

Psychometric properties and factor analysis of the Engagement and Independence in Dementia Questionnaire (EID-Q)

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Abstract

Background/ Aims: Independence and social engagement are important outcomes for people with dementia. The aim of this study was to conduct an in-depth psychometric assessment of the Engagement and Independence in Dementia Questionnaire (EID-Q); a measure of social independence. **Methods:** An observational study at five NHS sites across England. Participants completed the EID-Q alongside additional measures. Psychometric analysis included internal consistency, test-retest reliability, convergent validity and factor analyses. **Results:** 225 people living with dementia completed the study. Internal consistency was excellent ($\alpha=.921$) and the measure remained moderately stable over a one-week period (ICC= .768). Significant correlations were observed between quality of life ($r =.682$) and depression ($r = -.741$; both $p <.001$), indicating the importance of these concepts for wellbeing in dementia. Factor analysis indicated the presence of five factors which loaded onto a second order two latent factor solution. These latent factors were named 'Sense of Independence' and 'Social Engagement'.

Conclusions: The EID-Q demonstrated acceptable psychometric properties and the factor solution had an adequate model fit. The strong correlations suggest that social independence is strongly related to depression and quality of life. Future work will entail an analysis of responsiveness to intervention and further large-scale work.

Introduction

Promoting independence is widely accepted as a valuable outcome for the maintenance of wellbeing for people with dementia, also decreasing the potential stress felt by carers and delaying nursing home entry[1]. Increasingly, research is being conducted to maintain this independence through interventions including exercise[2] and occupational therapy[3]. Furthermore, feelings of loneliness have been suggested as a risk factor for the onset of dementia, regardless of objective isolation[4] and feelings of loneliness have been associated with cognitive decline within longitudinal studies[5].

Within research, independence appears to be often operationalised as a functional ability and outcome measures used to measure independence reflect this definition[6]. Whilst this is certainly an area that is of importance for people with dementia, as their ability to complete activities of daily living decreases, it does not recognise the subjective, multifaceted and complex nature of independence. In relation to this, social engagement is often measured in terms of quantity[7] and can fail to take into account the unique and vitally important relationship between a carer and a person living with dementia, with reciprocal relationships proposed as a potential means of mitigating a loss of autonomy[8].

A sense of social independence for people with dementia may refer to whether a person has the perceived ability to make free choices with or without support from others and maintain control over important aspects of their lives in order to sustain a sense of personhood. The EID-Q was developed using an asset-based or strengths

capabilities approach to dementia; an area of research previously identified as lacking for this population[9]. The aim of this study was, therefore, to evaluate the psychometric properties of the EID-Q; a measure of social independence for people with dementia.

Material and Methods

Design

An observational, questionnaire-based research study conducted at five NHS sites across England from April 2016 to August 2017. Data collection consisted of one baseline assessment and one re-test for a subsample of 48 participants.

Questionnaires could either be completed within an interview with a trained researcher or using a self-complete procedure outlined below. As this was an observational study, refusal rates were not included.

Participants

Recruitment was conducted via a number of avenues. Firstly, participants were identified and recruited through the Join Dementia Research (JDR) register (<https://www.joindementiaresearch.nihr.ac.uk/>). The JDR allows people with dementia and their carers to register their details and interests with regard to research on a website. Secondly, participants were recruited through referrals from support groups, memory clinics and previous research. To be eligible participants were required to have: a diagnosis of dementia according to DSM-IV-TR criteria[10] (American Psychiatric Association, 2000) and capacity to give informed consent.

Procedure

Participants were identified and approached by research assistants or clinical support officers within National Health Service (NHS) Trusts. Staff were responsible for ascertaining interest and establishing capacity to provide informed consent, via an informal capacity assessment conducted in accordance with established guidelines[11]. As part of this assessment, participants were required to understand what the study would involve for them, retain this information and provide a verbal summary of the study. All staff had current Good Clinical Practice (GCP) training and were trained to undertake informal capacity assessments. Participants were provided with information sheets, both a shortened accessible version and a standard version, and a consent form prior to participation. Staff were also instructed to discuss with potential participants their preferred manner of completion. Participants were informed they could either be sent the outcome measure booklet by post with a free return envelope or that a research assistant could visit them at a place and time of their choosing to assist them in completing the booklet. A subsample of participants completed the study twice, within a one-week period. This time frame was selected to minimise external or confounding life events that may have impacted on levels of independence or engagement.

Outcome Measures

Participants were asked to provide demographic and clinical information consisting of age, gender, ethnicity, type of dementia (e.g. Alzheimer's disease or vascular dementia), diagnosis date, co-morbid major physical or mental health conditions and current medication. Five outcome measures were used within the current study, four of which are relevant to this analysis. These four outcome measures were selected

as it was hypothesised that the underlying concept may correlate with engagement and independence and, consequently, provide convergent validity for the EID-Q.

The Engagement and Independence in Dementia Questionnaire (EID-Q)

The EID-Q is measured on a five-point Likert scale (0- not true at all, 4- true nearly all the time) and uses a one-month time frame. The EID-Q was developed during a two-year period using both qualitative and quantitative methodology and measures subjective independence and social engagement for people with dementia. It reflects the multifaceted nature of independence in dementia and includes items pertaining to remaining active, decision making, reciprocity and connectedness to others. A preliminary evaluation indicated promising psychometric properties with excellent internal consistency ($\alpha = .907$) and emerging correlations with both depression ($r = -.46, p = .009$) and quality of life ($r = .56, p < .001$). However, the sample size ($n=33$) was too small to conduct a meaningful analysis of psychometric properties and factor structure[12].

The Control, Autonomy, Self-realisation and Pleasure Scale (CASP-19)

The CASP-19 views wellbeing as the satisfaction of the above named domains. Developed from a humanist perspective, it is measured on a four-point Likert scale (0- never, 3 often). The CASP-19 has adequate psychometric properties for older adults[13] and was also assessed psychometrically for people with dementia as part of this study[14].

The Geriatric Depression Scale Short Form (GDS-15)

The GDS consists of 15 yes/ no items with a score of 10 or higher indicating depression[15]. The GDS has been found to have adequate psychometric properties for people with dementia[16].

The Quality of Life in Alzheimer's Disease Scale (QoL-AD)

The QoL-AD is a 13-item measure and possible scores range from 13 to 52. It is measured on a 4-point Likert scale (1- poor, 4 – excellent) with higher scores denoting higher levels of quality of life. Internal consistency has been reported as between 0.77 – 0.84 and the measure can be used either in a self-complete manner or within an interview[17].

Analysis

Missing data was adjusted for using a combination of mean imputation and multiple imputation. Mean imputation was used at the 10% level for the EID-Q, GDS and CASP-19. Therefore, if a case had two or less instances of missing data, the mean of remaining items was imputed. The QoL-AD was imputed at the 20% level, based on the author's suggestion[17]. Multiple imputation was subsequently applied at a measure level[18].

Internal consistency was assessed at a subscale and measure level using a Cronbach Alpha. Mean, standard deviations, range and possible range were calculated to examine floor and ceiling effects of the EID-Q. If more than 15% of participants achieved the highest or lowest possible scores, floor and ceiling effects were considered significant[19]. Test-retest reliability was assessed using Intraclass Correlation Coefficients (ICC) to examine change over a one-week period.

Convergent validity was assessed with a Pearson's r correlation between the EID-Q and the CASP-19, QoL-AD and GDS.

To further evidence the content validity of the EID-Q, an exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) was undertaken. To accomplish this, data was randomly halved and imported into MPlus and an EFA was run. No hypotheses were made at this point as an EFA is data led rather than theory led.

Latent factors were identified using Kaiser's criterion, which considers eigenvalues of one or greater as distinct factors[20]. After the number of factors had been identified, the remaining random half of data was imported into Mplus and the structure identified within the EFA was applied as a model within the CFA. Goodness of fit indexes were then used to determine whether the proposed model was an adequate fit for data. 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. To test the goodness of fit, a number of fit indices were used including chi-squared statistics, comparative fit index (CFI), standardised root mean square residuals (SRMR) and root mean square error of approximation (RMSEA).

Results

Participants

Two-hundred and twenty-five people with dementia were recruited and completed the outcome measures (Table 1). Participants were on average 77.1 years of age and most commonly been diagnosed with Alzheimer's disease (Table 2). A series of non-significant independent samples t-tests indicated that the retest sample were representative of the sample in full.

INSERT TABLES 1 AND 2 AROUND HERE.

Internal Consistency

Internal consistency was $\alpha=.91$. The deletion of one item ('people take decisions away from me') would have improved the internal consistency but to a negligible amount ($\alpha=.92$). The sense of independence subscale had an internal consistency of $\alpha=.85$ and the social engagement subscale had an internal consistency of $\alpha=.85$.

Floor/ Ceiling Effects

Average scores on the EID-Q did not differ according to completion style (i.e. interview or by self-report). The possible range of the EID-Q was 0- 104 with the observed range being calculated as 26 – 103. The mean score was 79 and the standard deviation was 15.3. Analysis of skew indicated the EID-Q had a moderately negative skew (-0.825) and the kurtosis value was .29. No participants scored zero or the maximum of 104 and, therefore, floor and ceiling effects were not considered significant.

Test-Retest Reliability

The EID-Q remained moderately stable at re-test (ICC= .768), with 95% CI of .614 to .866 ($F(43,44)= 7.606, p<.001$). At a subscale level, sense of independence showed moderate consistency (ICC= .757, with a 95% CI of .597 to .860 ($F(43,44)= 7.24, p<.001$) and social engagement also showed moderate consistency (ICC= .713), with a 95% CI of .531 to .832 ($F(43,44)= 5.98, p<.001$).

Convergent Validity

A significant, positive correlation was identified between the sense of independence subscale and the QoL-AD ($r = .626, p < .001$) and between the social engagement subscale and the QoL-AD ($r = .688, p < .001$). A significant correlation was also observed for the EID-Q overall and total scores on the QoL-AD ($r = .682, p < .001$). The EID-Q was also positively correlated with the CASP-19 ($r = .75, p < .001$) as were both the engagement ($r = .659$) and independence ($r = .696$) subscales (both $p < .001$). Negative correlations were observed between the GDS and the EID-Q ($r = -.741, p < .001$). The sense of independence subscale was negatively correlated ($r = -.7, p < .001$) as was the social engagement subscale ($r = -.737, p < .001$). People who scored less than five on the GDS, indicating few depressive symptoms scored significantly higher on the EID-Q ($M = 84.02, SEM = 1.08$) than those who scored ten or greater on the GDS, ($M = 57.73, SEM = 3.248$) ($t(3115002.145) = 7.680, p < .001$), indicating those who were more likely to have significant depressive symptomology were less likely to feel independent or engaged with those around them.

Factor Structure

The 26 items of the EID-Q were loaded into Mplus and eigenvalues indicated the presence of five factors all above 1 (9.623, 2.159, 1.529, 1.422, 1.358). As there was a substantial drop between factors one and two, a CFA with a one factor solution was proposed. This factor was named 'interdependence' in recognition of the relationship between a person with dementia and their carer contributing to independence. However, model fit indices were not adequate and the model was rejected.

Following this, an examination of item loadings indicated that there were potential subscales within the measure that had not been anticipated. The measure was subsequently split into five subscales: Activities of Daily Living (Act; items 1-6), Decision making (Dec; items 7-10), Support (Supp; items 14-20), and Reciprocity (Rec; items 21-26) and a second order analysis was conducted using 'social engagement' and 'sense of independence' as latent factors. This solution was subject to a CFA to establish whether this was an acceptable model of the data. Within the five-factor and second order model, all items loaded onto their respective factors and all factors loaded onto the two latent second order factors (Figure 1). Furthermore, both second order latent factors were significantly correlated with each other ($r = .561$, $SE = .09$, $p < .001$). Average variance explained by the factors was 0.5 ($SE = .095$) for 'sense of independence' and 0.8 ($SE = .175$) for 'engagement'. Model fit was moderate and was accepted (Table 3).

Discussion

This study provides good evidence that social independence (independence and social engagement) can be measured accurately using the EID-Q. The EID-Q demonstrated excellent internal consistency, moderate test-retest reliability and convergent validity with both measures of depression and quality of life.

Factor structure was established using best practice factor analyses and indicated the presence of five subscales, each of which loaded onto a second order two-factor solution. Fit indices indicated an acceptable model fit. Whilst the CFI fell below the recommended value of .90, the SRMR and RMSEA values were both within an

acceptable range (<.08 and .06 - .08 respectively), meaning model fit was acceptable.

Future Research and Clinical Implications

Strong correlations were observed between the EID-Q, quality of life and depression suggesting that how people with dementia feel about their level of social independence may have an important impact upon quality of life and symptoms of depression. As discussed, measures of independence within dementia are usually limited to functional abilities, which often do not correlate with depression[21]. These findings are in line with the stroke literature with a similar concept of 'self-care self-efficacy', or the perceived ability to care for oneself, strongly related to both quality of life and depression[22].

The quality rather than quantity of social engagement has been previously noted as a protective factor for the development of dementia. Both satisfaction and reciprocity within relationships have been identified as having protective effects for dementia risk up to 15 years later[23]. Whilst classical measures of social network tend to be more strongly oriented to the quantity of social contact (e.g. Lubben Social Network Scale[7]), the EID-Q measures reciprocity, engagement with others and connectedness.

The EID-Q, therefore, may be a useful measure for both research and clinical practice in determining how satisfied an individual with dementia is with their level of independence and their social network or support system. This may also allow clinicians to act upon high levels of depressive symptomology or low levels of quality

of life vicariously, by attempting to improve independence and engagement as measured by the EID-Q. Furthermore, the measure could be used in research interventions targeted at improving levels of independence and quality of social engagement for people with dementia.

Methodological Problems and Limitations

Participants here were predominantly White British, with Black, Asian and Minority Ethnic (BAME) groups accounting for 10.6 % of the sample.. It is recommended that future recruitment avenues target these groups to ensure they are represented in research. This is especially important as the EID-Q was developed in a sample of mostly White British participants and it is noted that perceptions of independence and engagement may differ cross-culturally. Furthermore, participants here were all capable of providing informed consent and, consequently, were more likely to have milder cognitive impairment. This means the EID-Q holds the most content validity for people in earlier stages of dementia. Also, education levels or socioeconomic status were not examined and future researchers may wish to explore the impact of these factors on the EID-Q.

No proxy reporting was used in the current study allowing people who could not identify someone to act as a carer to take part. As such, no inferences can be made regarding the relationship between self and proxy reporting of the EID-Q. It is possible that, as with the quality of life literature[24] carers may report differing levels of independence and social engagement and future researchers may wish to examine this. However, it is not in keeping with the theoretical underpinning of this research to routinely include proxy measures. Within the development study[12],

people with dementia were able to explore these often complex concepts and, within the current study, were able to make insightful self-judgements. The EID-Q, therefore, is a psychometrically robust self-report or interview led measure for people with dementia.

Finally, future research is needed to assess the EID-Q's responsiveness to change. This is an important step in determining whether the EID-Q can successfully document change as a result of an intervention and whether feelings of independence and engagement can be acted upon in dementia and how this may relate to improvements in wellbeing or quality of life.

Conclusions

The EID-Q measures a sense of social independence (perceived independence and social engagement) and has acceptable psychometric properties for people with dementia. Evidence was documented for a five factor, second order solution and the measure is now considered ready to be used in dementia research. Future work will entail examining properties in ethnically diverse groups and assessing the EID-Qs sensitivity to change or intervention.

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Conflict of Interest

The authors declare no conflicting interests.

Ethics

Ethical approval was granted by the East of England Research Ethics Committee (15/EE/0443). All participants were required to provide informed consent.

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Table 1 Participant Demographics

	Total Sample (n =225)	Subsample (n =48)
Gender <i>n</i> (%)		
Male	129 (57.3)	29 (60.4)
Female	96 (42.7)	19 (39.6)
Age <i>M</i> (<i>SD</i>) Range	77.1 (9.4) 50-99	76.63 (10.2) 59-99
Marital status <i>n</i> (%)		
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 Characteristics

	Total Sample (n = 225)	Subsample (n =48)
Dementia diagnosis <i>n</i> (%)		
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)

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Time since diagnosis <i>n</i> (%)		
<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 <i>n</i> (%)		
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 <i>n</i> (%)		
None	167 (74.2)	34 (70.8)
Depression	17 (7.6)	2 (4.2)
Other	41 (18.2)	10 (25)
Other psychotropic medication <i>n</i> (%)		
None	186 (82.7)	41 (85.4)
Antidepressant	26 (11.6)	4 (8.3)
Other	13 (5.7)	3 (6.3)

Table 3 Fit indices for 5-factor, second order factor structure of EID-Q

	χ^2	<i>df</i>	CFI	RMSEA	SRMR
5- factor, second order.	693.6*	293	0.826	.079	.069

χ^2 = Chi-Square goodness of fit; *df*= degrees of freedom; RMSEA= Root Mean Square Error of Approximation; SRMR= Standardised Square Root Mean Residual.

*statically significant at $p < .001$.

Figure 1 EID-Q Factor Loadings