

Large scale psychometric validation of two positive psychology outcome measures for people
with dementia in Hong Kong
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Thesis Declaration Form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:



Name: Sze Ngar Vanessa Yuan

Date: 30th July 2021

Overview

A systematic review was presented in Part one of this thesis, which aimed to identify measures of social support for caregivers of people with dementia (PwD) and to investigate their psychometric properties. Social support are resources perceived or provided by non-professionals in support groups or informal helping relationships. It was suggested that the availability of resources including social support could protect caregivers against stress and burden, which could be a protective factor for PwD and their carers. Having well-validated and standardised measures for this population is crucial for research and clinical use, especially for making meaningful comparisons between results across studies done across different time and places.

Part two of the thesis involved an empirical paper that aimed to complete a large-scale psychometric validation of two positive psychology outcome measures for PwD in Hong Kong. Positive psychology in dementia shifts away from the traditional loss-oriented model to a non-pathologising approach that emphasises the strengths or capabilities used to achieve wellbeing despite difficulties. Due to unforeseeable challenges from COVID-19, it was not possible to recruit the sample size intended to complete in-depth analyses and draw conclusive results. Regardless, the preliminary results have provided valuable insight to the use of positive psychology approach and measures for PwD in Hong Kong.

Part three involved a critical reflection and further discussion on findings while elaborating on the difficulties and challenges in the process, particularly in the face of COVID-19, as well as any dilemmas or scope for future research.

Impact Statement

This study enhances our knowledge to the research in dementia in response to the global phenomenon of population ageing and increase in people with dementia (PwD). Outcome measures play a significant role in clinical and research use which stresses the importance of having well-validated and culturally adapted measures.

This was the first systematic review to date to investigate the psychometric properties of measures of social support for caregivers of PwD. While there was an abundance of social support measures, this review highlighted a lack of standardised, validated measures of important psychometric properties in this population. Only one measure was developed with PwD and another measure was validated with PwD recently. By investigating and reviewing the measures according to the population concerned and the type of social support measure, this review may help clinicians and researchers to select measures best fitted for their usage. As social support was suggested to be a protective factor while the lack of such could be a risk factor to caregivers of PwD, the availability of psychometrically sound measures may open a gateway for caregivers and clinicians to consider the importance of social support and relevant psychosocial interventions. This may also encourage caregivers of PwD to have an enhanced understanding of their needs and seek social support in different ways.

The empirical study highlighted the feasibility of moving towards to a non-pathologising approach in dementia in Hong Kong, following evidence seen in the western research. To our knowledge, this was the first quantitative research completed in the field of positive psychology in dementia in Hong Kong. The study provides preliminary evidence on the culturally validated measures of Positive Psychology Outcome Measure (PPOM), a measure of hope and resilience, and the Engagement and Independence in Dementia Questionnaire (EID-Q), a measure of social independence, in people with dementia (PwD) in Hong Kong. This allows clinicians and researchers to use these measures to examine these

constructs in their work. While the sample size is too small in the empirical research to draw any conclusive result at this point, the established psychometric properties have emphasised the feasibility of using PPOM and EID-Q in Hong Kong.

Outcome measures were not always translated and validated appropriately before they were used in a different cultural context. By completing this research study on the cultural adaptation of the two positive psychology measures, it enables meaningful comparisons of results across studies. The limitations and findings highlighted in this study could act as helpful guidance for future research.

The results of both the systematic review and the empirical study may generate new learning for researchers and stimulate further research ideas in the field. Both findings contribute to the enhancement of quality of life, health and well-being of PwD and their caregivers, and to the shift towards a non-pathologising approach towards dementia. This shift of perspective may have an added impact to lessen the socio-economic and healthcare burden in the long run.

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Part 1: Literature Review

A psychometric appraisal of social support outcome measures for caregivers of people with dementia: A systematic review

Abstract

Aims: To identify measures of social support for caregivers of people with dementia and to investigate their psychometric properties.

Method: Systematic literature searches on OVID Medline, Embase and PsycINFO were completed to identify all social support measures developed or used with carers of people with dementia from 1999 to 2021. The included measures were analysed via an established quality appraisal tool.

Results: Nineteen social support measures used with caregivers of people living with dementia were identified but only one was developed with this population and another one had undergone a psychometric validation with this population. Social support measures examined social network, received social support, provided social support, negative interaction, perceived social support, and satisfaction with social support. The Multidimensional Scale of Perceived Social Support (MSPSS) received the highest score against the standardised quality criteria, suggesting it has adequate psychometric properties for carers of people with dementia.

Conclusions: There was an abundance of social support measures identified, but there was a lack of information on important psychometric properties for many of them. MSPSS, which measured perceived social support, was the only tool with data to suggest it is of high psychometric quality for carers of people with dementia and is thus recommended for use. Further research is required for the other types of social support, and it is recommended that responsiveness to change is evaluated wherever possible. It is important to use measures with sound psychometric properties while a homogeneity in used measures can encourage meaningful comparisons and interpretations in future research and clinical use.

Introduction

Population ageing and growth is a global demographic phenomenon that is related to an increase in life expectancy (World Health Organization, 2019). This leads to many societal and policy implications, one of which is an increased need in caregiving for older people. Often, family members are responsible to provide the health and social care for those with long-term health conditions. The amount of care spans over many years, requiring a significant amount of family resources to manage the activities of daily living, household activities, emotional support, companionship and social stimulation. Nonetheless, a recent study in the United States has found that 65% of caregivers state that the support they receive is mostly inadequate (Bevan, Urbanovich, & Vahid, 2021).

Dementia Caregiving

The number of people living with dementia worldwide has increased more than double from 20.2 million in 1990 to 43.9 million in 2016 (Nichols et al., 2019). The number of people living with dementia is estimated to rise to 100 million by 2050 (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). This is an increasing global health challenge, especially given that there is currently no effective cure for dementia itself (Nichols et al., 2019). Disability from dementia has a higher burden than all other conditions except spinal cord injury and terminal cancer, with a disproportionate impact on independent living compared to other health conditions (European Association of Palliative Care, 2013). Until breakthroughs are made in treatment and intervention, the care and support for people living with dementia will continue to have significant effects on caregivers and families, the healthcare systems and the society (Etters, Goodall, & Harrison, 2008).

Dementia caregiving is a widely researched topic that is especially important for clinicians and healthcare policy makers. The burden and stress of caregiving are greater for

dementia compared to other medical diagnoses (Schoenmakers, Buntinx, & DeLepeleire, 2010). Informal caregivers of people living with dementia, usually family members, experience a high level of stress because people living with dementia depend upon them to support their activities of daily living. Further, safety concerns and behaviours that challenge have been associated with increased stress (Allen et al., 2017). As all types of dementia are progressive, the symptoms typically get worse overtime and more basic functional abilities decline. It is suggested that it is most challenging for caregivers to manage behavioural and psychological symptoms of dementia (Finkel, e Silva, Cohen, Miller, & Sartorius, 1997). The care demands posed by people living with dementia, the functional limitations and the availability of resources can affect caregiver stress and depression (Sörensen & Pinquart, 2005). Research has suggested an increased risk of mental health difficulties including increased levels of anxiety and depression associated with caregiving (Mahoney, Regan, Katona, & Livingston, 2005). Some of the themes that emerge from family caregivers' subjective description of caregiving include enduring stress and frustration, suffering through the losses, and gathering support, but also in terms of finding meaning and joy or preserving integrity (Butcher, Holkup, & Buckwalter, 2001). There is a high need for effectively identifying and supporting distressed caregivers (Livingston et al., 2020).

Types of Social Support

Cohen, Underwood, and Gottlieb (2000) has defined social support as 'the social resources that persons perceive to be available or that are actually provided to them by non-professionals in the context of both formal support groups and informal helping relationships' (p. 4). Social support is a multi-dimensional concept with the structure and the function of support regarded as the two main aspects of social support. The structure of support considers the extent to which one is connected within a social network, which often involves objective

measures of the number of social relationships, the frequency of social contact and the framework of the network (Friedman & Silver, 2007). The function of support refers to the perception of available social support from one's social network which often includes measures on both the frequency and the perceived availability of social support. Social support can also be considered from a subjective and evaluative perspective, particularly in terms of satisfaction with support (Amieva et al., 2010).

There are three main types of functional social support, including instrumental support, emotional support, and informational support (Friedman & Silver, 2007). Instrumental support is also known as tangible support as it is defined by the assistance and services that one receives in their everyday lives, such as with activities of daily living, housework or transportation to appointments. Emotional support, on the other hand, is the non-tangible support which includes others' expressions of warmth, understanding, empathy, concern and care. Informational support involves receiving knowledge about current difficulties and stressors. It is defined as others' provision of advice and information, typically from health professionals and from those with similar experiences. The perception of the above functional support is the most important in predicting quality of life and physical and mental functioning (Zhou, 2014). Other subcategories of social support include esteem support which refers to support resulting in self-esteem and approval, affectionate support which refers to expressions of love and affection, and companionship support which refers to support that provide a sense of belonging. Negative social interactions are also considered in measuring social support.

Social support is a complex concept with differences between actual and perceived support, formal and informal support, and tangible and emotional support (Brodaty & Donkin, 2009). It is therefore important to differentiate between these dynamics. It has been hypothesised that received social support enhances coping which buffers the effects of stress

on health outcomes, while perceived support influence the appraisal of stress and buffer the effects of stress on health outcomes (Cohen et al., 2000).

Social Support and Dementia Caregiving

Insufficient social support is one of the six risk factors for adverse outcomes associated with family caregiving for an older adult with a health condition or functional limitation (National Academies of Sciences & Medicine, 2016). Caregiving for people living with dementia can result in unique risk factors including a lack of social support and other limitations in social life (Almberg, Grafström, & Winblad, 1997). For example, demands and stress associated with caregiving have been identified as a risk factor for social isolation (Brodaty & Luscombe, 1998; Pinquart & Sörensen, 2006). It is a big burden for caregivers of people with moderately severe dementia to maintain social contacts (Schlomann, Schacke, Leipold, & Zank, 2020).

Adequate social support, however, can increase the caregiver's self-efficacy in managing the care of the people living with dementia (Au et al., 2009). According to the stress process model in dementia caregiving, coping and social support may act as a mediator (Pearlin, Mullan, Semple, & Skaff, 1990). For example, social support may prevent the development of secondary stressors. An increase in the perception of available resources can protect caregivers against stress and both psychological and non-psychological burden (Cohen, 2004; Han et al., 2014). Psychological burden can be reduced up to 20% by positive social interaction and reduced up to 10.3% by affectionate support, while non-psychological burden can be reduced up to 15.1% by tangible support (Han et al., 2014). Furthermore, positive social interaction has both direct and indirect effects on the mental health of the caregivers of people living with dementia (Zhang, Edwards, Yates, Guo, & Li, 2013).

Social support interventions have been developed to provide befriending and peer support, family support and social network, support groups and virtual or remote interventions (Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016). In the stress/health model, interventions including social support and other resources have been identified as modifiers of the effects of the stressors on caregiver strain and caregiver morbidity in terms of psychological and physical health outcomes (Schulz & Martire, 2004). This has emphasised the importance of considering the resources and social support of the caregiver to minimise caregiver strain and morbidity (Schulz & Martire, 2004). Having closer social network members, higher frequency of seeing family and friends and greater emotional support has been associated with greater support satisfaction, even at the 5-year follow-up of a counselling and support intervention (Drentea, Clay, Roth, & Mittelman, 2006). As such, caregivers are often asked by authorities to seek out to their social networks for support to allow them to continue with their supportive role (World Health Organization, 2012).

Rationale and Aim of the Review

Understanding and recognising the importance of social support for caregivers of people living with dementia is crucial while social support can be measured with outcome measures. They constitute an important part of routine care to gather information, guide any intervention decisions and for caregivers to recognise their own needs and improvement. In particular, reliable outcome measures are needed to capture change in social support. It is important to consider the psychometric properties of these outcome measures for use in research and clinical setting because the quality of the psychometric properties can have an implication on the quality of the associated data collected. Currently in dementia caregiver research, there is an abundance of measures on social support with no previous study of their psychometric properties for caregivers of people living with dementia. A recent systematic

review on outcome measures measuring positive psychology constructs found that the quality of the measures was often lower than what the authors have concluded in the development or validation papers (Pione, Spector, Cartwright, & Stoner, 2021).

The progressive nature of dementia creates tremendous, unique physical and emotional health challenges in caregivers of people living with dementia (Schulz & Martire, 2004). The nature or the appraisal of social support perceived or required by the caregivers may be very different due to these challenges. Family members or individuals with a close relationship often take on the role as the primary caregiver. This may imply that the caregiver has lost their main conversational partner, resulting in a significant loss of social support. As dementia progresses and the demand on caregiving increases, caregivers may lose social relationships and spare time of their own (de Oliveira et al., 2019). The routine of caregiving for people living with dementia is generally at home, which may imply that they are more likely to be locally bound due to the caregiving responsibilities. Compared to non-caregivers, caregivers are more likely to miss work and have impairment at work and in activities (Goren, Montgomery, Kahle-Wroblewski, Nakamura, & Ueda, 2016). Furthermore, compared to caregivers of people with physical difficulties, caregivers of people living with dementia are more likely to give up their hobbies or holidays, and have less time for their other family members (Ory, Hoffman III, Yee, Tennstedt, & Schulz, 1999). Therefore, social support is accessed and viewed differently in caregivers of people with dementia, making it crucial to have an independent systematic review on social supports measures for this population.

To our knowledge, there has not been a systematic review on social support outcome measures for caregivers of people living with dementia. The aim of this paper is to identify and review social support outcome measures for carers of people living with dementia and to investigate their psychometric properties. This paper seeks to evaluate these social support outcome measures using an established quality appraisal tool and to examine the

responsiveness of included measures in identified studies in order to identify the most appropriate measures for future research and clinical use.

Method

Design

A systematic search was carried out to identify measures of social support used in research studies where the sample consisted of caregivers of people living with dementia. The process was guided by the PRISMA 2020 statement, which is an update to the 2009 statement with new reporting guidance (Moher, Liberati, Tetzlaff, Altman, & Group, 2009; Page et al., 2021). The aim was to identify development, validation or usage of the measures in intervention research with caregivers of people living with dementia. Particular attention was paid to identifying research articles that described the development of an outcome measure of social support in caregivers of people living with dementia hereafter referred to as a ‘development paper’ or a research article that evaluated the psychometric properties of an existing measure of social support with a carer population, hereafter referred to as a ‘validation paper’. However, as these were expected to be minimal, all interventional research studies that utilised a social support measure for caregivers of people living with dementia were sourced. Reference lists for each included study were also searched for relevant studies and corresponding authors were contacted for the research articles that were not otherwise accessible.

Search Strategy

Searches were completed using OVID Medline, Embase and PsycINFO on 27th January 2021. The search terms were derived from the headings, ‘dementia’ AND ‘carer’ AND ‘social support’ AND ‘intervention’. The search terms were influenced by related

literature review and discussions with the authors (Pione et al., 2021). The heading ‘intervention’ was used to identify intervention studies using targeted outcome measures.

Search terms for dementia included ‘dementia’ or ‘cognitive impairment’ or ‘senile’. Search terms for carer included ‘caregiver’ or ‘family carer’ or ‘relative’ or ‘family’ or ‘friend’ or ‘spouse’ or ‘informal carer’ or ‘supporter’. Search terms for social support included ‘social support’ or ‘support’. Finally, the search terms for intervention included ‘intervention’ or ‘therapy’ or ‘treatment’ or ‘group’ or ‘group psychotherapy’. The search was limited to heading word, subject heading, key concept and title in their equivalent terms across the three databases.

The reference lists and cited articles were searched, and relevant studies were evaluated for inclusion. The search terms were truncated to broaden the search and include all various terms. All texts were imported into EndNote (version X9). Duplicates were removed using the software and manually. The remaining papers were screened against the inclusion and exclusion criteria.

Inclusion Criteria

We included studies that employed outcome measures of social support used with caregivers of people living with dementia. Measures on the structural, functional and evaluative aspects of social support were included. This included but was not limited to perceived social support, received social support, provided social support, satisfaction with support, social network and negative interactions. The social support considered involved spouse, children, friends and family. Additional criteria were:

- Both the development (or validation) paper of the measure and the research paper citing the measure were published in an English, peer-reviewed journal
- The study using the measure was published between 1999-2021

- Adapted or modified measures based on another included measure were included, as long as both measures were psychometrically validated and subsequently used in the population of caregivers with people living with dementia

Exclusion Criteria

- The development or validation paper of the measure was unavailable despite attempts to contact the researcher
- The primary focus of the measure (defined as 50% or more of the items on a measure) was not on social support, unless it was identified as a subscale of a comprehensive measure
- Qualitative studies

Screening Process

The titles were screened to determine whether caregivers of people living with dementia were the target population of the studies. The abstracts were screened and qualitative studies, studies with a focus other than the caregivers and studies in other languages were excluded. The full texts were then examined to determine the suitability for inclusion. If there was a lack of clarity at any stage, the paper would be further examined in the next stage of screening. Papers were excluded if there was a clear indication of the exclusion criteria at any stage. After social support measures were identified in the text, the development or validation studies of the measures were identified and examined. All development and validation papers were included, even if their publication preceded the original search dates of 1999–2021.

Quality Appraisal Tool

An established quality appraisal tool was used to determine the properties of the measures (Terwee et al., 2007). This evaluates the measures against nine criteria, including content validity, internal consistency, criterion validity, construct validity, agreement, reliability, responsiveness, floor and ceiling effects and interpretability.

Content validity is defined as the extent the concepts of interest are represented thoroughly in the questionnaire items, in which the authors should provide a clear description of the measurement aim of the questionnaire, the target population, the concepts that the questionnaire intended to measure and the interpretability of the items (Terwee et al., 2007). Internal consistency measures the extent to which the questionnaire items are correlated, using a criterion of Cronbach's alpha between 0.70 and 0.95 and the inclusion of factor analyses completed with at least 100 participants or seven times the number of items on the measure (Terwee et al., 2007). Criterion validity refers to whether the questionnaire relates to a gold standard, with a correlation of 0.70 or above considered as high criterion validity. Construct validity measures the extent of the scores relate to other measures consistent to established theories. The hypotheses must be stated in advance with at least 75% of the results relate to the hypotheses in groups of at least 50 participants (Terwee et al., 2007). Reproducibility refers to the test-retest reliability in which the repeated test should be done in a well-justified time period, usually in one to two weeks. Specifically, agreement measures the absolute measurement effort, typically expressed as the standard error of measurement (SEM) (Beckerman et al., 2001). Reliability refers to the extent the participants can be distinguished from each other, which is the relative measurement error measured as the intraclass correlation coefficients (ICC) or weighted Kappa coefficient, in a sample of at least 50 participants. Responsiveness is the ability of a questionnaire in detecting clinically important change over time. Floor and ceiling effects are present if more than 15% of the

participants had lowest or highest possible scores respectively, which indicate limited content validity (McHorney & Tarlov, 1995). Interpretability measures the extent that qualitative meaning can be assigned to quantitative scores, in which minimal important change should be defined and interpreted with mean and standard deviation scores (Lohr et al., 1996).

Scores were given instead of ratings for more direct comparisons across measures. A score of two was given for positive ratings, a score of one was given for intermediate rating and a score of zero was given for negative ratings or when no information is found. Criterion validity was not assessed because there was no gold standard measure for social support for caregivers of people living with dementia. Scores between 13 and 16 were considered as ‘very good’, scores between 9 and 12 were considered as ‘good’, scores between 3 and 8 were considered as ‘moderate’ and scores between 0 and 2 were considered as ‘poor’ (Stansfeld et al., 2017).

Results

Included Studies

The original search resulted in 1385 articles and 221 duplicates were removed. 1164 papers were screened for titles and abstracts to determine whether caregivers of people living with dementia were the target population and 336 papers were examined for full text. Additional papers were screened from reference lists for further inclusion.

A total of 52 studies with social support was included. 19 outcome measures were subjected to quality appraisal (Barrera, Sandler, & Ramsay, 1981; Brookings & Bolton, 1988; Cartwright, Pione, Stoner, & Spector, 2020; Cohen & Hoberman, 1983; Cohen, Mermelstein, Kamarck, & Hoberman, 1985; Cutrona & Russell, 1987; Goodman, 1991; Gurung, Taylor, & Seeman, 2003; Kempen & Van Eijk, 1995; Koenig et al., 1993; Krause, 1987a, 1987b, 1995; Krause & Borawski-Clark, 1995; Lubben, 1988; Lubben et al., 2006; Newsom, Nishishiba,

Morgan, & Rook, 2003; Parkerson Jr et al., 1989; Power, Champion, & Aris, 1988; Procidano & Heller, 1983; Sarason, Sarason, Shearin, & Pierce, 1987; Sherbourne & Stewart, 1991; Van Eijk, Kempen, & Van Sonderen, 1994; Wenger, 1991; Zimet, Dahlem, Zimet, & Farley, 1988). The measure, Arizona Social Support Interview Schedule, was excluded because it was largely a qualitative interview (Barrera, 1980). One study utilized ‘The Heller scale’ and Main Helper Questionnaire but neither measures were referenced to locate the original development or validation paper hence they were excluded from the study (Shurgot & Knight, 2005). A measure called ‘Gain Through Group Involvement Scale’ was excluded because the primary focus was on gain and not social support itself (Kaye, 1996). A summary of this process is presented in Figure 1 (Page et al., 2021). A summary of the scores on each measure has been presented in Table 1. Psychometric properties of each included measure are reported in Table 2.

Measures Developed or Validated with Caregivers with People Living with Dementia

Perceived Social Support for Caregiving (PSSC) and its Social Conflict scale (SC) was the only measure developed with caregivers of people living with dementia (Goodman, 1991). It had a score of ‘moderate’ in the quality appraisal. The Multidimensional Scale of Perceived Social Support (MSPSS) was recently validated with caregivers of people living with dementia and it obtained the highest scoring across all measures in the quality appraisal (Cartwright et al., 2020; Zimet et al., 1988).

Small to medium correlations were reported for convergent validity with natural network, and good and acceptable internal consistency for PSSC ($\alpha = .84$) and SC ($\alpha = .72$) respectively. A principal component analysis was completed in which 12 of the items loaded on the factors of Perceived Social Support for

Figure 1

PRISMA flow diagram

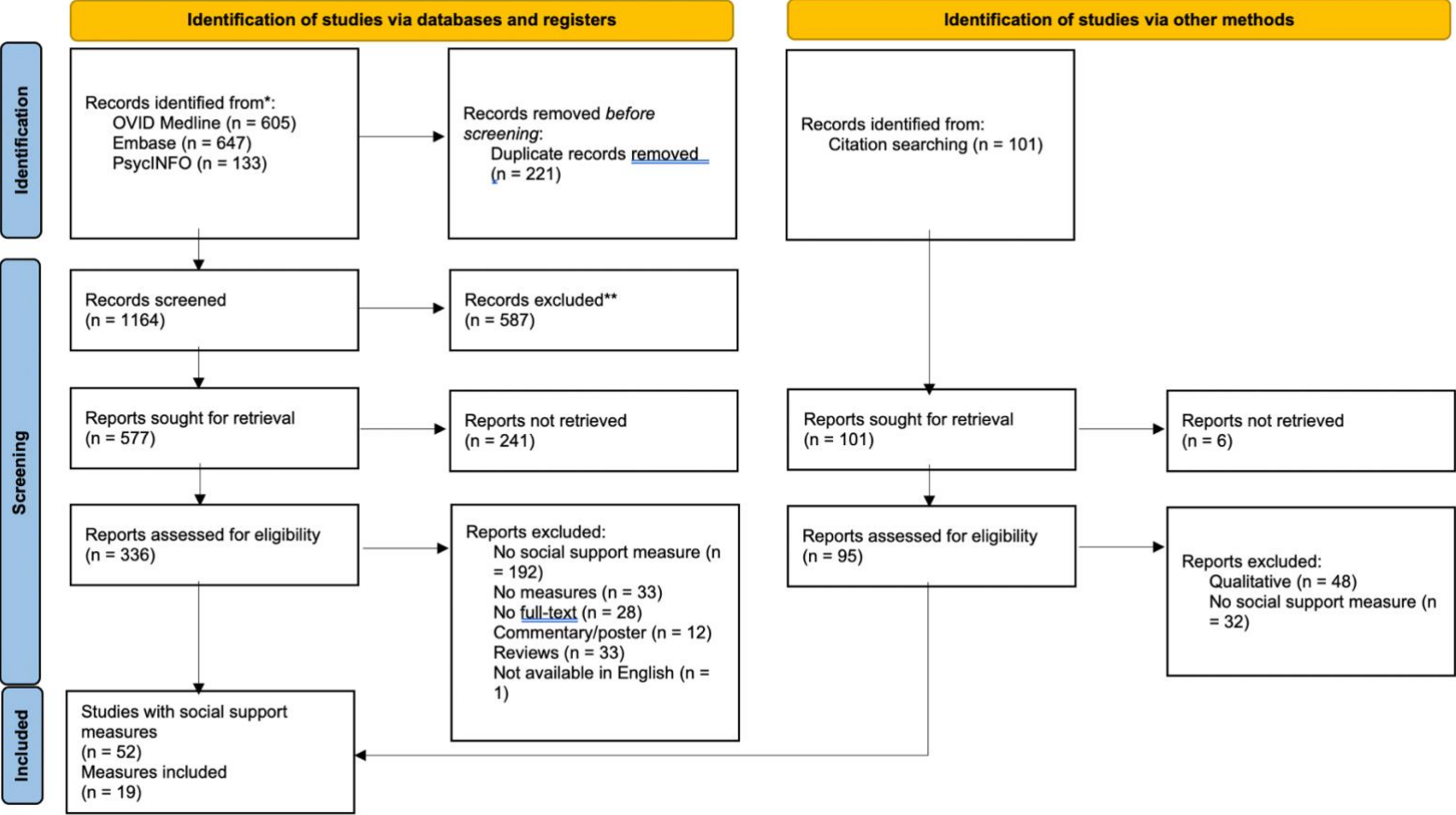


Table 1*Quality appraisal scores for social support measures for caregivers*

Outcome measure	Content validity	Internal consistency	Construct validity	Agreement	Reliability	Responsiveness	Floor and ceiling effects	Interpretability	Total score
Multidimensional Scale of Perceived Social Support (MSPSS; Cartwright, Pione, Stoner & Spector, 2020; Zimet, Dahlem, Zimet, & Farley, 1988)	2	2	2	0	2	0	2	0	10
Perceived Social Support for Caregiving (PSSC) & Social Conflict (SC; Goodman, 1991)	2	2	1	0	0	1	0	0	6
MacArthur Battery (social support measure; Gurung, Taylor & Seeman, 2003)	1	1	1	0	0	0	0	1	4
Social Support List of Interactions (SSL12-I; Kempen & Van Eijk, 1995, Van Eijk, Kempen & van Sonderen, 1994)	2	2	2	0	0	0	0	0	6

Outcome measure	Content validity	Internal consistency	Construct validity	Agreement	Reliability	Responsiveness	Floor and ceiling effects	Interpretability	Total score
Modified Inventory of Socially Supportive Behaviours (Modified-ISSB; Krause, 1987, Krause, 1987, Krause & Markides, 1990)	2	2	1	0	0	0	0	0	5
Krause's 'Social support measures' (Krause, 1995, Krause & Borawski-Clark, 1995)	2	0	1	0	0	0	0	0	3
Lubben Social Network Scale (LSNS; Lubben, 1988)	2	1	1	0	0	0	0	0	4
Lubben Social Network Scale-6 Item Version (LSNS-6; Lubben et al., 2006)	2	2	2	0	0	0	0	0	6
The Positive and Negative Social Exchanges (PANSE; Newsom, Nishishiba, Morgan & Rock, 2003)	2	2	1	0	0	0	0	0	5

Outcome measure	Content validity	Internal consistency	Construct validity	Agreement	Reliability	Responsiveness	Floor and ceiling effects	Interpretability	Total score
Practitioner Assessment of Network Type/Typology (PANT; Wenger 1990, 1991)	1	0	0	0	0	0	0	0	1
Inventory of Socially Supportive Behaviors (ISSB; Barrera, Sandler & Ramsey, 1981)	2	1	1	0	1	0	0	0	5
Interpersonal Support Evaluation List (ISEL; Brookings & Bolton, 1988, Cohen & Hoberman, 1983; Cohen, Mermelstein, Karmarck & Hoberman, 1985)	2	1	1	0	0	0	0	0	4
Significant Others Scale (Power & Champion, 1988)	2	1	1	0	1	0	0	0	5
Perceived Social Support from Friends (PSS-Fr) & Perceived Social Support from Family (PSS-Fa; Procidano & Heller 1983)	2	1	1	0	1	0	0	0	5

Outcome measure	Content validity	Internal consistency	Construct validity	Agreement	Reliability	Responsiveness	Floor and ceiling effects	Interpretability	Total score
Social Support Questionnaire, Short Form—Revised (SSQSR; Sarason, Sarason, Shearin & Pierce, 1987)	2	2	1	0	1	0	0	0	6
Social Provisions Scale (SPS); Revised Social Provisions Scale (SPS; Cutrona & Russell 1987)	2	2	2	0	0	0	0	0	6
Abbreviated Duke Social Support Index (DSSI; Koenig et al., 1993)	2	2	1	0	0	0	0	0	5
The Duke Social Support and Stress Scale (DUSOCS; Parkerson 1989)	2	1	2	0	1	0	0	0	6
The Medical Outcomes Study Social Support Survey (Sherbourne & Stewart 1991)	2	2	2	0	1	0	0	0	7

Table 2

Detailed Analyses of Included Measures

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
Measures Developed or Validated with Caregivers with people living with dementia (n = 2)				
Multidimensional Scale of Perceived Social Support (MSPSS; Cartwright, Pione, Stoner & Spector, 2020; Zimet, Dahlem, Zimet, & Farley, 1988)	Family caregiver of people living with dementia (n = 270, mean age = 60.5)	12-item self-report measure on perceived social support from family, friend and significant other, 7-point Likert scale	<u>Cartwright et al., 2020</u> Internal consistency: Cronbach's $\alpha = .92$ (total), .92 to .94 (subscales) Test-retest reliability: ICC = .90 (total), .84 to .89 (subscales) Construct validity: Depression ($r = -.48, p < .001$) Mental health related QoL ($r = .32, p < .001$) Physical health related QoL ($r = .17, p = .003$) CFA: three factor solution with acceptable fit indices: significant other, family, friends	<i>Significant responsiveness for overall and significant others subscale</i> (Smith, Drennan, Makenzie & Greenwood, 2018, n = 19) <i>Significant responsiveness for perceived support from family</i> (Dam, van Boxtel, Rozendaal, Verhey & Vugt, 2017, n = 23) <i>Significant responsiveness for overall and significant others</i> (Smith, Drennan, Mackenzie, & Greenwood, n = 16) <i>No significant responsiveness</i> (Charlesworth et al., 2008, n = 236;

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
				Tremont, Davis, Bishop, & Fortinsky, 2008, n = 33)
Perceived Social Support for Caregiving (PSSC) & Social Conflict (SC; Goodman, 1991)	Caregivers of people with Alzheimer's disease (n = 206)	9-item scale on social support and 3-item scale on social conflict	<u>Goodman, 1991</u> Cronbach's $\alpha = .84$ (PSSC), $.72$ (SC) Convergent validity: PSSC & Natural network ($r = .19$ to $.34$) SC & burden ($r = .34$, $p = .001$) PCA which loaded to two factors	<i>Significant responsiveness demonstrated</i> (Goodman & Pynoos, 1989)
Measures Developed or Validated with Older Adults (n = 8)				
MacArthur Battery (social support measure; Gurung, Taylor & Seeman, 2003)	High functioning men and women aged 70-79 = (n = 439, mean age = 76.39)	18-item self-report measure on frequency of emotional support, instrumental support and negative interaction from spouse, children, and friends and family, 4-point scale	<u>Gurung et al., 2003</u> Inter-item correlation: Emotional support ($.34$ to $.49$, $p < .001$) Instrumental support ($.20$ to $.26$, $p < .001$) Negative interaction ($.28$ to $.48$, $p < .001$)	N/A
Social Support List of Interactions (SSL12-I;	Elders aged 57 or above with no severe cognitive	12-item self-report measure of received social support	<u>Kempen et al., 1995</u>	<i>Significant responsiveness for total received support and esteem support</i>

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
Kempen & Van Eijk, 1995, Van Eijk, Kempen & van Sonderen, 1994)	impairments (n = 5356, mean age = 69.6)	on everyday social support, support in problem situations and esteem support	Cronbach's $\alpha = .83$ (total), $.70$ (everyday support), $.72$ (support in problem situations), $.72$ (esteem support) Convergent validity: Loneliness (total, $r = -.38$; everyday support, $r = -.43$; support in problem situations $r = -.25$; esteem support, $r = -.27$) PCA & CFA – three-factor solution	<i>subscale</i> (Dam, van Boxtel, Rozendaal, Verhey & Vugt, 2017, n = 23) <i>No significant responsiveness</i> (Droes, Breebaart, Meiland, Tilburg & MellenBerg, 2004, n = 55); (Droes, Meiland, Schimitz & van Tilburg, 2006, n = 84)
Modified Inventory of Socially Supportive Behaviors (Modified-ISSB; Krause, 1987, Krause, 1987, Krause & Markides, 1990)	Older adults 65 years old or above (n = 351, mean age 73.4)	41-item modified self-report measure of receiving informational, tangible and emotional support, and integration, 4-point scale	<u>Krause et al., 1987a</u> Cronbach's $\alpha = .82$ (informational support), $.67$ (tangible support), $.83$ (emotional support), $.82$ (integration) <u>Krause et al., 1990</u> Maximum likelihood EFA: three-factor; second-order factor analysis	<i>Significant responsiveness for race in satisfaction with social support</i> (Burgio, Stevens, Guy, Roth, & Haley, 2003; n = 140) <i>No significant responsiveness</i> (Ducharme, Lachance, Levesque, Kergoat & Zarit, 2012, n = 97; Hebert et al., 2003, n = 158)

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
Krause's 'Social support measures' (Krause, 1995, Krause & Borawski-Clark, 1995)	Non-institutionised and retired household residents 65 years old or above (n = 1103, mean age = 74.1)	35-item self-report measure of social support on social contact, support received from others, support provided to others, negative interaction (4-point scales), and satisfaction with support (2-point scale)	<p><u>Krause & Borawski-Clark, 1995</u></p> <p>Cronbach's $\alpha = .62$ (contact with family), $.65$ (contact with friends), $.84$ (support received), $.87$ (support provided), $.81$ (negative interaction), $.69$ (satisfaction with support)</p> <p><u>Krause, 1995</u></p> <p>CFA</p>	<p>'Clinically meaning effect' favouring intervention for social support (Belle et al., 2006, n = 642)</p> <p>Significant responsiveness for satisfaction with social support but not negative interactions and received social support (Czaja, Loewenstein, Schulz, Nair & Perdomo, 2013, n = 110)</p> <p>Significant responsiveness with negative interactions (Gallagher-Thompson, 2003, n = 257)</p>
Lubben Social Network Scale (LSNS; Lubben, 1988)	Elderly Medicaid recipients (n = 1037, mean age 77.2)	10-item self-report composite measure of social networks on family networks, friends networks	<p><u>Lubben, 1988</u></p> <p>Cronbach's $\alpha = .70$</p> <p>Construct validity:</p> <p>Mental health (r = $.21$, p < $.001$)</p> <p>Health practices (r = $.13$, p < $.001$)</p>	No significant responsiveness (Burgio, Stevens, Guy, Roth, & Haley, 2003; n = 140)

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
		and interdependent social supports, 6-point scale	Hospital use ($r = .10, p < .01$)	
Lubben Social Network Scale-6 Item Version (LSNS-6; Lubben et al., 2006)	Community dwelling patients aged 65 or older (n = 7432, mean age = 74)	6-item self-report measure of social network on family and friendships, 6-point scale	<u>Lubben et al., 2006</u> Cronbach's $\alpha = .83$ (total), .84 to .89 (family), .80 to .82 (friend) Construct validity: Living with a partner ($r = .12$ to $.24, p < .001$) Availability of caregiver ($r = .20$ to $.30, p < .001$) No group activity ($r = -.27$ to $-.32, p < .001$) Emotional support ($r = .37$ to $.46, p < .001$) Presence of social isolation (LSNS-6 <12): Availability of caregiver ($r = -.17$ to $-.24, p < .001$) Emotional support ($r = -.26$ to $-.36, p < .001$) Principal component analysis – two-factor with no discernible cross-loadings	N/A

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
The Positive and Negative Social Exchanges (PANSE; Newsom, Nishishiba, Morgan & Rock, 2003)	Older adults enrolled in university senior adult learning programme of ages over 65 (n = 277, mean age = 74.3)	24-item self-report measure on positive and negative social exchanges, 5-point Likert scale	<u>Newsom et al., 2003</u> Cronbach's $\alpha = .90$ (positive exchanges), $.90$ (negative exchanges) CFA	N/A
Practitioner Assessment of Network Type (PANT; Wenger 1990, 1991)	Older adults aged 65 or above (n = 525), and aged 73 or above (n = 197)	8-item self-report or clinician-rated measure	N/A	N/A
Measures Developed or Validated with Students (n = 5)				
Inventory of Socially Supportive Behaviors (ISSB; Barrera, Sandler & Ramsey, 1981)	Female undergraduate psychology students (first sample: n = 71; second sample: n = 45)	40-item self-report measure of the frequency of received support on material aid, behavioural assistance, intimate interaction, guidance, feedback and positive social interaction, 5-point Likert scale	<u>Barrera et al., 1981</u> First sample: Cronbach's $\alpha = .93$ and $.94$ Test-retest correlation: $r = .88$, $p < .001$ Second sample: Convergent: Available social support network size ($r = .42$, $p < .01$)	N/A

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			Actual social support network size ($r = .32, p < .05$)	
Interpersonal Support Evaluation List (ISEL; Brookings & Bolton, 1988; Cohen & Hoberman, 1983; Cohen, Mermelstein, Karmarck & Hoberman, 1985)	Cohen: College students (n = 63) Brookings: College students (n = 133)	40-item (general population) or 48-item (college student) self-report measure of perceived social support with tangible, belonging, self-esteem and appraisal subscales, 2-point scale	<u>Cohen & Hoberman, 1983</u> Cronbach's $\alpha = .77$ (total), $.71$ (tangible), $.75$ (belonging), $.60$ (self-esteem), $.77$ (appraisal) Convergent: Behavioural/emotional problems ($r = -.29, p < .05$) Construct validity: Social support ($r = .46, p < .001$) Depression ($r = -.47, p < .05$) <u>Cohen et al., 1985</u> Test-retest reliability (4-week): $r = .87$ (total), (tangible), $.82$ (belonging), $.71$ (self-esteem), $.87$ (appraisal) <u>Brookings & Bolton, 1988</u>	Significant responsiveness for assistance subscale (Glueckauf et al., 2012, n = 11)

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			CFA – four-factor first-order model	
Significant Others Scale (SOS; Power & Champion, 1988)	Female university students (n = 135, mean age = 41 years old)	Self-report 10-item measure of emotional and practical support on 12 possible significant relationships, rated on actual and ideal level of support, 7-point scale	<u>Power & Champion, 1988</u> Intercorrelations (r = .42 - .76, p < .001) Test-retest reliability: r = .73 - .83 Factor analyses: three-factor solution	N/A
Perceived Social Support from Friends (PSS-Fr) & Perceived Social Support from Family (PSS-Fa; Procidano & Heller, 1983)	Undergraduate students (n = 222, mean age = 19)	20-item self-report measure of declarative statements of perceived social support from friends, 2-point scale with additional answer of 'don't know' not scored	<u>Procidano & Heller, 1983</u> Cronbach's α = .88 Construct validity: Psychiatric symptoms (friends; rs = -.27, p < .001) Psychiatric symptoms (family; rs = -.29, p < .001)	N/A

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
Social Support Questionnaire, Short Form–Revised (SSQSR; Sarason, Sarason, Shearin & Pierce, 1987)	Undergraduate students (Study 1 SSQ3: n = 182; Study 2 SSQ6 n = 182, 217, 146)	6-item self-report measure on the number of perceived availability of others and satisfaction on a 6-point scale	<u>Sarason et al., 1987</u> SSQ3: Cronbach's $\alpha = .75 - .79$ Test-retest reliability: $r = .84 - .85, p < .001$ Construct validity: Anxiety (Number $r = -.28, p < .001$; Satisfaction $r = -.19, p < .01$) Depression (Number $r = -.27, p < .001$; Satisfaction $r = -.21, p < .01$) Hostility (Number $r = -.22, p < .001$; Satisfaction $r = -.15, p < .05$) Social competence (Number $r = .41, p < .001$; Satisfaction $r = .17, p < .05$) Loneliness (Number $r = -.50, p < .001$; Satisfaction $r = -.57, p < .001$) Beck depression (Number $r = -.21, p < .05$; Satisfaction $r = -.22, p < .05$)	No significant responsiveness (Wang 2011, n = 80); (Chien & Lee, 2008, n = 88); (Chien & Lee, 2010, n = 92)

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			<p>SSQ6:</p> <p>Cronbach's $\alpha = .90 - .93$</p> <p>Construct validity:</p> <p>Sample 1:</p> <p>Anxiety (Number $r = -.26, p < .001$; Satisfaction $r = -.17, p < .05$)</p> <p>Social skill (Number $r = .39, p < .001$; Satisfaction $r = .20, p < .01$)</p> <p>Loneliness (Number $r = -.49, p < .001$; Satisfaction $r = -.59, p < .001$)</p> <p>Beck depression (Number $r = -.19, p < .05$; Satisfaction $r = -.19, p < .05$)</p> <p>Sample 2:</p> <p>Social anxiety (Number $r = -.31, p < .001$; Satisfaction $r = -.25, p < .001$)</p> <p>Shyness (Number $r = -.31, p < .001$; Satisfaction $r = -.20, p < .01$)</p>	

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			<p>Loneliness (Number $r = -.52, p < .001$; Satisfaction $r = -.60, p < .001$)</p> <p>Social desirability (Number $r = .23, p < .001$; Satisfaction $r = .19, p < .001$)</p> <p>Sample 3: State-trait anxiety (Number $r = -.38, p < .001$; Satisfaction $r = -.55, p < .001$)</p> <p>Beck depression (Number $r = -.29, p < .001$; Satisfaction $r = -.47, p < .01$)</p>	
Measures Developed or Validated with Other Populations (n = 4)				
Social Provisions Scale (SPS; Cutrona & Russell, 1987)	College students, public school teachers and nurses (n = 1792) Discriminant validity: college students (n = 242)	24-item self—report measure on the perception of six social provisions, 4- point scale	<p><u>Cutrona & Russell, 1987</u></p> <p>Cronbach's $\alpha = .92$ (total social provisions); .65 to .76 (subscales)</p> <p>Construct validity: Satisfaction with support ($r = .35, p < .001$) Number of supportive persons ($r = .40, p < .001$) Number of helping behaviours ($r = .35, p < .001$) Attitudes toward support ($r = .46, p < .001$)</p>	N/A

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			Social desirability ($r = .12, p < .05$) Depression ($r = -.28, p < .001$) Introversiion-extraversion ($r = .29, p < .001$) Neuroticism ($r = -.20, p < .01$) CFA	
Abbreviated Duke Social Support Index (DSSI; Koenig et al., 1993)	Community dwelling adults (n = 2954)	11-item shortened version of Duke Social Support Index (DSSI), a self-report measure on social interaction and subjective support	<u>Koenig et al., 1993</u> Cronbach's $\alpha = .75$ (overall 7-item subjective support scale) Construct validity: Mental distress ($r = -.41, p < .0001$) Factor analysis	N/A
The Duke Social Support and Stress Scale (DUSOCS; Parkerson et al., 1989)	Medical centre patients aged 18-49 (n = 249, mean age not reported)	24-item self-report social support measure on family support, family stress, non-family support and non-family stress, 3-point scale	<u>Parkerson et al., 1989</u> Test-retest reliability: $r = .76$ (family support), $r = .40$ (family stress) Convergent: Family strength (Family support, $\rho = .43, p = .0001$; Family stress, $\rho = -.44, p = .0001$)	N/A

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			<p>Intrafamily and marital strains (Family support, $\rho = -.19, p = .003$; Family stress, $\rho = .45, p = .0001$)</p> <p>Two-factor analysis of variance</p>	
<p>The Medical Outcomes Study Social Support Survey (MOS-SSS; Sherbourne & Stewart, 1991)</p>	<p>Patients in the Medical Outcomes Study (MOS) (n = 2987, mean age = 55)</p>	<p>19-item self-report social support measure on emotional support, informational support, tangible support, positive social interaction and affectional support,</p>	<p><u>Sherbourne & Stewart, 1991</u></p> <p>Cronbach's $\alpha = .97$ (overall), .96 (emotional and informational support), .92 (tangible support), .94 (positive interaction), .91 (affection)</p> <p>Test-retest reliability: .78 (overall), .72 (emotional and informational support), .74 (tangible support), .72 (positive interaction), .76 (affection)</p> <p>Convergent validity:</p> <p>Loneliness ($r = -.67$)</p> <p>Family functioning ($r = .53$)</p> <p>Marital functioning ($r = .56$)</p> <p>Mental health ($r = .45$)</p>	<p>N/A</p>

Measure	Sample population	Description	Reliability and validity	Responsiveness studies
			P-value all < .01 CFA	

Note. CFA = Confirmatory Factor Analysis; PCA = Principal Component Analysis; EFA = Exploratory Factor Analysis

Caregiving and Social Conflict with a final explained variance of 60.7%, indicating content validity (Table 2).

For MSPSS, internal consistency was excellent for the total score ($\alpha = .92$) and the subscale scores ($\alpha = .92 - .94$) and it was not indicative of multicollinearity. Test-retest reliability was excellent, with ICC = .90 for total score and ICC = .84 to .89 for subscale scores. There was high convergent validity, with depression score significantly negatively correlated to MSPSS total score ($r = -.48, p < .001$) and to each of the subscales respectively. Total MSPSS score has a small correlation with the physical health-related quality of life ($r = .17, p = .003$) and mental health-related quality of life ($r = .32, p < .001$). The subscales were significantly positively correlated with both physical health- and mental health-related quality of life, except between significant other and physical health related-quality of life, and between friends and physical health related-quality of life. It was the only included study that had reported that there were no floor and ceiling effects observed. The responsiveness of the MSPSS was not established as part of its psychometric validation.

Measures Developed or Validated with Older Adults

Eight of the measures were developed or validated with older adults, including MacArthur Battery (social support measure; 70 to 79 years old), Social Support List of Interactions (SSL12-I; 57 years old or above), Modified Inventory of Socially Supportive Behaviors (Modified-ISSB; 65 years old or above), Krause's 'Social support measures' (65 years old or above), Lubben Social Network Scale (LSNS; 'elderly Medicaid recipients'), Lubben Social Network Scale-6 Item Version (LSNS-6; 65 years old or above), Positive and Negative Social Exchanges (PANSE;

65 years old or above) and Practitioner Assessment of Network Type (PANT; 65 years or above) (Gurung et al., 2003; Kempen & Van Eijk, 1995; Krause, 1987a, 1987b, 1995; Krause & Borawski-Clark, 1995; Krause & Markides, 1990; Lubben, 1988; Lubben et al., 2006; Newsom et al., 2003).

All of the above measures received a score of ‘moderate’ on the criteria, except for PANT which received a score of ‘poor’. Cronbach’s α was reported for internal consistency in all measures except in MacArthur Battery, which was reported as inter-item. Internal consistency was reported as good in LSNS-6, SSL12-I, PANSE, three of the subscales in Krause’s social support measures and three of the subscales in Modified-ISSB ($\alpha = .82$ to $.90$) and acceptable in LSNS ($\alpha = .70$) and in one of the subscales in Krause’s social support measures and Modified-ISSB respectively ($\alpha = .65$ to $.67$). Test-retest reliability was not evaluated in any of the measures.

Construct validity was presented only for LSNS, LSNS-6 and SSL12-I. Small correlations were reported for LSNS with mental health, health practices and hospital use. Small to medium correlations were reported for LSNS-6 with the availability of support in different forms, and for SSL12-I with loneliness and other support measures, although no p-values were reported for SSL12-I. Factor analyses were completed for Modified-ISSB, LSNS-6 and SSL12-I, which all indicated content validity (Table 2).

Measures Developed or Validated with Students

Five of the measures were developed or validated with college or university students: the Inventory of Socially Supportive Behaviors (ISSB; female psychology

undergraduate students), Interpersonal Support Evaluation List (ISEL; college students), Significant Others Scale (SOS; female university students); Perceived Social Support from Friends (PSS-Fr) and from Family (PSS-Fa; undergraduate students) and Social Support Questionnaire Short Form-Revised (SSQSR; undergraduate students) (Barrera et al., 1981; Brookings & Bolton, 1988; Cohen & Hoberman, 1983; Cohen et al., 1985; Power et al., 1988; Procidano & Heller, 1983; Sarason et al., 1987).

Cronbach's α was reported for internal consistency for all measures except SOS. Internal consistency was excellent for ISSB ($\alpha = .93$ to $.94$), good for PSS-Fr and PSS-Fa ($\alpha = .88$) and acceptable for ISEL and SSQSR ($\alpha = .75$ to $.79$). Test-retest correlation was reported as Pearson correlation coefficient in ISSB, SSQSR and SOS. However, the Pearson correlation coefficient is considered an inappropriate measure of reliability as the coefficient will usually be higher than the actual reliability (Streiner, Norman, & Cairney, 2015).

Construct validity was present in all measures except for SOS. Small correlations were reported in ISEL, PSS-Fr and PSS-Fa while medium correlations were reported in ISSB. There were small, medium and large correlations reported for SSQSR. Factor analyses were completed for SOS and a confirmatory factor analysis (CFA) was completed for ISEL (Table 2).

Measures Developed or Validated with Other Populations

The remaining four measures were validated in other populations, including Social Provisions Scale (SPS; college students, public school teachers and nurses), Abbreviated Duke Social Support Index (DSSI; community dwelling adults), The

Duke Social Support and Stress Scale (DUSOCS; patients aged 18-49) and The Medical Outcomes Study Social Support Survey (MOS-SSS; patients in the study) (Cutrona & Russell, 1987; Koenig et al., 1993; Parkerson Jr et al., 1989; Sherbourne & Stewart, 1991). A 40-item ISEL (as opposed to the 48-item student version) was also validated in the general population across several studies.

Cronbach's α was reported for internal consistency for all measures except DUSOCS. Internal consistency for MOS-SSS was $\alpha = .97$ and an α level higher than .95 may indicate multicollinearity. Internal consistency was acceptable for DSSI ($\alpha = .75$) and excellent for SPS ($\alpha = .92$). Test-retest reliability was reported as Pearson correlation coefficient for MOS-SSS and DUSOCS.

Construct validity was present for all measures. Small to medium correlations were reported in both DUSOCS and SPS while medium to large correlations were reported in MOS-SSS. A medium correlation was reported in DSSI. CFA were executed in MOS-SSS and SPS, while factor analyses were carried out in DUSOCS and DSSI.

Types of Social Support

For further comparisons, the measures were recategorised by the structural, functional and evaluative aspects of support. Social support measures referring to social networks were considered to be measures of the structural aspect. Measures on received social support, provided social support and negative interactions were considered to be measures of the functional aspect while measures on perceived social support and satisfaction of support concerned the evaluative aspects of social support.

Measures of Social Network

Measures on social network measure structure of social support including the number and frequency of social contacts. There were five measures that assessed social network, including LSNS, LSNS-6, Krause's social support measures, PANT and DSSI (Koenig et al., 1993; Krause, 1995; Krause & Borawski-Clark, 1995; Lubben, 1988; Lubben et al., 2006; Wenger, 1991). These measures were not developed or validated with caregivers of people living with dementia. All of these measures scored moderately except for PANT which scored poor in the quality appraisal. LSNS-6 had the highest quality appraisal score with a 6-item scale measuring the number of social contacts with family and friends. It was derived from LSNS which had the largest number of items (10-item) measuring family networks, friends networks and interdependent social networks. LSNS was revised in later studies to a 12-item measure (LSNS-R), with interdependent social support items redeveloped into three additional items under family and friends networks respectively, and LSNS-6, the abbreviated version. The Social Interaction subscale on DSSI had the least number of items (4-item) and considered the number of family members and frequency of social contacts. There were six items on Krause's social support measures measuring the frequency of contact with family and friends in the past two weeks. PANT was an 8-item measure on both the frequency and physical distance of social contact. All measures were scored on scales of number and frequency of social contact, except PANT which was scored against a network type matrix to determine the network type of the respondent.

Measures of Received Social Support

Measures on received social support typically involve the frequency of the social support received over a given period of time. There were eight measures that considered received social support, including MacArthur Battery, ISSB, Modified-ISSB, SOS, Krause's social support measures, SSL12-I, MOS-SSS and PANSE (Barrera et al., 1981; Gurung et al., 2003; Kempen & Van Eijk, 1995; Krause, 1987a, 1987b, 1995; Krause & Borawski-Clark, 1995; Krause & Markides, 1990; Newsom et al., 2003; Power et al., 1988; Sherbourne & Stewart, 1991). None of the measures were validated in the population of caregivers of people living with dementia. All measures obtained a moderate score with MOS-SSS scoring the highest in the quality appraisal.

ISSB consisted of 40 items on both tangible and intangible (guidance and esteem) forms of social support. There were 27 items on Modified-ISSB and 11 items on Krause's social support measuring tangible, emotional and informational support respectively. The 11 items of received social support along with the items on satisfaction with support were most frequently cited and used among Krause's social support measures. Other than tangible, emotional and informational support, PANSE also covered companion support while MOS-SSS covered affectional support and positive social interaction (i.e. companionship) as well. The MacArthur Battery covered 12 items on emotional and instrumental support from the spouse, children and friends and family respectively and SSL12-I covered everyday support, support in problem situations and esteem support. All measures were scored on scales of frequency except the SOS which was a matrix with 10-items on 12 role relationships

measuring emotional and practical support while differentiating the respondent's ideal support versus actual support received.

Measures of Provided Social Support

Measures on provided social support involve the frequency of the social support provided over a given period of time. Krause's social support measures, Modified-ISSB and LSNS were the only measures that assessed social support provided to others by the caregivers (Krause, 1987a, 1987b, 1995; Krause & Borawski-Clark, 1995; Krause & Markides, 1990; Lubben, 1988). The measures scored moderately on the quality appraisal. Krause's social support measures involved 11 items on tangible, emotional and informational support that correspond to the received social support in the same measure. The 13-item Integration subscale on the Modified-ISSB measured social support provided for others under the same types of support. There was an overlap on nine of the items between the Krause's social support measures and Modified-ISSB. There was only one item on the entire LSNS on provided social support and it was specifically on tangible support. Measures and items on provided social support were less frequently cited and included in studies of caregivers of people living with dementia. For example, the Modified-ISSB was used in several research studies with the exclusion of the integration subscale (Belle et al., 2006; Ducharme et al., 2011; Huang, Musil, Zauszniewski, & Wykle, 2006).

Measures of Negative Interactions

While research often focuses on the positive and benefits of social support and network, sometimes there are unpleasant or negative interactions as well. There were two measures that considered negative social interactions, including Krause's social support measures and PANSE (Krause, 1995; Krause & Borawski-Clark, 1995; Newsom et al., 2003). Both measures received the same score in the 'moderate' range in the quality appraisal. These measures included items on negative interactions and experiences on top of the positive interactions (received support) discussed above. Krause's social support measures included 4 items on frequency of negative interaction. PANSE included 12 items on the frequency of negative social exchanges including unwanted advice or intrusion, failure to provide help, unsympathetic or insensitive behaviours, and reject or neglect, which provided the most comprehensive list of negative interactions.

Measures of Perceived Social Support

Measures of perceived social support involve evaluative aspects of the quality or availability of different types of support. For instance, the measures may ask for subjective responses on how the respondent feels about the statement, such as responding on Likert scales of agreement or simply 'yes' or 'no'. There were eight measures that assessed perceived social support, including MSPSS, PSSC and SC, PSS-Fr and PSS-Fa, ISEL, DSSI, SPS, SSQSR and DUSOCS (Brookings & Bolton, 1988; Cartwright et al., 2020; Cohen & Hoberman, 1983; Cohen et al., 1985; Cutrona & Russell, 1987; Goodman, 1991; Koenig et al., 1993; Parkerson Jr et al., 1989; Procidano & Heller, 1983; Sarason et al., 1987; Zimet et al., 1988). MSPSS

received a 'good' score in the quality appraisal with excellent content validity, construct validity, internal consistency and reliability, and a report on floor-and-ceiling effect. The only limitation is that data responsiveness was not available due to the design of the study. All of the other measures received a 'moderate' score.

ISEL consisted of 40 items in the general population version and 48 items in the student version, with 10 and 12 items on tangible, belonging, appraisal and self-esteem subscales. It was also modified exclude the self-esteem subscale to avoid overlaps with other self-esteem measures. The four highest-loading items were included for the remaining three subscales, making it a 12-item self-report measure on a four-point scale known as ISEL-12, which was also used in some studies (Arango Lasprilla, Moreno, Rogers, & Francis, 2009). MSPSS, PSS and DUSOCS all distinguished between the source of support in the measures. MSPSS consisted of three subscales of family, friends and significant other, PSS consisted of two subscales of friends (PSS-Fr) and family (PSS-Fa) and DUSOCS considered perceived support and stress from both family and non-family members. SPS was composed of six social provisions including guidance, reassurance of worth, social integration, attachment, nurturance and reliable alliance. SSQSR focused on the respondent's perceived availability of support while DSSI measured perceived reciprocal support on seven items. PSSC and SC included items on perceived peer support and social conflict specific to caregiving.

Measures of Satisfaction with Support

There were three measures that assessed the satisfaction with support, including Modified-ISSB, Krause's social support measures and SSQSR (Krause,

1987a, 1987b, 1995; Krause & Borawski-Clark, 1995; Krause & Markides, 1990; Sarason et al., 1987). The measures received a 'moderate' score in the quality appraisal with SSQSR having the highest score. Krause's social support measures included three items on satisfaction corresponding to received tangible, emotional and informational support. The four items on Modified-ISSB were specified to each of the subscales on informational support, tangible support, emotional support and integration. The overall satisfaction with available supports were scored for all six items in SSQSR.

Discussion

To our knowledge, this is the first systematic review exploring the psychometric properties of social support measures for caregivers of people living with dementia. Nineteen social support measures were identified to have been developed, psychometrically validated or used in research studies with caregivers of people living with dementia. These outcome measures examined structural, functional and evaluative social support and they were categorised into social network, received social support, provided social support, negative interactions, perceived social support and satisfaction with social support. PSCC was the only measure developed with caregivers of people living with dementia (Goodman, 1991). The rest of measures were developed with other populations and MSPSS was the only measure to have undergone a recent psychometric validation with caregivers of people living with dementia (Cartwright et al., 2020). Most of the measures were developed with an older adult population, but as not all carers are older adults, this may imply that the psychometric properties of these measures are less comparable.

The majority of the measures obtained a ‘moderate’ score in the quality appraisal except MSPSS which obtained a ‘good’ score and PANT which obtained a ‘poor’ score (Cartwright et al., 2020; Wenger, 1991). Floor and ceiling effects were under-reported across all measures, with only the validation of the MSPSS reporting this information. Content validity was adequate across most of the measures, followed by internal consistency and construct validity. As there was no ‘gold standard’ measure of social support in this population, criterion validity was not considered. None of the measures reported on standard error of measurement and interpretability was seldom considered. Only one measure attempted to report on responsiveness.

Measures with items on received and perceived social support were most commonly found. There were only three measures on satisfaction with support and two measures on negative interactions. There has been increasing interest in investigating the consequences of perceived negative support. For example, negative experience with social interactions that involve criticism and hostility may lead to future avoidance of social interactions (Frick, Motzke, Fischer, Busch, & Bumedel, 2005) and there is the suggestion that social support can do harm when it is unwelcomed (Edwards & Cooper, 1988).

Limitations of the Evidence

There was an abundance of social support measures that were developed in the 1980s and 1990s due to a rapid growth of research on social support at the time. While the researchers made adaptations and modifications on different measures, the names of the measures were used interchangeably across studies with no clear

indication or differences in the names, which made it difficult to gather the evidence for the review. In addition, some studies used incorrect citations and references for measures described. This could make it difficult for studies to be replicated or to establish effectiveness and responsiveness for each specific outcome measure. This suggests the need to establish a homogeneous use of measures to allow for making comparisons in research and clinical use.

Specifically, there were many inconsistent versions of abbreviated measures across the studies. For example, the original development of MacArthur battery was an 18-item measure with a 4-point scale but it was described as a 12-item measure using a 5-point scale in a Chinese version of the measure (Au et al., 2009; Gurung et al., 2003). During the screening process, there were confusion and discrepancy with ISSB and Modified-ISSB. For example, some studies used 27-item instead of the 41-item modified scale by dropping the integration subscale (Ducharme et al., 2011; Huang et al., 2006). Another study created an 18-item version and used a 7-point scale instead of a 4-point scale (MaloneBeach & Zarit, 1995). The REACH-II social support evaluation adopted 10 items from ISSB, Modified-ISSB and Krause's social support measures but it was unclear which ones were used while there was a discrepancy on the scale used with satisfaction with support between the cited studies and the original papers (Belle et al., 2006; Czaja, Loewenstein, Schulz, Nair, & Perdomo, 2013; Martindale-Adams, Nichols, Zuber, Burns, & Graney, 2016). While there may be valid research reasons for such abbreviations of measures, there was no evidence on the validity of these adapted measures and the findings from these measures and studies may not be generalised.

Rather than not meeting the standard on reporting the measurement properties, most studies failed to report on some measurement properties entirely, for example, the floor and ceiling effects. PSSC was the only measure that was validated in an intervention study, but the design was not adequate according to the quality appraisal tool. None of the other measures were validated in an intervention study, hence data on responsiveness was not available across the evidence. However, it was understandable as most of the included measures were developed before the importance of using a well-established quality appraisal tool was emphasised. Future validation studies of any measures in this population should endeavour to adhere to the quality appraisal guidelines such as the criteria used here.

Gender, race, culture, individual preference and neuroticism influence how support is perceived and used (Brodaty & Donkin, 2009). LSNS-6 was the only study that involved population from different cities (Lubben et al., 2006). It was unclear whether the other measures could be generalised to other geographical locations or cultures. The reported demographics varied across the studies and was seldom taken into consideration in the analysis. For example, ethnicity was not reported in some of the validation or development studies.

Limitations of the Review

Intervention as a search term was included in the search strategy with an aim to examine responsiveness in the quality criteria, but most of the studies were cross-sectional, which made it impossible to draw conclusions on their ability to demonstrate significant differences across time and make recommendations in intervention work. Some measures were not included due to inability to access its

original development or validation paper. A substantial number of studies, especially the original validation studies, were identified via the reference list.

As discussed, there were many support measures developed in the 1980s and the 1990s and these measures were subsequently modified or adapted by different researchers. If we were to include only the original measure, we may lose important details and changes that may have been adapted by other studies. If we were to include only the most recent modified version, we may lose important details of the original development. After consideration, it seemed crucial to also include the development or validation studies on the adapted or modified measures that were used with caregivers with people living with dementia to avoid missing any important information for future research and clinical use. In some of the identified studies, the researchers had added or removed some items on the validated measures in their studies. Although this did not affect the primary focus on this review to assess the psychometric properties of the measures, the evidence on responsiveness studies was limited by this.

Future Research

There is currently an abundance of social support measures used with caregivers of people living with dementia in the literature which makes it challenging to compare and integrate research findings. While there were two measures on perceived social support that were developed or validated with this population, there was none for the measures on received social support, social network or other constructs (Cartwright et al., 2020; Goodman, 1991). As the nature and accessibility of social support are inherently different between caregivers and the general

population, future studies could consider validating social support measures on other types of social support.

Most of the included social support measures were developed or validated before the quality criteria for measurement properties were proposed. Thus, it was not surprising to observe a consistent lack of information on some psychometric properties, such as the floor and ceiling effects. The quality criteria for future development or validation studies on health status questionnaires should be considered in future research (Terwee et al., 2007). In particular, it would be helpful to consider using longitudinal designs to detect clinically important changes over time and assess responsiveness and cross-cultural validity. It may also be helpful to consider whether factors such as the length of the measure influence the routine use of social support measures.

As many researchers attempted to modify or abbreviate measures for their studies, there seemed to be a need for the validation of the abbreviation of any current measures in-use, such as the Modified-ISSB (Krause & Markides, 1990). To avoid confusion and to allow for replication of study, researchers could attempt to provide a more thorough explanation on the item selection, or the specific changes made to the original measure in their studies.

Clinical Implications

Caregiver burden, self-efficacy, resilience and other measures are constructs commonly used with the caregivers of people living with dementia, yet social support is often not emphasised. As social support reduces both psychological and non-psychological care burden in caregivers of people living with dementia, it is

important to incorporate such measures into routine clinical use to identify those who may benefit from having more support, either through the recognition of such needs or by providing some social support interventions (Han et al., 2014). To ensure the measures are used appropriately, social support (by non-professionals) must not be confused with professional support, such as those offered by dementia services. It is crucial for healthcare professionals to understand this clearly to be able to identify caregivers' needs and explain to them appropriately.

Furthermore, with limited time and availability of clinic appointments, it is important to consider time efficiency for both carers and professional that a careful balance may be required between the depth of detail and the length of the measure. People are less likely to respond to very long measures (Taylor-Powell & Marshall, 1998). For example, SOS provided the most comprehensive information on the source of social support, but it is possible that a complex matrix may take up a long time to be completed. Subject to further research or service evaluation, a briefer, shorter measure seems to be more appropriate as a screening tool in clinical practice taking into consideration of time, manpower and completion rates. However, this may mean losing information on either the source of the support or on the specific dimension of social support. This may suggest the need for a range of different briefer social support measures to fit different clinical purposes. The MSPSS can be recommended for research and clinical use due to its excellent psychometric properties which is validated with caregivers of people living with dementia.

Conclusions

This review highlighted that there were some social support measures with good psychometric properties, but further validation is required in the population of caregivers of people living with dementia for some types of social support. MSPSS was validated in the studied population with the strongest psychometric properties from all the identified measures. It is recommended for this measure to be included in intervention studies to determine its ability to detect clinically significant change over time. However, the MSPSS only measures perceived social support from family, friends and significant other, while there is more complexity in the construct of social support. This highlights the importance for further development and validation of other social support measures with caregivers of people living with dementia.

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Part 2: Empirical Paper

Large scale psychometric validation of two positive psychology outcome measures
for people with dementia in Hong Kong

Abstract

Aims: Positive psychology has been an increasingly popular area of interest in Western research but less so in Asian research. The present study aims to conduct a full-scale psychometric validation study of the Positive Psychology Outcome Measure (PPOM), a measure of hope and resilience, and the Engagement and Independence in Dementia Questionnaire (EID-Q), a measure of social independence, in people with dementia (people living with dementia) in Hong Kong.

Method: The study involves an investigation of psychometric properties of two culturally adapted positive psychology measures for people living with dementia. A sample of people living with dementia recruited from Hong Kong completed the measures in-person or online, independently or with some support. As a factor structure with acceptable model fit has been identified in the studies conducted in UK, a confirmatory factory analysis (CFA) was applied to determine the fit of this model in the Hong Kong population.

Results: A total of 58 people living with dementia completed the study. Internal consistency was good for the PPOM ($\alpha = .870$) and excellent for the EID-Q ($\alpha = .904$). There were significant correlations between PPOM and quality of life ($r = .523, p < .001$) but not depression, and significant correlations between EID-Q and quality of life ($r = .634, p < .001$) and depression ($r = -.295, p = .026$) respectively. Factor analysis suggested that the factor structure from UK may not be applicable to the current population.

Conclusions: PPOM and EID-Q demonstrated acceptable psychometric properties, but no acceptable model fit was found, possibly due to the current small sample size.

Future research on a larger-scale psychometric validation with analysis of responsiveness to intervention is required.

Introduction

Dementia is a global health priority affecting 46.8 million people in the world in 2015 and is estimated to affect 131.5 million people by 2050 (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). It is characterised by cognitive deficits and declines in short-term and long-term memory impacting daily functioning (American Psychiatric Association, 2013). People living with dementia display multiple cognitive deficits including memory impairment and at least one of the following: aphasia, apraxia, agnosia or disturbance in executive functioning, while there is also social or occupational impairment (American Psychiatric Association, 2013).

Traditionally, dementia was characterised as a medical disease with defined symptoms that unavoidably develops into the loss of function and end-of-life. As a result, the psychology of dementia was generally constructed in terms of progressive deterioration and dependency, along with the negative aspects of cognitive, emotional and behavioural symptoms. This led to the predominant usage of a pathological, decline- or loss-oriented model in dementia that was criticised for being too narrow and portraying people living with dementia as a burden rather than being burdened by dementia, which resulted in stigma in people living with dementia themselves, their carers and in the society (Lyman, 1989). Researchers later attempted to address the role of social and individual factors in dementia, for instance, emphasising the interrelationship between cognitive impairments, psychological and social factors (Kitwood, 1993). A highly individualistic model incorporated the interaction of biological, psychological and socio-cultural factors,

and presented dementia as a process beginning with early organic changes, diagnosis, institutionalisation and culminating in death (Spector & Orrell, 2010).

Similar to empirical research, media portrayal of dementia usually emphasises the challenging aspects of dementia and its social and economic burden on our society. The constant negative and problematising narrative may neglect the positive experiences and personal strengths that people living with dementia also experience despite living with this condition. While there were psychosocial interventions developed to promote quality of life in people living with dementia, the goal was often emphasised to reduce the negative aspects of symptoms like depression or agitation, rather than focusing on the positive experiences (Whitaker et al., 2014).

Positive Psychology

Positive psychology is the study of positive emotions, functioning and traits that allow individuals, communities and organisations to thrive (Seligman, Steen, Park, & Peterson, 2005). It offers perspectives, conceptual models and findings to help us understand how people may live well as they become to face various health problems as they age (Moniz-Cook et al., 2016). Positive psychology helps to shift away from the historical phenomenon of pathology and negativity in the field. The more recent, second-wave positive psychology, is a non-pathologising approach to mental health, which seeks to examine and understand how people attempt to flourish despite challenges encountered (Lomas & Ivtzan, 2016). It promotes a science of thriving and makes an important contributing factor for well-being.

Positive psychology in dementia emphasises the strengths or capabilities used in achieving or maintaining wellbeing in the face of difficulties or challenges (Stoner, Orrell, & Spector, 2018a). Since positive psychology is a highly subjective concept, the research with people living with dementia has been largely qualitative. A meta-analysis identified three themes of positive psychology in dementia, including the experience of engaging with life in ageing rather than living with dementia, the focus on using personal strengths to face dementia, and different ways that people living with dementia may seek to maintain their identity and achieve personal growth despite the condition (Wolverson, Clarke, & Moniz-Cook, 2016).

While there were many measures developed since the inception of positive psychology, there was a lack of standardised positive psychology outcome measures developed or validated with people living with dementia. A systematic review on positive psychology outcome measures identified the potential usage of some measures with people living with dementia but further validation and adaptation with this population was required to ensure that the measures were measuring what they were supposed to measure with people living with dementia (Stoner, Orrell, & Spector, 2015). Two positive psychology measures for people living with dementia were recently developed and validated in the United Kingdom. Positive Psychology Outcome Measure (PPOM) measures hope and resilience, which were essential to maintain wellbeing, with hope seen in multiple aspects of daily life and resilience as emotional stamina in the face of difficulties (Stoner et al., 2018a). Engagement and Independence in Dementia Questionnaire (EID-Q) measures independence and social engagement (Stoner, Orrell, & Spector, 2018b). It was developed using a capability approach to dementia and examined the perceived ability of people living with

dementia in making choices and maintaining control over important aspects of their life to maintain a sense of autonomy and independence (Stoner et al., 2018b).

Dementia in Hong Kong

Population ageing in Hong Kong is expected to continue and the number of older adults aged 65 and above is projected to increase more than double in the next 20 years (Census and Statistics Department, 2017). The life expectancy in Hong Kong is the highest among the world where it was estimated to be 81.3 years in males and 87.3 years in females in 2016 (Census and Statistics Department, 2017).

In the past, research suggested a lower prevalence in dementia compared to Western countries but this phenomenon changed to a drastic increase over time (Ferri et al., 2005). A recent systematic review reported that the crude prevalence of dementia increased from 1.9% before 1990 to 6.4% in 2010-15 in Hong Kong, Taiwan and China (Wu et al., 2018). The number of people aged 60 and above with dementia was projected to increase by 222% from 2009 to 2039 (Yu et al., 2012). The increasing trend in prevalence brings significant burden and impact to the healthcare system which suggests the importance of developing a better long-term care strategy in Hong Kong to respond to the foreseeable challenges ahead.

Recently, there has been more positive psychology research conducted in Hong Kong. However, the focus was primarily on general older adults population and those suffering from pain and physical illnesses (Ho, Yeung, & Kwok, 2014). The shift towards person-centred care and positive psychology in dementia research in Western countries was not observed in Hong Kong as the majority of the research continued to focus on the negative aspects of dementia. A positive psychology

approach that considers positive experiences and strengths despite the declining nature of dementia may be of high value in the development and planning of a care system and the empowerment of people with dementia in Hong Kong. By developing an understanding on how people understand, experience and improve their well-beings, the attention shifts from negativity and burden to positive outcomes and personal strengths. The availability of culturally validated positive psychology measures may help direct future research directions and help clinicians and families to shift towards non-pathologising discussions of dementia and guide interventions. This would also allow researchers to make comparisons of results between Hong Kong, the United Kingdom and any other countries that the measure was validated.

The current study built on a study of cultural translation and piloting of the culturally adapted versions of PPOM and EID-Q in a Hong Kong dementia population (Lau, 2020). Conceptual focus groups and individual interviews were conducted to explore the meaning of the positive psychology constructs (hope, resilience, social engagement and independence) in people living with dementia, their caregivers and healthcare professionals in Hong Kong (Lau, 2020). Continuity, companionship, family and realism were identified in the thematic analysis (Lau, 2020). At the next stage, more focus groups and interviews were conducted to gather qualitative feedback on the translated versions of PPOM and EID-Q (Lau, 2020). A visual analogue scale and a manual were developed based on the feedback and a pilot study was completed (Lau, 2020).

In the pilot study, there was some preliminary evidence for the usage of Cantonese PPOM and EID-Q, but the sample size was too small for in-depth analysis such as examining the factor structure of the two measures. Therefore, the aim of the

present study was to complete further in-depth psychometric analysis in a larger sample of people living with dementia in Hong Kong. Following the same procedures as the pilot study, we aimed to add on to the pilot sample, describe the demographic and clinical characteristics of participants, and explore any differences between identified subgroups. We also aimed to evaluate the measure's internal consistency, test-retest reliability, convergent validity and factor structure.

Methods

Design

The study was an extension of a pilot, cross-sectional, questionnaire-based study using a non-probabilistic, purposive sampling across different community centres and nursing homes in Hong Kong (Lau, 2020). The measures were completed in person or online. As all types of dementia are progressive and the symptoms and abilities may vary, in-person completions were completed independently, completed with minimal support from a researcher, or completed using an interview. In-person versus online completions were decided based on the participants' preference, convenience and ability and was decided with the staff members or the participants directly at the first point of contact.

Ethics

Ethical approval was not required as this was an extension of the pilot study (Lau, 2020). Ethical amendment was approved by UCL Research Ethics Committee to extend the project to 1st September, 2021 (Research Registration 14667/001; see

Appendix A). As the study was completed in Hong Kong, there was ethical approval in place and approved by The University of Hong Kong Human Research Ethics Committee until 21st November, 2022 (Research Registration EA1811016).

Participants

Participants had a diagnosis of dementia according to the DSM-5 (American Psychiatric Association, 2013), the capacity to provide informed consent and the ability to communicate in Cantonese verbally. Regardless of literacy, participants were given detailed verbal explanation, witnessed by staff member or carer, and were able to sign and provide their consent.

A minimum of 100 subject was required to enable stability of the variance in factor analyses while the rule-of-thumb ranged from four to 10 subjects per variable (Kline, 2000). We aimed to follow the commonly referenced quality criteria and used the criterion of having seven subjects per item, which made a total of 182 subjects after multiplying 26 items on EID-Q by seven (Terwee et al., 2007). A total of 33 participants completed the pilot study in Hong Kong from December 2019 to January 2020, although one participant only completed PPOM and not EID-Q (Lau, 2020). Therefore, we aimed to recruit 150 more participants, with the first 50 participants asked to complete a retest one week later to test for test-retest reliability. In the end, the aimed number of participants was not met, and no retests were completed. This was due to the difficulties in recruitment and the limited availability of rooms and timeslots available at the homes and centres during the pandemic.

Procedures

Recruitment started in February 2020, shortly after the pilot study was completed (Lau, 2020). The same procedures to the pilot study were followed. Participants were recruited via ongoing discussions with nursing homes and community centres in Hong Kong. Participants were also recruited through referrals from charity work and previous research. The details of the present study were discussed with staff to identify potential participants who fit with the inclusion criteria and to ensure that appropriate plans and support were put in place prior to data collection. Potential participants were contacted by the staff, and they were invited to indicate their preference to complete the measures in-person or online.

If the participants preferred to complete the measures online, they were directly sent a link on Qualtrics, a GDPR (General Data Protection Regulation) compliant online platform (Wachter, Mittelstadt, & Russell, 2017). An instructional video recorded by the researcher was provided to emphasise that the measures must be completed by the people living with dementia. The carers were told to only provide technical support to the people living with dementia. Informed consent was also collected online with information provided on the study aim, procedure, risks and discomforts, benefits, confidentiality and right to withdraw consent anytime (see Appendix B). Participants were required to acknowledge that they understand that the measures must be completed by themselves and confirm that they have a diagnosis of dementia to begin completing the measures.

If the participants preferred to complete the measures in-person, an appointment was scheduled in the participant's affiliated nursing home or community centre. In-person data collection was completed by the author of the

study. Participants could complete the measures by self-report, with support from the researcher (including but not limited to having the verbatim read out for participants with poor eyesight or limited literacy), or by in-person interview. The participants' capacity to participate was informally evaluated based on Mental Capacity Act guidance while following Research Ethics Compliance from Human Research Ethics Committee at The University of Hong Kong. Informed consent was obtained after the researcher provided above mentioned information and answered any queries about the present project. All participants received a copy of consent form for their record.

Participants who were able to read and understand the measures themselves were provided with a paper copy of the measures to complete individually and they could ask for clarification at any time. A visual analogue scale was used to provide people living with dementia with visual support in understanding the scale of the measure (see Appendix C). Clarifications were offered using the verbatim from the manual developed in the pilot study to maintain consistencies across participants. The participants who required more extensive support (e.g. poor eyesight or illiteracy) completed the measures via in-person interview. The researcher read aloud the instructions and the items in Cantonese Chinese based on the predetermined verbatim.

Generally, it took approximately 30-60 minutes in total to complete the demographic information and four questionnaires. Completing time varied depending on the completion method used, the participant's presentation, and level of literacy and communication. However, approximately 5% of participants required over 75 minutes to complete the assessment. The researchers checked through the

measures to ensure there were no missed questions, unless the participants declined to answer any particular question intentionally. Participants received a thank you pack consisting of surgical masks and hand sanitiser in response to the COVID-19 situation and a hand-written thank you card for their time and participation.

Measures

The measure pack consisted of the two positive psychology measures, two other outcome measures and demographic information. Participants were asked to provide demographic information on age, sex, marital status, education level, dementia diagnosis, living situation and religion. The demographic information was sometimes completed by their carers or staff.

The Positive Psychology Outcome Measure (PPOM)

The PPOM measures the degree of hope and resilience for people with dementia on a five-point Likert scale, with 0 indicating not true at all and 4 indicating true nearly all the time, under a one-month time frame (see Appendix D). The original version of PPOM has established excellent psychometric properties in the United Kingdom (Stoner, Orrell, Long, Csipke, & Spector, 2017; Stoner et al., 2018a). The PPOM was translated to Chinese from a series of qualitative interviews and feedback conducted in Hong Kong (Lau, 2020).

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

The EID-Q measures the subjective independence and social engagement for people with dementia on a five-point Likert scale, with 0 indicating not true at all and

4 indicating true all the time, under a one-month time frame (see Appendix E). It has demonstrated acceptable psychometric properties with an adequate model fit in the factor solution (Stoner et al., 2017; Stoner et al., 2018b). The EID-Q was translated to Chinese following focus groups and individual interviews conducted in Hong Kong (Lau, 2020).

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

The QoL-AD was included to measure the convergent validity between positive psychology and quality of life (see Appendix F). Quality of life is expected to be positively correlated to both hope and resilience in PPOM, and sense of independence and social engagement in EID-Q. QoL-AD is a self-report measure of quality of life on a four-point Likert scale with 1 indicating poor and 4 indicating excellent (Logsdon, Gibbons, McCurry, & Teri, 1999). It has 13 items, and a higher score indicates a higher level of quality of life across different domains, with 52 as the maximum possible score. It is considered to be a broad measure considering both objective and subjective indicators of quality of life (Ready & Ott, 2003). A Chinese version with good internal consistency, test-retest reliability and inter-rated reliability was used (Chan, Chu, Lee, Li, & Yu, 2011). The internal consistency was .889 in this study.

The Geriatric Depression Scale Short Form (GDS-15)

The GDS-15 was included to measure the convergent validity between positive psychology and depression (see Appendix G). Research showed an inverse relationship between depression and resilience where greater resilience is associated

with less depressive symptoms. Therefore, this measure was expected to be negatively correlated to PPOM and EID-Q respectively. The GDS-15 measures depression with 15 items on a yes/no scale with a higher score indicating a higher level of depression. A score of ten or above indicates clinical significant depression (Sheikh & Yesavage, 1986). A validation study completed with people with dementia indicated adequate psychometric properties (Leshner & Berryhill, 1994). The GDS-15 was translated into Chinese in Hong Kong and it showed good psychometric properties for geriatric depression (Lee, Chiu, Kwok, Leung, & Kwong, 1993; Lee, Chiu, & Kwong, 1994). A Cantonese version with a standardised verbal instruction manual was utilised (Wong et al., 2002). The internal consistency was .833 in this study.

Analysis

Data normality was assessed with mean, standard deviation, range and skewness, and with the use of a histogram with a distribution curve. Shapiro-Wilk test was used to test for normality. Independent t-tests and Chi Square were used to identify differences between those who completed the measures in person versus those who completed them online. Mean imputation was used at 10% level for PPOM, EID-Q and GDS-15, and at 20% level for QoL-AD for missing data (Logsdon et al., 1999).

Internal consistency for scales and subscales was measured using Cronbach's alpha. Floor and ceiling effects were examined with mean, standard deviations, the observed range of scores and the possible range of scores. Floor and ceiling effects are considered to be significant if more than 15% of participants achieved the highest

or lowest possible scores (Terwee et al., 2007). Convergent validity was measured using Pearson's r correlation to examine the degree to which theoretically related concepts were observed to be related in the outcome measures.

As latent factors were explored previously with an exploratory factor analysis (EFA) in the original development paper, a confirmatory factor analysis (CFA) was first conducted (Stoner et al., 2018a, 2018b). The CFA was conducted to determine the goodness of fit using χ^2 statistics, comparative fit index (CFI), standardised root mean square residuals (SRMR) and root mean square error of approximation (RMSEA). CFI values should be greater than 0.90 and SRMR values should be below 0.08 (Hu & Bentler, 1999). RMSEA values less than 0.05 were considered good, values between 0.06 and 0.08 were considered acceptable, values between 0.08 to 0.10 were considered marginal fit and values greater than 0.10 were considered poor fit (Fabrigar, Wegener, MacCallum, & Strahan, 1999). As the goodness of fit indices showed that the model was not an adequate fit for data, an Exploratory Factor Analysis (EFA) was conducted using Kaiser's criterion which considers eigenvalues of one or greater as distinct factors, and by examining the scree plot to identify the inflection point where subsequent components add little to the variance (Kaiser, 1960). Eigenvalue indicates the amount of variance explained by each variable in the correlation matrix (Schumacker & Lomax, 2016). All statistical analysis were run in SPSS Statistics 27, with the exception of CFA which was run in SPSS AMOS 27.

Results

As the nursing homes restricted visits from the public while the community centres remained closed during each wave of COVID-19, only a limited number of participants were recruited when the homes and centres were opened for restricted access with safety precautions in place.

Participants

In the end, an additional 27 participants were recruited from the nursing homes and community centres and 25 completed the outcome measures. Two participants did not complete the measures due to physical condition and discomfort ($n = 1$) and a lack of confidence in completing the measures ($n = 1$). The current sample of 25 was added to the pilot sample of 33 participants, which made a total sample of 58 people living with dementia for this study.

All participants understood and spoke Cantonese Chinese. The mean age of the participants was 79.62 (SD 8.70) and 60.3% of participants were female. The majority of participants were either married (56.1%) or widowed (42.1%). Most participants received some primary level education (36.2%), followed by not having had any formal education (24.1%) and some secondary level education (20.7%). The most common dementia type was Alzheimer's Disease (25.9%) although the majority of people living with dementia (and their carers or staff members) were unsure of the type of the diagnosis (44.8%). The complete demographic details are available in Table 1.

Table 1*Demographic and clinical characteristics of the sample (n = 58) and subsamples*

	Total sample (n = 58)	Pilot sample (n = 33)	Current sample (n = 25)
Sex, n (%)			
Male	23 (39.7)	13 (39.4)	10 (40.0)
Female	35 (60.3)	20 (60.6)	15 (60.0)
Age M±SD (range)	79.62±8.70 (40-95)	81.06±6.64 (69-95)	77.72±10.68 (40-91)
Marital status n (%)			
Married	32 (56.1)	14 (42.4)	18 (72.0)
Widowed	24 (42.1)	18 (54.5)	6 (24.0)
Divorced	1 (1.8)	0 (0.0)	1 (4.0)
Missing data	1 (1.8)	1 (3.0)	0 (0.0)
Education level n (%)			
No formal education	14 (24.1)	12 (36.4)	2 (8.0)
Primary level education	21 (36.2)	13 (39.4)	8 (32.0)
Secondary level education	12 (20.7)	4 (12.1)	8 (32.0)
Postsecondary level education	3 (5.2)	1 (3.0)	2 (8.0)
Bachelor degree or above	8 (13.8)	3 (9.1)	5 (20.0)
Living situation n (%)			
Self-owned private flat	20 (34.5)	9 (27.3)	11 (44.0)
Self-owned government-subsidized flat	14 (24.1)	8 (24.2)	6 (24.0)
Public rental flat	18 (31)	12 (36.4)	2 (8.0)
Private rental flat	3 (5.2)	1 (3.0)	6 (24.0)
Missing data	3 (5.2)	3 (9.1)	0 (0.0)
Living alone n (%)	7 (12.1)	4 (12.1)	3 (12.0)
Dementia type n (%)			
Alzheimer's Disease	15 (25.9)	7 (21.2)	8 (32.0)
Vascular dementia	6 (10.3)	5 (15.2)	1 (4.0)

Frontotemporal dementia	1 (1.7)	0 (0.0)	1 (4.0)
Dementia of mixed aetiology	4 (6.9%)	3 (9.1)	1 (4.0)
Other	3 (5.2)	3 (9.1)	0 (0.0)
Unsure of diagnosis	26 (44.8)	12 (36.4)	14 (56.0)
Missing data	3 (5.2)	3 (9.1)	0 (0.0)
Religion <i>n</i> (%)			
Christian	14 (24.1)	4 (12.1)	10 (40.0)
Buddhist	4 (6.9)	2 (6.1)	2 (8.0)
Taoist	3 (5.2)	3 (9.1)	0 (0.0)
Other	2 (3.4)	1 (3.0)	1 (4.0)
No religion	29 (50.0)	17 (51.5)	12 (48.0)
Missing data	6 (10.3)	6 (18.2)	0 (0.0)

In the total sample, 51 participants completed the measures in person while 7 of them completed the measures online. There were no statistically significant differences between the completion styles for PPOM ($t(56) = 1.007$, $p = 0.318$), EID-Q ($t(55) = 0.005$, $p = 0.996$), QoL-AD ($t(56) = -0.636$, $p = 0.527$) and GDS-15 ($t(55) = 0.784$, $p = 0.212$) respectively.

Similarly, there were no statistically significant differences between the participants in the pilot sample and the current sample for PPOM ($t(56) = 0.547$, $p = 0.587$), EID-Q ($t(55) = 0.283$, $p = 0.778$), QoL-AD ($t(56) = -0.131$, $p = 0.896$) and GDS-15 ($t(55) = -1.793$, $p = 0.078$) respectively. As such, further analyses were completed as planned with the total sample.

Internal Consistency

Internal consistency was good for total PPOM ($\alpha = 0.870$) and Resilience subscale ($\alpha = 0.804$), and acceptable for Hope subscale ($\alpha = 0.763$). The Cronbach's

alpha decreased if any items on the measure were removed, suggesting optimal content validity.

Internal consistency was excellent for EID-Q ($\alpha = 0.904$), acceptable for the latent factor Sense of Independence ($\alpha = 0.793$) and good for Social Engagement ($\alpha = 0.884$). For the subscales, internal consistency was excellent for Support ($\alpha = 0.857$), acceptable for Reciprocity ($\alpha = 0.741$), questionable for Activities of Daily Living ($\alpha = 0.657$) and Decision Making ($\alpha = 0.657$), and poor for Activity Engagement ($\alpha = 0.586$). The correlations between the individual items and the total score were explored to identify any item that was not measuring the same construct. The items with low correlations were removed to determine whether that made a difference on the internal consistency. Specifically, there were very low correlations between the reversed items in the IED-Q and the total score. There was a negligible improvement to the Cronbach's alpha for Activities to daily Living subscale ($\alpha = 0.657$ becomes $\alpha = 0.681$) if item 6 was removed. The Cronbach's alpha for Decision Making subscale changed from 0.657 to 0.832 if item 10 was removed. The Cronbach's alpha for Reciprocity subscale increased from 0.741 to 0.849 if item 22 was removed. There was no improvement to the Cronbach's alpha if any of the items were removed in Activity Engagement or Support subscale respectively.

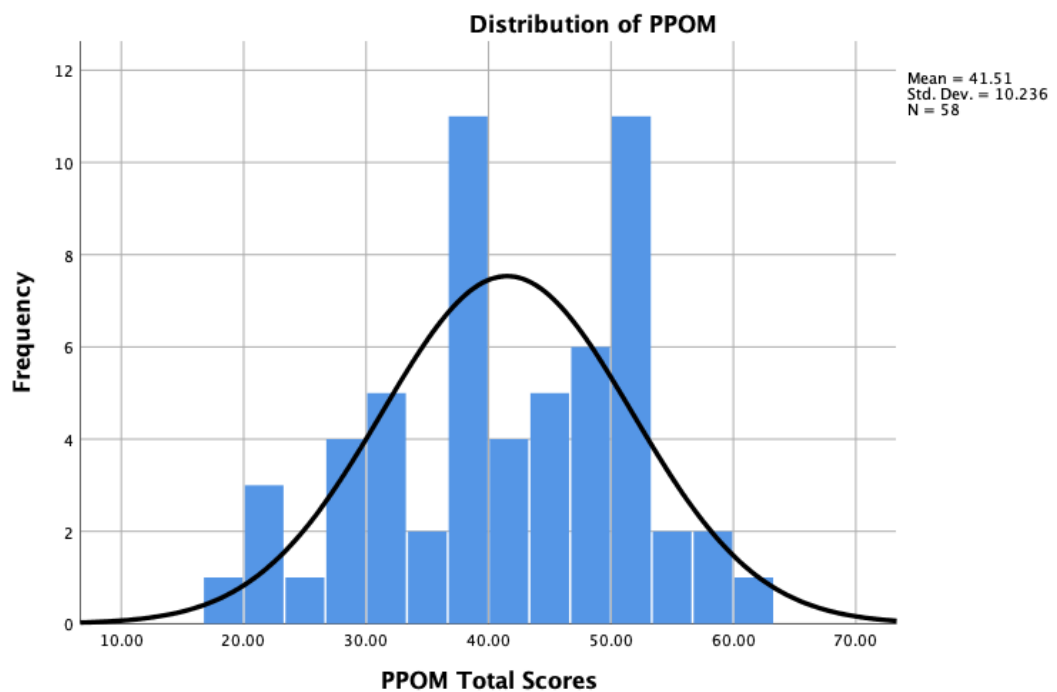
Floor and Ceiling Effects

The possible score of PPOM ranged from zero to 64, with a higher score indicating a higher level of hope and resilience in positive psychology. The observed scores ranged from 18 to 61 ($M = 41.51$, $SD = 10.24$). PPOM was fairly symmetrical

with a slight negatively skew (-0.326) with a kurtosis value of -0.584. Shapiro-Wilk test indicated no significant departure from normality $W(58) = 0.976$, $p = 0.316$. None of the participants scored the lowest or highest possible score in PPOM. The distribution of PPOM is presented in Figure 1.

Figure 1

Distribution of PPOM

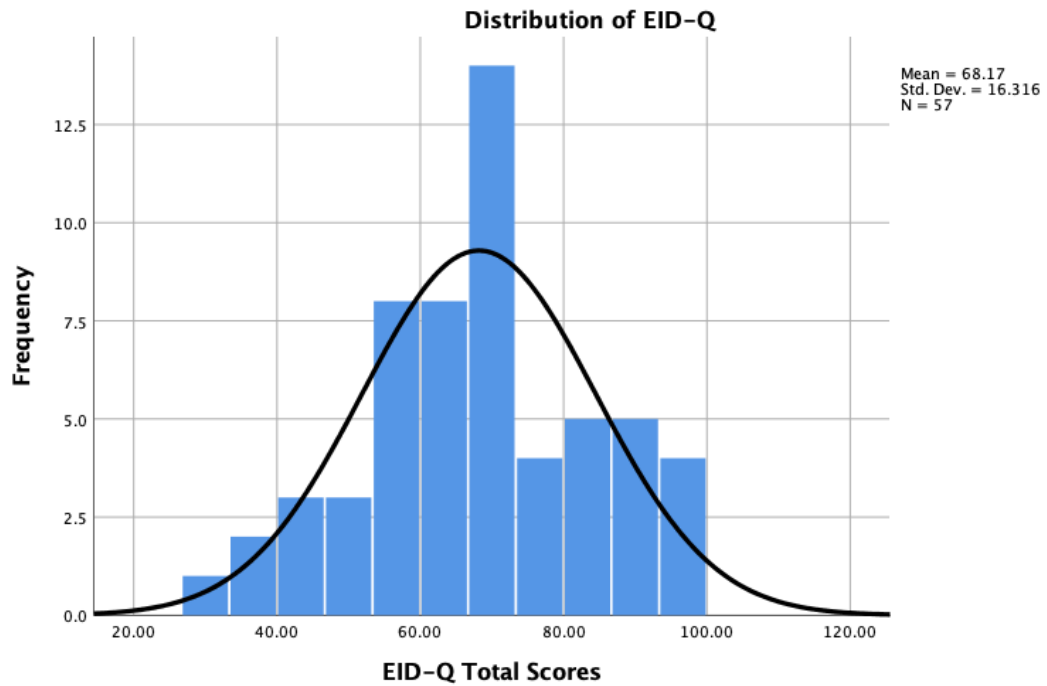


The possible range of EID-Q was zero to 104, with a higher score indicating a higher level of independence and social engagement. The observed range was from 30 to 100 ($M = 68.17$, $SD = 16.32$). Skewness was -0.063 and kurtosis was -0.363, indicating that the data is fairly symmetrical. Shapiro-Wilk test indicated no significant departure from normality, $W(57) = 0.983$, $p = 0.589$. None of the

participants scored the lowest or highest possible score in EID-Q. The distribution of EID-Q is presented in Figure 2.

Figure 2

Distribution of EID-Q



The possible range of QoL-AD was from 13 to 52, with a higher score indicating a higher level of quality of life. The observed range was from 20.58 to 52 ($M = 33.63$, $SD 6.05$), with one participant scoring the highest possible score. Shapiro-Wilk test indicated no significant departure from normality, $W(58) = 0.971$, $p = 0.181$, skewness was -0.010 and kurtosis was 0.434 .

A higher score on GDS-15 indicates a higher level of depressive symptomatology. The possible and observed range of GDS-15 was from zero to 15. Shapiro-Wilk test indicated a significant departure from normality, $W(57) = 0.926$, p

= 0.002, skewness was 0.769 and kurtosis was -0.134. With skewness between 0.5 and 1, this shows that the distribution is moderately skewed. However, this was not a concern since the scores on the other measures did not depart from normality and that the GDS-15 is not the target measure of this study.

Convergent Validity

There was a large positive correlation between PPOM overall score and QoL-AD ($r = 0.523, p < 0.001$). There were also significant positive correlations between Hope subscale and QoL-AD ($r = 0.521, p < 0.001$), and between Resilience subscale and QoL-AD ($r = 0.444, p < 0.001$). The GDS-15 subscale was negatively correlated with PPOM Resilience subscale ($r = -0.289, p = 0.029$). However, there were no statistically significant correlation between GDS-15 and PPOM overall score or Hope subscale.

The EID-Q was positively correlated to QoL-AD for total score. There were also significant positive correlations between QoL-AD and all EID-Q subscales and latent factors (Table 2). There was a negative correlation between EID-Q and GDS-15 ($r = -0.295, p = 0.026$). There were no statistically significant correlations between EID-Q and GDS-15 except for Activities of Daily Living and Activity Engagement subscales and Sense of Independence latent factor (Table 3).

Table 2*Convergent validity for EID-Q subscales and latent factor and QoL-AD*

	Pearson's r	p-value
Sense of Independence	0.648	< 0.001
Activities of Daily Living	0.616	< 0.001
Decision-making	0.441	< 0.001
Activity Engagement	0.463	< 0.001
Social Engagement	0.526	< 0.001
Support	0.426	< 0.001
Reciprocity	0.560	< 0.001

Table 3*Convergent validity for EID-Q subscales and latent factor and GDS-15*

	Pearson's r	p-value
Sense of Independence	-0.295	0.026
Activities of Daily Living	-0.476	< 0.001
Decision-making	-0.250	0.061
Activity Engagement	-0.266	0.045
Social Engagement	-0.137	0.311
Support	-0.068	0.615
Reciprocity	-0.137	0.155

Factor Structure

The 16 items on PPOM were entered to SPSS AMOS using maximum likelihood to establish whether the two-factor structure in the original development paper was an adequate model to fit the data. All indices of the proposed model fell outside of the acceptable limits, indicating that the proposed model was not an adequate fit (Table 4). The factor loadings ranged from 0.44 to 0.72 (Figure 3).

Table 4

CFA Validation indices for two-factor structure of PPOM

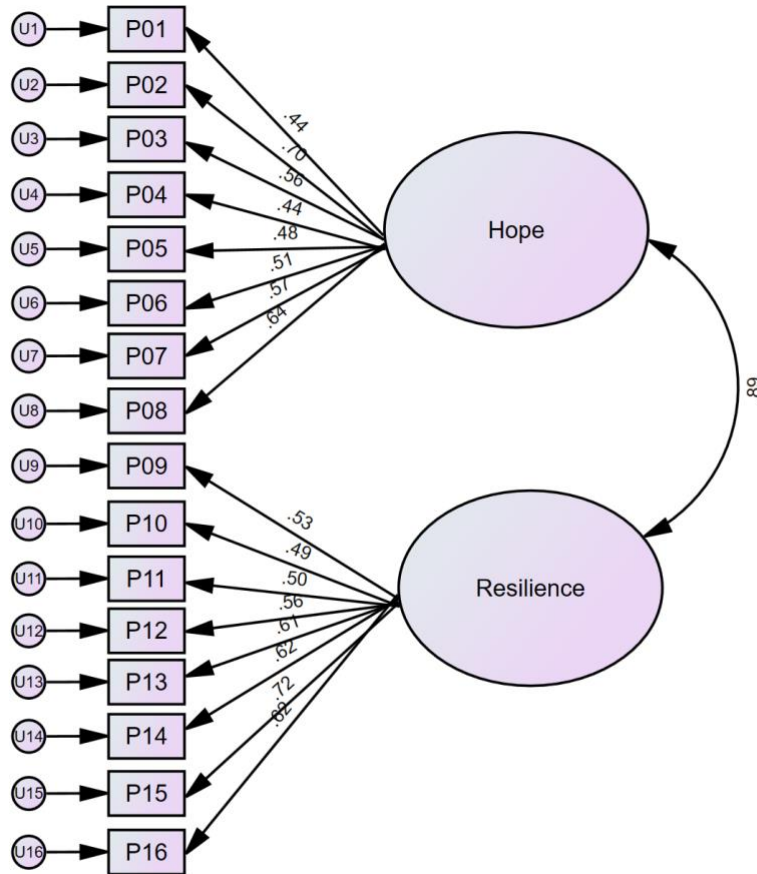
	χ^2	<i>df</i>	CFI	RMSEA	SRMR
2 Factors	162.810*	103	0.773	0.101	0.0937

Note. χ^2 = Chi-Square goodness of fit; *df* = degrees of freedom; CFI = Comparative Fit Index; RMSEA = Root Mean Square Error of Approximation; SMRM = Standardised Square Root Mean Residual

* $p < 0.0005$

Figure 3

CFA Validation factor loadings of PPOM using two factor solution

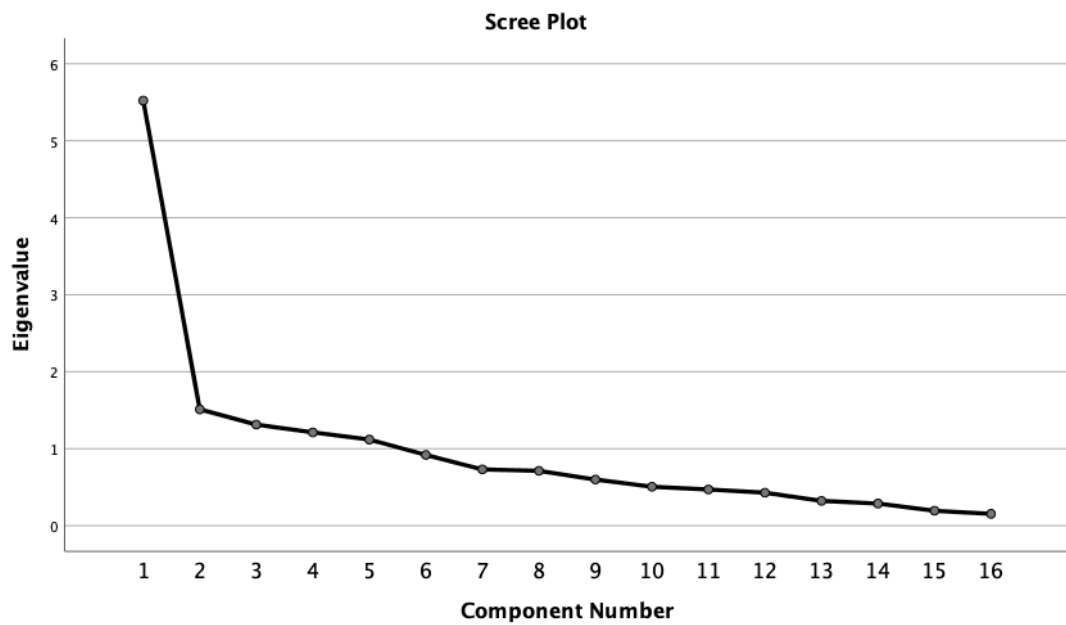


Therefore, an EFA was performed. The 16 items were examined in SPSS using maximum likelihood because the data set is largely normally distributed. Direct Oblimin, an oblique rotation, was used to allow for correlation between the two theoretically correlated latent factors, hope and resilience. Eigenvalues indicated that five factors were present (5.521, 1.511, 1.313, 1.212 and 1.118) and it explains for 66.7% of total variance (Figure 4). However, two communality estimates were

greater than one, which is something commonly caused by not having a sufficient number of variables in each loading (McDonald, 2014).

Figure 4

Scree Plot of eigenvalues for PPOM



As there was a substantial drop between the first two factors, it was hypothesised that these concepts could be more closely correlated than expected, so a one-factor solution was examined, and the factor loadings ranged from 0.42 to 0.74 (Figure 5). However, the model fit was less adequate than the two-factor model, with indices falling out of the acceptable limits (Table 5).

Figure 5

CFA Validation factor loadings of PPOM using one factor solution

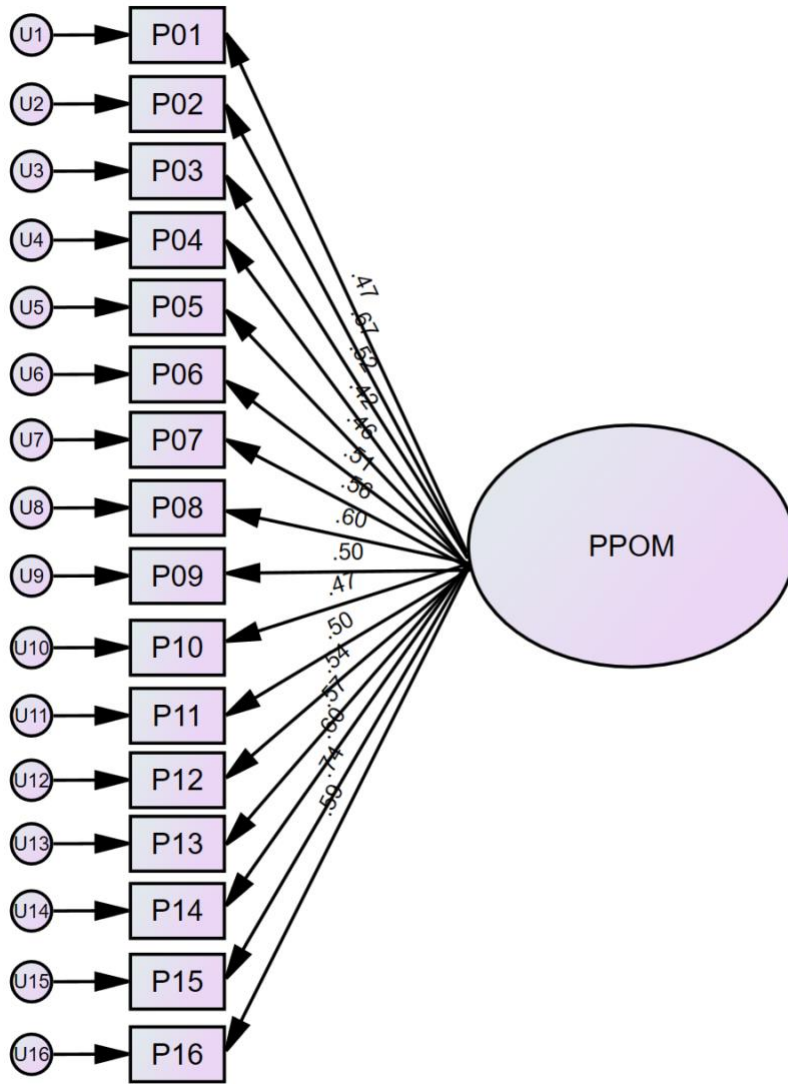


Table 5

CFA Validation indices for one-factor structure of PPOM

	χ^2	<i>df</i>	CFI	RMSEA	SRMR
1 Factor	165.990*	104	0.764	0.102	0.0948

Note. χ^2 = Chi-Square goodness of fit; *df* = degrees of freedom; CFI = Comparative

Fit Index; RMSEA = Root Mean Square Error of Approximation; SMRM =

Standardised Square Root Mean Residual

* $p < 0.0005$

The 26 items of EID-Q were also entered to SPSS AMOS using maximum likelihood to establish whether the five-factor structure with second order analysis in the original development paper was an adequate model to fit the data in this study. The fit indices were poor (Table 6). The factor loadings ranged from 0.06 to 0.88 (Figure 6). As noted above, the reverse-coded items (6, 10 and 22) fit had poor internal consistency with the items.

Table 6

CFA Validation indices for five-factor structure of EID-Q

	χ^2	<i>df</i>	CFI	RMSEA	SRMR
5 Factors	561.207*	294	0.648	0.128	0.109

Note. χ^2 = Chi-Square goodness of fit; *df* = degrees of freedom; CFI = Comparative

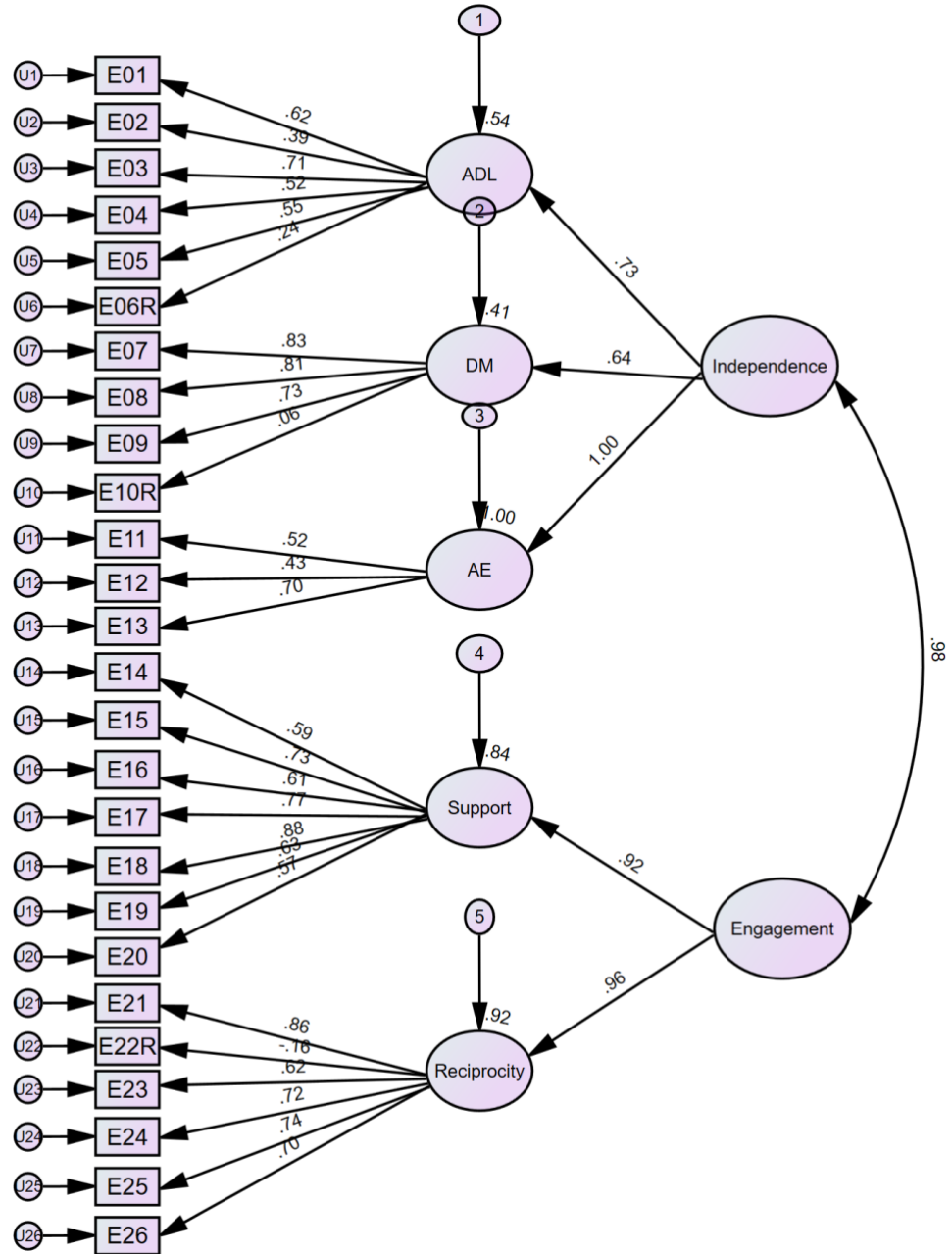
Fit Index; RMSEA = Root Mean Square Error of Approximation; SMRM =

Standardised Square Root Mean Residual

* $p < 0.0005$

Figure 6

CFA Validation factor loadings of EID-Q using five-factor solution



The EFA stage was revisited subsequently to remove some items and rerun different analyses. It was found that the Activity Engagement subscale fit better with the Social Engagement latent factor rather than Sense of Independence. In the end,

items 2, 6, 10, 12 and 22 were removed and a new five-factor solution was derived. The factor loadings ranged from 0.45 to 0.88 (Figure 7). The solution was subject to a CFA to determine whether this was an acceptable model, but while fit indices improved, they still fell outside the acceptable ranges (Table 7). The proposed model did not represent a fit to the data.

Figure 7

CFA Validation factor loadings of EID-Q using a new five-factor solution

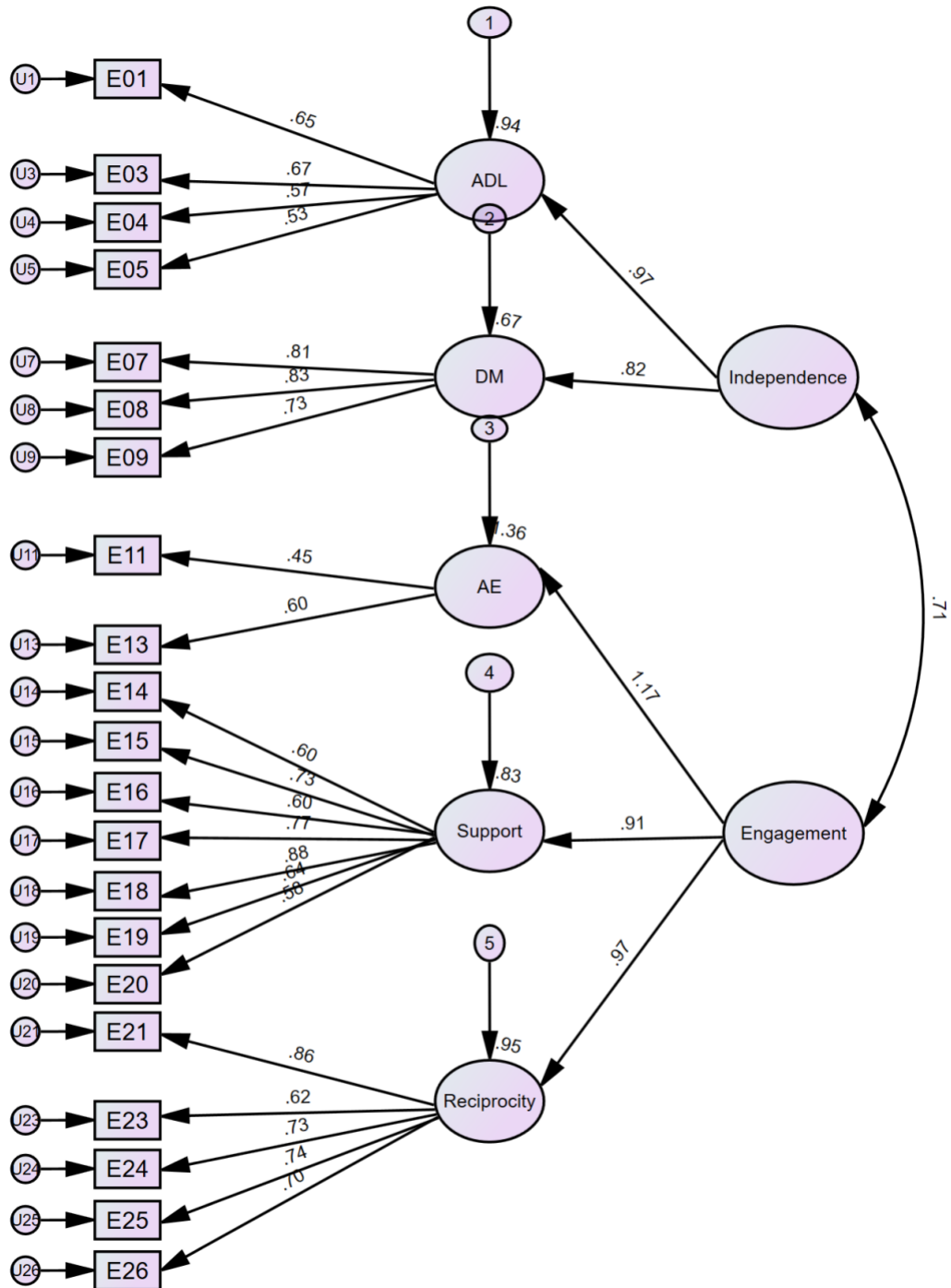


Table 7

CFA Validation indices for five-factor structure of EID-Q

	χ^2	<i>df</i>	CFI	RMSEA	SRMR
5 Factors	325.826*	183	0.774	0.118	0.900

Note. χ^2 = Chi-Square goodness of fit; *df* = degrees of freedom; CFI = Comparative

Fit Index; RMSEA = Root Mean Square Error of Approximation; SMRM =

Standardised Square Root Mean Residual

* $p < 0.0005$

Discussion

The present study provided evidence on how positive psychology, specifically hope and resilience, and social independence, can be measured in Hong Kong using PPOM and EID-Q respectively. The psychometric properties were largely similar to the original development and validation paper in the United Kingdom (Stoner et al., 2017; Stoner et al., 2018a, 2018b). However, factor analyses did not indicate an appropriate factor solution to both PPOM and EID-Q.

PPOM and EID-Q demonstrated good and excellent internal consistency overall. However, the internal consistency for Activities of Daily Living, Decision Making and Activity Engagement subscales in EID-Q were especially low. This may be a result of a much smaller, homogenous sample than expected due to the current COVID-19 restrictions on data collection. Cronbach's value is based on inter-item correlations through its derivation from the Generalised Spearman-Brown formula, which can be affected by homogeneity of responses to the items on the scale (Pike &

Hudson, 1998). After item deletion, the number of items remaining for some subscales on the EID-Q was low, so it may be more appropriate to consider the internal consistency by its latent factors rather than each individual subscale. There were different possible reasons why the culturally adapted PPOM and EID-Q did not fit with the factor structure in the original development. For example, the language and cultural adaptation process could be flawed, or that it could be wrong to assume that the same construct exists across the two settings. However, beyond the translation and language differences, there are many cultural and institutional factors such as the individualism-collectivism dynamic and capital markets that make this cultural adaptation process incredibly difficult (Farh, Cannella, & Lee, 2006). It may also be important to consider adding new items to the instruments as there may be components important to the culture in Hong Kong that were not highlighted in the United Kingdom (Gjersing, Caplehorn, & Clausen, 2010).

Both PPOM and EID-Q demonstrated significant convergent validity with quality of life but varied results in correlation with depression. The positive correlations between QoL-AD and the total and subscale scores of PPOM and EID-Q suggested that hope, resilience, social engagement and sense of independence were all related to the construct of quality of life. There was a negative correlation between EID-Q and GDS-15 in the total score, Activities of Daily Living subscale and Activity Engagement subscale. The correlation between GDS-15 and PPOM was only statistically significant for the resilience subscale. A small sample size may have contributed to the inconsistent findings with the original development paper, but it was also possible that there were cultural specificities in the relationship between depression and these constructs that require further research. For example, it

is common to see a stigma, especially perceived stigma, towards depression in Chinese community (Yang et al., 2020). People living with dementia may see themselves as burden and respond to the items in a more socially acceptable, less stigmatising way. In the sample, 22.8% of participants scored 8 or above on GDS-15, which is the clinical cut-off for suggested depression in Hong Kong. It may be possible that the inverse relationship between positive psychology measures and GDS-15 in Hong Kong is only identified at a more severe level of depression.

There were very small correlations between the reversed items in the EID-Q and the total score, which was not observed in the previously validated measure in the United Kingdom. This is a common dilemma faced by researchers with data collected through Likert scales that contain reversed items. Response bias arises from discrepancies between the response that researchers want to elicit, and the actual response answered by the respondent (Tourangeau, Rips, & Rasinski, 2000). Item reversal is often used to prevent or reduce the effect of response bias, with reverse oriented items using words with negative particles (e.g. 'not' or 'no') or affixal morphemes (e.g. 'un-', 'non-', 'dis-' or '-less'), and reverse wording using words with an opposite meaning (Swain, Weathers, & Niedrich, 2008). While item reversal is often advocated to address acquiescent answering, research has suggested that doing so does not prevent it from happening (Sonderen, Sanderman, & Coyne, 2013). However, reversed items can be more confusing or difficult to process, potentially leading to false responses as the increase in number of cognitive operations required to respond to an item interferes with the participant's ability to articulate their beliefs (Swain et al., 2008). While balancing between straightforward and reversed worded items did not stop inattentive or acquiescent answering, fewer

mistakes were observed with items all presented in the same direction (Swain et al., 2008).

Reverse wording was used in some of the reversed items in the EID-Q, for example, 'people take decisions away from me' was used rather than 'people allow me to make my decisions'. As there are different levels of cognitive declines in people living with dementia, the small correlations in the reversed items on EID-Q may arise from the item verification difficulty as a result of cognitive difficulties. Negative particles were not used in the original development of PPOM and EID-Q, which minimises respondent inattention related to missing the negative particle that results in measurement error. However, item 22 on EID-Q was translated with a negative particle because of the common usage of the language. Previous researchers have reported difficulties in translating double negative phrases in Chinese (Leung, Moneta, & McBride-Chang, 2005). It is hard to reconcile the balance between controlling for response bias but also maintaining simplicity and straightforwardness for outcome measures, especially for a population with limited or declining cognitive ability.

This may also explain the lack of correlation between GDS-SF and the positive psychology measures. The questions on the GDS-SF can be less straightforward, and some used negative particles, which require more cognitive steps to understand and answer the questions accurately. This difficulty was anecdotally observed by the researcher when reading out negative particles to participants, who appeared to need greater clarification for these items.

With the restrictions and limitations due to COVID-19, different strategies were attempted to make data collection possible. Data collection was attempted with

some people living with dementia on the phone, but it was difficult to engage them without having the measures in front of them. It was also difficult for people living with dementia to understand the questions or the scale, especially without the support of the visual analogue scale. The online platform was carefully thought through and tested before publicising it to the centres and participants. The format and styling were kept with a simplistic style while visual aids like the visual analogue scale and an instructional video were attached to the measure. Preliminary results revealed no differences between those who completed the measures in-person or online, suggesting that these measures could be set up as online measures by services to facilitate convenience and an easy retrieval and storage of data.

Limitations

Due to COVID-19, the sample size of the present study was much smaller than planned due to difficulties with recruitment when all centres were closed. Data collection was supposed to be completed with a team, similar to how pilot data was collected by four different researchers. However, this was not possible during the pandemic. Therefore, analysis and conclusions drawn here must be interpreted with caution, as it was likely that the small sample size made an effect on the results. For example, factor loadings should typically be above .707 to demonstrate that half of the variance is captured by the latent construct (Gefen, Straub, & Boudreau, 2000). The scree test is only reliable when the sample size is at least 200 so a much larger sample size is required (Yong & Pearce, 2013). On the other hand, it was possible that the factor structure is different in Hong Kong, as some ideas and constructs may be measured and viewed differently in a different culture, especially after the

translation to Chinese. For example, the same word, ‘堅強’ meaning ‘(emotionally) strong’, that was used in the actual phrase for item 15 was also used in the verbatim for item 4 to describe ‘inner strength’. ‘Inner strength’ is a terminology that is seldom used in spoken Cantonese, and it could be translated very differently under different contexts that it may be difficult for people living with dementia to understand, hence the word ‘(emotionally) strong’ was used in verbatim to support the participants’ understanding. However, this could be flawed in that the same word were essentially used across two latent factors. It remains unclear whether the non-significant results are due to the small sample size or other underlying reasons, hence results should be treated with caution. Data on responsiveness or test-retest reliability were also not available due to the challenges in data collection.

Quality of life is a highly subjective concept and proxy completion of these measures have been suggested to not truly reflect people living with dementia’s own appraisal (Thorgrimsen et al., 2003). This emphasises the need for these self-report measures. In the original development study, qualitative results suggested that carers often had differing views compared to people living with dementia. For in-person data collection, we attempted to ask the carers to wait outside of the room whenever possible because we noticed that some carers may interrupt and answer the items on behalf of the people living with dementia despite giving clear instructions and prompt to let the people living with dementia answer the question themselves. While this is less controllable in online completion where participants were completed independently without the presence of the researchers, the sample size is currently too small to conclude whether there was a difference between the two groups.

While we did not collect data regarding cognitive ability of the participants or limit the inclusion criteria to those of a certain level of severity, all participants had the capacity to provide informed consent and were likely to present with milder symptoms of dementia. Research suggested that orientation, attention and language skills should be considered to obtain reliable data from older adults with cognitive impairment (Mozley et al., 1999). Staff from nursing homes and community centres considered the cognitive and communication abilities of people living with dementia before reaching out to participants in the recruitment. As a result, despite our inclusion criteria of people living with dementia with any type or severity with dementia, conclusions may not be generalised to people living with dementia in all symptom severities or stages of dementia. It is possible that people in the moderate to severe stage of dementia may require proxy reports rather than self-report measures (Ready & Ott, 2003).

Low education attainment is a risk factor for dementia among older adults and it is suggested that higher education contribute to cognitive reserve (Meng & D'arcy, 2012). Low literacy is common in older adults compared to other age groups (Kutner, Greenberg, & Baer, 2006). There is a relatively low literacy among older adults in Hong Kong, with 24.1% of our participants having no formal education and 36.2% having only primary level education. Different to the original study in United Kingdom, substantial support from others was required in completing the measures. Most of the data collection was completed with the support from the researcher or an extensive in-person interview, using the explanation with the verbatim to answer. Outside of a research setting, it is unclear whether similar support could be provided to the respondents especially in a busy clinical setting, while it is also difficult to

ensure that the measures are completed based on the perspective of the people living with dementia.

Finally, all of the participants were recruited via the community centres or nursing homes. This may not be a representative sample of people living with dementia in Hong Kong as there are people living with dementia who do not engage with any services, and they may be more socially isolated and provide a different representation of demographics and responses in the outcome measures.

Future research

Due to COVID-19 restrictions, the original plan of recruiting 182 participants was not feasible. The sample size of this study remained relatively small which had an impact on the results and increased risk of type II error. Further large-scale research is required for an accurate and in-depth analysis of the psychometric properties and factor structure. While we had planned to arrange a subsample of participants to complete the questionnaires again after one week to examine test-retest reliability, it was also not feasible due to limited opening hours and access due to COVID-19 situation. This is an important psychometric property to be examined in future research. Further investigation should also examine the relationship between depression and the two studied outcome measures. As the idea of positive psychology becomes more widely accepted and examined, other constructs of positive psychology could also be examined. Future research could also explore and distinguish any differences between those who self-report and those who completed the measures with some support, or between those who completed them online and those who completed them in-person. This would be particularly important as we

start to consider and allow for a digital-only way of working and doing assessments and interventions. It is an important consideration for those who may have limited access to in-person sessions (due to mobility, distance, or availability of help from carers) but also for clinicians and researchers in terms of convenience and time efficiency. For example, an online self-complete form could allow the scores to be calculated automatically on the system rather than manually. Future research could consider the feasibility of usage of PPOM and EID-Q in people living with dementia with different levels of severity in cognitive impairment and levels of orientation, attention and language skills.

Clinical Implications

While positive psychology is still a relatively new area of interest with people living with dementia and their caregivers in Hong Kong, this study suggests that people living with dementia are able to provide their views on these concepts. Research has shown that hope may be an important factor to help people living with dementia manage threats to self-esteem in early-stage dementia, which suggests the use of PPOM to consider strategies to inspire hope at an early stage (Cotter, Gonzalez, Fisher, & Richards, 2018). The availability of such measures may be a start to promote awareness and understanding of positive psychology and help to reduce stigma towards them. Clinicians may also use the measures to understand the lived experience of people living with dementia, identify their personal strengths and motivate them based on a person-centred approach in their clinical work.

Conclusions

Both the culturally adapted PPOM and EID-Q demonstrated adequate psychometric properties which suggested that these positive psychology constructs are generalisable to this population although some cultural specificities are to be explored with further examination.

While both measures demonstrated significant positive correlations with quality of life, EID-Q demonstrated that higher engagement and independence are significantly correlated with lower depressive symptoms. Further large-scale study is required to provide a more comprehensive understanding of these two measures in Hong Kong, particularly with examining its factor structure along with responsiveness and test-retest reliability. The incorporation of positive psychology measures may be beneficial in moving away from a problem- and loss-focused approach and emphasise positive experiences and strengths in people living with dementia in Hong Kong.

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Part 3: Critical Appraisal

Dementia research spans on a number of expertise with psychologists typically interested in improving the treatment and care and providing the best support for people living with dementia and their caregivers. Outcome measures allow clinicians to assess the patient's current status which allow for interpretation to make decisions on how to provide the best support to the patients. Therefore, it was important to identify and develop outcome measures for people living with dementia and their caregivers, especially where there is a lack of measures on social support and positive psychology.

Throughout the years of studying and working abroad, I have always felt a sense of belonging and connectedness to my hometown, Hong Kong. This is of significant personal and professional importance to complete this empirical study in Hong Kong to allow for cultural adaptation of Positive Psychology Outcome Measure (PPOM) and the Engagement and Independence in Dementia Questionnaire (EID-Q) in people living with dementia in Hong Kong. With my doctorate completed in the United Kingdom and in English, it was an exciting challenge to return to my hometown for what seemed to be missing in dementia research in Hong Kong.

Despite having advantages of knowing the language and culture in Hong Kong well along with the support and guidance from pioneering and experienced researchers in the United Kingdom, the entire process of the thesis was not without its challenges. Participant recruitment started slow due to time differences and difficulties to communicate from overseas when I was still in London. The proposed recruitment and data collection process coincided with the beginning of the COVID-19 pandemic. Although I was in Hong Kong for a few months during the pandemic,

the nursing homes and community centres remained closed. While efforts were made to consider other points of contact for promotion and recruitment, such as on online platforms, there was little success with these attempts. This was probably an effect of the panic consequences seen in the society due to COVID-19.

When the centres reopened with limited and restricted access, data collection was at a slower pace than expected due to restrictions in place and a lack of resources and manpower. Due to different ways of operation across services, the data collection sessions were sometimes shorter than the minimum required time to complete the measures (i.e. 30 minutes) while some data collection sessions were scheduled or cancelled within 24 hours. While the initial plan was to invite the first 50 participants to complete a retest in one week's time, this was not feasible due to the arrangement in the community centres. This had a significant impact on the number of participants recruited which limited the scope of the present study, especially in terms of making meaningful in-depth analysis.

During the stage of data collection, face masks and social distancing were mandatory for safety precautions for COVID-19. Face masks increased the perception of vocal effort and discomfort, and resulted in reduced speech intelligibility and difficulties in coordinating speech and breathing (Ribeiro et al., 2020). Adaptations were required to assist with data collection. For example, the items must be read out louder and slower and there was more clarification required. The visual analogue scale definitely supported the data collection process by enhancing understanding and allowing participants to point at the rating directly. It was crucial for the researcher to take some breaks in between data collection sessions, especially when the data collection was done solely by one researcher in

this study. Administration of the measures on the phone was deemed unsuccessful due to difficulties in communicating and a lack of understanding without visual support. The online platform for data collection was only available in the last few weeks of data collection, which limited the number of participants who completed the measures online in this study.

Despite difficulties with participant recruitment and data collection, the interactions with the people living with dementia and their caregivers were enjoyable and heart-warming. While the frustration with the slow progress and the resulted neverending changes from the pandemic led to tears and worries about the study, it was motivating and encouraging to see the smiles of the people living with dementia from the completion and interviews of these positive psychology constructs. It was a reminder to self that this research would hope to help support future research and make positive changes to their lives.

There were a few important reflections in relation to the language and cultural adaptation of the measures. The fluency in Cantonese, Mandarin and English and my previous postgraduate studies in translation has given me privilege to complete clinical and research work that involve these languages which led to valuable insights. On one hand, it feels natural for me to use these languages interchangeably in different conversations, while on the other hand, there are words and terms that are used in one language but without an exact equivalence in the other language. This was evident in the data collection process when people living with dementia asked for clarifications on some uncommonly used Chinese words that were translated from some common English terms. This again emphasised the

importance of this study in terms of completing cultural validation studies before using any measures in a different population.

It was observed that some people living with dementia struggled with reading or hearing and understanding the items when they were read out as-is (i.e. in written Chinese). This was understood as how written and spoken Cantonese are inherently different in terms of both the characters and the pronunciation. The availability of the verbatim and the manuals for the measures were crucial for administration, particularly to those who had low to no literacy. This emphasised the importance of having a manual with directions in spoken Cantonese, especially how it is likely that people living with dementia may require some verbal explanation or support to complete the measures.

There is no universal standard in cultural adaptation of measures. It was suggested that a thorough and comprehensive cross-cultural adaptation process begins with literature review and discussions with experts, followed by translating the original document by two translators then synthesised to one, and subsequent back-translation through the same procedures which results in a revised measure before the psychometric properties are examined (Gjersing, Caplehorn, & Clausen, 2010). However, this may not always be feasible due to lack of resources and funding. Translating and back-translating is always a challenge in research especially when cultural factors have to be considered.

While the results in the empirical study was not conclusive due to the small sample size, there were some interesting findings that may be reflected upon and considered in future research. In our sample, 24.1% received no formal education while 36.2% received primary level education. It is possible that the representation in

demographics and results were biased as only those who were literate or had better understanding and confidence in answering the questions were invited or were able to complete the measures. It may be interesting to consider administering the measures to people living with dementia with other varying severities or in other stages of dementia. High level education in early life is related to a significant reduction in dementia for Alzheimer's disease and vascular dementia (Meng & D'arcy, 2012). This may bring hopes that the prevalence and incidence of dementia will decline as it is now common for the younger generations to receive high level education.

Alzheimer's disease is estimated to contribute to 60-70% of dementia but only a quarter of the participants in the empirical study reported having Alzheimer's Disease (World Health Organization, 2012). This may be due to the fact that close to half of the participants and their caregivers or staff members were unsure of the type of their dementia diagnosis. As there is no one test to diagnosis dementia but rather it depends on a combination of medical history, assessments, physical examinations, laboratory tests and clinical observation, it is hard to determine the exact type of dementia. However, knowing what type of dementia has an impact on understanding about the progression and guide treatment intervention. This is perhaps an important implication in the long term in terms of considering about the social and health care system in Hong Kong.

Participants were asked whether they were experiencing any serious difficulties on their mental or physical health as part of the demographics, information. The majority of participants who answered yes mentioned about physical health difficulties but very few mentioned about mental health difficulties. It

may be of interest to consider whether there would be a difference in response if the question is separated to two questions about physical health and mental health respectively. However, there may also be a change in the response rate so this should be considered with caution. This may be related to the stigma in relation to mental health which is still quite phenomenal, especially in Hong Kong and China.

It was reported that people living with dementia in Hong Kong and China tend to visit neurologists rather than psychiatrists due to stigma (Sun, 2014). It may also be important for these measures to be widely available to professional of different disciplines to enhance access. Taking a positive psychology approach may support and empower people living with dementia and caregivers to alleviate stress from these concerns from social environment. As we shift to a non-pathologising approach and emphasise on strengths and capabilities, we may see a reduce in stigma and ultimately improve the quality of life for the affected ones. It is hopeful that an increase in discussions and research about positive psychology will be observed. Regardless of geographical location or specialisation, it feels very important to continue to work on cultural differences and adaptation to continue to fill any gaps and bridge the unknowns between the east and the west.

In terms of broadening the usage of these positive psychology measures, while there are language and cultural differences between Hong Kong and China, most of the languages used on the items could be understood by Mandarin. When the psychometric properties and factor structure of PPOM and EID-Q are established in future research, researchers could consider using the translated versions to establish a mandarin verbatim and make any cultural or language adaptations. This could have a

significant impact on burden as people living with dementia in China make up approximately 25% of the worldwide prevalence (Nichols et al., 2019).

Last but not least, as much as it was challenging with many unforeseeable obstacles because of COVID-19, it was an incredible learning experience and provided invaluable insights and ideas to the world of research and clinical work. Despite advances in technology in the last decades, there were some concerns about offering online intervention while there was still a lack of online system in place for many services. This was particularly evident in the population of older adults and people living with dementia due to technology literacy. However, as the world was pushed into a new normal in the past year and half, there was a significant increase and need to consider using online platform to administer measures and deliver assessment and interventions. It was observed that many families were able to use online digital communication platforms with detailed instructions given to them. While there was a loss of valuable context such as body language and other non-verbal communication with online intervention and interviews so face-to-face appointments still seemed to be most ideal, the availability of online appointments enhanced the accessibility for many. For example, for people who were less physically able, or those with no caregivers or busy caregivers who were not available to take them to community centres or appointment in the day, having the option to attend appointments online definitely opened doors for them. Although not a direct experience from the empirical study, there was a memorable reflection from a discussion that I had with one of the participant dyads in another research project by the HKU research team. The people living with dementia and carer talked about their experience of attending intervention online. While they mentioned how they

had never used any video conferencing programmes before, they thought that it was fairly straight-forward to follow simple instructions to attend them. They mentioned how the people living with dementia had never been able to join any groups or activities offered by the community centres because the caregiver worked long hours every day. They were very grateful for the opportunity to attend online and wished that it could be offered routinely. While many people living with dementia and caregivers would like to contribute to dementia research, sometimes it was not possible due to their unavailability during the day. This felt particularly relevant in Hong Kong given that the long working hours and busy lifestyle and schedule there. As research suggested how social isolation could be a risk factor in dementia, future research and clinical use should consider providing more options and flexibility with the medium of attendance (Brodaty & Luscombe, 1998; Pinguart & Sörensen, 2006).

This research would not have been possible without the tremendous amount of dementia research from the last decades. All of the research helped us to understand the causes of dementia, develop treatment and intervention and improve the care and quality of life for people living with dementia. It is delightful to see a shift to a non-pathologising narrative of dementia and how the continuous effort of researchers offer hope to the community.

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Appendix A

Ethics amendment approval

From:
Subject: RE: Ethics amendment - 14667/001 APPROVED
Date: 1 April 2020 at 15:56
To:



Dear Vanessa

The REC Chair has approved your attached amendment request and the approval now runs until 01/09/2021. Please take this email as confirmation of that approval.

IMPORTANT: For projects collecting personal data only.
You should inform the Data Protection Team – data-protection@ucl.ac.uk of your proposed amendments to include a request to extend ethics approval for an additional period.

With best wishes for your ongoing research,

Office of the Vice-Provost (Research)
University College London, Gower Street, London WC1E 6BT

Please do not feel obliged to reply to this email outside of your normal working hours.

Appendix B

Informed consent form and English translation

香港大學社會工作及社會行政學系和倫敦大學學院心理學系
認知障礙症人士的積極生活方式
參與研究同意書

香港大學社會工作及社會行政學系和倫敦大學學院心理學系邀請您參與由黃凱茵博士和袁詩雅小姐主理的研究調查。

研究目的

本研究的主要目的是了解認知障礙症人士的優勢和積極的生活方式，以創建一系列調查問卷，用以衡量和監測香港認知障礙症人士的個人優勢。

研究程序

您將需要參與需時約 30-45 分鐘的個人面談，或透過郵寄服務或網上直接填妥問卷。

潛在的風險/不適

本研究不會產生任何風險，或超越您日常生活常見的不適。

對參加者的益處

本研究將提供機會讓參加者反思自己或受其照護者的個人優勢。本研究所創建的調查問卷將能用以衡量和監測香港認知障礙症人士的個人優勢。

參與後，您將會收到一份感謝禮物。

隱私與保密

本研究所得的任何資料只會作研究用途，個人資料絕對保密，不會公開予第三者。在此項研究的各項報告中，均不會出現受訪者的名字以及其他私隱資料。在此項研究中獲得的含個人標識符的數據將會保留最多五年，之後所有保留的數據將以匿名格式存儲。只有研究團隊的成員才能訪問數據。

參與或退出

您的參與純屬自願性質。您有權拒絕參與，亦有權隨時終止參與此研究而不會受到阻止。如果您選擇退出研究，則可能會保留已收集的匿名數據。

疑問與查詢

此研究已獲香港大學非臨床研究操守委員會認可。如您想知道更多有關研究參與者的權益，請聯絡香港大學非臨床研究操守委員會（電話：_____）。

如您對本研究有任何查詢，請與研究員袁詩雅小姐（電郵地址：_____，電話：_____）。

參與者同意及簽署

本人_____（參與者姓名）明白上述條文並同意參與是項研究。

參與者簽名：_____

日期：_____

（一式兩份：參與者及香港大學）

Living Positively with Dementia

Informed consent form

You are invited to participate in a research study conducted by Dr Gloria Wong and Vanessa Yuan. This is a joint project between the University of Hong Kong and University College London.

PURPOSE OF THE STUDY

The purpose of the study is to better understand the strengths and positive areas of living for people with dementia in Hong Kong. With this understanding, this project will also allow us to monitor the personal strengths in Hong Kong people living with dementia.

PROCEDURES

You will complete a set of questionnaires which will take around 30-45 minutes. We will ask some people to complete these questionnaires again within one-week period. The researcher will discuss this with you.

POTENTIAL RISKS / DISCOMFORTS AND THEIR MINIMIZATION

This study will not cause any risks or discomforts that are greater than those commonly encountered in your everyday life.

POTENTIAL BENEFITS

The study will provide an opportunity to reflect on your personal strengths. The questionnaire developed by the research team will measure and monitor the personal strengths of people with dementia in Hong Kong.

At the end of the study, you will be given a thank you gift e for your time and participation.

CONFIDENTIALITY

All information gathered through this study will be kept strictly confidential. Your personal information will not be shared to any third parties. The information obtained in the study will be used for research purposes only and none of your personal information will be mentioned in any reports resulting from this study. All data will be encrypted for storage. Data containing personal identifiers will be kept for a maximum of 5 years, after which all retained data will be stored in an anonymised format and only members of the research team will be able to access the data.

PARTICIPATION AND WITHDRAWAL

Your participation is entirely voluntary. This means that you have right to refuse participation and right to stop participation at anytime without being stopped. If you decide to terminate participation, the collected data may be retained anonymously.

QUESTIONS AND CONCERNS

This research has been approved by The University of Hong Kong Human Research Ethics Committee. If you have questions about your rights as a research participant, contact the Human Research Ethics Committee, HKU at (phone number).

If you have any questions about the research, please feel free to contact Vanessa Yuan through email at (email address) or at (phone number).

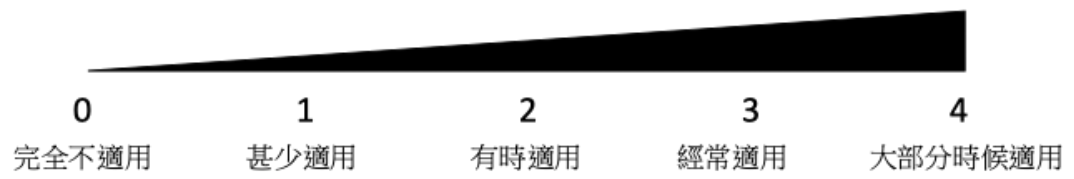
SIGNATURE

I _____ (Name of Participant) understand the procedures described above and agree to participate in this study.

Signature

Date

Appendix C
Visual Analogue Scale



'0' denotes 'Not true at all'

'1' denotes 'Rarely true'

'2' denotes 'Sometimes true'

'3' denotes 'Often true'

'4' denotes 'True nearly all the time'

Appendix D

PPOM

Date:

Interviewer:

Participant number (copy to demographics sheet):

指示:

我們想知道您過去一個月的狀況。對每條問題，請選出一個數字來反映您的感受（0, 1, 2, 3 或 4）。請回答所有問題。如果您不確定，請圈出您覺得最合適的數字。

C-PPOM					
	完全不適用	甚少適用	有時適用	經常適用	大部分時候適用
1. 我對生命有樂觀的看法	0	1	2	3	4
2. 我能夠在困難的狀況中看到正面的事情	0	1	2	3	4
3. 我能夠想起開心/快樂的時刻	0	1	2	3	4
4. 我有內在的力量	0	1	2	3	4
5. 我能夠給予和接受關心/愛	0	1	2	3	4
6. 我的人生有方向	0	1	2	3	4
7. 我相信每一天都有新的可能	0	1	2	3	4
8. 我的生命有價值和意義	0	1	2	3	4
9. 我能夠適應不同的情況	0	1	2	3	4
10. 無論發生甚麼，我都能夠應付	0	1	2	3	4
11. 我能夠看到事情幽默的一面	0	1	2	3	4
12. 我能夠妥善處理壓力	0	1	2	3	4
13. 我能夠從逆境中站起來	0	1	2	3	4
14. 我能夠保持專注	0	1	2	3	4
15. 情緒上，我是一個堅強的人	0	1	2	3	4
16. 我能夠應付不愉快的感受	0	1	2	3	4

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

PPOM					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
I have a positive outlook on life	0	1	2	3	4
I can see positive things in difficult situations	0	1	2	3	4
I can recall happy/ joyful times	0	1	2	3	4
I have inner strength	0	1	2	3	4
I can give and receive care/ love	0	1	2	3	4
I have a sense of direction in life	0	1	2	3	4
I believe that each day has potential	0	1	2	3	4
My life has value and worth	0	1	2	3	4
I am able to adapt to things	0	1	2	3	4
I am able to deal with whatever happens	0	1	2	3	4
I am able to see the humorous side	0	1	2	3	4
I can cope with stress well	0	1	2	3	4
I can bounce back	0	1	2	3	4
I can stay focused	0	1	2	3	4
I am an emotionally strong person	0	1	2	3	4

Appendix E

EID-Q

指示:

我們想知道您過去一個月的狀況。對每條問題，請選出一個數字來反映您的感受（0, 1, 2, 3 或 4）。請回答所有問題。如果您不確定，請圈出您覺得最合適的數字。

C-EID-Q					
	完全不適用	甚少適用	有時適用	經常適用	大部分時候適用
1. 我能夠安排最適合自己的生活方式	0	1	2	3	4
2. 我覺得我日常生活是活躍的	0	1	2	3	4
3. 我能夠因應我的能力去調整我的願望	0	1	2	3	4
4. 我能夠因應我的能力去改變我的生活	0	1	2	3	4
5. 如果我有需要，我能夠自己找到食物	0	1	2	3	4
6. 我是別人的負擔	0	1	2	3	4
7. 如果我有需要，我能夠照顧自己	0	1	2	3	4
8. 如果我想的話，我有機會自己做決定	0	1	2	3	4
9. 我有信心做決定	0	1	2	3	4
10. 別人奪去我的決定權	0	1	2	3	4
11. 我有我喜歡做的嗜好/活動	0	1	2	3	4
12. 我能夠做我認為重要的事	0	1	2	3	4
13. 我讓自己忙於各種活動/嗜好	0	1	2	3	4
14. 如果我有需要，我有可以交談的人	0	1	2	3	4
15. 我喜歡與他人交談	0	1	2	3	4
16. 如果我有需要，我有可以尋求協助的人	0	1	2	3	4
17. 如果我有需要，我能夠聯絡到朋友/家人	0	1	2	3	4
18. 我的朋友/家人關心我	0	1	2	3	4
19. 我覺得我的朋友和家人想花時間陪伴我	0	1	2	3	4
20. 我能夠向我的朋友/家人傾訴	0	1	2	3	4
21. 我在我的社交圈子裡有自己的角色	0	1	2	3	4
22. 我身邊的人經常不理會我	0	1	2	3	4
23. 我能夠幫助我關心的人	0	1	2	3	4
24. 我能夠和其他人一起參加小組/活動	0	1	2	3	4
25. 如果我想的話，我能夠幫助我的朋友/家人	0	1	2	3	4
26. 我覺得與別人有連繫	0	1	2	3	4

Additional File 1

The Engagement and Independence in Dementia Questionnaire (EID-Q) and Positive Psychology Outcome Measure (PPOM)

Instructions

We would like to know how you have been feeling over the **past month**. Please answer the below questions by **circling one number** (0, 1, 2, 3 or 4) that most closely reflects how you have felt for each question. Please answer all the questions. If you are unsure, circle the number that is your best guess.

EID-Q					
	Not true at all	Rarely true	Sometimes true	Often true	True nearly all the time
1. I can look after myself as much as I need to	0	1	2	3	4
2. I have people who I can talk to if I need to	0	1	2	3	4
3. I have hobbies/ activities that I enjoy doing	0	1	2	3	4
4. I have a role in my social circle	0	1	2	3	4
5. I am a burden to others	0	1	2	3	4
6. I enjoy conversations with others	0	1	2	3	4
7. I can make my own decisions as much as I'd like to	0	1	2	3	4
8. There are people I could ask for help if I need to	0	1	2	3	4
9. I'm confident in making decisions	0	1	2	3	4
10. I am often ignored by those around me	0	1	2	3	4
11. I can do activities that are important to me	0	1	2	3	4

12. I can get in touch with friends/ family if I need to	0	1	2	3	4
13. People take decisions away from me	0	1	2	3	4
14. My friends/ family care about me	0	1	2	3	4
15. I can arrange my life in a way that suits me best	0	1	2	3	4
16. I can help the people I care about	0	1	2	3	4
17. I feel I am active in everyday life	0	1	2	3	4
18. I can take part in groups/ activities with others	0	1	2	3	4
19. I can adapt my wishes to be in line with what I can do	0	1	2	3	4
20. I feel that my friends/ family want to spend time with me	0	1	2	3	4
21. I can make changes to my life to match my abilities	0	1	2	3	4
22. I can confide in my friends/ family	0	1	2	3	4
23. I can get myself food if I need to	0	1	2	3	4
24. I can help my friends/ family as much as I would like	0	1	2	3	4
25. I keep myself busy with activities/ hobbies	0	1	2	3	4
26. I feel connected to others	0	1	2	3	4

Appendix F

QoL-AD

QoL-AD

使用指引：評審員在使用此量表時，須根據附上的標準指引，並選出受訪者的回應。

	差	麻麻地	好	非常好
1. 健康狀況	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. 體力	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. 心情	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. 居住環境	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. 記憶力	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. 與家人關係	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. 婚姻關係	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. 與朋友關係	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. 成個人	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. 做家務或其他瑣事的能力	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. 參與娛樂活動的能力	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. 財政狀況	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. 一生	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

意見欄

UWMC/ADPR/QOL Aging and Dementia: Quality of Life in AD Quality of Life:AD (Participant Version)					Score (for clinician's use only).
ID Number □□□□□□	Assessment Number □□	Interview Date □□ □□ □□ Month Day Year			
Instructions: Interviewer administer according to standard instructions. Circle your responses.					
1. Physical health	Poor:	Fair:	Good:	Excellent:	
2. Energy	Poor:	Fair:	Good:	Excellent:	
3. Mood	Poor:	Fair:	Good:	Excellent:	
4. Living situation	Poor:	Fair:	Good:	Excellent:	
5. Memory	Poor:	Fair:	Good:	Excellent:	
6. Family	Poor:	Fair:	Good:	Excellent:	
7. Marriage	Poor:	Fair:	Good:	Excellent:	
8. Friends	Poor:	Fair:	Good:	Excellent:	
9. Self as a whole	Poor:	Fair:	Good:	Excellent:	
10. Ability to do chores around the house	Poor:	Fair:	Good:	Excellent:	
11. Ability to do things for fun	Poor:	Fair:	Good:	Excellent:	
12. Money	Poor:	Fair:	Good:	Excellent:	
13. Life as a whole	Poor:	Fair:	Good:	Excellent:	
Comments: _____ _____					Total

Appendix G

GDS-15

GDS-SF

以下的問題是人們對一些事物的感受，答案是沒有對與不對。請想一想，在過去一星期內，你是否會有以下的感受。如有的話，請圈「是」，若無的話，請圈「否」。

- | | 是 | 不是 |
|----------------------------------|--------------------------|--------------------------|
| 1. 你基本上對自己的生活感到滿意嗎？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. 你是否已放棄了很多以往的活動和嗜好？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. 你是否覺得生活空虛？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. 你是否常常感到煩悶？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. 你是否很多時感到心情愉快呢？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. 你是否害怕將會有不好的事情發生在你身上呢？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. 你是否大部分時間感到快樂呢？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. 你是否常常感到無助？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. 你是否寧願留在院舍 / 屋企裏，而不出外做些有新意的事情？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. 你是否覺得你比大多數人有多些記憶的問題呢？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. 你認為現在活著是一件好事嗎？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. 你是否覺得自己現在是一無是處呢？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. 你是否感到精力充足？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. 你是否覺得自己的處境無望？ | <input type="checkbox"/> | <input type="checkbox"/> |
| 15. 你覺得大部份的人的境況比自己好嗎？ | <input type="checkbox"/> | <input type="checkbox"/> |

Geriatric Depression Scale (short form)

Instructions: Circle the answer that best describes how you felt over the past week.

- | | | |
|---|-----|----|
| 1. Are you basically satisfied with your life? | yes | no |
| 2. Have you dropped many of your activities and interests? | yes | no |
| 3. Do you feel that your life is empty? | yes | no |
| 4. Do you often get bored? | yes | no |
| 5. Are you in good spirits most of the time? | yes | no |
| 6. Are you afraid that something bad is going to happen to you? | yes | no |
| 7. Do you feel happy most of the time? | yes | no |
| 8. Do you often feel helpless? | yes | no |
| 9. Do you prefer to stay at home, rather than going out and doing things? | yes | no |
| 10. Do you feel that you have more problems with memory than most? | yes | no |
| 11. Do you think it is wonderful to be alive now? | yes | no |
| 12. Do you feel worthless the way you are now? | yes | no |
| 13. Do you feel full of energy? | yes | no |
| 14. Do you feel that your situation is hopeless? | yes | no |
| 15. Do you think that most people are better off than you are? | yes | no |

Total Score _____