eighty-five PWD provided data at baseline. However, two participants were recruited in error as their diagnosis of dementia could not be confirmed with medical notes. Therefore, all the tests were conducted with a sample of 83 PWD except for the analysis of sensitivity to change that used data from the main trial intention-to-treat analysis with 85 PWD at baseline and 70 at follow-up. Descriptive characteristics of PWD are shown in Table 1 and the test results are shown in Table 2. The Pearson correlations supported the hypotheses in that there was a significant negative correlation between quality of life and fear of falls, and a non-significant correlation between quality of life and age. In the trial, there was an even balance in baseline characteristics and PWD lost to follow-up (n=6 intervention and n=8 control, see [8]). The results indicated the ICECAP-O was sensitive to change with a significant difference between the Tai Chi and control groups at the 6-month follow-up post-baseline. The confirmatory factor analysis indicated that there was an adequate fit for the model. This suggested that all five items of the ICECAP-O scale measured a single construct of quality of life.

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Discussion

In this study, for the first time, we tested the psychometric properties of the ICECAP-O as a self-report measure for use with older people with mild and moderate dementia. The results suggested the ICECAP-O was valid (convergent and discriminant), sensitive to change, and each item measured a single construct of quality of life.

The confirmatory factor analysis suggested that the ICECAP-O is a coherent scale with each item contributing to the assessment of a single construct of quality of life among PWD. Quality of life was significantly negatively correlated with fear of falls (convergent validity; quality of life reduces when fear of falls increases), but not significantly correlated with age (discriminant validity). The results from the trial indicated that the ICECAP-O was sensitive to change. Overall, these results suggest that the ICECAP-O is a valid, generic measure of quality of life that can be completed by self-report by older people with mild and moderate dementia. Our results are in agreement with a systematic review of studies that have psychometrically tested the ICECAP-O with a range of populations [6]. Prior studies have found the ICECAP-O to be valid and responsive, with good test-retest agreement. The systematic review however did not identify reports as to the internal reliability or factorial structure of the scale, perhaps due to it only containing five items [6].

The implication of our results is that the ICECAP-O can be a valid measure of generic quality of life among older people with mild and moderate dementia, and so would be suitable for evaluating interventions designed to facilitate older people 'living well' with dementia. The ICECAP-O as a self-report tool with PWD has four advantages to other approaches. First, using the ICECAP-O overcomes the disadvantages of using proxy reports, which are known to be discrepant with PWD's scores and are in discord with person-centred dementia care principles [2,3]. Second, the ICECAP-O enables comparisons of scores with adults without dementia. Third, as the ICECAP-O only contains five items it can be used in time-limited contexts. Fourth, the ICECAP-O is broader in scope than health-related measures in its use of attributes identified by older people as important to wellbeing[5].

This study was limited in that we recruited community-dwelling older people into a Tai Chi trial that may not be generaliseable to the general UK population. Data was collected by structured interview, and so further research should assess whether the ICECAP-O is equally valid when completed without assistance. We were not able to collect test-retest reliability data that should be collected in a future study. Future research could compare ICECAP-O scores with other generic and dementia-specific quality of life scales, and compare with proxy reports, to further test convergent validity.

In conclusion, the results suggest that the ICECAP-O is a valid, generic measure of quality of life for use with older people with mild and moderate dementia without the need for a proxy.

Nyman, S. R., Casey, C., & Polman, R. (in press). Psychometric properties of the ICECAP-O quality of life measurement tool when self-reported by community-dwelling older people with mild and moderate dementia. *Alzheimer Disease & Associated Disorders*.

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Table 1. Baseline demographic characteristics of people with dementia[1].

Characteristic (N = 83)	Statistic	Value
Age (years)	Mean (SD)	77.44 (7.95)
Male / female	n	50 / 33
White ethnicity	n (%)	81 (98%)
Education		
None	n (%)	3 (4%)
Primary school	n (%)	2 (2%)
Secondary school	n (%)	45 (54%)
Higher education, college, university	n (%)	24 (29%)
Further education, professional qualification	n (%)	9 (11%)
Relationship status		
Single	n (%)	2 (2%)
Married	n (%)	68 (82%)
With partner	n (%)	1 (1%)
Divorced	n (%)	2 (2%)
Widowed	n (%)	10 (12%)
Living situation		
Living alone	n (%)	7 (8%)
Living with family or friends	n (%)	76 (92%)
Mini Addenbrooke's Cognitive Examination score	Mean (min - max scores)	15.47 (10-27)
Time since dementia diagnosis (months)	Median (range)	14.5 (107)
Dementia diagnosis		
Alzheimer's	n (%)	56 (68%)
Vascular	n (%)	6 (7%)
Mixed Alzheimer's and Vascular	n (%)	15 (18%)

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Other	n (%)	6 (7%)
Quality of life total score[2]	Mean (SD)	0.87 (0.10)

Notes:

1. PWD who were eligible were: aged 18 or above, community-dwelling, had a diagnosis of a dementia (indicated on their medical record held by the NHS or general practitioner), physically able to do standing Tai Chi, and willing to attend weekly Tai Chi classes. Several exclusion criteria were applied: living in a care home; in receipt of palliative care; severe dementia (score of 0-9 on the Mini Addenbrooke's Cognitive Examination) [8]; diagnosis of Lewy body dementia or dementia with Parkinson's disease; severe sensory impairment; currently or within the past 6 months practising Tai Chi (or similar exercise – Qi Gong, yoga or Pilates) weekly or more; under the care of, or referred to, a falls clinic for assessment; currently attending a balance exercise programme; or lacking mental capacity to provide informed consent.

2. Sum of the weighted five ICECAP-O items. The best/worst responses to the five items were: "I can have all / cannot have any of the love and friendship that I want"; "I can think about the future without any concern / I can only think about the future with a lot of concern"; "I am able to do all / unable to do any of the things that make me feel valued"; "I can have all / cannot have any of the enjoyment and pleasure that I want"; "I am able to be completely independent / I am unable to be at all independent".

Table 2. Psychometric test results for the ICECAP-O quality of life scale with older people with dementia

Test	Measure	Output
Convergent validity	Pearson correlation between ICECAP-O and fear of falls	r = -0.36 (95% CI = -0.57, -0.16), p = 0.001 (medium strength of association)[1]
Discriminant validity	Pearson correlation between ICECAP-O and age	r = 0.12 (95% CI = -0.10, 0.34), p = 0.29
Sensitivity to change	Difference in ICECAP-O scores between the Tai Chi group and control group at six-month follow-up (mean [M]=0.86, standard deviation [SD]=0.10, n=36; M=0.83, SD=0.14, n=34 respectively) accounting for baseline scores (M=0.87, SD=0.09, n=42; M=0.88, SD=0.11, n=43 respectively)	Mean difference = 0.051 (95% CI = 0.002, 0.100), p = 0.04, d = 0.51 (medium effect size)
Factorial structure	Confirmatory factor analysis using the maximum likelihood method of estimation and a covariance matrix[2]	All fit indices were acceptable with only the RMSEA at the upper boundary and the TLI acceptable rather than a good fit (χ^2 df 5 = 7.82; P = 0.17; χ^2/df = 1.56; SRMR = 0.03; RMSEA = 0.08; TLI = 0.91; CFI = 0.96; GFI = 0.97 and Pclose = 0.26)

Notes:

1. Strength of association of Pearson r values were interpreted as either small (0.1 to 0.3), medium (0.3 to 0.5), or large (0.5 to 1.0).

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2. For model fit determination the following indices were used: Chi-square statistic (χ^2), Chi square/df (χ^2/df), standardised root mean square residual (SRMR), root mean square of approximation (RMSEA), Tucker-Lewis index (TLI), Goodness-of Fit Index (GFI), Comparative Fit Index (CFI) and P of close fit (Pclose). A non-significant P value for χ^2 and a value of ≤2 for χ^2/df indicates a good fit of the data to the model. A value of ≤0.08 for SRMR and ≤0.06 for RMSEA indicates a good fit (≤0.10 and ≤0.08 acceptable respectively). For the TLI, GFI and CFI a value ≥0.095 indicates a good fit (≥0.90 adequate). The Pclose is required to be non-significant.

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