The development of positive psychology outcome measures and their uses in dementia research: A systematic review

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Abstract

Positive psychology is gaining credence within dementia research but currently there is a lack of outcome measures within this area developed specifically for people with dementia. Authors have begun adopting positive psychology measures developed with other populations but there is no consensus around which are more appropriate or psychometrically robust. A systematic search identified measures used between 1998- 2017 and an appraisal of the development procedure was undertaken using standardised criteria enabling the awarding of scores based on reporting of psychometric information. Twelve measures within the constructs of identity, hope, religiosity/ spirituality, life valuation, self-efficacy, community and wellbeing were identified as being used within 17 dementia studies. Development procedures were variable and scores on development criterion reflected this variability. Of the measures included, the Herth Hope Index, Systems of Belief Inventory and Psychological Well-being Scale appeared to be the most robustly developed and appropriate for people with dementia.

Keywords: psychometrics, outcome measures, dementia, Alzheimer's, hope, spirituality, community, wellbeing.

Introduction

In the last 20 years there have been efforts to explore dementia from a positive methodology perspective rather than just a narrative of decline, centred on the medical model. Historically, behavioural and psychological symptoms of dementia were viewed as being caused solely by a somatic organic illness (Dawson & Reid, 1987) and people with dementia were often viewed as dependent and unable to contribute to society (Lyman, 1989). Person centred theory (Kitwood, 1993) represented a shift from the prevailing biomedical view point to a more holistic approach, in which social and individual factors contributed to a unique experience of dementia for each person (Kitwood, 1997).

This shifting awareness and empowerment for people with dementia was also represented through the use of outcome measurement within research. Previously, there was the view that people with dementia were unable to make accurate judgements within research and proxy rated outcome measures were often relied upon (Dawson, Welsh-Bohmer, & Siegler, 2000). Furthermore, outcome measures used were based on deficits or problem such as depression (Alexopoulos, Abrams, Young, & Shamoian, 1988), anxiety (Shankar, Walker, Frost, & Orrell, 1999) or neuropsychiatric symptoms (Cummings, 1997). Quality of life is now recognised as a desired outcome for psychosocial research (Logsdon, Gibbons, McCurry, & Teri, 1999) and people with dementia are being asked to complete outcome measures themselves, in conjunction with proxy report.

Positive psychology may be the next step within this framework and refers to the use of empirical approaches to examine human strengths and capabilities that contribute to wellbeing, sometimes called ‘flourishing’ (Seligman, 2002). This theory is beginning to be applied to dementia populations, for example, the role of hope (Wolverson, Clarke, & Moniz-Cook, 2010) and humour (Clarke & Irwin, 2016). People with dementia are capable of using these strengths to actively seek enjoyment and pleasure but there has been no quantitative research to supplement the qualitative findings. As positive psychology refers to the scientific study of wellbeing, quantative measurement of positive constructs is needed.

The use of outcome measures has long been held as a gold standard in research and they often undergo a rigorous development procedure (Moniz-Cook, et al., 2008). However, currently there is a lack of positive psychology outcome measures developed for this population (Clarke, Wolverson, Stoner, & Spector, 2016).

Existing measures of positive psychology have begun to be applied within dementia research but there is no consensus as to which are more appropriate or psychometrically robust. This review aimed to identify those measures currently in use for dementia populations and conduct an appraisal of the measures' psychometric properties, including data from dementia populations in order to guide future choice of measures in research and practice.

Methods

Design

A systematic search of positive psychology outcome measures used within research for people with dementia was undertaken. Systematic principles for searching, screening and appraising studies were followed (Moher, Liberati, Tetzlaff, Altman, & PRISMA Group, 2009) and searches were then conducted to identify development information of included measures.

Search Strategy

PsychInfo, PubMed and MedLine were searched for results from 1998 – 2017. Search terms were: self-efficacy, life satisfaction, hope, resilience, wisdom, growth, coherence, control, autonomy, pleasure, self-realisation, sense of agency, gratitude, happiness, optimism, transcendence, positive, dignity, social participation, social inclusion, self-concept, reciprocity, connectedness, engagement, humour, creativity, flow, spirituality, love, compassion, benefit finding, community integration, opportunity, social adjustment, mindfulness, acceptance, successful aging, wellbeing, quality of life, independence, social health (Seligman, 1998). These search terms were then combined again with: dementia, Alzheimer, cognitive impairment, senile, vascular. Truncations of search terms were used where appropriate.

Terms indicative of related fields were also included (quality of life; wellbeing; social health) and in depth search strategy was employed in order to fully capture positive

psychology measures. Titles were included if the study reported on a dementia population, abstracts were then screened for methodology indicative of the use of outcome measures and full texts were sought for the remaining results to identify positive psychology outcome measures. Ambigious titles or abstracts were included until a decision could be made, including research with 'dyads'.

Inclusion Criteria

1) Use of positive psychology outcome measure as identified within the search terms.
2) Use of above measure(s) within a dementia population.
3) Both development of measures and use of measures published within a peer-reviewed journal
4) Published between 1998- 2017.

Exclusion criteria

1) Studies published in a language other than English if a translation was not available.
2) Only used proxy-reporting.
3) Development information for outcome measures was not freely available.

Appraisal of Psychometric Properties

Included measures were grouped and a quality assessment was undertaken using an established criteria (Terwee, et al., 2007) (Figure 1), which assesses development procedures of measures and has been used successfully in other reviews (Stoner, Orrell, & Spector, 2015; Windle, Bennett, & Noyes, 2011). For each item within the criterion, a score of two was awarded if the study was adequately designed and appropriate statistics given, a score of one was awarded if there were methodological shortfalls such as inadequate design. If, despite adequate design, the study produced results indicating poor psychometric properties or no information was reported a zero was awarded (possible range 0-18). Two authors (CS and JS) undertook this analysis independently and a consensus meeting was held to ensure reliability of reporting (Table 1).

INSERT FIGURE 1 HERE

Results

After limitations were applied and duplicates removed, 3910 results were identified of which 2363 were included on title. The 1547 papers excluded at this stage did not report on a dementia population. At the second stage, 828 abstracts were included, for which full texts were sourced. Of these, the vast majority were excluded as no positive psychology outcome measures were identified (568) or measures were used in caregiver studies with no outcomes used for the person with dementia (78) (Figure 2). Twelve studies were subsequently excluded as development information for the measures used was not published in a peer-reviewed journal or was not freely available. This left a total of 12 positive psychology outcome measures used within 17 studies for analysis (Table 2). Of the studies included here, three used a combination of self and proxy reporting (Cohen-Mansfeld, Thein, Dakheel-Ali & Marx, 2010; Hilgeman et al., 2014; Jolley et al., 2010). The remainder used self-report only for the measures included here. Development scores were variable, with scores ranging from three to 11. CS and JS agreed on most ratings, apart from the interpretability section of the Terwee criteria. Disagreements were discussed until a consensus could be reached.

INSERT FIGURE 2 HERE

Identity

The Self-identity in Dementia (SID; Cohen-Mansfeld, Golander, & Arnheim, 2000) (3/18) was the only measure identified to have been developed within a dementia population. It was notably lacking all psychometric information on the assessment criteria apart from content validity, for which it scored two points, and construct validity for which it scored one point. This was due to the involvement of the target population and experts in item development and a clear description of the aims and domains to be measures. In a predictive analysis of variance in mood and quality of life from aspects of identity, authors suggested a model including aspects of identity could predict depression. More specifically, scores on the SID family and leisure subscales, significantly predicted depression ($p<.01$) (Caddell & Clare, 2012) lending evidence to the SID's predictive validity. An indication of discriminant validity was found between identity and cognition, as Caddell and Clare (2013a) observed no significant correlation between mean SID scores and the CERAD cognitive battery.

The SID was also used in an additional study examining differences in identity of people with dementia and older adults without dementia. Both groups scored family role as the strongest aspect of their identity and occupational identity as their weakest, suggesting that dementia may not negatively affect identity, within early stages. This provides a further indication of the SID's content validity and is supported by an additional study that reported family identity as being most important (87%) (Cohen-Mansfeld, Thein, Dakheel-Ali, & Marx, 2010). Evidence of the SID's convergent validity was also observed between self-identity, engagement duration, attention and attitude ($p<.001$). Healthy older adults reported significantly more distress relating to identity than people with dementia (Caddell & Clare, 2013b), possibly indicating some degree of interpretability or discriminant validity.

INSERT TABLE 1 HERE

Hope

The Herth Hope Index (HHI; Herth, 1992) and Adult Hope Scale (AHS; Snyder, et al., 1991) were of the most robustly developed measures (10/18 and 11/18) and The Life Orientation Test- Revised (LOT-R; Scheier, Carver, & Bridges, 1994) scored less (7/18). All three measures failed to define a minimal important change to assess the responsiveness of the measure and the HHI reported an internal consistency indicative of multicollinearity (α=.97). The HHI was used in a small scale feasibility study for dignity therapy for people with dementia (Johnston, et al., 2016). Pre and post intervention scores, as percentage changes, on the HHI were only available for four participants and were variable. The maximum increase was 6.25% and one participant had a decrease of 18.7%. This may indicate an issue with sensitivity to change as the HHI was found to be stable over a two-week period (.91) during the development stage. However, as this was a feasibility study, the sample size was small and no firm conclusions can be drawn for the sensitivity of the HHI in people with dementia.

The AHS was the most thoroughly developed measure of all the measures included here. Notably, it had high levels of construct and convergent validity with correlations being observed between a number of scales including life orientation, self-esteem,

hopelessness and depression. Furthermore, discriminant validity was established between hope and self-consciousness.

The LOT-R was reported as having a good level of internal consistency (.82) and convergent validity was established between dispositional optimism, self-mastery, trait anxiety, neuroticism and self-esteem. Both the AHS and the LOT-R were used in a study examining biological markers of allostasis (the ability to maintain stability in a changing environment through psychological or behavioral change) as an index of psychological resilience. These biological markers were compared to baseline resources including hope (Meeks, et al., 2016). However, the authors reported no significant findings in relation to allostasis and hope.

Religiosity/ Spirituality

The Systems of Belief Inventory (SBI-15; Holland, et al., 1998) and the Royal Free Interview for Religious and Spiritual Beliefs (RFIRSB; King & Speck, 1995) scored 11/18 and 5/18 respectively. Internal consistency for the SBI-15 was excellent (.93) as was test-retest reliability (.95) for both religious and non-religious groups. Furthermore, criterion validity was adequate, with the SBI-15 correlating with other measures of religiosity and there was a significant difference between scores for religious and non-religious participants, indicating discriminant validity. A small-scale study utilised the SBI to examine spiritual beliefs in people with early stage dementia (Katsuno, 2003) and a positive correlation was observed between spirituality and quality of life ($p<.05$) indicating convergent validity between these measures.

The RFIRSB was developed with the use of experts and population involvement but the internal consistency analysis indicated an issue with the philosophical belief subscale (.60) and the overall internal consistency was not provided. However, test-retest reliability was adequate over a one-week period for both philosophical and spiritual subscales (.91 and .95 respectively). Furthermore, construct validity was established as there was a significant relationship between spirituality and the frequency of practice of religious faith ($p<.0005$) and people with dementia appeared to rate the strength of belief as most important (Jolley, Benbow, Grizzell, Willmott, Bawn, & Kingston, 2010), suggesting additional content validity of the measure.

Life Valuation

The Meaning in Life Scale (MLS; Krause, 2004) and the Terrible Delightful Scale (TDS; Michalos, 1980) scored 6/18 and 3/18 resepctively. The MLS was developed in a large sample of older adults. Whilst item selection did not involve target population or experts, the internal consistency (.925) and factor analysis yielded satisfactory results. No significant effects or trends of MLS were reported in a trial of advanced care planning and identity for people with dementia (p=.71) (Hilgeman, Allen, Snow, Durkin, DeCoster, & Burgio, 2014), potentially indicating an issue with sensitivity or low sample size and study design.

The TDS was developed without the input of experts or the use of a target population and was not awarded points for content validity. Michalos (1998) undertook an extensive pathway analysis but did not report the internal consistency. However, it was one of the few papers to report the floor and ceiling effects of the measure. Predictive validity of the TDS was examined in an observational study examining the relationship life satisfaction and functional impairment (St. John & Montgomery, 2010). Within this study, people with dementia or mild cognitive impairment had slightly lower overall life satisfaction than those without.

Self-efficacy

The General Self-efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) and the Self-efficacy Scale (SES; Sherer et al., 1982) both scored moderately (6/18). Authors did not report on aspects of content validity of the GSE, but internal consistency was .86. Subgroups were explored but no minimal important change was defined, limiting the measures interpretability. The GSE was used in an evaluation of a health promotion course for 89 people with dementia (Buettner & Fitzsimmons, 2009) but no significant differences between pre and post testing were reported. However, this may be an issue with intervention fidelity, as the authors reported significant findings in an earlier unpublished pilot study.

Authors of the SES did report some aspects of content validity but failed to report responsiveness, floor and ceiling effects or interpretability. The authors reported the internal consistency for both subscales (.86 and .71) but not the overall internal

consistency. However, the measures demonstrated a high level of convergent validity with locus of control, ego strength, interpersonal competency and self-esteem. Clements-Cortes (2013) used the SES to assess the effectiveness of a choir group for older adults, an unclear proportion of which had dementia. It is, therefore, not possible to draw conclusions about the content validity of this measure for people with dementia. Furthermore, the authors were not able to demonstrate the measures responsiveness on either subscale following the intervention (p=.20; p=.37) but this may be attributable to the low sample size.

Community

The Brief Sense of Community Scale (BSCS; Peterson, Speer, & McMillan, 2008) scored moderately low (5/18) lacking information regarding test-retest reliability, responsiveness, skew of data and interpretability. There was no target population involvement or information regarding item selection. However, convergent validity was established between the BSCS and measures of community participation, depression and intrapersonal psychological empowerment (p<.01). Within a dementia setting, the measure was used to assess the efficacy of an intergenerational intervention but no significant were found (p= .168) (Low, Russell, McDonald, & Kauffman, 2015). Authors reported no significant findings of other measures in the study including agitation and quality of life, possible indicating issues with study design.

Wellbeing

The Ryff Psychological Wellbeing Scale (PWB) (7/18) contains six subscales that measure self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth. It was found to have robust criterion validity and interpretability but lacked information on stability and responsiveness. One study utilized the measure in its entirety (Gonzalez, Mayordomo, Torres, Sales, & Meléndez, 2015), one used the environmental mastery subscale (Wettstein, Wahl, Shoval, Auslander, Oswald, & Heinik, 2014) and one used the purpose in life subscale (Mak, 2011). Gonzalez, Mayordomo, Torres, Sales and Meléndez (2015) examined the effect of reminiscence therapy within two retirement homes. The authors found significant improvements on all dimensions of the PWB, except for the purpose in life subscale, indicating the measures ability to detect change. There was a

significant interaction effect of time and group for self-acceptance (p=.002), positive relations with others (p=.019), autonomy (p=.001) and environmental mastery (p=.003). The second study utilised the environmental mastery subscale of the PWB in an observational study and provided further evidence for the measures construct validity noting that higher walking distances and walking speed were significantly related to higher environmental mastery (r=.40 and r=.45, p<.05) (Wettstein, Wahl, Shoval, Auslander, Oswald, & Heinik, 2014). Mak (2011) utilised the purpose in life scale in a randomised trial and reported the internal consistency as .73, lower than the original reported alpha of .90 but still satisfactory. A positive correlation was observed between purpose in life and goal pursuit (p<.001), further evidencing construct validity.

INSERT TABLE 2 HERE

Discussion

Twelve positive psychology outcome measures were identified within the constructs of identity, hope, religiosity/ spirituality, life valuation, self-efficacy, community and wellbeing as being used in 17 research studies of people with dementia. Only one of these measures was developed for people with dementia (SID). Most outcome measures identified scored moderately on their development procedures, with hope scales developed the most robustly and identity the least robustly.

Whilst the development information was lacking for the SID, it has been used in a number of studies successfully and suggests the measure is an appropriate tool for assessing identity for people with dementia. Despite the AHS scoring slightly higher than the HHI at the quality assessment stage, it is possible that the HHI may be more applicable as hope for people with dementia appears to be more generalised in nature (Wolverson, Clarke, & Moniz-Cook, 2010), rather than goal oriented (Snyder, et al., 1991). Therefore, the HHI may hold more content validity for this population. Spirituality and religiousness appears to be a pervading concept, in that spirituality and religiousness hold significance in the self-concept and change, hope for the future and positive attitudes for people with dementia (Dalby, Sperlinger, & Boddington, 2011). The SBI-15 appears to be an adequate tool to detect and measure spiritual beliefs, as development procedures were robust and some psychometric properties

have been found to be satisfactory in dementia populations. Both the TDS and the MLS scored moderately for their development procedures. Whilst the TDS appeared to be more successful within a dementia population, it is recommended that both measures are in need of further psychometric examination before they are routinely used. Both self-efficacy scales and the BSCS scale failed to show sensivitiy to their respective interventions. Whilst this may be due to issues with the study design, rather than the measures, it is recommeneded that a more detailed examination of self-efficacy scales and community scales for people with dementia is needed.

Of the scales included Ryff's PWB appeared to be the most successful, in terms of its development procedures and the studies in which it was used. The lower alpha reported within a dementia population is still within the acceptable range it appears to be sensitive to change. It would then appear that this scale is appropriate for people with dementia and it is recommended for use within research.

Methodological Problems

All measures included here failed define a minimal important change, which is a requirement of the Terwee criteria for interpretability. This meant that it was nearly impossible to award scores for responsiveness. Reporting on reliability was mixed with only four studies reporting the test-retest reliability of measures. Inferring sensitivity of change of measures within dementia studies included here was problematic, due mostly to study design including low sample sizes. A large majority of the studies included were feasibility studies and were not powered to detect effect sizes. Additionally, obtaining the development papers of included measures was sometimes difficult and could only be accomplished by extensive searching.

Limitations

Whilst an effort was made to include search terms that were all-encompassing and indicative of positive psychology, it is noted that definitions of what constitutes this theory vary. Consequently, broad search terms including the related fields were used resulting in a large number of studies excluded. The criteria used here is one of the few comprehensive enough to cover most aspects of a measures psychometric properties. However, it may have been overly constraining as responsiveness and

interpretability were rarely reported. Future authors may wish to include such information for the purpose of reviews or for measure selection.

Future Research

These studies highlight the need for authors to consider psychometric analyses when designing their research. All measures included here provided no information regarding responsiveness to change. This is particularly important when considering interventional research as most studies here failed to find a significant effect of the interventions detailed. Whilst this may be due to a range of factors including low sample size or the effectiveness of the actual intervention, it is recommended that future researchers select measures that have been established as sensitive to intervention to ensure the most accurate appraisal of efficacy of their intervention.

Furthermore, only one measure identified here was developed within a sample of people with dementia, drawing on their perceptions and experiences. The majority of studies included here used measures developed for other populations and, as such, may not have been suitable to detect meaningful change for a person with dementia. It is possible that positive dementia specific measures such as those developed for quality of life (e.g. Logsdon, Gibbons, McCurry, & Teri, 1999) may be a more valid tool for detecting change within interventional research. It is, therefore, also recommended that dementia specific measures of positive psychology are developed to ensure valid and reliable tools are consistently used in this emerging area of research.

Whilst positive experiences have been an emerging theme for people with dementia, it is often within a 'coping' paradigm in which positive experiences are conceptualised as a strategy to adapt or retain normality when faced with negative experiences and loss (Clare, et al., 2013). This prevailing model of positive psychology and dementia is not supported within the qualitative literature (see Wolverson, Clarke, & Moniz-Cook, 2015 for a review) and this should be reflected in future outcome measure development or adaptation. By reducing positive psychology to coping or as a means of denial (de Boer, Hertogh, Dröes, Riphagen, Jonker, & Eefsting, 2007), potentially valuable positive characteristics are at risk of being not investigated properly. Future researchers should be wary of assuming that content validity remains the same,

despite using measures with populations they were not designed for. This is exampled through the use of the AHS, despite multidimensional hope measures potentially being more applicable.

Conclusion

12 positive psychology outcome measures, with development information available, have been used within dementia research. However, the quality of the development procedures was variable, with authors failing to report important aspects of psychometric analyses including responsiveness and stability. The HHI, SBI-15 and PWB appear to be the most psychometrically sound and appropriate for people with dementia and it is recommended that future authors explore these concepts.

Declaration of Conflicting Interests

The authors declare no competing interests.

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References

Alexopoulos, G. S., Abrams, R. C., Young, R. C., & Shamoian, C. A. (1988). Cornell scale for depression in dementia. *Biological Psychiatry, 23* (3), 271-284.

Bandura, A. (1997). *Self-efficacy: The exercise of control.* New York: Freeman & Co.

Buettner, L. L., & Fitzsimmons, S. (2009). Promoting health in early-stage dementia: Evaluation of a 12-week course. *Journal of Gerontological Nursing, 35* (3), 39-49.

Caddell, L.S., & Clare, L. (2013a). A profile of identity in early-stage dementia and comparison with healthy older people. *Aging & Mental Health, 17*(3), 319 327

Caddell, L. S., & Clare, L. (2013b). How does identity relate to cognition and functional abilities in early-stage dementia? *Aging, Nuropsychology and Cognition, 20* (1), 1-21.

Caddell, L. S., & Clare, L. (2012). Identity, mood, and quality of life in people with early-stage dementia. *International Psychogeriatrics, 24* (8), 1306-1315.

Clare, L., Whitaker, C. J., Nelis, S. M., Martyr, A., Markova, I. S., Roth, I., et al. (2013). Self-concept in early stage dementia: Profile, course, correlates, predictors and implications for quality of life. *International Journal of Geriatric Psychiatry, 28*, 494-503.

Clarke, C., & Irwin, H. (2016). Humour and Dementia. In C. Clarke, & E. Wolverson, *Positive Psychology Approaches to Dementia* (pp. 110- 132). London: Jessica Kingsley Publishers.

Clarke, C., Wolverson, E., Stoner, C., & Spector, A. (2016). Overview and Ways Forward for a Positive Psychology Approach to Dementia. In E. Wolverson, & C. Clarke, *Positive Psychology Approaches to Dementia* (pp. 253-279). London: Jessica Kingsley Publishers.

Clements-Cortes, A. A. (2013). Buddy's Glee Club: Singing for life. *Activities, Adaptation & Aging, 37* (4), 273- 290.

Cohen-Mansfeld, J., Golander, H., & Arnheim, G. (2000). Self-identity in older persons suffering from dementia: Preliminary results. *Social Science and Medicine, 51*, 381-394.

Cohen-Mansfeld, J., Thein, K., Dakheel-Ali, M., & Marx, M. S. (2010). The underlying meaning of stimuli: Impact on engagement of persons with dementia. *Psychiatry Research, 177*, 216-222.

Cummings, J. L. (1997). The Neuropsychiatric Inventory: assessing psychopathology in dementia patients. *Neurology, 48* (5 Suppl 6), S10-16.

Dalby, P., Sperlinger, D. J., & Boddington, S. (2011). The lived experience of spirituality and dementia in older people living with mild to moderate dementia. *Dementia, 11* (1), 75- 94.

Dawson, D., Welsh-Bohmer, K. A., & Siegler, I. (2000). Premorbid personaility predicts level of rated personality change in patients with Alzheimer's Disease. *Alzheimer Disease and Associated Disorders, 14* (1), 11-19.

Dawson, N. T., Powers, S. M., Krestar, M., Yarry, S. J., & Judge, K. S. (2013). Predictors of self-reported psychosocial outcomes in individuals with dementia. *The Gerontologist, 53* (5), 748-759.

Dawson, P., & Reid, D. W. (1987). Behavioural dimensions of patients at risk of wandering. *The Gerontologist, 24*, 104-107.

de Boer, M. E., Hertogh, C. M., Dröes, R., Riphagen, I. I., Jonker, C., & Eefsting, J. A. (2007). Suffering from dementia- the patient's perspective: A review of the literature. *International Psychogeriatrics, 19* (6), 1021-1039.

Fankhauser, S., Drobetx, R., Mortby, M., Maercker, A., & Forstmeier, S. (2014). Depressive symptoms in later life: differential impact of social support and motivational processes on depression in individuals with and without cognitive impairment. *European Journal of Ageing, 15* (4), 321- 332.

Gonzalez, J., Mayordomo, T., Torres, M., Sales, A., & Meléndez, J. C. (2015). Reminiscence and dementia: A therapeutic intervention. *International Psychogeriatrics, 27* (10), 1731- 1737.

Herth, K. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. *Journal of Advanced Nursing, 17*, 1251- 1259.

Hilgeman, M. M., Allen, R. S., Snow, A. L., Durkin, D. W., DeCoster, J., & Burgio, L. D. (2014). Preserving identity and planning for advance care (PIPAC): Preliminary outcomes from a patient-centered intervention for individuals with mild dementia. *Aging & Mental Health, 18* (4), 411- 424.

Holland, J. C., Kash, K. M., Passik, S., Gronert, M. K., Sison, A., Lederberg, M., et al. (1998). A brief spiritual beliefs inventory for use in quality of life research in life-threatening illness. *Psycho-Oncology, 7*, 460- 469.

Hyde, M., Wiggins, R. D., Higgs, P., & Blane, D. B. (2003). A measure of quality of life in early old age: The theory, development and properties of a needs satisfaction model. *Aging & Mental Health, 7* (3), 186- 194.

Johnston, B., Lawton, S., McCaw, C., Law, E., Murray, J., Gibb, J., et al. (2016). Living well with dementia: Enhancing dignity and quality of life, using a novel intervention, Dignity Therapy. *International Journal of Older People Nursing, 11*, 107- 120.

Jolley, D., Benbow, S. M., Grizzell, M., Willmott, S., Bawn, S., & Kingston, P. (2010). Spirituality and faith in dementia. *Dementia, 9* (3), 311-325.

Katsuno, T. (2003). Personal spirituality of persons with early-stage dementia: Is it related to perceived quality of life? *Dementia, 2* (3), 315-335.

King, M., & Speck, P. (1995). The Royal Free Interview for Religious and Spiritual Beliefs: Developments and standardisation. *Psychological Medicine, 25*, 1125- 1134.

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health, 1* (1), 13-22.

Kitwood, T. (1993). Towards a theory of dementia care: The interpersonal process. *Ageing and Society, 13*, 51- 67.

Krause, N. (2004). Stressors in highly valued roles, meaning in life and physical health of older adults. *The Journals of Gerontology Sereies B: Psychological Sciences and Social Science, 59,* S287- S297.

Lee, C., & Bobko, P. (1994). Self-efficacy beliefs: Comparison of five measures. *Journal of Applied Psychology, 79,* 364-369.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*, 21-32.

Low, L., Russell, F., McDonald, T., & Kauffman, A. (2015). Grandfriends, and intergenerational program for nursing-home residents and preschoolers: A randomised trial. *Journal of Intergenerational Relationships, 13* (3), 227-240.

Lyman, K. A. (1989). Bringing the social back in: A critique of the biomedicalisation of dementia. *The Gerontologist, 29* (5), 597- 605.

Mak, W. (2011). Self-reported goal pursuit and purpose in life among people with dementia. *Journal of Gerontology: Psychological Sciences*, *66B* (2), 177-184.

Meeks, S., Van Haitsma, K., Mast, B. T., Arnold, S., Streim, J. E., Sephton, S., et al. (2016). Psychological and social resources related to biomarkers of allostasis in newly admitted nursing home residents. *Aging & Mental Health, 20* (1), 88-99.

Michalos, A. C. (1980). Satisfaction and happiness. *Social Indicators Research, 8*, 385- 422.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Public Library of Science, 6* (7), 1-6.

Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., Vught, M. D., et al. (2008). A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging & Mental Health, 12* (1), 14-29.

Peterson, N. A., Speer, P. W., & McMillan, D. W. (2008). Validation of a brief sense of community scale: Confirmation of the principle theory of sense of community. *Journal of Community Psychology, 36* (1), 61- 73.

Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery and self-esteem): A re-evaluation of the Life Orientation Test. *Journal of Personality and Social Psychology, 67*, 1063- 1078.

Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-efficacy Scale. In J. Weinman, S. Wright, & M. Johnston, *Measures in health psychology: A user's portfolio* (pp. 35-37). Windsor, UK: NFER-NELSOn.

Seligman, M. E. (2002). *Authentic happiness.* New York: Free Press.

Seligman, M. E. (1998). *The President's Address.* American Psychological Association. Washington, DC: American Psychological Association.

Shankar, K. K., Walker, M., Frost, D., & Orrell, M. W. (1999). The development of a valid and reliable scale for rating anxiety in dementia (RAID). *Aging Mental Health, 3* (1), 39-49.

Sherer, M., Maddox, J. E., Mercandante, B., Prentice-Dunn, S., Jacobs, B., & Rogers, R. W. (1982). The Self-Efficacy Scale: Construction and validation. *Psychological Reports, 51*, 663-671.

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T., et al. (1991). The will and the ways: Development and validation of an individual differences measure of hope. *Journal of Personaility and Social Psychology, 60* (4), 570- 585.

St. John, P. D., & Montgomery, P. R. (2010). Cognitive impairment and life satisfaction in older adults. *International Journal of Geriatric Psychiatry, 25*, 814- 821.

Stoner, C. R., Orrell, M., & Spector, A. (2015). Review of positive psychology outcome measures for chronic illness, traumatic brain injury and older adults: Adaptability in dementia. *Dementia and Geriatric Cognitive Disorders, 40* (5-6), 340-357.

Terwee, C. B., Bot, S. D., de Boer, M. R., van Der Windt, D. A., Knol, D. L., Dekker, J., et al. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. *Journal of Clinical Epidemiology, 60* (1), 34- 42.

Wettstein, M., Wahl, H., Shoval, N., Auslander, G., Oswald, F., & Heinik, J. (2014). Cognitive status moderates the relationship between out-of-home behavious (OOHB), environmental mastery and affect. *Archives of Gerontology and Geriatrics, 59*, 113- 121.

Windle, G., Bennett, K. M., & Noyes, J. (2011). A methodological review of resilience measurement skills. *Health and Quality of Life Outcomes, 9,* 1- 18.

Wolverson, E. L., Clarke, C., & Moniz-Cook, E. D. (2015). Living positively with dementia: A systematic review and synthesis of the qualitative literature. *Aging & Mental Health*, 1-25.

Wolverson, E. L., Clarke, C., & Moniz-Cook, E. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Aging & Mental Health*, *14* (4), 450-460.

Figure 1 Terwee Criteria

Property		Definition	Quality criteria	
1	Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire (the extent to which the measure represents all facets of the construct under question).	2	A clear description of measurement aim, target population, concept(s) that are being measured, and the item selection AND target population (investigators OR experts) were involved in item selection.
			1	A clear description of the above-mentioned aspects in lacking OR only target population involved OR doubtful design or method.
			0	No target population involvement OR no information found on target population involvement.
2	Internal consistency	The extent to which items in a (sub)scale are inter-correlated, thus measuring the same construct.	2	Factor analyses performed on adequate sample size (7* #items and > = 100) AND Cronbach's alpha(s) calculated per dimension AND Cronbach's alpha(s) between 0.70 and 0.95
			1	No factor analysis OR doubtful design or method
			0	Cronbach's alpha(s) <0.70 or >0.95, despite adequate design and method OR No information found on internal consistency
3	Criterion validity	The extent to which scores on a particular questionnaire relate to a gold standard	2	Convincing arguments that gold standard is "gold" AND correlation with gold standard > = 0.70
			1	No convincing arguments that gold standard is "gold" OR doubtful design or method
			0	Correlation with gold standard <0.70, despite adequate design and method OR no information found on criterion validity
4	Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured	2	Specific hypotheses were formulated AND at least 75% of the results are in accordance with these hypotheses
			1	Doubtful design or method (e.g.) no hypotheses)
			0	Less than 75% of hypotheses were confirmed, despite adequate design and methods OR no information found on construct validity
5	Reproducibility			
5.1	Agreement	The extent to which the scores on repeated measures are close to each other (absolute measurement error)	2	SDC < MIC OR MIC outside the LOA OR convincing arguments that agreement is acceptable
			1	Doubtful design or method OR (MIC not defined AND no convincing arguments that agreement is acceptable)
			0	MIC < = SDC OR MIC equals or inside LOA despite adequate design and method OR no information found on agreement
5.2	Reliability	The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error)	2	ICC or weighted Kappa > = 0.70
			1	Doubtful design or method
			0	ICC or weighted Kappa < 0.70, despite adequate design and Method OR no information found on reliability
6	Responsiveness	The ability of a questionnaire to detect clinically important changes over time	2	SDC or SDC < MIC OR MIC outside the LOA OR RR > 1.96 OR AUC > = 0.70
			1	Doubtful design or method
			0	SDC or SDC > = MIC OR MIC equals or inside LOA OR RR < = 1.96 or AUC <0.70, despite adequate design and methods OR no information found on responsiveness
7	Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score	2	=<15% of the respondents achieved the highest or lowest possible scores
			1	Doubtful design or method
			0	>15% of the respondents achieved the highest or lowest possible scores, despite adequate design and methods OR no information found on interpretation
8	Interpretability	The degree to which one can assign qualitative meaning to quantitative scores	2	Mean and SD scores presented of at least four relevant subgroups of patients and MIC defined
			1	Doubtful design or method OR less than four subgroups OR no MIC defined

0	No information found on interpretation

SDC - smallest detectable difference (this is the smallest within person change, above measurement error. A positive rating is given when the SDC or the limits of agreement are smaller than the MIC).
MIC - minimal important change (this is the smallest difference in score in the domain of interest which patients perceive as beneficial and would agree to, in the absence of side effects and excessive costs).
SEM -standard error of measurement.
AUC - area under the curve.
RR - responsiveness ratio.

Figure 2 Review Process

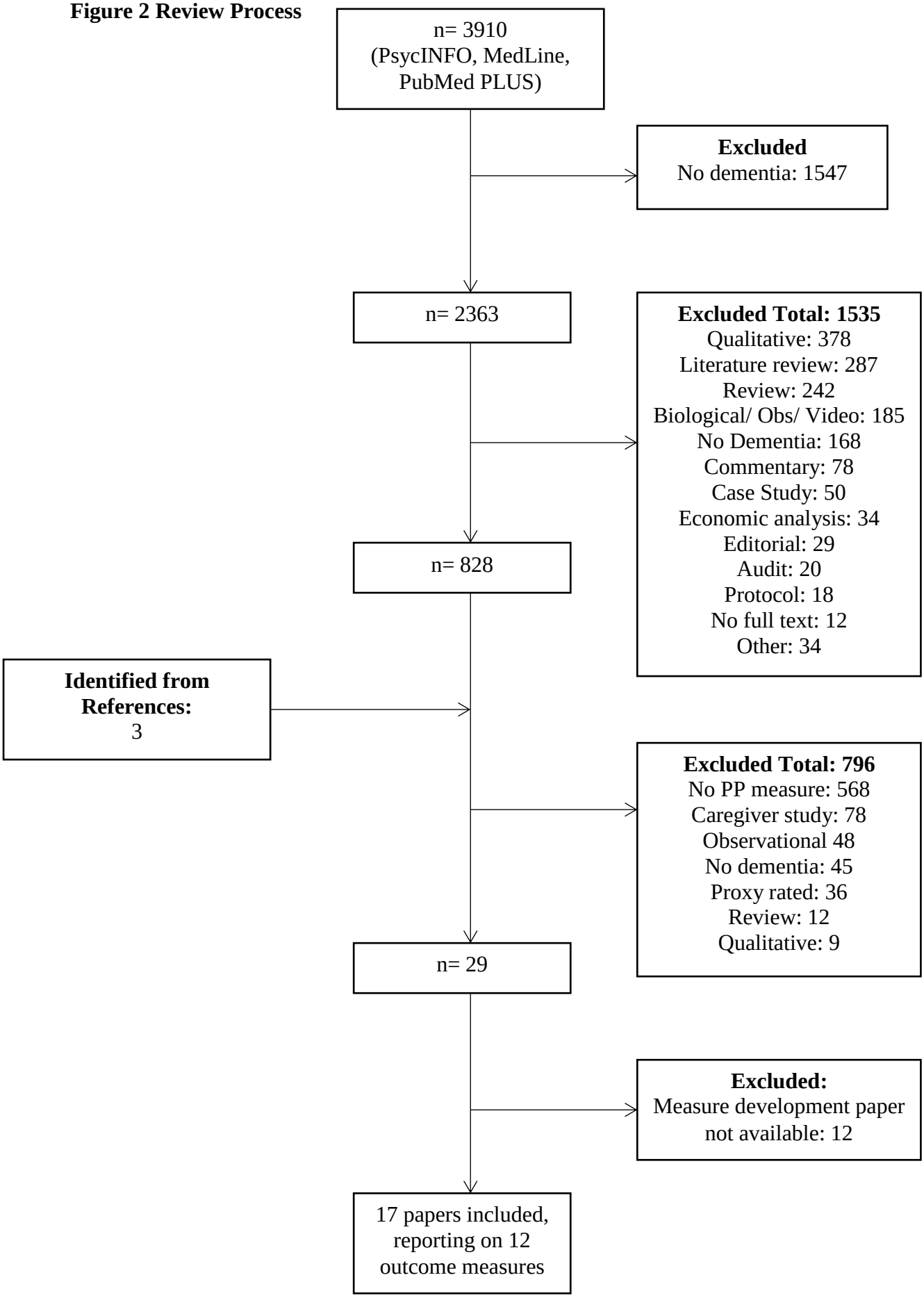

Table 1 Quality Assessment of development procedures

Construct	Scale	Content Validity	Internal Consistency	Criterion Validity	Construct Validity	Reproducibility Agreement	Reproducibility reliability	Responsiveness	Floor/ ceiling effect	Interpret ability	Total
Identity	Self-Identity in Dementia Questionnaire	2	0	0	1	0	0	0	0	0	3
Hope/ Optimism	Herth Hope Index	2	0	2	1	0	2	0	2	1	10
	Adult Hope Scale	2	2	2	2	0	2	0	0	1	11
	Life Orientation Test – Revised.	2	2	0	2	0	0	0	0	0	7
Religiosity/ Spirituality	Systems of Belief Inventory	2	2	1	1	0	2	0	2	1	11
	Royal free interview for religious and spiritual beliefs	1	0	1	1	0	2	0	0	1	6
Life Valuation	Meaning in Life Scale	2	2	0	2	0	0	0	0	0	6
	Terrible Delightful Scale	0	0	0	1	0	0	0	2	0	3
Self-efficacy	General Self-efficacy Scale	0	2	0	1	0	0	0	2	1	6
	The Self-efficacy Scale	1	2	1	2	0	0	0	0	0	6
Community	Brief Sense of Community Scale	1	2	0	2	0	0	0	0	0	5
Wellbeing	Ryff Psychological Wellbeing Scale	1	1	0	2	0	2	0	0	1	7

Table 2 Description of Included Studies

Construct	Outcome Measure	Study authors	Characteristics of participants with dementia	Methods	Results pertaining to measures
Identity	**Self-Identity in Dementia Questionnaire (SID)** (Cohen-Mansfeld, Golander & Arnheim, 2000)	1) Caddell & Clare (2012)	1) 50 PwD (52% female, 64% married, 22% widowed, 90% secondary education level)	1) Multiple regression analyses to determine the possibility of predicting variance in mood and quality of life (QoL) from aspects of identity.	1) Depression significantly predicted by model containing Tennessee Self-Concept scale physical and personal items subtotals and SID family and leisure subscales ($F4,44= 4.66$ $p<.01$, $Ra2 = 0.234$).
		2) Caddell & Claire (2013)	2) 50 PwD (52% female, 64% married, 22% widowed, 90% secondary education)	2) Cross-sectional questionnaire based study to examine the profile of identity in early-stage dementia and healthy older people.	2) Within both groups, family role was reported as strongest, occupational weakest.
		3) Caddell & Claire (2013b)	3) 50 PwD (mean age: 77.8; SD 7.4, 52% female, 76% Alzheimer's disease (AD), 90% secondary education)	3) Cross-sectional study investigating relationships between identity and cognitive and functional abilities of people in early-stage dementia	3) Positivity of identity was significantly predicted by a model containing CERAD (cognitive battery) naming, constructional praxis and constructional praxis recall scores and Functional Activities Questionnaire (FAQ) total score $F(4,41) = .4557$, $p<.01$, $RA2 = .240$.
		4) Cohen-Mansfeld, Thein, Dakheel-Ali, & Marx (2010)	4) 193 PwD in nursing home (mean age: 86, 78% female, 81% Caucasian, 65% widowed)	4) Examination of identity roles on engagement in tasks. Participants presented with stimulus twice, one with explanation of how stimulus should be used and once without modelling.	4) Self-identity most salient was family self-identity (87%), followed by leisure (62%). Positive relationship between self-identity and engagement duration, attention and attitude. All $p<.001$

Hope	**Herth Hope Index (HHI)** (Herth 1992)	Johnston et al., (2016)	7 PwD (mean age 78.4, 71.43% male)	Mixed methods, feasibility study with a pre and post design. Intervention was Dignity therapy.	No discussion of significant findings. One participant had difficulty completing HHI. Pre and post percentage scores available for four participants: Participant one: -18.7%, Participant two: +6.25% Participant three: +2.08% Participant four: 0% change.
	Adult Hope Scale (Snyder et al., 1991)	Meeks et al., (2016)*	26 PwD (mean age 76.7; SD 10.23, 61.5% female, 88.5% white American	Study of biological markers to capture allostasis as an index of psychological resilience, relating to other baseline resources including hope and optimism.	Non-significant z-stasis index (markers) of hope .33 Optimism and hope significantly negatively correlated ($p<.01$).
	Life Orientation Test – Revised (LOT-R) (Scheier, Carver, & Bridges, 1994)	Meeks, et al., (2016)*	As above.	As above.	Optimism and hope (Adult Hope Scale) significantly negatively correlated ($p<.01$).
Religiosity/ Spirituality	**Systems of Belief Inventory (SBI-15)** (Holland et al., 1998)	Katsuno (2003)	23 PwD (mean age 79; SD 6.2, 78% female, 78% white).	Descriptive mixed methods study. Observational, cross-sectional examining spirituality in early-stage dementia	22 completed SBI-15. Average score of 32.8, range of 11-45. Positive correlation between SBI and quality of life .44, $p<.05$. Not between Health/ Functioning subscale of QoL measure
	Royal Free Interview for Religious and Spiritual Beliefs (King & Speck, 1995)	Jolley, et al., (2010)	29 PwD (89.7% female, 10.3% male, 96.6% white, mean Mini Mental State Examination (MMSE) score of 24).	Observational questionnaire study of PwD drawn from a memory clinic.	Strength of belief rated as most important. No statistical differences between carer and PwD ratings of own spiritual belief.

Life Valuation	**Meaning in Life Scale** (Krause, 2004)	Hilgeman, et al., (2014)	19 dyads (PwD mean age 82.8; SD 6.46, 68.4% female, 94.7% white).	Randomised to either intervention of minimal support group. Four sessions of intervention. Focus on maintaining identity through PIPAC intervention	No significant effect of intervention on meaning in life (p=.71).
	Terrible Delightful Scale (TDS) (Michalos, 1980)	St. John & Montgomery, (2010)	58 PwD (mean age 82.9, 60.3% female).	Observational study examining overall life satisfaction with its subscales and to examine the impact of cognition on life satisfaction.	Life satisfaction broken down into two subscales: material and social. Moderate correlation between scales (p<.001). PwD had significantly lower life satisfaction on subscales
Self-efficacy	**General Self-efficacy scale (GSE)** English Version (Schwarzer & Jerusalem, 1995)	1) Fankhauser, Drobetz, Mortby, Maercker, & Forstmeier, (2014) (German version)	1) 229 adults (mean age 74, 64 Mild Cognitive Impairment (MCI), 47 AD, 118 no impairment.	1) Investigated a mediation relationship of motivation (self-efficacy, decision regulation, activation regulation and motivation regulation) on the relationship between social support and depression.	1) Early AD: social support not correlated with depression (r= -.16, p= .30). Motivational processes predicted depression significantly in regression (beta= 0.39, p<.001).
		2) Buettner & Fitzsimmons (2009) (English Version)	2) 89 PwD (mean age experimental group 81.4, mean MMSE 25.6, 48 men, 41 women).	2) Evaluation of 12-week health promotion course for PwD.	2) Investigated impact of a health promotion course on well-being. No significant findings at post-test for self-efficacy
	The Self-efficacy scale (Sherer, Maddox, Mercandante, Prentice-Dunn, Jacobs, & Rogers, 1982)	Dawson, Powers, Krestar, Yarry, & Judge, (2013)	131 PwD (mean age 77.15; SD 9.45, mean MMSE 22.48; SD 5.84, 55.7% female, 61.8% married, 85.5% Caucasian, 26.8% college graduate).	Stress process modelling for PwD, using strains and QoL outcomes.	Self-efficacy perception emerged as a significant and unique predictor of QoL (β= .30, p<.001)

Community	**Brief Sense of Community Scale (BSC)** (Peterson, Speer, & McMillan, 2008)	Low, Russell, McDonald, & Kauffman (2015)	40 older adults (mean age 91, 80% female, 80% cognitive impairment).	Randomised controlled trial of 12-week programme of 'Grandfriends'– intergenerational intervention.	No significant effects of group by time interaction (p=.168).
Wellbeing	**Ryff Psychological Wellbeing scale** (RPWB)	1) (Mak, 2011)	1) 91 PwD (mean age 75.28; SD 9.23, 70 females, 51% African American, 47% European American, 2% Filipino American.	1) Randomised trial of goal-directed activity. Used Purpose in Life Subscale from RPWB)	1) Alpha for purpose in life α= .73, lower than original study (α= .90). Positive correlation between purpose in life and goal pursuit (r= .53, p<.001), significant correlation between dementia severity and purpose in life (r= .35, p<.001). Prediction analysis indicated people with higher goal pursuit were more likely to score higher on purpose in life, regardless of dementia severity.
		2) Gonzalez, Mayordomo, Torres, Sales, & Meléndez (2015)	2) 42PwD (mean age 80.24; SD 9.22; 69 women, 31 men, 59.5 widowed, 31 married, average MMSE 20; SD 2.55.	2) Quasi-experimental in two retirement homes, measure effect of reminiscence therapy. 23 experimental, 19 control	2) PWB all dimensions significant except for purpose in life. Significant increase in self-acceptance (p= .002), positive relations with others (p= .019), autonomy (p=.001) and environmental mastery (p=.003) for interaction effect of time and group
		3) Wettstein, et al., (2014)	3) 35 PwD (mean age 74.1; SD 7.1, 60% male).	3) Used Environmental Mastery Subscale of RPWB. Observational study of out of home behaviour using GPS tracking, and self-report questionnaires.	3) Higher walking distances and higher levels of walking speed were significantly related to higher environmental mastery (r=.40 and r=.45 respectively p<.05).