

Consumer Access, Appraisal, and Application of Services and Information for Dementia (CAAASI-Dem): A validation study

Author Names

Hoang Nguyen, Kathleen Veronica Doherty, Claire E. A. Eccleston, Aidan Bindoff, Laura Tierney, Ron Mason, Andrew Robinson, James Vickers, Fran McInerney

Wicking Dementia Research & Education Centre, University of Tasmania, Hobart, Australia

Corresponding author:

Hoang Nguyen (Hoang.Nguyen@utas.edu.au)

Consumer Access, Appraisal, and Application of Services and Information for Dementia (CAAASI-Dem): A validation study

The CAAASI-Dem was developed to examine individuals' self-assessed confidence in their ability to access, appraise and use dementia services and information. The CAAASI-Dem is the only tool to date to measure this crucial component of dementia literacy. This study was designed to validate its structural validity. Data was collected from 3,277 participants enrolled in an on-line dementia course. The five-factor structure of the CAAASI-Dem, which was derived from a previous exploratory factor analysis (EFA), was evaluated using confirmatory factor analysis (CFA). Internal reliability, convergent and divergent validity, and known-groups validity were assessed. The five-factor model demonstrated good fit with the observed data with the removal of 2 items and movement of 1 item across the factors. The resultant 24-item five-factor CAAASI-Dem showed very good sub-scale internal reliability and satisfactory convergent and divergent validity. There was good discrimination between groups of participants with different levels of care experience. The results provided evidence for the 24-item CAAASI-Dem as a valid and reliable five-dimensional scale. Limitations of the study are discussed, and recommendations are made for future research and practice.

Keywords: health literacy; dementia literacy; consumer access; dementia services; validation study; tool development;

Introduction

Dementia literacy: definition, importance, and measurement

Health literacy can be generically described as the capacity to access, understand and use information to support decision making about health for oneself and others. In its broadest sense, it encompasses the knowledge, skills, and motivation of the individual to take action within the setting in which health services operate (Chinn, 2011; Nutbeam, 2008). Low health literacy has been linked to poorer health outcomes, increased use of emergency services, and lower uptake of preventative health measures, particularly for older adults (Berkman et al., 2011; Loi & Lautenschlager, 2015). As the health care system progressively becomes more complicated, a key challenge for the consumer is to learn how to navigate a complex and often unfamiliar system. For those providing care for people living with dementia, this can be particularly challenging. Access to information, diagnosis, support, and services is often confusing, and further complicated by changing needs as dementia progresses. Understanding health literacy gaps specific to dementia is one step toward reducing inequities and improving care and service provision (Grace & Horstmanshof, 2019); While many generic health literacy tools are available, they are more about basic skills such as comprehension and numeracy, or confidence/ability to access, understand, and use generic healthcare information/services (Chinn & McCarthy, 2013; Jordan, et al., 2013; Murphy, Davis, Long, Jackson, & Decker, 1993; Parker, Baker, Williams & Nurss, 1995). For chronic diseases that require complex, prolonged care and the engagement of both the person affected by the condition and their family and/or friends in the decision-making process, disease specific literacy tools are more appropriate (Dumenci, et al., 2014; Yeh, et al., 2018). Therefore, a dementia-specific tool is warranted.

A lack of awareness of services and/or the process of applying for such services has been reported to be a barrier to service use for caregivers of people with dementia (Brodaty, Thomson, Thompson, & Fine, 2005), which suggests poor dementia health literacy. Dementia literacy evaluation is often limited to recognition, knowledge of, and attitude to dementia, and does not explicitly address health literacy concepts such as access, appraisal and use of information and services. The Consumer Access, Appraisal, and Application of services and information for Dementia (CAAASI-Dem) was designed to address this gap.

The CAAASI-Dem

The CAAASI-Dem was designed to examine individuals' confidence in accessing, appraising and using dementia service and information – either for themselves or in providing care for others. It was developed to address the absence of a valid measurement for this crucial component of dementia literacy.

The construction of the CAAASI-Dem was reported in a previous paper by the authors (2020), which included three phases of scale development, refinement, and preliminary EFA validation on two independent pilot samples ($n_1 = 1,412$; $n_2 = 3,146$). A pool of 70 items were initially generated, with 26 items adapted from the literature (e.g. Chinn & McCarthy, 2013; Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013) and 44 items from content analysis of discussion posts from four offerings, from 2014 to 2017, of an online dementia program. These initial items were reduced to a final set of 26 items (Doherty et al., 2020).

Our previous EFA results (Doherty et al., 2020) identified the CAAASI-Dem as a multi-dimensional scale with five factors: (1) *Evaluation and engagement* (EE) has nine items and is defined as confidence in critically and independently engaging with dementia-related information and advice from a range of sources; (2) *Readiness* (R) consists of eight items and measures confidence in both knowledge of and ability to access a range of appropriate

healthcare information and supports over the course of the dementia trajectory; (3) *Social supports* (SS) contains three items and refers to personal assessment of and access to available human and community supports; (4) *Specific dementia services* (SDS) consists of three items and describes confidence in organizing and accessing specific dementia-related services; and (5) *Practical aspects* (PA) has three items and addresses confidence in physically navigating elements of the health care system. The CAAASI-Dem's factorial structure and constituent items were arguably aligned with established theoretical models of health literacy, such as the three-level model of functional, critical, and communicative health literacy (Nutbeam, 2000); however, the inclusion of additional elements informed by the carer's perspective has made the CAAASI-Dem distinctive and useful as a screening tool (Doherty et al., 2020).

As a newly developed scale, the preliminary validity of the CAAASI-Dem had only been examined using exploratory factor analysis (EFA). Further testing was needed to further refine the scale and establish its construct validity. This study aimed to examine the CAAASI-Dem's hypothesized five-factor structure as identified in the previous EFA study, and to provide evidence for its factorial validity or further refinement.

Methods

Procedure and ethics approval

Participants in an online dementia course were invited to complete the web-based CAAASI-Dem on a voluntary basis in July 2019. The course is a free, online course available to anyone with access to the internet and advertised widely through multiple media. There are no restrictions on enrolment. A generic invitation to complete the CAAASI-Dem was available online prior to commencement of the course. There was no requirement to complete the survey for course enrollees. There was no remuneration or incentive for their participation,

and no identifiable data were collected. It took approximately 15 minutes to finish the survey, and consent was implied by completion and submission. Data analysis was conducted using SPSS (Version 26) and AMOS (Version 20.0.0). Ethical approval for this study was granted by the Social Sciences Human Research Ethics Committee of the university (Ethics approval reference number: H00177429). The study was conducted in accordance with the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council).

Participants

The data used to examine the factor structure of the CAAAASI-Dem was collected from 3,277 voluntary participants from the course. The sample consisted of a significantly higher proportion of females than males, and the mean age was 49.2 (SD = 14.4). The participants varied in levels of completed education and care experience. Nearly half of the participants (45.3%) completed a bachelor's degree or higher, while a slightly smaller proportion (43.5%) completed Year 12 or up to Diploma/Associate degree. A very small proportion had no formal education (0.4%) or completed primary school (0.3%). Most of the participants (59.4%) were involved in paid care (including those providing paid care only, and those providing both paid and unpaid care). 17% provided unpaid care only, and nearly a quarter (23.4%) had never been involved in caring for people living with dementia.

Table 1 presents the demographic profile of the participants.

Research tool

The CAAASI-Dem contains a total of 26 items rated on a 5-point Likert scale, ranging either from 1 "Not at all confident" to 5 "Extremely confident" (18 items), or from 1 "Strongly disagree" to 5 "Strongly agree" (8 items). The CAAASI-Dem measures consumer confidence in accessing, appraising, and using dementia services and information in five dimensions or

sub-scales as identified in the previous EFA study: Evaluation and Engagement (EE), Readiness (R), Social supports (SS), Specific dementia services (SDS), and Practical aspects (PA). A total score (ranging from 26 to 130) and a sub-score for each sub-scale can be computed, with higher scores indicating higher degrees of confidence.

Confirmatory factor analysis

To validate the five-factor solution of the CAAASI-Dem, we conducted a confirmatory factor analysis (CFA).

The EFA-based solution (Authors, 2020) was used as the *a priori* framework to guide the model specification in this study. This five-factor model was specified in which each observed variable loaded on only one factor that it was postulated to measure. Specifically, items 1-9 were loaded onto Evaluation and Engagement (EE), items 10-17 loaded onto Readiness (R), items 18-20 loaded onto Social supports (SS), items 21-23 loaded onto Specific dementia services (SDS), and items 24-26 loaded onto Practical aspects (PA). This proposed model had a total of 26 variables and was structurally over-identified with 289 positive *df* (31 variances, 10 covariances, 62 freely estimated parameters). Each factor had a minimum of three variables, and the variable that had the highest factor loading on each factor based on prior EFA results was used as the marker indicator for the respective factor. All five factors were presumed to be correlated, and all measurement errors uncorrelated. In the absence of multivariate normality and given the ordinal nature of the data, the Unweighted Least Square (ULS) estimation method was used. This estimator does not have distributional assumptions and is considered to be suited for non-normal ordinal/categorical data (Bollen, 1989). CFA analysis using ULS was computed in AMOS software (version 20.0.0).

Several criteria were used to evaluate the acceptability of the specified model, including the examination of overall goodness of fit, localized areas of strains, and the strength and

interpretability of parameter estimates. Three types of goodness-of-fit indices were used to ensure a reliable evaluation of the model, including: (1) absolute fit indices (Root Mean Square Residual [RMR], Goodness-of-Fit Index [GFI], and Adjusted Goodness-of-Fit [AGFI]); (2) comparative or incremental fit indices (Norm Fit Index [NFI] and Relative Fit Index [RFI]); and (3) parsimony fit indices (Parsimony Normed Fit Index [PNFI]). RMR values of 0.08 or below indicate reasonable or adequate fit (Brown, 2015), and 0.05 or below suggest close/good fit between the hypothesized model and the observed data. Other absolute and comparative fit indices (i.e. GFI, AGFI, NFI, RFI) should be equal to or above 0.90 and 0.95 to be considered reasonable and close/good fit respectively. Parsimony fit indices typically have lower acceptable values (Meyers, Gamst, & Guarino, 2016), and greater values would suggest better fit (Hair, Black, Babin, & Anderson, 2014).

After the examination of fit indices, any re-specifications of the model were guided by substantive considerations, with reference to the theoretical integrity of the factor structure, localized areas of strains (e.g. large standardized residuals), and parameter estimate strength (e.g. factor loadings, factor variances and covariances, and indicator errors).

Reliability and validity

As part of the validation process, the best-fitting CAAASI-Dem model was assessed in both internal reliability and construct validity.

To establish internal reliability or consistency, Cronbach's alpha and construct reliability were evaluated. For both of these statistics, values equal to or greater than 0.70 are acceptable (Hair et al., 2014).

Convergent validity was assessed using factor loadings of observable variables and average variance extracted (AVE) values. Item factor loadings of at least 0.50 were required, and greater than 0.70 preferable. An AVE value of .05 or above for each factor in the model would suggest adequate convergence (Hair et al., 2014). Discriminant validity was examined

using two criteria: (1) The squared root of the AVE for each factor should be higher than the absolute value of its correlations with other factors (or AVE should be higher than the squared correlation estimate); and (2) the AVE for each factor should be higher than its maximum shared variance (MSV) (Hair, 2010).

The best fitting CAAASI-Dem model was also assessed for known-groups validity or its ability to discriminate **between** groups of people **that may be expected a priori to have different levels of confidence in their ability to access, appraise and use dementia services and information**. Kruskal-Wallis test was used to compare the overall and factor scores of participants of different levels of care experience for people living with dementia.

Results

CFA results

The hypothesized model of the CAAASI-Dem with 26 indicator variables and five factors was initially examined using ULS. Overall goodness of fit indices suggested an acceptable match between the proposed model and the observed data, with RMR (.062) and PNFI (.889) indicating a reasonable fit, and with absolute and comparative fit indices (GFI = .982; AGFI = .978; NFI = .978; RFI = .975) indicating a good fit. However, a number of standardized residuals exceeded 4.0, suggesting the need for modifications (Hair et al., 2014). All factor loadings (or standardized regression weights) were greater than the minimum recommended value of .50, but those for 8 variables did not reach the ideal value of .70. Inter-correlations between factors EE and PA (.810) and factors R and PA (.897) were too high, implying potential redundancy, overlap or poor discriminant validity (Cohen, Cohen, West, & Aiken, 2003; Tabachnick & Fidell, 2013). The model was therefore re-specified, with additional consideration of conceptual issues.

The first re-specification of the model involved the movement of Item 17 (Finding dementia-related health services) from factor R (Readiness) to Factor PA (Practical aspects). This was suggested by the variable's pattern of standardized residuals and supported by improved factor interpretability. This change led to improvement in all goodness of fit indices (RMR = .058; GFI = .984; AGFI = .981; NFI = .978; PNFI = .872), and a reduction in factor inter-correlations, all being below the cut-off threshold of .80. However, the RMR indicated a reasonable rather than a good fit, so further re-specification of the model was undertaken. This involved the sequential removal of item 15 (Knowing which healthcare services are available) and item 24 (Getting myself to healthcare appointments). These two items were considered problematic due to their large standardised residuals with other variables across factors and the high correlations between their purported factors (i.e. R and PA). The modifications resulted in further improvement in all absolute and comparative fit indices, with RMR (.048) now suggesting a good fit. The parsimony fit index of PNFI remained above .86. Table 2 presents the fit values of the initial and re-specified models.

The results support the hypothesized five-factor structure of the CAAASI-Dem with modifications to three poorly performing items. The resultant 24-item 5-factor CAAASI-Dem (Model 4) fit the data well (RMR = .048; GFI = .988; AGFI = .985; NFI = .985; RFI = .983; PNFI = .864). Factor loading estimates were sufficiently and consistently high, ranging from .64 to .91, providing evidence that the indicator variables were strongly related to their purported factors (Table 3). Correlations between factors were between .318 and .685, implying adequate discriminant validity. Therefore, Model 4 was considered the best fitting structure of the CAAASI-Dem. This final model and its parameter estimates are presented in Figure 1 and Table 3.

Internal reliability

Table 4 presents the results of the Cronbach's Alpha and Construct reliability analyses for each of the five factors of the best fitting 24-item CAAASI-Dem. The alpha estimates indicated high internal consistency for all five factors, ranging from .854 to .938. All item-total correlations were well above .50 and the item-deleted alphas indicated that internal consistency would not significantly improve with the removal of any item (maximum observed increment = .032). Similarly, construct reliability coefficients of all factors were much higher than the recommended threshold of .70. These results suggest that each factor of the final CAAASI-Dem is internally reliable.

Convergent and discriminant validity

Factor loadings and AVE values showed satisfactory evidence for convergent validity of the best fitting model of CAAASI-Dem, with AVE estimates and factor loadings of all factors exceeding .05 (Table 3 and Table 5). Adequate discriminant validity of the five factors was indicated, as the squared root of each factor's AVE was higher than its correlations with other factors; and (2) each factor's AVE was larger than its MSV (Table 5).

Known-groups validity

The Kruskal-Wallis test ($H = 33.558, p < .001, d.f. = 3$) showed a statistically significant difference in the total score of the best fitting CAAASI-Dem model across levels of care experience. The mean rank score of participants who provided both paid and unpaid care for people living with dementia was the highest (612.94). Paid carers had the second highest mean rank score (566.34), followed by unpaid carers (486.83), while those without care experience for people living with dementia scored the lowest (427.82). Participants with different care experience also had significantly different sub-scale scores across the four factors of EE ($H = 14.446, p < .01, d.f. = 3$), R ($H = 65.784, p < .001, d.f. = 3$), SS ($H =$

12.023, $p < .01$, d.f. = 3), and SDS ($H = 46.415$, $p < .001$, d.f. = 3). Accordingly, paid carers and those providing both paid and unpaid care were more likely to have a higher sub-score than unpaid carers and those without care experience. No significant difference was found ($H = 3.653$, $p = .301$, d.f. = 3) between the carer groups in the PA factor sub-score.

Discussion

This study provided empirical evidence to support the reliability and construct validity of the 5-factor model of CAAASI-Dem with modifications to three items. The final 24-item, 5-factor CAAASI-Dem model is highly interpretable and displays a good fit of the model to the observed data. Movement of one variable (Item 17) and the removal of two variables (Item 15 and Item 24) address issues found with the initial EFA-derived 26-item model, including potential redundancy and poor discriminant validity.

All three re-specifications of the model were on the basis of both empirical and conceptual justifications. The movement of item 17 (Finding dementia-related health services) from factor R (Readiness) to factor PA (Practical aspects) was statistically justified and conceptually supportable. The HLQ (Osborne, Batterham, Elsworth, Hawkins, & Buchbinder, 2013) has a similar item (Finding the right healthcare) under the domain of navigating the health system, aligning with the focus of factor PA on the individual's confidence in physically navigating the health care system. Removal of Item 15 (Knowing which healthcare services are available) was statistically justified in the final model but requires further explanation in the context of the CAAASI-Dem domain of Readiness. A positive response to Item 15 suggests having adequate and appropriate information. In the context of applying this tool to a needs-analysis of carers of people living with dementia, its removal will not diminish the utility of the CAAASI-Dem.

Removal of Item 24 (Getting myself to healthcare appointments) – while retaining item 25 (Getting others to health care appointments) – supports the utility of this tool for carers of

people with dementia in particular, who are the primary target for the CAAASI-Dem scale. While not negating the agency of those living with dementia, it is recognized that a dementia diagnosis, when obtained, is often only after significant cognitive changes have occurred and there is subsequent reliance of the person diagnosed on others (Brooker, La Fontaine, Evans, Bray, & Saad, 2014). In the study sample, there was a high frequency of respondents who identify as family members, care workers, or community members. These groups play a crucial role in providing support and care for people living with dementia, including providing assistance in accessing healthcare services. Within this context, it is appropriate to measure participants' confidence in getting others, rather than themselves, to healthcare appointments.

It is worth noting that the best-fitting model showed high internal reliability. With all five factors ranking over 0.85, the Cronbach alphas in this validation study are all sound. In addition, the findings yielded good convergent and discriminant validity, adding strong psychometric properties to support the CAAASI-Dem's five-factor structure. The results also showed evidence for the final model's **sensitivity to differences; in other words, its** ability to discriminate between groups of people with different care experience for people living with dementia, **who were expected to have different levels of confidence** in accessing, appraising and using dementia services and information. The provision of care, either in paid or unpaid work, requires one to be actively involved in navigating the healthcare system and related support channels to leverage dementia services and information on behalf of and for the benefit of the person living with dementia (Ames, Burns, & O'Brien, 2010).

Notable strengths of this independent validation study include the large sample size and diverse demographic profile. Participants varied widely in age and level of completed education and included those with no care experience through to those with both work and personal care experience. However, participants were recruited from enrollees of the same

massive open online course aimed at expanding understanding of dementia. This might have created a selection bias in favor of those with an interest in and/or need for increased dementia knowledge, those with some level of exposure to dementia information and services, or those with easy access to online resources. This should not have impacted on the validation process but may have led to higher confidence scores overall and under-representation of people with poor or limited access to online resources. In addition, male and younger populations are under-represented in the present study. The majority of those caring for people living with dementia are middle aged (Boccardi, 2017; Brodaty & Donkin, 2009) women (Erol, Brooker, & Peel, 2015). However, those men or younger adults in the caring or supportive role of someone living with dementia have been reported to struggle with limited support and access to services (Greenwood & Smith, 2015; Hamblin, 2016; Hutchinson, Robert, Daly, Bulsara, & Kurrle, 2016). In light of this, it is suggested that further testing of the CAAASI-Dem involve samples that adequately represent those population groups to increase representativeness of data.

This study confirmed the EFA-derived five-factor solution, and contributed empirical evidence for the validity and reliability of the revised 24-item CAAASI-Dem. It promises to be a sound instrument to assess individuals' confidence in accessing, appraising and using dementia services and information. As a newly developed tool, however, further validation and/or refinement of the CAAASI-Dem is needed. Future validation of the CAAASI-Dem might seek to examine its test-retest reliability or criterion-related validity, for example, in relation to outcome measures of dementia knowledge, dementia-related help-seeking behaviors, or actual access and usage of dementia services. **The sensitivity of the instrument in detecting differences between distinct groups has been demonstrated using care experience. Other variables are expected from the literature to be related to one's ability to access, appraise, and use dementia services and information, for example education level,**

age, income, or other social-economic variables. Future research will explore such relationships. The potential for the CAAASI-Dem to be used in other geographical and cultural contexts should also be explored.

Conclusion

This paper contains a description of the process of validating the Consumer Access, Appraisal, and Application of Services and Information for Dementia (CAAASI-Dem) tool. The instrument goes beyond considerations of recognition, knowledge of, and attitudes to dementia, to address the more explicit literacy concepts of access, appraisal and use of information and services. The results provide evidence for the 24-item CAAASI-Dem as a valid and reliable five-dimensional scale which is sensitive to group differences related to care experience. Further testing with men and younger age groups will be worthwhile to understand its applicability beyond the most common users of dementia services, middle-aged women. Nonetheless, the measure is of particular importance to help assess the dementia literacy of those caring for the growing number of people living with this major health condition, and determine their needs or identify gaps that need to be addressed in the relevant services. Such data collected across populations could be used to guide efforts to maximize well-tailored dementia health information/services and inform educational programs/interventions at different levels.

References

- Ames, D., Burns, A., & O'Brien, J. (Eds.). (2010). *Dementia* (4 ed.). FL: Taylor & Francis Group.
- Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., Viera, A., Crotty, K., . . . Viswanathan, M. (2011). *Health literacy interventions and outcomes: An updated systematic review*. Retrieved from Rockville (MD):
- Boccardi, V. (2017). The aging caregiver in the aged world of dementia. *Journal of Systems and Integrative Neuroscience*, 3. doi:10.15761/JSIN.1000177
- Bollen, K. A. (1989). *Structural equations with latent variables*. NY: John Wiley & Sons Inc.
- Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. *Dialogues in Clinical Neuroscience*, 11(2), 217-228.
- Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services *Geriatric Psychiatry*, 20(6), 537-546. doi:https://doi.org/10.1002/gps.1322
- Brooker, D., La Fontaine, J., Evans, S., Bray, J., & Saad, K. (2014). Public health guidance to facilitate timely diagnosis of dementia: Alzheimer's COoperative Valuation in Europe recommendations. *International Journal of Geriatric Psychology*, 29(7), 682-693. doi:doi: 10.1002/gps.4066
- Brown, T. A. (2015). *Confirmatory factor analysis for applied research*. New York: The Guilford Press.
- Chinn, D. (2011). Critical health literacy: a review and critical analysis. *Soc Sci Med*, 73(1), 60-67. doi:10.1016/j.socscimed.2011.04.004
- Chinn, D., & McCarthy, C. (2013). All Aspects of Health Literacy Scale (AAHLS): developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings. *Patient Educ Couns*, 90(2), 247-253. https://doi.org/10.1016/j.pec.2012.10.019
- Cohen, J., Cohen, P., West, S. G., & Aiken, L. S. (2003). *Applied multiple regression/correlation analysis for the behavioral sciences* (3 ed.). NJ: Erlbaum.
- Doherty, K. V., Nguyen, H., Eccleston, C., Tierney, L., Mason, R., Bindoff, A., . . . McInerney, F. (2020). Measuring consumer access, appraisal and application of services and information for dementia (CAAASI-Dem): A key component of dementia literacy. *BMC Geriatrics*, 20(484). https://doi.org/10.1186/s12877-020-01891-3
- Dumenci, L., Matsuyama, R., Riddle, D. L., Cartwright, L. A., Perera, R. A., Chung, H., & Siminoff, L. A. (2014). Measurement of cancer health literacy and identification of patients with limited cancer health literacy. *J Health Commun*, 19 Suppl 2, 205-224. https://doi.org/10.1080/10810730.2014.943377
- Erol, R., Brooker, D., & Peel, E. (2015). *Women and Dementia: A Global Research Review*. Retrieved from London:
- Grace, S., & Horstmanshof, L. (2019). A realist evaluation of a regional Dementia Health Literacy Project. *Health Expectations*, 22(3), 426-434. doi:https://doi.org/10.1111/hex.12862
- Greenwood, N., & Smith, R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. *Maturitas*, 82(2), 162-169. doi:https://doi.org/10.1016/j.maturitas.2015.07.013
- Hair, J. (2010). *Multivariate data analysis*. Upper Saddle River, NJ: Prentice Hall.
- Hair, J., Black, W. C., Babin, B. J., & Anderson, R. E. (2014). *Multivariate data analysis* (7 ed.). UK: Pearson

- Hamblin, E. (2016). *Young people caring for adults with dementia in England*. Retrieved from London:
https://www.ncb.org.uk/sites/default/files/field/attachment/young_people_caring_for_adults_with_dementia.pdf
- Hutchinson, K., Robert, C., Daly, M., Bulsara, C., & Kurrle, S. (2016). Empowerment of young people who have a parent living with dementia: A social model perspective. *International Psychogeriatrics*, 28(4), 657-668. doi:10.1017/S1041610215001714
- Jordan, J. E., Buchbinder, R., Briggs, A. M., Elsworth, G. R., Busija, L., Batterham, R., & Osborne, R. H. (2013). The health literacy management scale (HeLMS): a measure of an individual's capacity to seek, understand and use health information within the healthcare setting. *Patient Educ Couns*, 91(2), 228-235.
<https://doi.org/10.1016/j.pec.2013.01.013>
- Loi, S. M., & Lautenschlager, N. T. (2015). Dementia literacy in older adults. *Asia Pac Psychiatry*, 7(3), 292-297. doi:10.1111/appy.12153
- Meyers, L. S., Gamst, G., & Guarino, A. J. (2016). *Applied multivariate research* (3 ed.): SAGE Publications, Inc.
- Murphy, P. W., Davis, T. C., Long, S. W., Jackson, R. H., & Decker, B. C. (1993). Rapid estimate of adult literacy in medicine (REALM): A quick reading test for patients. *Journal of Reading*, 37(2), 124-130.
- Nutbeam, D. (2000). Health literacy as a public health goal: A challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), 259-267.
- Nutbeam, D. (2008). The evolving concept of health literacy. *Soc Sci Med*, 67(12), 2072-2078. doi:10.1016/j.socscimed.2008.09.050
- Osborne, R. H., Batterham, R. W., Elsworth, G. R., Hawkins, M., & Buchbinder, R. (2013). The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*, 13, 658.
- Parker, R. M., Baker, D. W., Williams, M. V., & Nurss, J. R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, 10, 537-541.
- Tabachnick, B. G., & Fidell, L. S. (2013). *Using multivariate statistics* (6 ed.). MA: Pearson.
- Yeh, J.-Z., Wei, C.-J., Weng, S.-F., Tsai, C.-Y., Shih, J.-H., Shil, C.-L., & Chiu, C.-H. (2018). Disease-specific health literacy, disease knowledge, and adherence behavior among patients with type 2 diabetes in Taiwan. *BMC Public Health*, 18(1).
<https://doi.org/doi:10.1186/s12889-018-5972-x>

Tables and Figures

Table 1. *Characteristics of the participants*

	Overall (n=3277)
Gender	
Female	2830 (86.4%)
Male	426 (13.0%)
Other	4 (0.1%)
Prefer not to say	10 (0.3%)
Not indicated	7 (0.2%)
Age (years)	
Mean (SD)	48.0 (14.4)
Median [Min, Max]	50.0 [18.0, 89.0]
Not indicated	111 (3.4%)
Highest level of completed education	
No formal education	12 (0.4%)
Primary school	10 (0.3%)
Secondary school, incomplete (any of years 7 to 11)	322 (9.8%)
Secondary school, completed (year 12)	308 (9.4%)
Certificate or Apprenticeship	498 (15.2%)
Diploma or Associate Degree	620 (18.9%)
Bachelor degree or equivalent	864 (26.4%)
Honours, Graduate Certificate, Graduate Diploma or equivalent	256 (7.8%)
Postgraduate Degree (Masters or Doctorate)	364 (11.1%)
Not indicated	23 (0.7%)
Carer role/s	
Paid Carer	1201 (36.6%)
Unpaid Carer	558 (17.0%)
Both Paid and Unpaid Carer	749 (22.9%)
Neither Paid nor Unpaid Carer	767 (23.4%)
Not indicated	2 (0.1%)
Lives in Australia	
No	763 (23.3%)
Yes	2505 (76.4%)
Not indicated	9 (0.3%)

Table 2. *Fit index values of all tested models*

Model	RMR	GFI	AGFI	NFI	RFI	PNFI
Model 1_Initial 5-factor model	.062	.982	.978	.978	.975	.869
Model 2_Item 17 moved	.058	.984	.981	.981	.978	.872
Model 3_Item 17 moved, Item 15 removed	.056	.985	.981	.981	.979	.867
Model 4_Item 17 moved, Item 15 & 24 removed	.048	.988	.985	.985	.983	.864

Table 3. *Unweighted Least Square (ULS) Standardized regression weights of the best fitting 24-item model of CAAASI-Dem (Model 4)*

Item	Item content	Factor				
		1	2	3	4	5
1	Deciding if dementia health information is relevant to me	.789				
2	Knowing whether to believe information about dementia	.786				
3	Understanding the health care advice that I am given about dementia	.812				
4	Questioning advice on dementia given to me by a healthcare provider	.804				
5	Comparing dementia health information from different sources	.795				
6	Discussing dementia with a healthcare provider by myself	.824				
7	Reading information from a healthcare provider by myself	.751				
8	Discussing very sensitive and personal issues about dementia with healthcare providers	.814				
9	Finding dementia health information by myself	.747				
10	I have enough information about dementia to plan for future needs		.755			
11	I have enough information about dementia to help me deal with current needs		.703			
12	I have good quality information about dementia		.734			
13	I can rely on at least one healthcare provider to help when there is urgent need		.642			
14	I have a least one healthcare provider who can give me advice about dementia-related healthcare needs		.657			
16	Working out what dementia services may be needed in the future		.807			
18	If I need help, I have people I can call			.840		
19	There are people I can spend time with			.831		
20	I have support from my community			.809		
21	Accessing respite care				.914	
22	Organizing an aged care assessment				.860	
23	Organizing an advance care plan				.888	
17	Finding dementia related health services					.822
25	Getting others to healthcare appointments					.851
26	Filling out forms on paper					.772

Table 4. *Cronbach alpha and Construct reliability*

Factor	Factor label (initial)	Number of items	Cronbach's Alpha	Construct reliability
Factor 1	Evaluation & engagement (EE)	9	.938	.939
Factor 2	Readiness (R)	6	.868	.864
Factor 3	Social supports (SS)	3	.865	.866
Factor 4	Specific dementia services (SDS)	3	.917	.918
Factor 5	Practical aspects (PA)	3	.854	.856

Table 5. Average variance extract (AVE), Maximum shared variance (MSV), the squared root of AVE (in bold), and correlations between the factors

Factor	AVE	MSV	Factor				
			EE	R	SS	SDS	PA
Evaluation & engagement (EE)	.630	.469	.794				
Readiness (R)	.516	.469	.685	.719			
Social supports (SS)	.684	.242	.375	.492	.827		
Specific dementia services (SDS)	.788	.375	.484	.612	.318	.888	
Practical aspects (PA)	.665	.410	.640	.493	.410	.466	.816

Figure 1. Model 4 - Best-fitting model of the CAAASI-Dem and its parameter estimates

