MEASURING QUALITY OF LIFE IN PERSONS WITH DEMENTIA

MEASURING QUALITY OF LIFE IN PERSONS WITH DEMENTIA

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Lay Abstract

Dementia is a disease that affects an individual's thinking and memory and can affect one's quality of life (QOL). Family caregivers have firsthand knowledge of their loved ones' dementia progression and their needs. QOL questionnaires can be used to better understand the health and well-being of an individual who is living with dementia. For individuals with dementia these measures tell us how dementia is changing an individuals QOL over time and how effective the treatment is on their QOL. In this thesis, we explored caregivers' perspectives on the behaviours and activities of the person living with dementia that should be assessed when monitoring symptom progression and impact of treatment on QOL. We found that domains related to difficulty with everyday activities, changes in mood and behaviour, cognitive difficulties and extrinsic factors are all important to assess when evaluating the impact of treatment on the individual living with dementia. We also reviewed studies that evaluated the measurement properties of QOL questionnaires in individuals living with dementia in the community. QOL questionnaires can be used to measure these outcomes, but there is mixed quality of evidence on the reliability and validity of QOL questionnaires in people living with dementia.

Abstract

Introduction: Dementia is a debilitating health condition affecting all aspects of an individual's well-being. Quality of life (QOL) and health related quality of life (HRQOL) assessments play a large role in understanding the limitations within the patients' lifestyle and helping care providers manage their needs better. Therefore, our aims for this thesis were twofold: 1. Explore the symptoms, behaviors, or activities deemed as priorities by caregivers for monitoring dementia progression, impact of treatment, or exploring alternative care, and 2. Examine the measurement properties of QOL and HRQOL measures used for people with dementia living in the community.

Methods: For the first aim, a qualitative descriptive study was performed with caregivers of individuals living with dementia. Caregivers from various regions in Canada were enlisted, and virtual listening sessions took place between November 2022 and January 2023. Open-ended questions were employed to prompt participants to express their viewpoints.

For the second aim, a systematic review guided by COsensus-based Standards for the selection of health Measurement Instruments (COSMIN) was performed to identify literature surrounding measurement properties of QOL and HRQOL measures used in community-dwelling adults with a diagnosis of dementia. A search was performed through four databases (Ovid MEDLINE, EMBASE, CINAHL, and PsychInfo) to identify literature published up until June 2022, followed by abstract and title screening and full-text review, which was performed in duplicate. Measurement properties extracted included structural validity, internal consistency, reliability (test-retest and inter-rater reliability), construct validity, and responsiveness. Risk of bias assessments and quality assessments were also performed for all identified QOL and HRQOL measures.

Results: Through the listening sessions, we identified that mobility limitations, social interactions, emotions, feeding behaviors, cognitive difficulties and extrinsic factors were priority topics that caregivers wanted to highlight when assessing QOL for people with dementia.

There were 13 dementia-specific and generic QOL and HRQOL measures included in the systematic review. Results showed varying quality of evidence for each of the measures with many having a moderate to very low score for some of the measurement properties.

Conclusion: The first study showed dementia caregivers' perspectives on how routine activities, mobility, social interactions, and behaviors, are important pillars of QOL and should be assessed in clinical and research settings for individuals living with dementia. The second study highlighted the importance of rigorously testing QOL instruments in order to provide accurate measurements when evaluating health concerns and impact of therapy. QOL measures can help researchers and healthcare providers obtain a comprehensive assessment of the individual they are treating.

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List of Abbreviations and Symbols

QOL: Quality of Life

HRQOL: Health-related quality of life

COSMIN: COsensus-based Standards for the selection of health Measurement Instruments guideline

ADL: Activities of Daily living

PWD: People with dementia

QOL-AD: Quality of Life in Alzheimer's Disease

DEMQOL: Dementia Quality of Life Measure

DQOL: Dementia Quality of Life Instrument

BASQID: Bath Assessment of Subjective Quality of Life in Dementia

CBS: Cornell-Brown Scale

ADRQL: Alzheimer Disease Related Quality of Life

QLDJ: Quality of Life Instrument for Japanese Elderly with Dementia

QOLAS: Quality of Life Assessment Schedule

EQ-5D: EuroQOL- Five Dimension

HUI: Health Utilities Index

SF-36: Short Form 36

WHOQOL: World Health Organization Quality of life

ROB: Risk of Bias

GRADE: Grading of Recommendations Assessment, Development, and Evaluation

PROSPERO: International Prospective Register of Systematic Review

ROC: Receiver Operating Characteristic

PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses

ICC: Intra-class correlation coefficient

CFI: Comparative fit index

TLI: Tucker Lewis Index

Declaration of Academic Achievement

I, Fariha Chowdhury, am the first author for all the thesis components/chapters. Chapter 1 and 4 have been primarily completed by myself with feedback and guidance from Dr. Ayse Kuspinar, and review from Dr. Jenna Smith-Turchyn and Dr. Carole White.

For Chapter 2, I contributed to the study's conceptualization, design and interpretations, with collaboration from all co-authors (Dr. Ayse Kuspinar, Eunjung Na, Dr. Carole White and Dr. Jenna Smith-Turchyn). Data collection and analysis was performed by Eunjung and I under the supervision of Dr. Ayse Kuspinar. Contents of this chapter were written by myself with edits and review from Dr. Ayse Kuspinar, and all co-authors.

For Chapter 3, I contributed to the study's conceptualization, design and interpretations, with collaboration from all co-authors (Dr. Ayse Kuspinar, Dr. Jenna Smith-Turchyn and Dr. Carole White). Screening of articles were performed by myself, Tarin Moni and Ashwaak Rhayel under the supervision of Dr. Ayse Kuspinar. Data extraction was primarily completed by myself and Eunjung Na. The writing of this chapter was written by myself with preliminary edits from Dr. Ayse Kuspinar, and review from all co-authors.

CHAPTER 1

Introduction and Literature Review

1.1 Dementia

The current prevalence of people living with dementia in Canada is over 500,000 (Alzheimer's Society, 2020). This prevalence is expected to rise 68% in the next two decades due to the projected growth in Canada's senior population (CIHI 2019). Dementia is a collection of degenerative neurological conditions related to loss of thinking, memory and communication that are grouped together under one umbrella term (Alzheimer's Association 2023; Government of Canada 2023; Lyketsos et al., 2002). Examples of conditions include vascular dementia, frontotemporal, lewy body and Alzheimer's disease (AD) (Government of Canada, 2023; Aalten et al., 2005; Lyketsos & Olin, 2002 and Lyketsos et al., 2000). Vascular dementia is when an individual experiences impairment in their thinking abilities that is due to reduced blood flow in the brain causing oxygen and nutrients deprivations (Alzheimer's Association, 2023a). Frontotemporal dementia is a degeneration through nerve cell loss in the brain's frontal or temporal lobes. This affects behaviour, personality and language ability in the individual (Alzheimer's Association, 2023a). Dementia with lewy bodies is caused by the accumulation of alpha-synuclein protein that affects thinking, mobility, mood and behaviour in the person with dementia (NIH, 2021; Alzheimer's Association, 2023a). AD is the most common form of irreversible dementia which makes up approximately 60 to 80% of dementia cases (Alzheimer's Association, 2023). There are several theories that suggest how AD is caused by aging, impairment in cholinergic and cortico-cortical pathways, environmental and genetic mutations (Armstrong, 2013). This can lead to impairments in memory, thinking and behaviour (Alzheimer's Association, 2023b).

1.1.1 Risk factors, diagnosis and symptoms

Dementia symptoms can vary from person to person. Risk factors for dementia include age, high blood pressure, diabetes, smoking, excessive alcohol drinking, isolation and inactivity (Chen et al., 2009; Aggarwal & DeCarli 2007 and Flier & Scheltens 2005). Symptoms include forgetfulness of recent events, losing items, getting lost, difficulty with problem solving, speech impairment (apraxia, dysarthria), language impairment (trouble finding words, anomia) being unaware of their environment, and loss of ability in conducting daily living activities (Klimova & Kuca, 2016; WHO, 2023; Mace & Rabins, 2011; La Rue et al., 1993). Daily living activities are day to day tasks such as going to the bathroom, household chores, and managing finances (Mace & Rabins 2011; Desai et al., 2004). Emotions are also affected by dementia where individuals may become confused due to their new symptoms and have other negative emotions, such as feeling frustrated, angry, anxious, depressed, and isolated (Mace & Rabins 2011; Kolanowski et al., 2002). These symptoms may get worse as dementia progresses and affect the individual's quality of life and the lives of their loved ones (Gottesman & Stern, 2019; Desai et al.,2004; Kolanowski et al., 2002). To diagnose someone with dementia, a health care professional looks at the patterns of changes in mood, behaviour and function employing various cognitive, physical, imaging, and neuropsychological tests as well as a thorough medical history (Mace & Rabins 2011; Löppönen et al., 2003).

1.1.2 Pharmacological and non-pharmacological interventions

There are various pharmacological and non-pharmacological interventions that can help people with dementia (PWD) cope with their symptoms. There are different types of medications that can help reduce symptoms (Lannfelt et al., 2014; Hersch & Falzgraf, 2007). Cholinesterase

inhibitors (Aricept, Adlarity, Exelon) increases the chemical messengers with memory and judgement (Hersch & Falzgraf, 2007; Geldmacher 2004; Larkin, 2002 and Stahl, 2000). Memantine (Ebixa, Nemdatine, Valios) regulates chemical messengers such as glutamate to decrease abnormal activity in the brain and improve learning and memory abilities (Hersch & Falzgraf, 2007; Sonkusare et al., 2005; McShane et al., 2019 and NHS, 2022). Amyloid targeted medications (Aducanumab, Leqembi, Donanemab) reduces amyloid plaques which helps slow down cognitive decline (Lannfelt et al., 2014; Musiek et al., 2021; Molchan & Fugh-Berman, 2023 and Karran & Strooper, 2022). Recently, Leqembi has been approved by the U.S Food and Drug Administration (FDA) (U.S. Food & Drug, 2023). Leqembi prevents amyloid formation by targeting oligomeric Aβ peptides and is administered as an intravenous infusion every two weeks (Kurkinen, 2023; Ernst, 2023). In general, there are limited number of medications to treat symptoms of dementia. These may not work for everyone or work for limited amounts of time (Hogan et al., 2008; Kalles et al., 2015), and studies have shown that their effect sizes are quite small (Hogan et al., 2008; Kalles et al., 2015).

Numerous non-pharmacological approaches, such as engaging in physical exercise and boosting other various activities, which are in harmony with the preferences and interests of individuals with PWDs, can potentially alleviate symptoms and behavioral issues (Kouloutbant et al., 2022; Demurtas et al., 2020; Trahan et al., 2014 and Blankevoort et al., 2010). Examples of physical exercise include aerobic exercise and muscle strengthening, which can help reduce anxiety, agitation, apathy and other dementia symptoms (Kouloutbant et al., 2022). Sometimes activities are introduced to target specific behaviours such as agitation. For example, work-related activities or reading activities may help reduce such behaviours in PWD (Trahan et al., 2014).

Another example is occupational therapy (OT) for help with behaviours, lifestyle changes (e.g., keeping only important things at home with no clutter), creating modifications to tasks to make them easier to perform and being engaged in activities with family or other people in the community (Yuill & Hollis, 2011; Graff et al., 2007 and Graff et al., 2006). There are support groups that families and PWD can join where both caregiver and PWD learn more about ways to cope with dementia and preparing for the changes that occur with the condition (Ontario Shores, 2023; Cheng & Zhang, 2020 and Geddes et al., 2020). Studies have shown some evidence that support groups can reduce depression and improve quality of life (QOL) in both PWD and their caregivers (Leung et al., 2015; Toms et al., 2015; Chien et al., 2011).

1.1.3 Caregivers of individuals with Dementia

Formal caregivers such as healthcare professionals (doctors, nurses, OTs), personal support workers and family caregivers, most often family members (spouses, children, grandchildren, relatives) support the care of PWD (Broadaty & Donkin, 2022). Individuals with dementia who are living in the community (about 61%) are mostly taken care of by family caregivers (Canadian Institute for Health information, 2023). A 2020 study found that there are over 300,000 in family caregivers in Canada, and this may rise to over one million by 2050 (Alzheimer Society Canada, 2022; Canadian Centre for Economics Analysis, 2022). Caregivers work long hours by assisting with daily living activities such as bathing, personal hygiene and feeding (Brodaty & Donkin, 2022). By spending long hours and assisting with the PWDs' needs, family caregivers often face difficulties in taking care of themselves (Brodaty & Donkin, 2022). Caregivers understand the needs of their loved ones who are living with dementia and can help enhance their QOL (Brodaty & Donkin, 2009; Leon-Salas et al., 2013; Jennings et al., 2019). For

instance, studies found that PWD who live at home have a higher QOL than PWD living in a nursing home (Olsen et al., 2016 and Nikmat et al., 2013)

1.1.4 Family caregivers' experiences

Previous studies have explored caregivers' experiences and the impact of caregiving on their overall well-being (Cross et al., 2018; MacDonald et al., 2020; Hazzan et al., 2022). Gaining insights from caregivers about their experiences with dementia progression, coping strategies, and available resources can enhance the QOL of both caregivers and those under their care (Cross et al., 2018). The experiences of caregivers and their understanding of dementia may change over time (Cross et al., 2018;). Caregivers may not notice symptoms early on due to assuming they are symptoms related to normal aging, and only seek help later in the disease course (Cross et al.,2018). Similarly, they can face difficulties in providing care due to denial about dementia from the care-recipient, and making decisions on their behalf (Cross et al.,2018). Addressing the needs of new caregivers is crucial, as they often lack the knowledge and information necessary for effective care in the initial stages (Macdonald et al., 2020). In previous studies, caregivers have indicated how support groups have helped them understand dementia as well as help cope with their responsibility changes (Cross et al., 2018; MacDonald et al., 2020; Hazzen et al., 2022). Most caregivers work around the clock to provide care to their loved ones with dementia and alter their own lifestyle to accommodate their loved ones (Cross et al., 2018; MacDonald et al., 2020; Hazzan et al., 2022). Oftentimes when dementia symptoms and behaviours worsen, caregivers realize their limitations and seek out alternative care with hesitation as they want to keep the care-recipient at home as long as possible (Hazzen et al., 2022).

1.2 Quality of life and health-related quality of life of PWD

QOL is a concept that assesses an individual's well-being in the context of various facets of their lives such as health, environment, social relationship, and satisfaction with life (Statistics Canada, 2023; Patrick & Erickson, 1988). Oftentimes, QOL and health-related quality of life (HRQOL) are used interchangeably with various definitions available for HRQOL (Karimi et al., 2016). One example is that HRQOL refers to how well an individual does daily living activities and sees their physical and mental health over time (Hays & Reeve, 2010; Smith et al., 2005; Bullinger et al., 1993). It can also be defined as a multidimensional construct that encompasses factors related to the individual's health such as emotions, mobility and function (Torrance, 1987). Karimi et al. define HRQOL as focusing on specific QOL areas that have been affected by the disease (Karimi et al., 2016 & Ebrahim, 1995). Another definition for HRQOL mentioned in the literature is the emphasis on assigning values to various health states where calculated values that are less than one is loss of QOL (Karimi et al., 2016; Patrick & Erickson, 1993; Walker & Rosser, 1992 and Gold et al., 1996). With all the definitions in mind, HRQOL can be defined as a multidimensional, patient-reported construct that focuses and values different aspects in the health and well-being of an individual. There are dementia specific QOL and HRQOL measures that were created to measure dementia-specific symptoms, behaviours and daily living activities. The instruments help inform caregivers, healthcare professionals, and researchers on the PWD's QOL, areas of their lives that need improvement, and impact of treatment (Edelman et al., 2005).

1.3 Dementia QOL and HRQOL measures

QOL and HRQOL measures are important in evaluating patient-centered care and dementia progression (Li & Porock, 2014; Naglie, 2007; Van de Beek et al., 2019). The next section will describe QOL and HRQOL measures that have been used in PWD living in the community, and that have been included in the systematic review in Chapter 3.

1.3.1 Quality of Life in Alzheimer's Disease (QOL-AD)

QOL-AD is a QOL dementia-specific measure that evaluates life as a whole and various functions through 13 items (15 items for caregivers). The assessment is conducted through interviews with people with dementia (PWD), and their caregivers can complete the questionnaire (Logsdon et al., 1999; Wolak et al., 2009). The items are physical health, energy and initiative, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores, ability to do things for fun, financial situation and life as a whole (Logsdon et al., 1999). Items are rated on a four-point Likert scale with one being poor and four being excellent with total scores ranging from 13 to 52 (Logsdon et al., 1999). Higher scores represent better QOL. The items were developed with the help of PWD, caregivers and experts from geriatrics and gerontology (Logsdon et al., 1999). There is an option to combine the scores of both PWD and their caregivers into a single composite QOL score (Logsdon et al., 1999; Wolak et al., 2009).

1.3.2 Dementia Quality of Life Measure (DEMQOL)

DEMQOL was developed as a HRQOL dementia specific measure to address some of the methodological challenges that people were facing when using generic HRQOL measures (Smith

et al., 2005). The development team consisted of dementia family caregivers and community psychiatric nurses who provided care to PWD (Smith et al., 2005). DEMQOL has two versions, a self-report, and a proxy-report version. The self-report version is a 28-item questionnaire where the interviewer questions the PWD and the proxy one is a 31-item questionnaire completed by the caregiver (Smith et al., 2007). There are five domains; daily activities/looking after yourself, cognitive functioning, social relationships, health and well-being and self-concept (Smith et al., 2005). Each item is scored from one to four (a lot, quite a bit, a little and not at all) and scores range from 31 to 124 with higher scores equating to better HRQOL (Hughes et al., 2019).

1.3.3 Dementia Quality of Life Instrument (DQOL)

DQOL was developed by Meryl Bord and team in 1999 because they wanted to create a measure that has appropriate domains specific to dementia and can be patient administrated to assess PWD's overall well-being (Brod et al., 1999; Bowling et al., 2014). It includes 29-items encompassed in five domains with five subscales. These domains are positive affect, negative affect, sense of belonging, self-esteem, and sense of aesthetics (Brod et al., 1999; Ready & Ott, 2003; Bowling et al., 2014). Each item is scored from one to five (never to very often, not at all to a lot) (Broad et al., 1999). They have an optional item that looks at the individual's overall QOL (Brod et al., 1999; Ready & Ott, 2003). During the instrument's development phase, the team included both formal and informal caregivers and PWD (Bowling et al., 2014).

1.3.4 Bath Assessment of Subjective Quality of Life in Dementia (BASQID)

BASQID was created for PWDs with mild to moderate levels of dementia and is a patient-reported outcome (Trigg et al., 2007). It was developed by Richard Trigg and team who wanted

to capture dementia QOL from the perspectives of PWD but with a focus on health (Trigg et al., 2007). This instrument items was developed by interviewing PWD who have mild to moderate dementia to determine how to best create it for this population (Trigg et al., 2007). There are 14 items related to mood and emotional well-being, social interaction, engagement in activities, physical comfort, perception of memory problems and overall life satisfaction (Trigg et al., 2007). Items are scored by not at all satisfied, a little satisfied, satisfied, very satisfied, and extremely satisfied, with total scores ranging from 0 to 100 (high score indicating better QOL) (Trigg et al., 2011). Compared to other dementia QOL measures, it has broader questions that may not capture specific aspects of a PWD's QOL (Bowling et al., 2015).

1.3.5 Cornell-Brown Scale (CBS)

CBS was created to show that high QOL is based on having positive affect, satisfaction with physical and psychological health, self-esteem and the absence of negative affect and experiences (Ready et al., 2002; Ready & Ott, 2003). Both PWD and their caregiver are interviewed for this measure under one rating (Ready et al., 2002; Ready & Ott, 2003). It has 19 items in four domains that are physical comfort, emotional well-being, relationships and environmental comfort (Ready et al., 2002). Each item is rated from -2 to +2 and total scores range from -38 to +38 (Ready & Ott, 2002). Higher scores represent better QOL. CBS is a modification of the Cornell Scale for Depression and was created with the help of PWDs and their caregivers (Ready et al., 2002).

1.3.6 Alzheimer Disease Related Quality of Life (ADRQL)

The ADRQL was created by Peter Rabins and team from the perspective of people living with Alzheimer's disease and AD experts on what domains they found are important to assess for HRQOL in dementia (Rabins et al., 1997; Rabins et al., 1999). The development team consisted of people living with AD, AD caregivers, healthcare professionals, researchers, and the authors of the scale (Rabins et al., 1999). There are 48 items in five domains including social interaction, awareness of self, feelings and mood, enjoyment of activities and response to surrounding (Rabins et al., 1999; Kasper et al., 2009). It is a proxy measure that is filled out by the caregiver and scores are calculated by either summing the weighted items or each subscale (Kasper et al., 2009). Scores range from 0 to 100, higher scores represent better QOL (Kasper et al., 2009).

1.3.7 Quality of Life Instrument for Japanese Elderly with Dementia (QLDJ)

QLDJ is an adaptation from ADRQL created by Noriko Yamamoto-mitani and team to include an instrument that reflects the culture and lifestyle of Japanese PWD (Yamamoto-Mitani et al., 2002). This instrument was developed by dementia care experts which are clinical nurses, one nursing home director, three nursing school faculty members, one psychiatrist and one nurse researcher. It is a 24-item measure with three subscales such as interacting with surroundings, expressing self and experiencing minimum negative behaviours (Yamamoto-Mitani et al., 2002; Yamamoto-Mitani et al., 2003). Each item is scored on a four-point Likert scale (0= not at all applicable, 1 = not very applicable, 2=somewhat applicable and 3=very much applicable). Each domain is weighted, and the total score ranges from 0 to 100 (Yamamoto-Mitani et al., 2002; Yamamoto-Mitani et al., 2003).

1.3.8 Quality of Life Assessment Schedule (QOLAS)

QOLAS was developed by Caroline Selai and team to tailor the instrument to each PWD using a mixed methodology approach (Selai et al., 2001). It is a self-report measure that has 10 items with five domains such as physical functioning, psychological/emotional status, social and family life, daily activities and cognitive abilities (Selai et al., 2001; Bowling et al., 2015). Development of items was constructed with the help of PWD and their caregivers (Selai et al., 2001). Each item is scored on a five-point Likert scale ranging from 0-5; 0= no problem, 1 = very slight problem, 2 = mild problem, 3 = moderate problem, 4 = big problem and 5 = it could not be worse. Each domain is scored out of 10 and the total score is out of 50 (Selai et al., 2001). QOLAS is administered through an interview with the PWD and their caregiver.

1.4 Generic QOL or HRQOL measures

There are different types of generic measures for assessing QOL or HRQOL. The ones selected below are generic QOL and HRQOL measures that are commonly used with PWD (Orgeta et al., 2015; Kavirajan et al., 2009; Smith et al., 2005).

1.4.1 EuroQOL- Five Dimension (EQ-5D)

The EQ-5D measure has been created by the EuroQOL Group which comprises of various European experts from different institutions such as universities, health economics institutes and hospitals (The EuroQOL Group, 1990). EQ-5D measures HRQOL, and has five domains: mobility, self- care, usual activities, pain/discomfort, and anxiety/depression (Walker & Rosser, 1992; The EuroQOL Group, 1990). Items from each domain can be scored by three choices (1= no problem, 2= moderate, 3= severe) (Schrag et al.,2000). Respondents also rate their own health

today on a visual analogue scale (VAS) from 100 (best imaginable health state) to 0 (worst imaginable health state) (Devlin & Brooks, 2017). The data can be presented descriptively as a health profile and a single index utility score can be calculated (Walker & Rosser, 1992; The EuroQOL Group, 1990). The EQ-5D is designed with various versions that can be used as a self-report, interviewed-based as well as proxy- based (EuroQol Research Foundation, 2018; Devlin & Brooks, 2017). Versions include EQ-5D-3L, EQ-5D- 5L, EQ-5D-Y (for children and adolescents) and EQ-HWB (health and well-being) (EuroQol Research Foundation, 2023; Buchhloz et al., 2018; Peasgood et al., 2022; Brazier et al., 2022). In this thesis, the search strategy for the systematic review (Chapter 3) only included the EQ-5D-3L and EQ-5D-5L as these are the more commonly used versions, but we did not exclude the EQ-HWB. Among the included studies, there were no studies that reported on the EQ-HWB due to it being a new measure and because it has not been evaluated in individuals living with dementia in the community.

1.4.2 Health Utilities Index (HUI)

The Health Utilities Index (HUI) is a generic preference-based system measuring HRQOL. It includes a family of measures comprising of Mark 1 (HUI1), Mark 2 (HUI2), and Mark 3 (HUI3). HUI1 was the first of the series to be developed in 1982 and used to measure children in neonatal intensive care and later evolved to assess general pediatric health (Cadman & Goldsmith,1986; Torrance & Feeny,1986). However, HUI1 is rarely used now due to having other versions that are more comprehensive (Horsman et al., 2003; Furlong et al., 2001). HUI2 covers seven domains (sensation, mobility, emotion, cognition, self-care, pain, and fertility) which have three to five levels each, representing 24,000 health states (Horsman et al., 2003). HUI3 covers eight domains (vision, hearing, speech, ambulation, dexterity, emotion, cognition,

and pain), each with five to six levels, representing 972,000 health states (Horsman et al., 2003; Furlong et al., 2001). HUI2 scores can range from -0.03 (worst health) to 1.00 (best health), while HUI3 scores can range from -0.36 to 1.00 (Horsman et al., 2003; Feeny et al., 2002).

1.4.3 Short Form 36 (SF-36)

The Short Form 36-item questionnaire is a self-reported outcome measure used to quantify an individual's HRQOL and is commonly used across many disease-specific populations (Hayes et al., 1995). It was created by Ware and Sherbourne in 1992 to use in clinical practice, research health policy evaluation and general population survey with 146 items (Stewart et al., 1988; Ware Jr & Sherbourne, 1992; Hayes et al., 1995). Now, there are 36 items spanning eight domains: physical functioning, bodily pain, general health perceptions, limitations due to physical health problems, limitations due to personal or emotional problems, social functioning, vitality (energy or fatigue), and mental health (Hayes et al., 1995; Geschke et al., 2013). Scores in each domain range from 0 to 100, worse to best health state, respectively (Geschke et al., 2013). Pooling together scores from the first four domains result in the Physical Component Summary (PCS) and pooling the last 4 domains result in the Mental Component Summary (MCS) (Jenkinson et al., 1999). There are various version of the short form such as SF-36, SF-12 and SF-08 with each representing the number of items they have (Ware Jr et al, 1996; Wee et al., 2008; Turner-Bowker et al., 2003). The shortened versions of the SF-36 were created to reduce burden on participants and takes less time to complete (Ware Jr et al., 1998).

1.4.4 World Health Organization Quality of life (WHOQOL)

WHOQOL also known as WHOQOL-100 was developed in 1992 with 15 field centres around the world to include cross-cultural adaptation (WHOQOL Group, 1994). Centres include Australia, Europe, Asia, Africa and North America (WHOQOL Group, 1994). Patients with acute and chronic disorders were included alongside healthcare professionals during the development of the scale (WHOQOL Group, 1994). This measure is available as a self-report if the individual has the ability to fill it out, otherwise there are interview-assisted and interview-administered forms available (WHOQOL Group, 1998a). In WHOQOL-100, there are six domains (physical health, psychological, level of independence, social relations, environment and spirituality/religion/personal beliefs) with facets within in each domain which encompasses the 100 items in the measure (WHOQOL Group, 1998a). There is a shortened version of the WHOQOL called WHOQOL-BREF. The WHOQOL-BREF is a 26-item short form version of the WHOQOL-100 (WHOQOL Group, 1998b; Vahedi, 2010). It is a generic assessment of QOL across four domains: Physical health, Psychological, Social relationships, and Environment (Skevington, Lofty & O'Connell, 2004). Recently, another version of WHOQOL was published that focuses on spirituality, religiousness and personal belief (WHOQOL-SRPB) that can be used in addition to WHOQOL-100 (World Health Organization, 2012).

1.5 Psychometric properties

Psychometric properties are important when determining the quality of a measurement instrument and its usability when applying in clinical practice and research (De Vet et al., 2011). These properties can be characterized by reliability, validity, and responsiveness.

1.5.1 Reliability

Reliability evaluates the ability of a measure to produce the same results irrespective of the number of trials or raters (Mokkink et al., 2010). There are four types of reliability: internal consistency, test-retest reliability, inter-rater reliability, and intra-rater reliability. Internal consistency is the relationship of items with each other and is measured by Cronbach's alpha (Prinsen et al., 2018; Mokkink et al., 2010). Test-retest reliability is one type of reliability assessment that measures the ability of the instrument to reproduce the same results when administered at different times with different raters (Guttman, 1945; Mokkink et al., 2010; Bouter et al., 2015). Inter-rater reliability is another type of reliability assessment that looks at the extent of which two different raters measure the same patient at the same time (Mokkink et al., 2010 and Gifford & Cummings 1999). Intra-rater reliability is the degree of consistency of scores by the same rater over time (Mokkink et al., 2010 and Gifford & Cummings 1999).

1.5.2 Validity

Validity evaluates how accurately an instrument is able to measure its intended construct (Mokkink et al., 2010). For this project, three types of validity were assessed: convergent validity, known-group validity, and predictive validity (Mokkink et al., 2010). Although not assessed in this thesis, content validity identifies how well the components of an instrument represent the constructs it intends to measure. To evaluate content validity, COSMIN has a detailed guideline titled: COSMIN-methodology for content validity user manual (Terwee et al., 2018). Construct validity identifies how well an instrument measures the concepts that it intends to measure. Convergent validity assesses the relationship between two measures on a construct (Carlson & Herdman, 2010; Mokkink et al., 2010; Chin & Yao, 2014 and De Vet et al., 2011).

Known-groups validity is a subset of construct validity, in which it measures the ability of an instrument to distinguish results between groups known to produce different outcomes (Finch et al., 2002; De Vet et al., 2011; Davidson, 2014). Lastly, although there were no results for predictive validity among the studies included in the systematic review, predictive validity is assessing how a test score can predict a future outcome (Banerjee et al., 2009).

1.5.3 Responsiveness

Responsiveness evaluates the ability of an instrument to measure change over time pertaining to the constructs it intends to measure (Mokkink et al., 2010). This can be done through two approaches, the criterion or the construct approach. When there is a gold standard tool used to measure the same construct, the change scores from the measurement instrument are compared to the change scores from the gold standard tool such as the global rating scale (De Vet et al., 2011). This is known as the criterion approach (De Vet et al., 2011). When a gold standard tool is not available, another tool that measures this construct can be used and the change of scores of this tool is then compared to the change scores of the measurement instrument of interest such as using another outcome measurement instrument (Mokkink et al., 2017). This is known as the construct approach (De Vet et al., 2011).

2.0 Rationale and Objective of Thesis

The prevalence of dementia is increasing in Canada, with a significant impact on families and the healthcare system (Alzheimer's Society, 2020; Bronskill et al., 2020; Government of Canada, 2017). It affects many aspects of an individual's life such as their physical health, mental health, and their ability to do daily activities (WHO 2023; Alzheimer Association 2023 & NIA 2022).

Caregivers have firsthand experience in understanding PWDs' needs and QOL because of their responsibility in supporting the PWD. They assist with day-to-day activities like personal care and healthcare needs (Broadaty & Donkin, 2022). This experience positions them well to make informed decisions regarding treatment options and interventions for their loved ones (Brodaty & Donkin, 2022; Connell et al., 2004). Hence, it is important to understand caregivers' perspectives on what they consider as being important when evaluating QOL of the PWD. Furthermore, to assess PWD's QOL and HRQOL, healthcare workers and researchers rely on measures to make appropriate decisions about treatment, moving PWD to a facility and assessing their dementia progression (Ettema et al., 2005; Arons et al., 2013). These measures are often in a self-report or interview style format that are easy to administer either by the healthcare worker, researcher or caregiver (Ettema et al., 2005; Bowling et al., 2015 and Ready & Ott, 2003). However, before using a QOL or HRQOL measure, clinicians and researchers need evidence in support of its reliability and validity. Currently, there are many available QOL and HRQOL measures that assess QOL of PWDs, however they have inconsistent measurement properties and there is insufficient information to guide which measure(s) to use (Ettema et al., 2005; Perales et al., 2013; Bowling et al., 2015).

Therefore, the objectives of this thesis were to:

1. Explore, from the perspective of caregivers, the symptoms, behaviors, or activities that should be evaluated when monitoring dementia progression, measuring the impact of treatment, or seeking alternate levels of care (Chapter 2).
2. Examine the measurement properties of QOL and HRQOL measures used with community-dwelling PWD (Chapter 3)

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CHAPTER 2

Exploring caregivers' perspectives on which symptoms, behaviours or activities should be evaluated for dementia progression and alternative care

Exploring caregivers' perspectives on which symptoms, behaviours or activities should be evaluated for dementia progression and alternative care.

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Abstract

Background: Family caregivers see firsthand the progression of their care recipient's dementia and know every aspect of their lives and needs. They make important decisions on interventions and care. The aim of this study was to explore, from the perspective of caregivers, the symptoms, behaviors, or activities that should be evaluated when monitoring dementia progression, measuring the impact of treatment, or seeking alternate levels of care.

Methods: Participants were recruited from across Canada. Listening sessions were conducted virtually, using open-ended questions to encourage participants to share their perspectives. A semi-structured interview guide was developed to facilitate the sessions. The interviewer asked questions to encourage caregivers to share their experiences on providing care, dementia monitoring, treatment impact and seeking alternative care. The data were coded and analyzed using NVivo. A thematic analysis approach was applied by two reviewers.

Results: Six listening sessions were conducted with 30 caregivers who were providing care to people living with dementia. Four themes emerged from the data: (1) difficulty with everyday activities; (2) changes in mood and behaviour (3) cognitive difficulties; and (4) extrinsic factors when seeking alternative care.

Conclusion: This study explored the perspective of caregivers across Canada, the symptoms, behaviours and activities that are important to assess when evaluating dementia progression and the effects of treatment. It demonstrated the importance of including the voices of caregivers given the level of care they provide and the vast amount of information they know about the care recipient. The results can help inform health care providers and researchers on what patient factors are important to assess in clinical practice and research.

Introduction

The prevalence of dementia has increased worldwide, with more than 55 million people currently living with dementia (WHO, 2023). According to the Alzheimer's Society of Canada, more than 500,000 Canadians are living with dementia and the numbers are expected to double by 2030 (Alzheimer's Society, 2020). This rise in numbers increases the burden on family members who provide the majority of care to the person living with dementia. Oftentimes, it is the care-recipients' spouses, children or relatives who play an important role in providing their care (Peeters et al., 2010; Lindeza et al., 2020; Vugt & Verhey, 2013; Schulz & Martire, 2004). They are often referred to as "informal caregivers or primary caregivers" because they provide care to people with dementia at home (Vugt & Verhey, 2013). Without caregivers, people living with dementia may experience a lower quality of life and a faster need for institutional care (i.e., long-term care homes) (Broadaty & Donkin, 2022).

Caregivers help with activities of daily living (ADL) such as personal care, healthcare needs, feeding and financial needs, and these responsibilities increase as the care recipient's dementia progresses (Broadaty & Donkin, 2022). In 2020, it was estimated that there were 350,000 caregivers providing care for people living with dementia; totaling to 470 million hours of care in a year (Alzheimer's Society, 2022). By being involved in supporting the care recipient's health and wellbeing for an extended period of time, caregivers are well positioned and informed to make decisions when exploring various treatment options and seeking alternative care (Brodaty & Donkin, 2022; Connell et al., 2004). For instance, when it comes to evaluating dementia progression, caregivers often report symptoms to physicians during medical appointments (Fieldhouse et al., 2023; Rogers et al., 2017; Connell et al., 2004). This in turn helps physicians

to provide treatment options that may support the quality of life of the person living with dementia (Connell et al., 2004; Harris & Keady, 2004).

In 2014, Quebec implemented the Quebec Alzheimer Plan to ensure that physicians create a dementia management plan from initial diagnosis through disease progression (Khanassove et al., 2021). More recently in 2022, Ontario published a roadmap to enhancing care for people living with dementia at home (Ontario.ca, 2021; Alzheimer's Society, 2022). However, despite such strategies, caregivers still report that their family members living with dementia do not receive adequate information, timely care, and that services are not always catered to their specific needs (Lapierre et al., 2022; Harris & Keady, 2004, Cohen et al., 2000; Connell et al., 2004; Vugt & Verhey, 2013). Thus, it is essential to include caregivers' perspectives in the management of dementia. Caregivers are ideally situated to know whether a treatment is working or is making the symptoms and behaviors of the care-recipient worse (Jacklin et al., 2015). However, few studies to date have focused on dementia progression or treatment from the perspective of caregivers. Therefore, the objective of this study is to explore, from the perspective of caregivers, the symptoms, behaviors, or activities that should be evaluated when monitoring dementia progression, measuring the impact of treatment, or seeking alternate levels of care.

Methods

Study Design

A qualitative descriptive study design was used when creating this study (Sandelowski, 2000; Sandelwoski, 2010). This involved listening sessions with caregivers providing care to people

living with dementia (OHSU,2013). Participants were asked about their perspectives on symptoms, behaviours, and/or activities that are important to assess among people living with dementia. Ethical approval was obtained from Hamilton Integrated Research Ethics Board (Study # 14086).

Participants and Recruitment

Convenience sampling was used to recruit participants across Canada between September 2022 to January 2023 through the support of various organizations (i.e., Alzheimer's Society) and social media (i.e., Facebook). Flyers and posters were shared through newsletters and online posts. Interested participants sent an email to the research team, and the team determined their eligibility. Caregivers were included if they provided care within the past 3 years to an individual living with dementia in the community, and met the following criteria:

a) age ≥ 18 years at the time of listening session;

b) at least 6 months of caregiving experience to someone living with dementia;

c) speaks English; and

d) assists the care recipient with daily living activities (such as bathing, feeding).

Procedure

A semi-structured qualitative interview guide was developed by the research team that consisted of caregivers and researchers in dementia care. The interview guide was edited through an iterative process and was piloted with a caregiver who is part of the research team.

Listening sessions were conducted between November 2022 to January 2023. A trained graduate student (FC) who has experience with qualitative interviews, completed the listening sessions alongside the principal investigator (AK) and another researcher (EN). All listening sessions were conducted via Zoom (Zoom Video Communications), at the participant's convenience and each session lasted approximately one hour. In each listening session, there were three to five participants. Throughout the listening sessions, the interviewer asked open-ended questions to capture the details regarding what behaviours, symptoms and/or activities of dementia are important to assess when evaluating disease progression, treatment impact, and when considering alternative care for their care recipients.

Data analysis

Each listening session was audio-recorded and transcribed verbatim by using a transcription program (Otter.ai), and then verified by the interviewer. Conducting, transcribing, and analyzing listening sessions proceeded concurrently so that the analyzed data could guide the following sessions (DiCicco-Bloom & Crabtree, 2006). The transcripts from listening sessions were qualitatively analyzed by two researchers (FC and EN) using NVivo (QSR International Pty Ltd. Version 14.0), a software program for qualitative studies.

A thematic analysis approach was used to analyze the collected data (Braun & Clarke, 2006; Clarke & Braun, 2013; Clark & Braun, 2015). Two researchers (FC and EN) independently generated preliminary codes and collated the data relevant to each code. These codes were grouped into categories, and then the categories were collapsed into themes and subthemes. Data collection continued until data saturation was reached, that is until there were no new themes that

emerged during the analysis (Guest et al., 2006; Fusch & Ness, 2015). Any unclear codes and disagreements were resolved through discussion among two researchers and a senior researcher (AK).

Result

A total of 30 participants were recruited across Canada and six listening sessions were conducted. Participant characteristics are summarized in Table 1. All caregivers lived with the care-recipient while providing care.

Table 1. Socio-demographic characteristics of study participants

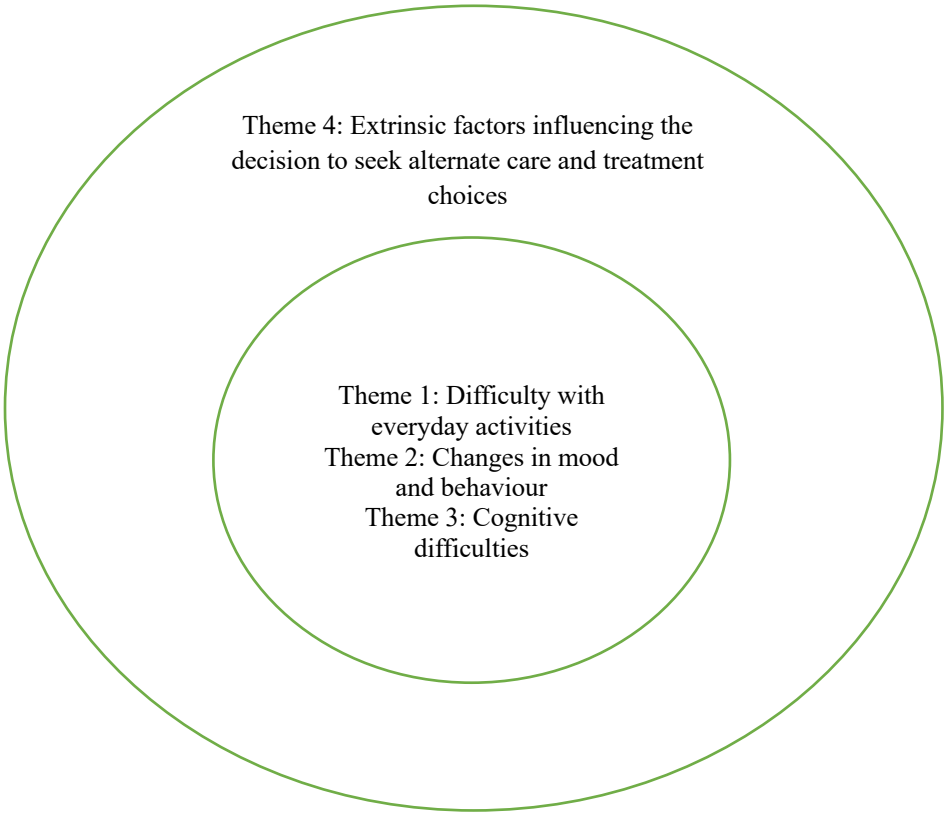
Characteristics	**Total Population (n=30)**
Sex, n (%)	
Female	23 (76.7)
Age (years), mean (SD)	38.9 (14.7)
Geographic location, n (%)	
Ontario	11 (36.7)
Canadian Prairies	9 (30.0)
Atlantic Canada	7 (23.3)
Quebec	2 (6.7)
British Columbia	1 (3.3)
Living community, n (%)	
Large Urban Population Centre [a]	13 (43.3)
Medium Population Centre [b]	11 (36.7)
Small Population Centre [c]	2 (6.7)
Rural Area [d]	4 (13.3)
Education level, n (%)	
High school graduate	1 (3.3)
CEGEP or College	6 (20.0)
Bachelor's degree	18 (60.0)
Graduate degree	5 (16.7)
Care recipient, n (%)	
Parent/ parent-in-law	22 (73.4)
Husband, wife common-law partner	6 (20.0)
Sibling or Cousin	2 (6.8)

a, Population ≥100,000; b, population 30,000-99,999; c, population 1,000-29,999; d, Population less than 1,000

Thematic analysis of the six listening sessions resulted in four themes: (1) difficulty with everyday activities; (2) changes in mood and behaviour (3) cognitive difficulties; and (4) extrinsic factors when seeking alternative care.

Figure 1 presents the themes in relation to each other. Themes 1 to 3 are intrinsic to the care-recipient whereas theme 4 is extrinsic. Both clusters may influence each other when it comes to dementia progression, impact of treatment and decisions regarding alternative care.

Figure 1:



Each theme included three to four sub-themes. A summary of the themes and sub-themes are provided in Table 2. Quotes are presented below to provide direct examples of what behaviour,

symptoms, and activities caregivers thought were important to assess for dementia progression, treatment and providing different levels of care.

Table 2. Summary of themes and sub-themes

Themes	**Subthemes**
Difficulty with everyday activities	Change in mobility
	Feeding
	Taking medication
	Social interaction
Changes in mood and behaviour	Anger
	Sadness
	Aggressive behaviour
Cognitive difficulties	Memory
	Language
	Reasoning
Extrinsic factors when seeking alternative care	Financial decision-making
	Quality of life in alternative care facility
	Communication barrier with healthcare provider
	24/7 care

Difficulty with everyday activities

Changes in mobility

Caregivers expressed the importance of assessing the mobility of care recipients. As dementia progressed, they discussed how it can affect one's balance and gait. Several participants mentioned that mobility limitations impacted their caregiving duties. Lifting the care-recipient and problems with balance were safety issues that were echoed by a number of participants.

"If he can't lift himself and walk, I'm sure not going to be lifting him out of a bed or helping him toilet or bath or whatever. So, mobility is a huge issue for us." (*Female Caregiver_28)*

Similarly, after caregivers noticed an issue with gait, they had to think of solutions to help alleviate caregiver burden and support the care-recipient. For some, this meant purchasing support systems, such as a lift, to help the care-recipient go up and down the stairs:

"…Mom is having a problem with her gait, and now that we know that her walking has gone from three blocks down to one block, we've just brought a lift into the home." (*Female Caregiver_13*)

Feeding

Another day-to-day activity that caregivers reported as being important to monitor and assess was feeding abilities and attitude towards eating. According to many participants, their care-recipients needed support with eating. They discussed how it was difficult to feed them due to no appetite or simply choosing not to eat.

"Getting my dad to eat…he doesn't really enjoy meals that much" *(Female Caregiver_17)*

"Most times, it was difficult for her to eat as well. So, there were several things I would try to force her to do. I'll literally have to force her to [eat] ..." *(Female Caregiver_22)*

Taking medication

Participants also discussed that they had a hard time providing medications because the care-recipient refused to take them, or the caregivers had to change their schedule to give medication.

Caregivers mentioned that taking medication was an important factor to assess because it can help with symptom management and dementia progression.

"There were times where she refused to take her medication. So, it was something very difficult compelling her to take her medication. At some point, the symptoms will get worse, sometimes the symptoms would reduce a bit." (*Female Caregiver_22)*

*"*The person I'm caring [for] has to take her medication in the afternoon, I have to come from [my] workplace in order to assist her." *(Female Caregiver_03)*

*"*He doesn't like to see himself as diagnosed [so] he doesn't really like taking medication…sometimes [I] force him, sometimes convince him." *(Male Caregiver_14)*

Social interaction

Participants described various activities they did with care-recipients to ensure that they were engaged with others and felt part of the community. Participants mentioned the importance of social interaction and the benefits that come with it because the care-recipients can talk to others, participate in activities, and be surrounded with other family members. This can help caregivers better assess their dementia progression and evaluate if their loved ones needs any social interaction related intervention.

“Something else that can be noted is the social interaction. Now, how they're interacting with family or how they're interacting with anyone else that is in the house....and I guess, interest in activities like, there’s such apathy growing.” (*Female Caregiver_28)*

Changes in mood and behaviour

Participants described the various emotions that their care-recipients displayed. At times, people living with dementia face difficulties in communicating their needs, resulting in emotional responses characterized by anger, sadness and aggression. Caregivers discussed the importance of assessing care recipients’ emotional change and behaviours when considering alternative care options because it may trigger negative emotions and behaviours.

Anger

Caregivers expressed that care recipients often showed difficulty in temper control towards them as dementia progressed. Assessing the causes or triggers for anger can help caregivers track care-recipients’ emotions to better support them and have action steps ready to reduce the causes or triggers of anger response.

“The anger issue is very important to assess because my dad is really quick and becoming angry. Everything that should be done to them should be with care and happiness.” (*Male Caregiver_04)*

“She was always shouting at me getting angry, easily, doing a lot of stuff that could easily make me turn away or look away.” (*Male Caregiver_23)*

Sadness

Many participants expressed that their care-recipients feel sad at times, and the need to monitor this to better support them. They mentioned that sometimes the sadness stemmed from changes that occurred in care-recipients' lives. For instance, in the example below, the caregiver needed to place the care-recipient in a long-term care home due to increased caregiving needs. The care-recipient was extremely sad and ultimately the caregiver needed to bring the care-recipient back home. Other participants had similar experiences with their care-recipients. Caregivers tried to cheer them up and emphasized the significance of evaluating their happiness alongside sadness.

"Last year, she was, she cried all the time, like all the time, and that's why she had to go into hospital to get treatment for that… so I don't know, in terms of those emotions, that in the emotional piece" (*Male Caregiver_30)*

*"*My mom, it really presented like…amplified anxiety, stress depression. It really seemed like a mental health issue. But now, and then it rolled into this…she had depression and stress and anxieties, But looking back, it just it just deepened, I guess is the way to say it or progressed into that." (*Male Caregiver_02)*

Aggressive behaviour

Participants expressed that sometimes their care-recipients would react aggressively towards themselves or at the caregivers. This included yelling, not listening and being violent. Oftentimes, it stemmed from a perception that was distorted from reality or even a simple action

made by the caregiver. Participants across the listening sessions echoed the need to assess and monitor aggression because it could help caregivers make informed decisions about seeking alternative care or make changes in their caregiver tasks.

"The behavioral stage of where they have different behaviors that you've never seen before…" *(Female Caregiver_08)*

In the quote below the care recipient believed her mother was still alive, wanted to visit her and assumed that the caregiver was purposely not listening to the care recipient's wishes.

"And she's hitting the dashboard, saying why won't you take me to my mother, I do everything for you, why won't you do this for me, and it just becomes a situation" (*Female Caregiver_15)*

Cognitive difficulties

Memory

All participants noted the need to monitor and assess memory when looking at dementia progression and considering alternate care. They described that loss of memory happens at different stages. It includes remembering pertinent details from the past to present and remembering individuals, including the caregiver.

"She didn't know me. And I sat with her all night and in the morning, she just looked at me and she said are you a worker, you know, dealing with that pain, trying to take an emotional setback." *(Female Caregiver_29)*

*"*Yeah, like my mom actually started calling me mom. And I just answer to that, I feel is like a role reversal for sure" *(Female Caregiver_11)*

Language

Similarly, participants expressed that language is important to assess because it is an important indicator of dementia progression. Some participants mentioned that it is a gradual loss of the ability to speak with the inability to find words, losing the ability to communicate- aphasia, whereas others mentioned that the care-recipient could speak but was incoherent.

"She's not, she's verbal, but she's not in that she makes no sense. It's just gibberish. So she has no way to tell us or to tell anybody what's happening..." (*Female Caregiver_30)*

"It would be his speech that's starting to go. He struggles now finding words." *(Female Caregiver_12)*

Reasoning

Participants shared that it is important to assess reasoning as well. They mentioned that reasoning is often tied to memory and language. The care-recipient becomes confused due to poor memory and lack of ability to communicate, which results in poor decision-making. Participants described how they noticed their care recipients' lack of reasoning through constant repetition and confusion.

"Yea I think it should be…difficulty in reasoning and solving problems [assessing reasoning]." *(Female Caregiver_17)*

"Here could be increments of confusion or poor judgement or greater or excessive memory loss. And also the issues could also be less the way they wander about could be reduced. And the way the constant repetition of words and questions could be reduced as well." (*Female Caregiver_22)*

Extrinsic factors influencing the decision to seek alternate care and treatment choices

Caregivers discussed various factors, not directly related to the person living with dementia, that affected their decision-making in seeking treatment or alternative care choices. These extrinsic factors are influenced from changes in caregiver duties and care recipients' dementia progression. This theme encompasses the overall decision-making process for alternative care and treatment as a result of dementia progression.

Financial decision-making

When it comes to decision-making, participants assessed the time they spent on finding resources and the effort that went into taking care of the care-recipient. As the symptoms and behaviours worsened in the person living with dementia, it increased the caregiver's duties and responsibilities. For some, their tasks went to a point that they could no longer handle them due to caregiver's physical inability or time constraints. This led to hiring additional support to come at home such as a personal support worker or finding a home that was suitable for the care-recipient to move to. The ability to afford alternative care options was important to assess alongside dementia progression because of how expensive it can be.

“She doesn’t qualify for long term care. So you have to go to personal care home, which you have to pay for” *(Female Caregiver_11)*

“It costs in your management time and in your finances. And then when things just got beyond being able to do anymore because she was by herself so much. We did move her to another private care home.” (*Female Caregiver_28)*

Quality of life in alternative care facility

Participants described the need to consider how care-recipients are when they are moved from their homes to an alternative facility. Many participants shared that the care-recipients want to stay home and refuse to be somewhere different. Caregivers emphasized the need of obtaining consent when introducing changes (i.e., moving to nursing home) in the care recipients’ lives. This ensures that the person living with dementia is content with these changes. Some participants tried to get additional support because caregiver burden was immense, however, the care-recipient would be resistant to the change and the help from others. On the other hand, participants reported that the level of care provided in alternative facilities is nowhere the same as the care the caregiver provides and can affect the quality of life of the care-recipient. Despite caregivers’ attempts to make alternative care facilities the care-recipient’s home, care-recipients are saddened by the change and have difficulty adjusting to the new environment.

“There were little short wings off of the main gathering space. And she was so unhappy. And we moved her furniture and we hung up her favorite paintings and all that stuff. She cried and cried

and cried. And wouldn't take her clothes off to go to bed. And she was just heartbroken." *(Female Caregiver_28)*

"Yes, if the patient's situation gets worse, and is far beyond what a caregiver can handle, I believe the best situation will be going for an in home care [service] if the patient with dementia also consents to being taken there [long-term care home] *(Female Caregiver_10)*

Communication barrier with healthcare providers

A number of participants shared that communication barriers with healthcare providers was a factor that influenced their decision-making when it came to services. Many caregivers felt that the care recipients needed to be part of the conversation when it comes to decision making regarding alternative care and treatment options. When deciding on alternate care options such as living in a care home, healthcare providers would not ask the care recipient for their needs and preferences. Instead, they rely on the caregivers for answers, suggestions or make their own assumptions. This leads the caregivers feel that their loved ones are not being considered as their own person and often are being neglected. Some caregivers went to the care homes to provide daily living activities such as brushing the care recipient's teeth because the healthcare provider neglected them despite many communications with the caregiver. Later, they decided to move their care recipient back home because it did not help alleviate some of the caregiving duties.

"It's annoying how people don't really talk to him, or they make assumptions that, you know," *(Female Caregiver_12)*

"It took a lot of energy and time, it was also very challenging for her as it was very hard for dignity to be maintained from the relationship with doctors and nurses and the community. They would never talk to her directly even if she was in the room, they would want to talk to me." (*Female Caregiver_02)*

"I've been brushing her teeth for years because we realized that was a gap at long term care… I'm even taking a break from work it and I feel like no one understands because [co-workers] assume well she lives in a nursing home so [healthcare workers are] caring for her" (*Female Caregiver_11)*

24/7 care

Providing nonstop care was expressed as a concern by several participants, where they felt exhausted and needed to seek additional help to get sleep and focus on other aspects of their lives. The utmost priority for caregivers was the well-being of the care recipients. Nevertheless, in moments where caregivers are overwhelmed, they may end up not giving the care and attention that is needed to their loved ones. Some participants mentioned their difficulties from the lack of support from other family members.

"I was providing 24/7 care for my mom alone for a very, very long time. And I think when I first started getting help, I got six hours of help a week. So, you know, I would maybe sleep one to four hours a night for several years. Because she was very energetic, and I needed help. And I needed her, I needed people to be able to sit with her." (*Female Caregiver_02)*

"She needs 24/7 supervision. And that's a safety issue. And safety issue is supposed to be a reason to qualify, but she's didn't qualify." *(Female Caregiver_11)*

Discussion

The aim of this study was to explore, from the perspective of caregivers, the symptoms, behaviors, or activities that should be evaluated when monitoring dementia progression, impact of treatment or seeking alternate levels of care. Four major themes emerged from the study, specifically the evaluation of: (i) difficulty with everyday activities; (ii) changes in mood and behaviour; (iii) cognitive difficulties; and (iv) extrinsic factors that influence caregiver's decisions on alternative care and treatment choice.

One of the major themes that emerged from this study was the importance of evaluating day-to-day activities. Caregivers shared their perspectives in difficulties of day-to-day activities such as changes in mobility, feeding, medication, and social interactions. For mobility, caregivers reported that changes in gait was important to assess. Social interaction was another important factor to assess as it is part of daily active living. Caregivers discussed the importance of keeping their loved ones engaged or else they may lose their ability to socially interact with their surroundings. These findings were similar to a qualitative study by Fieldhouse and colleagues who interviewed caregivers who care for people with behavioural variant frontotemporal dementia on symptom progression. They found poor social interaction in care recipients and noticed one of the early symptoms was decreased motivation to participate in social settings (Fieldhouse et al., 2023). This is similar to other studies that have explored poor social interaction and early symptoms (i.e., withdrawn behaviour, lack of joining with others) in people

living with dementia (Meaney et al., 2005; Shinagawa et al., 2006; Teitelman et al., 2010). Poor social interaction can contribute to the increase of other symptoms such as being more agitated, feeling sad, and language decline (Meaney et al., 2005; Acton et al., 2007; Teitelman et al., 2010; Mendez et al., 2013). Sometimes early symptoms may be undetectable to clinicians or healthcare workers but given the amount of time caregivers spend providing care to the care recipient, they may notice the subtle behavioural changes, early symptoms for diagnosis, treatment or alternative care decision-making (Fieldhouse et al., 2023; Rogers et al., 2017; Van Vliet et al., 2011; Hansen et al., 2008; Harris & Keady, 2004; Connell et al., 2004).

Another major theme that emerged from this study was the importance of evaluating emotional changes in people with dementia. As reported in many studies, aggressive behaviour is prevalent in people living with dementia (Hamel et al., 1990; Lyketsos et al., 1999; Kunik et al., 2010; Morandi et al., 2015). Our study also found that aggressive behaviour was a common behaviour emotion that was exhibited by the care-recipient, and was often towards the caregiver. In a recent study by Bernstein and colleagues that reported on multiple caregiver cases, caregivers mentioned physical aggression by the care-recipient towards them due changes in their environment and when taking medications (Bernstein et al., 2020). Similarly, in another qualitative study that explored behaviours exhibited in people living with dementia, caregivers mentioned that care-recipients were at times verbally or physically aggressive towards them (Thoma-Lurken et al., 2018). The reasons for aggressive behavior vary from situation to situation, and sometimes may be due to the care-recipients' distorted perception of reality, anxiety, or changes in environment (Kunik et al., 2010; Morandi et al., 2015; Thoma-Lurken et al., 2018; Rivera-Navarro & Contador, 2018). Overall, our study and previous published studies,

demonstrate the importance of considering caregivers' perspectives regarding changes in mood and behaviour when monitoring dementia progression.

Furthermore, in our findings, caregivers reported that cognition was important when assessing dementia progression. Aspects of cognition that were reported as being important to assess were memory, language, and reasoning. The deterioration of memory can be gradual and is often paired with language (Kempler & Goral, 2008; Blair et al., 2007). For example, it can be semantic losses such as naming the wrong fruit, or saying fruit and ultimately not knowing what the item is in front of them (Kempler & Goral, 2008). Further language impairments are often noticeable as a hierarchical decline such as grammar loss, forming sentences and complete loss of coherent conversation (Kempler & Goral, 2008; Emery, 2000). The subtle changes in memory, language and reasoning may be only noticeable to caregivers as symptoms of dementia progress (Shinagawa et al., 2006). This is echoed in our findings where caregivers shared the gradual changes in their loved ones, where initially the care recipient was able to make appropriate sentences which then changed to gibberish and confusion. Hence, our findings reinforce the need to assess cognition when evaluating dementia progression.

Lastly, a range of factors extrinsic to the person living with dementia influences caregivers' decision-making when seeking treatment or alternative care options. This decision-making is often made when the care-recipients' dementia worsens (difficulties with everyday activities, changes in mood and behaviour, cognitive difficulties) resulting in changes in caregivers' duties. In our study, caregivers described the cost of long-term care homes, treatment, and in-home care as being a major factor that influenced decisions about whether they can reduce some of their

caregiving tasks. A study by Adlimoghaddam and colleagues performed in Canada which explored the current and future economic burden of dementia found that the combined cost of medical (i.e., medication, long-term care healthcare providers, physician, administrative costs) and indirect expenses (i.e., loss of wages in both caregiver and care recipient, out of pocket expenses, over the counter medications) was 33 billion dollars annually (Adlimoghaddam et al., 2018). Other studies had similar findings, where if caregivers had more money, they could provide better care, hire more people, or move them to alternative care facilities (Vellone et al., 2012; Prorok et al., 2015; Smith et al., 2001).

In our study, caregivers also reported communication barriers between the caregiver and healthcare provider. They discussed how the healthcare workers would not always include the care recipient in conversations or would make assumptions about their dementia progression. Similar to our findings, previous studies have reported healthcare providers neglecting the care-recipient by stigmatizing against them or not treating them as an individual (Prorok et al., 2015; Livingston et al., 2010; VandeWeerd et al., 2006).

Outcome measures commonly used to assess treatment impact in clinical trials include cognitive measures such as the Mini-Mental State Examination (MMSE) and Montreal Cognitive Assessment (MoCA) (Garg et al., 2022; Harrison et al., 2016; Webster et al., 2017). However, our findings demonstrated that, in addition to cognition, it is important to look at other outcomes such as changes in mobility, feeding, social interactions, emotions, as well as extrinsic factors when evaluating treatment impact or changes in dementia status. The results from this study can help inform clinicians and researchers on what outcomes are important to assess in clinical

practice and research. Our results highlight that health-related quality of life measures that were developed through the perspective of caregivers such as the Alzheimer Disease Related Quality of Life (ADRQL) (Ready & Ott, 2003) and the Quality of Life in Alzheimer's Disease (QOL-AD) (Logsdon et al., 1999) may be important to include as outcome measures in the evaluation of treatment impact or disease progression. For example, the ADRQL has five domains that include social interactions, awareness, feelings and mood, enjoyment of activities and response to surrounding (Rabins et al., 1999). The QOL-AD has 13 items that measure physical health, mood, memory, and ability to do chores around the house (Logsdon et al., 1999). Such health-related quality of life measures include many of the domains that were reported by caregivers in our study, highlighting the importance of including outcomes beyond cognition in clinical trials.

A strength of this study was that a diverse sample from across Canada and from various provinces were recruited. We had at least one participant from each province. The caregivers who were part of the listening sessions had different experiences, backgrounds, and number of years they provided care. Additional strengths of the study included its methodological rigor. Analysis was done by two reviewers, and they collaborated on the interpretation of the listening sessions.

Some limitations are present within the study. This study was conducted towards the end of pandemic in late 2022 and early 2023 where caregivers returned to normal caregiving duties. The pandemic may have affected caregivers' duties and resources that they used pre-pandemic to aid the care recipients; disrupting the typical routine caregivers would have with the care recipients. However, the listening session questions were broad and incorporated their experiences from

over the years, and not just in recent years. The participants did not mention specific pandemic related changes to their caregiving duties. Although we had a diverse population from the provinces, we were unable to acquire participants from any of the Northwest Territories, Nunavut and Yukon. Certain populations were also hard to reach (i.e., Indigenous, newcomers). This may be due to the locations we recruited participants from. It would be beneficial to include other populations in future studies and increase the diversity of caregiver perceptions because of cultural practices and norms when providing care. Furthermore, although during the listening sessions, we asked about impact of treatment, there was less dialogue around this. This may be due to limited treatment options that are effective in helping people living with dementia (Lyketsos et al., 2007; Achterberg et al., 2013; Ringman et al., 2019). The themes related more towards assessment of dementia progression and decision making in seeking alternate care. Last, our sample may not be representative of all caregivers in Canada. The participants in this study were highly educated, where 60% of them had a bachelor's degree. Furthermore, the average age of our participants was 39.9 years old, which is younger than most caregivers in Canada. It is estimated that in Canada 56% of caregivers are 45 years and older, and only 14% are between 35 to 45 (Alzheimer's Society, 2022).

Conclusion

This study allowed us to identify key aspects of symptoms and behaviours of people with dementia from the perspectives of caregivers who are implicated in daily and personal care for their family members. The findings show the importance of including the voices of caregivers because of the level of care they provide and the vast amount of information they know about the care recipient. The information may assist in explaining differences in individual symptoms and

behaviours for people with dementia and provide new perspectives on decisions for alternative care. With limited dialogue surrounding treatment impact, it will be important for future studies to assess this when more dementia treatment options become available. This can help clinicians, researchers, and the community to better understand what is needed to help improve the quality of life of people living with dementia.

Ethics

This study was approved by Hamilton Integrated Research Ethics Board (Project # 14086).

Author Contribution

AK designed the overall study. FC and EN contributed to data collection. FC transcribed and error checked the transcripts. FC and EN analyzed the data, in consultation with AK. FC prepared the initial draft of the manuscript. All authors edited the manuscript and approved the final version.

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Conflict of Interest

No conflict of interests

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CHAPTER 3
Measurement Properties of Health-Related Quality of Life Outcome Measures in People Living with Dementia: A Systematic Review

Measurement Properties of Health-Related Quality of Life Outcome Measures in People Living with Dementia: A Systematic Review

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Abstract

Introduction: Quality of Life (QOL) and Health related quality of life (HRQOL) encompasses many facets of a person's life including their emotional, social, and physical wellbeing, which can affect an individual's outlook on life, especially for progressive health conditions such as dementia. Instruments capturing QOL and HRQOL have been developed for the general population and specific to dementia. However, before using such measures in clinical practice and research, it is important to provide appropriate evidence on their measurement properties. The aim of this study was to conduct a systematic review to identify the psychometric properties of both generic and disease-specific QOL and HRQOL measures that are used in community-dwelling adults with dementia.

Methods: COsensus-based Standards for the selection of health Measurement Instruments (COSMIN) guidelines were used to identify full-text English articles that used QOL or HRQOL measures in community-dwelling individuals living with dementia. We used Ovid MEDLINE, EMBASE, CINAHL, and PsychInfo for literature published up to June 2022. In line with COSMIN guidelines, we extracted data on structural validity, internal consistency, reliability, construct validity and responsiveness. Risk of bias and Grading of Recommendations Assessment, Development, and Evaluation (GRADE) was used to assess the quality of evidence.

Results: Of 2447 studies, 38 were included in the study, which captured a total sample of 9618 people with dementia and their caregivers. The studies covered eight dementia specific measures and four generic measures. The Quality of Life-Alzheimer's Disease (QOL-AD), Dementia Quality of Life (DEMQOL) and Bath Assessment of Subjective Quality of Life in Dementia (BASQID) had sufficient internal consistency and test-retest reliability. Most of the measures had insufficient convergent validity except for the BASQID . Responsiveness was sufficient for

Health Utilities Index 2 and 3 (HUI2 and HUI3), but insufficient for BASQID, Alzheimer Disease Related Quality of Life (ADRQL) and EQ-5D-3L. Quality of evidence for the measures ranged from moderate to very low for most measurement properties.

Conclusion: While many forms of measurement tools may exist, it is important to design robust and scientifically sound studies to ensure psychometric properties are evaluated with high quality evidence.

Introduction

The global prevalence of dementia is over 55 million and every year there are 10 million new cases (WHO, 2023). It is the seventh leading cause of death amongst older adults (WHO, 2023). In Canada, there are over 500,000 people living with dementia (Alzheimer's Society, 2020) and of these, 61% are community-dwelling individuals who live at home (CIHI, 2018). Common symptoms of dementia include memory loss, language deficits, and psychological changes (Cerejeira et al., 2012; Garcia-Alberca et al., 2010). Such symptoms can have a significant impact on the quality of life (QOL) and health-related quality of life (HRQOL) of people living with dementia (Whitehouse et al., 2003; Selwood et al., 2005; Burks et al., 2021).

QOL and HRQOL encompasses the well-being of an individual by looking at various positive and negative facets of their lives; this includes behaviours, physical health, and psychological health (Teoli & Bhardwaj, 2023). Assessing HRQOL in people living with dementia is an important outcome when evaluating its progression and the impact of treatment (Naglie, 2007; Van de Beek et al., 2019). HRQOL can be measured using generic measures such as the EuroQOL-5D (EQ-5D), Short Form Survey-36 (SF-36) and Health Utility Index (HUI) (Hounsome et al., 2011). Although generic measures are regularly used to assess the HRQOL of people living with dementia, there are also measures specifically for this population. Examples of such dementia-specific measures include the Quality of Life-Alzheimer's Disease (QOL-AD), Dementia Quality of Life (DEMQOL) and Dementia Quality of Life Instrument (D-QOL) (Ready & Ott, 2003). These measures have domains and items that capture the different facets of HRQOL affected in people living with dementia (Ready & Ott, 2003). However, before using generic or dementia-specific measures of HRQOL in clinical practice and research, it is

important to provide appropriate evidence on their measurement properties (reliability, validity, and responsiveness). While there are a number of reviews that have explored the measurement properties of different HRQOL measures in people with dementia (PWD) (Ettema et al., 2005; Perales et al., 2013; Bowling et al., 2015), these reviews were completed approximately 10 years ago or longer. Furthermore, some of the reviews were narrative reviews (Bowling et al., 2015) or included only dementia-specific measures (Perales et al., 2013). The reviews included PWD living in the community and in care homes. None of the reviews followed the COsensus-based Standards for the selection of health Measurement Instruments (COSMIN) guideline to report psychometric properties or used COSMIN's comprehensive search strategies (Ettema et al., 2005; Perales et al., 2013; Bowling et al., 2015).

Therefore, the purpose of this systematic review was to synthesize the psychometric properties of generic and disease-specific QOL and HRQOL measures in community-dwelling people with dementia.

Methods

The protocol for this systematic review is registered in the International Prospective Register of Systematic Reviews- PROSPERO (Registration number: CRD42022344364). The study design was created based on the COSMIN guideline for systematic reviews of patient-reported outcome measures and the PRISMA 2020 Checklist (Prinsen et al., 2018; Mokkink et al., 2018 and Page et al., 2021). The completed PRISMA Checklist is available in Appendix A.

Inclusion and exclusion criteria

Inclusion criteria were:

1. The study included adults over 18 years old living in the community, and who had a clinical diagnosis of dementia, Alzheimer's Disease or Early Onset Dementia. For studies with mixed samples, the majority of participants (at least 80%) would need to have a diagnosis of dementia.
2. The outcome measure under study was assessing QOL or HRQOL; and
3. The purpose of the study was to assess one or more measurement properties.

Exclusion criteria were:

1. Reviews, grey literature (abstracts, conferences);
2. Non-English papers; and
3. The sample included participants living in care homes or institutionalized settings. If mixed, 80% of the sample had to live in the community.

Search strategy

A search strategy was developed with the support of an academic librarian at McMaster University with expertise in systematic reviews. The final search strategy was reviewed by the librarian and research team. Search terms included dementia, Alzheimer's disease, early onset dementia, and a comprehensive list of HRQOL measures. The search filter for measurement properties developed by Terwee and colleagues (Terwee et al., 2009) was used in the search. Four electronic databases, specifically Ovid MEDLINE (1946- present), EMBASE (1947- present), CINAHL (1981- present) and PsycInfo (1806- present), were searched to access studies

published until June 2022. The full search strategy for the selected databases can be found in Appendix B.

Study selection

All papers were exported to Covidence for removal of duplicates. Covidence is a systematic review tool that helps with removing duplicates, allows for simultaneous reviewing by different users and flags any conflicts (COVIDENCE, 2023). Three reviewers (FC, AR, TM) first independently screened the title and abstracts, and then reviewed the full text articles within Covidence. Each abstract and full text was screened by two reviewers. Data extraction on study characteristics and Risk of Bias (ROB) assessment was completed by two reviewers (EN and FC). Hypothesis testing and Grading of Recommendations Assessment, Development, and Evaluation (GRADE) rating were conducted by one reviewer (EN or FC) and reviewed by a second reviewer (FC or AK). Any discrepancies or conflicts in ratings were resolved through team discussions.

Data extraction

A data extraction form was created for the review. Data on study characteristics, which included publication year, country, sample size, gender, age, and disease severity, was extracted. Data were also extracted on the outcome measure used and the following measurement properties and they were used in the study:

(1) Structural validity, how well the scores of a PROM accurately represent the dimensionality of the construct to be measured (Mokkink et al., 2010).

(2) Internal consistency, which is the relationship between different items in a test. This is measured by Cronbach's alpha (*a)* (Prinsen et al., 2018).

(3) Reliability, which evaluates the ability of a measure to produce the same results irrespective of the number of trials or raters.

a. Test-retest reliability is when scores of a measure is tested twice to verify its stability over time (Guttman, 1945 and Mokkink et al., 2010).
b. Inter-rater reliability refers to the extent to which a measurement exhibits consistency when assessed by two different raters during the same instance (Mokkink et al., 2010).

(4) Construct validity:

a. Convergent validity, which assesses the relationship between two measures on a construct (Carlson & Herdman, 2010; Mokkink et al., 2010; Chin & Yao, 2014).

b. Known-groups validity, which evaluates how well a measure can discriminate between two groups that differ (Finch et al., 2002; Davidson, 2014).

(5) Responsiveness evaluates the ability of an instrument to measure change over time pertaining to the constructs it intends to measure (Mokkink et al., 2010).

Risk of bias (ROB) assessment

A ROB assessment for each study was performed using COSMIN's ROB checklist (Mokkink et al., 2018a; Mokkink et al., 2018b). The ROB checklist has 10 boxes with each box representing a measurement property. The scoring is on a 4-point rating scale that goes from very good, adequate, doubtful, to inadequate (Mokkink et al., 2018a). The final score per box is determined by taking the lowest rating.

Data synthesis

Psychometric properties were assessed using COSMIN's criteria for good measurement properties (Mokkink et al., 2018b). Each of the measurement properties had hypotheses formed by the team to ensure results from the studies can be compared against each other and assessed in the appropriate manner. For structural validity, hypothesis for confirmatory factor analysis was a comparative fit index (CFI) or Tucker Lewis Index (TLI) or comparable measure >0.95 or root mean square error (RMSEA) <0.08. If Loevinger's H coefficient of scalability was used for structural validity, the hypothesis generated for this was > 0.3. For internal consistency, we hypothesized Cronbach's *a* greater than or equal to (≥) 0.70. For reliability, we hypothesized intra-class correlation coefficient (ICC) or weighted Kappa values of ≥ 0.70. For convergent validity we hypothesized absolute correlations ≥ 0.6 with instruments measuring similar constructs (e.g., comparing QOL-AD against another QOL measure); correlations greater than or equal to (≥) 0.3 but less than (<) 0.6 with instruments measuring related but dissimilar constructs (e.g., QOL-AD against an IADL measure); and < 0.3 with instruments measuring unrelated constructs (e.g., QOL-AD against the MMSE, see Appendix C). For known-groups validity, we hypothesized a p-value <0.05 between different subgroups. For responsiveness, we hypothesized an effect size of >0.5 or an area under the Receiver Operating Characteristic (ROC) curve of ≥ 0.70 in those who reported moderate or large change. If effect size values could not be calculated, we hypothesized a statistically significant difference at the 5% level in people who reported some change in their health status.

All the data were pooled together per measure and per measurement property. They were either rated as sufficient (+), insufficient (-) or inconsistent (±) (Mokkink et al., 2018b). The criteria

were sufficient (at least 75% of findings agree with hypotheses), insufficient (at least 75% of findings do not agree with hypotheses) and inconsistent (if mixed results with sufficient and insufficient <75%) (Mokkink et al., 2018b).

Overall quality assessment

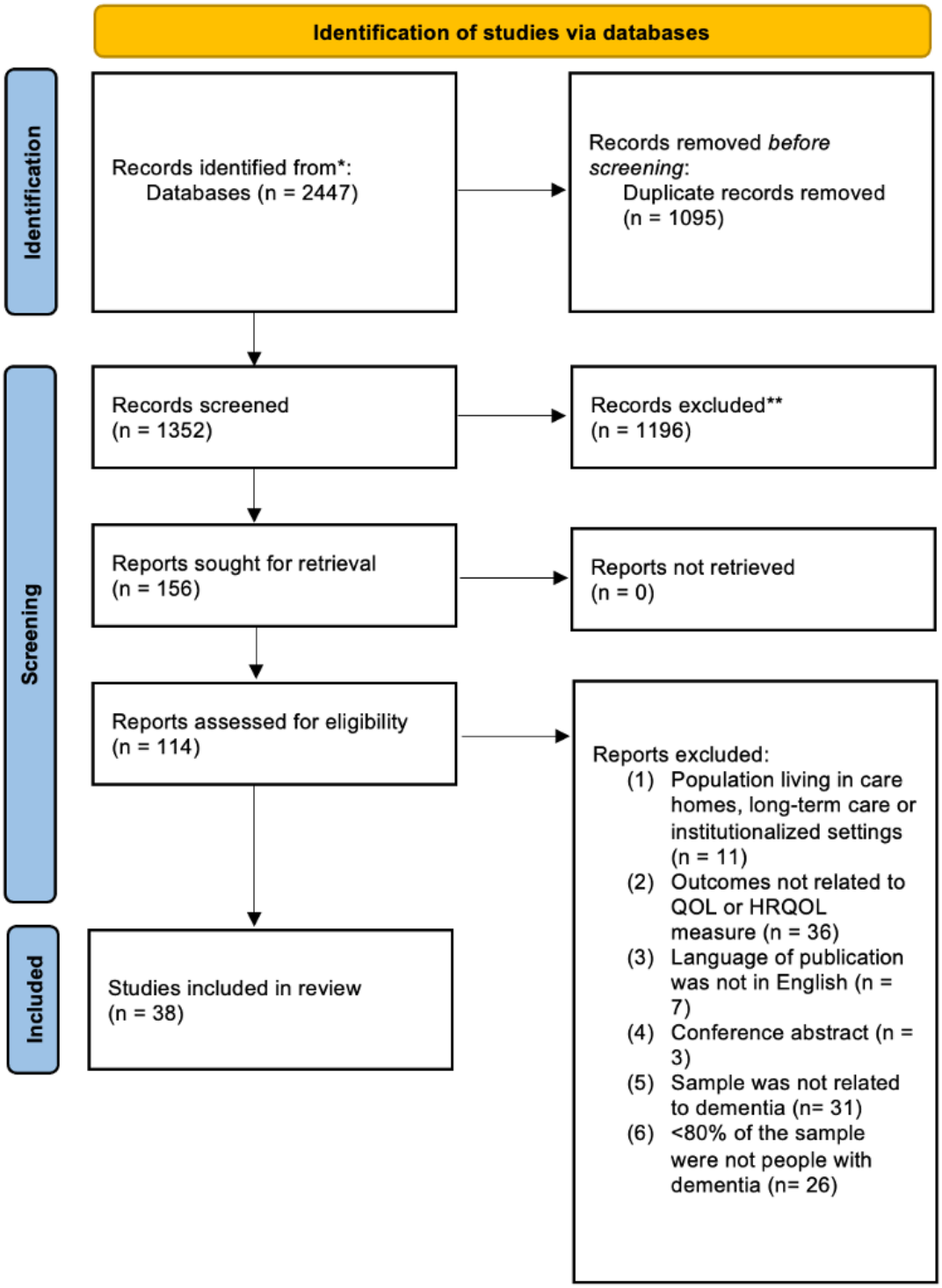
For each measure, overall quality was evaluated using the modified GRADE approach using three criteria: risk of bias, inconsistency, and imprecision (Appendix D) (Mokkink et al., 2018b, Schunemann et al., 2013 and Guyatt et al., 2011). Indirectness was not assessed as the study population was defined at the outset of the review (in the study inclusion criteria).

Results

Search results and study selection process

From the four databases, a total of 2447 studies were selected and uploaded to Covidence. One thousand and ninety-five studies were duplicates and were automatically removed by Covidence. One thousand three hundred and fifty-two went through title and abstract screening, yielding 156 records for full-text screening. One hundred and fourteen studies were removed due to the following reasons: (1) population living in care homes, long-term care or institutionalized settings [n=11]; (2) outcomes not a QOL or HRQOL measure [n=36]; (3) language of publication was not English [n=7]; (4) conference abstract [n=3]; (5) sample was not person's with dementia or Alzheimer's Disease [n=31]; and (6) <80% of the sample were people with dementia [n=26]. Figure 1 portrays the process of study selection using the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) In total, 38 studies were identified for data extraction.

Figure 1: PRISMA flow diagram



For dementia specific measures: ten studies (Akpinar & Küçükgüçlü., 2012; Hoe et al., 2005; Kisvetrova et al., 2018; Logsdon et al., 1999; Matsui et al. 2006; Novelli et al., 2010; Stypa et al., 2020; Wolak et al., 2009; Yap et al., 2008; Yu et al., 2013) examined the Quality of Life in Alzheimer's Disease (QOL-AD) measure, six studies (Chua et al., 2016; Lucas-Carrasco et al., 2011; Niikawa et al., 2019; Schwab et al., 2018; Smith et al., 2005; Smith et al., 2007) examined the Dementia Quality of Life (DEMQOL) measure, five studies (Brod et al., 1999; Karim et al., 2007; Lucas-Carrasco et al., 2011b; Voigt-Radloff et al., 2012; Wolak et al., 2010) examined the Dementia quality of life instrument (DQOL), two studies (Trigg et al., 2007a; Trigg et al., 2007b) examined the Bath Assessment of Subjective Quality of Life in Dementia (BASQID), two studies (Ready et al., 2002; Lucas-Carrasco et al., 2013) examined the Cornell-Brown Scale (CBS), one study (Kasper et al., 2009) examined the Alzheimer's Disease-Related Quality of Life (ADRQL), one study (Yamamoto-Mitani et al., 2002) examined the Quality of Life Dementia Japanese (QLDJ) and one study (Selai et al., 2001) examined the Quality of Life Assessment Schedule (QOLAS).

For generic QOL measures: seven studies (Coucill et al., 2001; Karlawish et al., 2008a; Karlawish et al., 2008b; Kunz, 2010; Michalowsky et al., 2020; Michalowsky et al., 2021; Orgeta et al., 2015) examined the EuroQOL 5 Dimensions (EQ-5D-3L and EQ-5D-5L), three studies (Karlawish et al., 2008a; Karlawish et al., 2008b; Kavirajan et al., 2009) examined the Health Utility Index (HUI), one study (Geschke et al., 2013) examined the Short Form-36 items (SF-36) and one study (Lucas-Carrasco et al., 2011a) examined the World Health Organization Quality of Life (WHOQOL).

Study characteristics

A total of 9,618 people with dementia (PWD) and dementia caregivers were included from all the studies. Sample size in individual studies ranged from 30 to 498. Disease severity ranged from early stage diagnosed dementia, mild/moderate dementia (MMSE score <25, CDR score 1-2, MoCA score 10-17) to severe dementia (MMSE score <10, CDR score 4-5, MoCA score <10) in the studies. Table 1 provides an overview of study characteristics such as country of origin, participants, gender, disease severity, age, outcome measure and psychometric properties of each study.

Measurement property results

Tables 2 to 7 present a summary of each of the psychometric properties for each measure with their ROB, overall rating, and quality of evidence (GRADE). Table 8 presents a summary of the results (psychometric properties and GRADE) across all measures.

Dementia-specific measures

Structural Validity

Findings for structural validity are reported in Table 2. Only two dementia-specific (QOL-AD and DEMQOL) measures were assessed for structural validity. The QOL-AD was reported to be a unidimensional scale and hence it was not assessed for risk of bias or GRADE. Two studies reported on the structural validity of the DEMQOL, which had sufficient structural validity, very good rating for ROB, and high quality of evidence.

Internal consistency

Details for internal consistency for each dementia-specific measure is presented in Table 3. From the nine disease-specific measures, internal consistency was reported on seven measures (QOL-AD, DEMQOL, DQOL, CBS, BASQID, ADRQL and QOLAS), (Akpinar & Küçükgüçlü, 2012; Hoe et al., 2005; Kisvetrova et al., 2018; Logsdon et al., 1999; Matsui et al., 2006; Novelli et al., 2010; Stypa et al., 2020; Wolak et al., 2009; Yap et al., 2008; Yu et al., 2013; Cua et al., 2016; Lucas-Carrasco et al., 2010; Niikawa et al., 2019; Schwab et al., 2018; Smith et al., 2005;Smith et al., 2007; Brod et al., 1999; Karim et al., 2008; Lucas-Carrasco et al., 2011b; Voigt-Radloff et al., 2012; Wolak et al., 2010; Lucas-Carrasco et al., 2013; Ready et al., 2022; Trigg et al., 2007a; Trigg et al., 2007b; Kasper et al., 2009; Selai et al., 2001). Internal consistency results ranged from 0.66 to 0.87. The QOL-AD, DEMQOL, CBS, BASQID, and QOLAS demonstrated sufficient internal consistency with Cronbach's α being greater than 0.7 (for at least 75% of hypotheses). However, the DQOL and the ADRQL had inconsistent results for internal consistency, as some of subscales do not exceed the cut point of 0.70 for internal consistency with limited explanation why that is the case. Quality of evidence for measures assessing internal consistency (QOL-AD, DEMQOL, DQOL, CBS, BASQID and ADRQL) was graded as moderate.

Reliability

Details for reliability for each dementia-specific measure is presented in Table 4. From the nine disease-specific measures, for five measures (QOL-AD, DEMQOL, DQOL, BASQID and QLDJ), reliability was reported in at least one study (Akpinar & Küçükgüçlü, 2012; Kisvetrova et al., 2018; Logsdon et al.,1999; Matwsui et al., 2006; Stypa et al., 2020; Wolak et al.,2009; Yap

et al., 2008; Yu et al., 2013; Lucas-Carrasco et al., 2010; Niikawa et al., 2019; Smith et al., 2005; Smith et al., 2007; Brod et al., 1999; Karim et al., 2008; Lucas-Carrasco et al., 2011b; Wolak et al., 2010; Trigg et al., 2007a; Trigg et al., 2007b; Yamamoto-Mitani et al., 2002) with interval periods ranging from 1 day to 12 months. Test-retest reliability results were reported using ICC which ranged from 0.64 to 0.97 across the measures (Akpinar & Küçükgüçlü, 2012; Logsdon et al.,1999; Matwsui et al., 2006; Stypa et al., 2020; Wolak et al.,2009; Yap et al., 2008; Yu et al., 2013; Lucas-Carrasco et al., 2010; Niikawa et al., 2019; Smithet al., 2005; Smith et al., 2007; Brod et al., 1999; Karim et al., 2008; Lucas-Carrasco et al., 2011b; Wolak et al., 2010; Trigg et al., 2007a; Trigg et al., 2007b).

QOL-AD, DEMQOL, BASQID and QLDJ demonstrated sufficient test-retest reliability with ICC being greater than 0.7. However, DQOL had inconsistent results for test-rest reliability, with subscales that did not pass ICC hypothesis and limited explanation for low scores, resulting in an inconsistency rating. QOL-AD had moderate quality of evidence, the DEMQOL, DQOL and QLDJ whereas BASQID had very low quality of evidence. Inter-rater reliability was only assessed for the QOL-AD and QLDJ (Kisvetrová et al,2018; Yamamoto-Mitani et al., 2002). QOL-AD had insufficient overall rating and moderate quality of evidence whereas QLDJ had sufficient overall rating however low quality of evidence.

Convergent validity

Details for convergent validity for each dementia-specific measure is presented in Table 5. Seven (QOL-AD, DEMQOL, DQOL, CBS, BASQID, ADRQL and QOLAS) of the nine dementia-specific measures reported convergent validity in at least one study (Hoe et al., 2005; Kisvetrova

et al., 2018; Logsdon et al.,1999; Matsui et al., 2006; Novelli et al., 2010; Stypa et al., 2020; Wolak et al., 2009; Yap et al., 2008; Yu et al., 2013; Lucas-Carrasco et al., 2010; Niikawa et al., 2019; Smith et al., 2005; Smith et al., 2007; Brod et al.,1999; Lucas-Carrasco et al., 2011b; Voigt-Radloff, 2012; Wolak et al., 2010; Geschke et al., 2013; Lucas-Carrasco et al., 2013; Ready et al.,2002; Trigg et al., 2007a; Kasper et al.,2009; Selai et al., 2001). Each measure was compared with commonly used measures such as the Mini Mental State Examination (MMSE), Activities Daily Living (ADL) composite, Geriatric Depression Scale (GDS), and World Health Organization Quality of Life- Brief (WHOQOL-BREF). Only BASQID had sufficient result (at least 75% of hypotheses were met) whereas QOL-AD, DEMQOL, DQOL, CBS, ADRQL and QOLAS had insufficient result. However, QOL-AD, DEMQOL, DQOL and BASQID demonstrated had high quality of evidence for convergent validity. ADRQL demonstrated moderate quality of evidence whereas CBS and QOLAS had low quality of evidence.

Known-groups validity

Known-groups validity was assessed for four dementia-specific measures: the DEMQOL, DQOL, CBS and ADRQL (Lucas-Carrasco et al., 2010; Karim et al., 2007; Lucas-Carrasco et al., 2011b; Wolak et al., 2010; Lucas-Carrasco et al.,2013; Kasper et al., 2009). Details for known-groups validity are presented in Table 6. Only the ADRQL demonstrated sufficient known groups validity (at least 75% of hypotheses were met). The DEMQOL, DQOL and CBS had insufficient results. DEMQOL and ADRQL had moderate quality of evidence, DQOL and CBS had low quality of evidence.

Responsiveness

Detailed findings for responsiveness are presented in Table 7 where only two dementia-specific measures, the ADRQL and BASQID, were evaluated for responsiveness (Kasper et al., 2009; Trigg et al., 2007a). The time interval for assessment ranged from 3 months to 1 year. Overall ratings were insufficient for both measures. The ROB was adequate for BASQID and inadequate for ADRQL, and both measures had very low quality of evidence. COSMIN guidelines suggest using a global rating scale or another measure that is commonly used in the same population when assessing responsiveness (Mokkink et al., 2010).

Generic measures

Internal consistency

Details for internal consistency for each specific measure is presented in Table 3. Internal consistency was reported for two generic measures, the EQ-5D-3L, SF-36 and WHOQOL (Michalowsky et al., 2020; Geschke et al., 2013; Lucas-Carrasco et al, 2011a). All three measures demonstrated sufficient internal consistency with Cronbach's α being greater than 0.7 (for at least 75% of hypotheses). ROB rating for the EQ-5D-3L and SF-36 was very good whereas it was adequate for WHOQOL. EQ-5D-3L had very good quality of evidence whereas SF-36 and WHOQOL had moderate quality of evidence.

Reliability

Details for reliability for each generic measure is presented in Table 4. Three measures (EQ-5D, HUI2 and WHOQOL) had at least one study that evaluated test-rest reliability and/or inter-rater

reliability (Coucill et al., 2001; Karlawish et al., 2008a; Karlawish et al., 2008b; Kunz et al., 2010; Orgeta et al., 2015;Lucas-Carrasco et al., 2011a). Time interval for test-retest reliability ranged from 3 days to 2 weeks. Test-retest reliability was reported using ICC which ranged from 0.51 to 0.70 across the measures (Karlawish et al., 2008a; Karlawish et al., 2008b; Lucas-Carrasco et al., 2011a). Inter-rater reliability was reported using weighted kappa which ranged from 0.09 to 0.49 (Kunz et al., 2010; Orgeta et al., 2015). All three measures (EQ-5D-3L, HUI2 and WHOQOL) demonstrated insufficient reliability, as the majority of the results had ICC values less than 0.7. The ROB for the EQ-5D and HUI2 was inadequate whereas for WHOQOL it was adequate. EQ-5D had low quality of evidence whereas HUI2 and WHOQOL had very low quality of evidence.

Convergent validity

Details for convergent validity for each measure is presented in Table 5. Out of the generic measures, the EQ-5D-3L, EQ-5D-5L, SF-36, HUI2, HUI3 and WHOQOL had at least one study evaluating convergent validity (Kunz et al., 2010; Michalowsky et al., 2020; Orgeta et al., 2015; Michalowsky et al., 2021; Geschke et al.,2013; Karlawish et al., 2008a; Karlawish et al., 2008b; Kavirajan et al., 2009; Lucas-Carrasco et al., 2011a). Each measure was compared with commonly used measures such as the MMSE, QOL-AD, GDS, SF-12, CDR and others.

Both EQ-5D versions, SF-36, both HUI versions and WHOQOL had insufficient convergent validity. ROB ratings for EQ-5D-3L were 'very good' to 'adequate', and EQ-5D-5L was rated 'adequate'. SF-36 was rated as mostly very good and for HUI2 it was mostly very good and for HUI3 it was doubtful whereas for WHOQOL it was adequate. EQ-5D-3L had high quality of

evidence, HUI2, SF-36 and WHOQOL had moderate quality of evidence whereas EQ-5D-5L and HUI3 had low quality of evidence.

Known-groups validity

The EQ-5D-3L, EQ-5D-5L and WHOQOL had at least one study that evaluated known-groups validity (Michalowsky et al., 2020; Michalowsky et al., 2021; Lucas-Carrasco et al., 2011a). Details for known-groups validity is presented in Table 6. All three measures (EQ-5D-3L, EQ-5D-5L and WHOQOL) had insufficient results for known-groups validity. The ROB for EQ-5D-3L and EQ-5D-5L were mostly adequate whereas it was inadequate for WHOQOL. The EQ-5D-3L and EQ-5D-5L had moderate quality of evidence, and the WHOQOL had very low quality of evidence.

Responsiveness

Detailed findings for responsiveness are presented in Table 7. Only the EQ-5D-3L, HUI2 and HUI3 had responsiveness evaluated (Kunz et al., 2010; Kavirajan et al., 2009). Time interval between assessments was 1 year for the measures with effect sizes ranging from 0.01 to 0.41 for the EQ-5D-3L, -0.78 to 0.04 for HUI2, and -0.67 to 0.06 for HUI3. The ROB for the HUI versions was adequate whereas for EQ-5D-3L was doubtful. EQ-5D-3L had insufficient responsiveness whereas HUI versions both had sufficient responsiveness. EQ-5D-3L had low overall quality of evidence whereas HUI2 and HUI3 had moderate quality of evidence.

Discussion

This study aimed to synthesize the psychometric properties of QOL and HRQOL measures in community dwelling people with dementia. A range of QOL and HRQOL measures emerged from the review and were divided between dementia-specific measures and generic measures. Thirty-eight studies were identified that assessed nine dementia-specific measures and four generic measures. Overall, results showed that most dementia-specific measures demonstrated sufficient measurement properties for internal consistency and reliability, inconsistent properties for known-groups validity, and insufficient measurement properties for convergent validity and responsiveness. For generic measures, measurement properties were sufficient for internal consistency, insufficient for reliability, known-groups validity, convergent validity, and mixed reviews for responsiveness. The quality of evidence using GRADE was mostly 'moderate,' 'low' or 'very low' for both dementia-specific and generic measures. This review stands out for its contemporary inclusion of participants of all ages, encompassing community-dwelling PWD with severity ranging from those with early onset dementia to severe dementia. It ensures comprehensive coverage and accurate reporting of measurement properties by following COSMIN guidelines and utilizing a precise search strategy. Notably, this review includes generic QOL and HRQOL measures, acknowledging their relevance to clinicians, researchers, and caregivers alongside dementia-specific instruments.

Based on the findings from this review, clinicians and researchers may use QOL-AD from the dementia-specific measure for individuals with dementia living in the community. QOL-AD had the most studies (n=10) for this population as well as consistent moderate quality of evidence in internal consistency and reliability. However, it should be noted that known-groups validity and

responsiveness were not evaluated for QOL-AD. Known-groups validity is important to assess to determine whether the measure can distinguish between groups (Davidson, 2014). Similarly, responsiveness is important to see whether the measure can effectively capture the changes in different quality of life domains over time (Mokkink et al., 2010). QOL-AD is one of the mostly commonly used measures among PWD in the community and other investigators have previously recommended its use (Bowling et al., 2015; Burks et al., 2021). It can be used as a self-report tool as well as a proxy-report tool for dementia individuals in the community (Logsdon et al., 1999). During the development of QOL-AD, it included individuals with AD and their caregivers (Logsdon et al., 1999).

From the other dementia-specific measures, the DEMQOL had five psychometric properties assessed by at least one study. DEMQOL's structural validity had sufficient and high quality of evidence, convergent validity also had high quality of evidence but with insufficient results. Internal consistency demonstrated moderate quality of evidence. Although the DEMQOL demonstrated adequate reliability, the quality of evidence was low. While the evidence quality varies, this measure exhibits potential for application in both clinical practice and future research.

It is essential that measures possess satisfactory psychometric properties in both clinical and research environments to facilitate informed decision-making by individuals within the circle of care. (Hughes et al., 2021; Banerjee et al., 2009 and Higginson & Carr, 2001). Informed decisions can be made together with care recipients and caregivers with conversations including treatment plans and goals, evaluating hidden problems and overall improvement (Higginson and

Carr, 2001). However, it is important to know whether the QOL and HRQOL measures clinicians and researchers are utilizing have been developed for people living with dementia in the community. For instance, a measure that was made for dementia individuals living in a nursing home may not be appropriate for someone who is living in the community (Hughes et al., 2021 and Banerjee et al., 2009). Hence, this review specifically focused on individuals with dementia living in the community. When using self-report or caregiver reported measures, it may give individuals living with dementia a positive outlook on their life and may show their caregivers what they would like to improve on (Thorgrimsen et al., 2003). Similarly, it may help finding solutions that are cost-effective through early detection of dementia progression or having a prevention plan (Ready & Ott, 2003; Jones et al., 2012 and Comans et al., 2020).

Limitation

Although this study was a comprehensive review of various psychometric properties, content validity was not assessed because it was beyond the scope of this review and future reviews should examine this. Only English written papers were included. There were papers that were published in Korean, German and Chinese but were not included. Lastly, while we wanted to include cross-cultural validity, studies only translated from English to a different language, and did not examine measurement invariance (Akpinar & Küçükgüçlü's, 2012; Kisvetrova et al., 2018; Lucas-Carrasco et al., 2011; Lucas-Carrasco et al., 2010; Matsui et al., 2006; Niikawa et al., 2019; Wolak et al., 2010; Yu et al., 2013). According to COSMIN guidelines, cross-cultural validity is whether measures are similar in different languages, gender or ethnicity (Mokkink et al., 2010).

This systematic review corroborates findings from other published reviews where they highlighted the need for further psychometric analysis and using dementia-specific measures (Ettema et al., 2005; Perales et al., 2013 and Bowling et al., 2015). Future studies are needed to rigorously evaluate the psychometric properties for all the measures especially those that have not been evaluated among PWD living in the community. Based on the results of this review, there is a need for further development of dementia-specific HRQOL measures that have high quality of evidence, consistent psychometric properties and are useful to individuals living with dementia in the community as well as their caregivers who can evaluate HRQOL as a proxy.

Conclusion

To our knowledge, this is the first systematic review to explore QOL and HRQOL measures in PWD living in the community using rigorous methods and reporting strategies. Over the past decade, there have been new studies evaluating psychometric properties and developing new measures for PWD. However, based on the diverse quality of evidence presented in this review some measures have high quality of evidence for specific psychometric properties while others have low quality of evidence. This suggests that more research is needed in evaluating the psychometric properties of HRQOL measures used in people living with dementia in the community.

Author Contribution

All authors (FC, EN, AR, TM, JST, AK) contributed to the study's conception and/or design. Screening of articles and quality assessments were performed by FC, EN, AR and TM. The first draft of the manuscript was written by FC. Preliminary edits were made by FC, EN and AK. All

authors commented on previous versions of the manuscript. All authors read and approved the final manuscript, and FC is the guarantor of the paper. Authors did not have any conflict of interests.

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AppendixA:PRISMA2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a literature review.	Page 1
ABSTRACT			
Abstract	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings. See the PRISMA 2020 for Abstracts checklist for the complete list.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge, i.e., what is already known about your topic.	Page 3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Page 3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses with study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Page 3-4
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 4
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Appendix B
Selection process	8	State the process for selecting studies (i.e., screening, eligibility). Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 5
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 5

Adapted From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71 *Adapted From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

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Section and Topic	Item #	Checklist item	Location where item is reported
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Appendix A
Study characteristics	17	Cite each included study and present its characteristics (e.g., study size, PICOS, follow-up period).	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Page 6
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Table 1
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 17- 20
	23b	Discuss any limitations of the evidence included in the review.	Page 20-21
	23c	Discuss any limitations of the review processes used.	Page 20-21
	23d	Discuss implications of the results for practice, policy, and future research.	Page 20-21
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 3
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 3
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 3
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 21
Competing interests	26	Declare any competing interests of review authors.	Page 21
Availability of data, code, and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N.A

Adapted From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71 *Adapted From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

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Appendix B: Search strategy for MEDLINE, CINAHL, EMBASE

	Terms
1. Construct	Quality of Life Health-related quality of life
2. Population	Dementia Alzheimer's
3. Instruments	Healthy Aging Brain Care Monitor HABC Monitor ASCertain Dementia 8 item questionnaire AD8 Quality of Life demenia QualiDEM The Quality of Life in Late-stage Dementia (QUALID) scale Dementia Questionnaire Brief Cope EQ-5D EQ-VAS EQ-6D European Quality of life-5 dimensions European Quality of life- 6 dimension EuroQol Short Form-36 SF-36 Health Survey Short Form-12 SF-12 SF-6D Alzheimer's Disease-related Quality of Life scale ADRQL Dementia Quality of Life Measure DEMQOL The Cornell-Brown Scale for Quality of Life in Dementia CBS Dementia Care mapping DCM Quality of Life-Alzheimer's Disease QOL-AD Quality of Life Assessment Schedule QOLAS Dementia-specific quality of life DQOL Bath Assessment of Subjective Quality of Life in Dementia (BASQID) Pleasant Events Schedule (PED-AD) Observing Quality of Life in Dementia OQOLD Observing Quality of life Dementia Advanced OQOLDA Schedule for the evaluation of individual quality of life SEIQOL Quality of Life Assessment Schedule QOLAS The community dementia QOL profile CDQLP Satisfaction with Life Scale SWLS

	Terms
	Progressive Deterioration Scale Alzheimer's Disease Health Related QoL ADRQL Quality of well-being scale WHOQOL 100 World Health Organization Quality of Life 100 HSQ Health Status Questionnaire Blau QOL scale Bryne-MacLean QOL index Cognitively impaired life quality scale CILQ
4. Measurement Properties	(instrumentation[sh] OR methods[sh] OR "Validation Studies"[pt] OR "Comparative Study"[pt] OR "psychometrics"[MeSH] OR psychometr*[tiab] OR clinimetr*[tw] OR clinometr*[tw] OR "outcome assessment (health care)"[MeSH] OR "outcome assessment"[tiab] OR "outcome measure*"[tw] OR "observer variation"[MeSH] OR "observer variation"[tiab] OR "Health Status Indicators"[Mesh] OR "reproducibility of results"[MeSH] OR reproducib*[tiab] OR "discriminant analysis"[MeSH] OR reliab*[tiab] OR unreliab*[tiab] OR valid*[tiab] OR "coefficient of variation"[tiab] OR coefficient[tiab] OR homogeneity[tiab] OR homogeneous[tiab] OR "internal consistency"[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR (item[tiab] AND (correlation*[tiab] OR selection*[tiab] OR reduction*[tiab])) OR agreement[tw] OR precision[tw] OR imprecision[tw] OR "precise values"[tw] OR test-retest[tiab] OR (test[tiab] AND retest[tiab]) OR (reliab*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR kappa's[tiab] OR kappas[tiab] OR repeatab*[tw] OR ((replicab*[tw] OR repeated[tw]) AND (measure[tw] OR measures[tw] OR findings[tw] OR result[tw] OR results[tw] OR test[tw] OR tests[tw])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR "known group"[tiab] OR "factor analysis"[tiab] OR "factor analyses"[tiab] OR "factor structure"[tiab] OR "factor structures"[tiab] OR dimension*[tiab] OR subscale*[tiab] OR (multitrait[tiab] AND scaling[tiab] AND (analysis[tiab] OR analyses[tiab])) OR "item discriminant"[tiab] OR "interscale correlation*"[tiab] OR error[tiab] OR errors[tiab] OR "individual variability"[tiab] OR "interval variability"[tiab] OR "rate variability"[tiab] OR (variability[tiab] AND (analysis[tiab] OR values[tiab])) OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR "standard error of measurement"[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR (limit[tiab] AND detection[tiab]) OR "minimal detectable concentration"[tiab] OR interpretab*[tiab] OR ((minimal[tiab] OR minimally[tiab] OR clinical[tiab] OR clinically[tiab]) AND (important[tiab] OR significant[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR "meaningful change"[tiab] OR "ceiling effect"[tiab] OR "floor effect"[tiab] OR "Item

	Terms
	response model"[tiab] OR IRT[tiab] OR Rasch[tiab] OR "Differential item functioning"[tiab] OR DIF[tiab] OR "computer adaptive testing"[tiab] OR "item bank"[tiab] OR "cross-cultural equivalence"[tiab])
5. Exclusion filter	NOT (‘delphi-technique’[ti] OR cross-sectional[ti] OR "addresses"[Publication Type] OR "biography"[Publication Type] OR "case reports"[Publication Type] OR "comment"[Publication Type] OR "directory"[Publication Type] OR "editorial"[Publication Type] OR "festschrift"[Publication Type] OR "interview"[Publication Type] OR "lectures"[Publication Type] OR "legal cases"[Publication Type] OR "legislation"[Publication Type] OR "letter"[Publication Type] OR "news"[Publication Type] OR "newspaper article"[Publication Type] OR "patient education handout"[Publication Type] OR "popular works"[Publication Type] OR "congresses"[Publication Type] OR "consensus development conference"[Publication Type] OR "consensus development conference, nih"[Publication Type] OR "practice guideline"[Publication Type]) NOT ("animals"[MeSH Terms] NOT "humans"[MeSH Terms])

Appendix C: Convergent Validity Hypotheses

Table. Summary of convergent validity hypothesis based on comparison measure

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
QOL-AD	Hoe et al. (2005)	37	MMSE	Cognitive Function	Correlations < |0.3| with instruments measuring unrelated constructs.
		37	ADCS-ADL	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		37	Cornell Scale for Depression in Dementia	Emotion	Correlations greater than (>) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs
		37	NPI	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		34	HSQ mental health	Health – Mental health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		35	HSQ role-mental	Health- mental	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		36	HSQ role-physical	Health- physical health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		31	HADS anxiety	Emotion	Correlations greater than or equal to (≥) |0.3| but less than

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					(<) |0.6| with instruments measuring related but dissimilar constructs.
		31	HADS depression	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Kisvetrová et al (2018)	212	SPPB	Performance based – lower extremity function and balance	Correlations < |0.3| with instruments measuring unrelated constructs.
			BADLS-CZ	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GDS	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Logsdon et al (1999)	77	MMSE Composite	Cognitive Function	Correlations < |0.3| with instruments measuring unrelated constructs.
			ADL Composite	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			IADL Composite	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments

Outcome measure	Study, year	Study sample (n)		Measure	Construct Measured	
						measuring related but dissimilar constructs.
				HDRSPD Composite	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				HDRSCD Composite	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				GDS (patient report) Composite	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				GDS (caregiver report) Composite	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				Pleasant Event Scale-AD Composite	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Matsui et al (2006)	PWD (83)	MMSE score ≥ 21	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				SMQ	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.

Outcome measure	Study, year	Study sample (n)		Measure	Construct Measured	
				HADL	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Mood factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Euphoria factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Psychosis factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			MMSE score < 21	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				SMQ	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				HADL	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)		Measure	Construct Measured	
				NPI Mood factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Euphoria factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Psychosis factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		Caregivers (83)	MMSE score ≥ 21	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				SMQ	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				HADL	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Mood factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)		Measure	Construct Measured	
				NPI Euphoria factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Psychosis factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			MMSE score < 21	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				SMQ	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				HADL	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Mood factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)		Measure	Construct Measured	
				NPI Euphoria factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Psychosis factor	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Novelli et al (2010)	120		MMSE Composite	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
				GDS (patient report) Composite	emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				Cornell scale	emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
				NPI Composite	symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			IADL Composite	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			ADL Composite	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Beck depression Composite	emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			PQOL Composite	QOL	we hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			C-PQOL Composite	QOL	we hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			CQOL Composite	QOL	we hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
	Stypa et al (2020)	28	DQOL Total	QOL	we hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		30	GDS	Emotion	Correlations greater than or equal to (≥) |0.3| but less than

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					(<) |0.6| with instruments measuring related but dissimilar constructs.
		27	Adapted NPI	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Wolak et al (2009)	119	ADL Composite	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			IADL Composite	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPIc Composite	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPId Composite	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Charlson Composite	comorbidity	Correlations < |0.3| with instruments measuring unrelated constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			Zarit Composite	Burden scale	Correlations < |0.3| with instruments measuring unrelated constructs.
	Yap et al. (2008)	67	PSMS Patient	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			PSMS Caregiver	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			IADL Patient	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			IADL Caregiver	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			RMBPC memory Patient	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			RMBPC memory Caregiver	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			RMBPC disruption Patient	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			RMBPC disruption Caregiver	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			RMBPC depression Patient	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			RMBPC depression Caregiver	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			PAS-AD Patient	Physical activity	Correlations < |0.3| with instruments measuring unrelated constructs.
			PAS-AD Caregiver	Physical activity	Correlations < |0.3| with instruments measuring unrelated constructs.
			SF-36 physical functioning Patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			SF-36 physical functioning Caregiver	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			SF-36 physical role limitation Patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			SF-36 physical role limitation Caregiver	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			GHQ Patient	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GHQ Caregiver	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Zarit Caregiver Burden Patient	Burden scale	Correlations < |0.3| with instruments measuring unrelated constructs.
			Zarit Caregiver Burden Caregiver	Burden scale	Correlations < |0.3| with instruments measuring unrelated constructs.
	Yu et al (2013)	PWD (195) Caregivers (87)	ADL-Behavior competence Patient	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			ADL-Behavior competence Caregiver	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 -Physical functioning Patient	Physical function	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			SF-36 -Physical functioning Caregiver	Physical function L	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 RP- Physical functioning Patient	Physical function	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 RP- Physical functioning Caregiver	Physical function	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GDS- Psychological status Patient	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GDS- Psychological status Caregiver	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 MH- Psychological status Patient	Mental health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 MH- Psychological status Caregiver	Mental health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					measuring related but dissimilar constructs.
			SDS- Interpersonal environment Patient	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SDS- Interpersonal environment Caregiver	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SAS- Interpersonal environment Patient	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SAS- Interpersonal environment Caregiver	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			CBS- Interpersonal environment Patient	Burden scale	Correlations < |0.3| with instruments measuring unrelated constructs.
			CBS- Interpersonal environment Caregiver	Burden scale	Correlations < |0.3| with instruments measuring unrelated constructs.
DEMQOL	Lucas-Carrasco et al (2010)	88	WHOQOL-BREF physical Patient	QOL – Physical Subscale	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
		92	WHOQOL-BREF physical Caregiver	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		87	WHOQOL-BREF psychosocial Patient	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		91	WHOQOL-BREF psychosocial Caregiver	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		88	WHOQOL-BREF social relation Patient	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		92	WHOQOL-BREF social relation Caregiver	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		88	WHOQOL-BREF environment Patient	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		92	WHOQOL-BREF environment Caregiver	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					measuring related but dissimilar constructs.
		102	GDS-15 Patient	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		95	GDS-15 Caregiver	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		102	Barthel Index Patient	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		95	Barthel Index Caregiver	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Niikawa et al (2019)	87	MMSE Patient	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			MMSE Caregiver	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			Barthel Index Patient	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			Barthel Index Caregiver	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GDS-S-J Patient	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GDS-S-J Caregiver	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPI-Q severity Patient	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPI-Q severity Caregiver	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPI-Q distress Patient	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPI-Q distress Caregiver	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments

Outcome measure	Study, year	Study sample (n)	Measure		Construct Measured	
						measuring related but dissimilar constructs.
			J-ZBI_8 Patient		Caregiver burden	Correlations < |0.3| with instruments measuring unrelated constructs.
			J-ZBI_8 Caregiver		Caregiver burden	Correlations < |0.3| with instruments measuring unrelated constructs.
			QOL-AD Patient	DEMQOL-J	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
				DEMQOL-P-J		
			QOL-AD Caregiver	DEMQOL-J	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
				DEMQOL-P-J		
			EQ-5D 3L Patient	DEMQOL-J	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
				DEMQOL-P-J		
			EQ-5D 3L Caregiver	DEMQOL-J	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
				DEMQOL-P-J		
			WHO-5-J	DEMQOL-J	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
				DEMQOL-P-J		
	Smith et al (2005)	PWD (16)	DQOL Self-esteem		QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (16)	DQOL Positive effect		QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
		PWD (16)	DQOL Negative affect	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (15)	DQOL Feelings of belongings	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (18)	DQOL Sense of aesthetics	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (36)	QOL-AD-PWD	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Caregivers (55)	QOL-AD-Carer	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (54)	SF-12 PCS-PWD	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Caregivers (30)	SF-12 PCS-Carer	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (54)	SF-12 MCS-PWD	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Caregivers (30)	SF-12 MCS-Carer	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (69)	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		Caregivers (84)			

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
		PWD (71)	GDS-30	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		Caregivers (96)			
		PWD (65)	Barthel Index	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		Caregivers (87)			
		Caregivers (90)	Carer GHQ-12	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Smith et al (2007)	PWD (33)	QOL-AD-PWD	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Caregivers (38)	QOL-AD-Carer	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (16)	DQOL Self-esteem	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (16)	DQOL Positive effect	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (16)	DQOL Negative affect	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
		PWD (16)	DQOL Feelings of belongings	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (16)	DQOL Sense of aesthetics	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (50)	SF-12 PCS-PWD	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Caregivers (38)	SF-12 PCS-Carer	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (50)	SF-12 MCS-PWD	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Caregivers (28)	SF-12 MCS-Carer	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		PWD (64)	GDS-30	Emotion		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		Caregivers (75)				
		PWD (58)	Barthel Index	Daily living		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		Caregivers (68)				
DQOL	Brod et al (1999)	PWD 95	Self-esteem	GDS	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments
			Positive affect			
			Negative affect			
			Feelings of belonging			

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
						measuring related but dissimilar constructs.
	Lucas-Carrasco et al (2011b)	101	Self-esteem	WHO QOL-BREF physical	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	WHO QOL-BREF psychosocial	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	WHO QOL-BREF social relation	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	WHO QOL-BREF environment	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	GDS-15	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	Barthel Index	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
	Voigt-Radloff (2012)	150	QOL-AD self	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
		147	QOL-AD carer	QOL		We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		112	SF-12-physical self	QOLPhysical Health		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		112	SF-12-mental self	Mental Health		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		122	CSDD carer	Emotion		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		285	IDDD carer	Daily living		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		267	MMSE	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		151	ADAS-cog	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
	Wolak et al (2010)	155	Self-esteem	Duke-Physic	QOL-Physic	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments
			Positive affect			
			Negative affect			

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
			Feelings of belonging	al health	al health	measuring related but dissimilar constructs.
			Sense of aesthetics			
			Self-esteem	Duke-Mental health	QOL-Mental health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	Duke-Social health	QOL-social health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	Duke-General health	QOL-general health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	Duke-Perceived health	QOL-perceived health	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	Duke-Self-esteem	QOL-self esteem	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem	Duke-Anxiety	QOL-anxiety	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Positive affect			
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
			Self-esteem			

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
			Positive affect	Duke-Depression	QOL-depression	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Negative affect			
			Feelings of belonging			
			Sense of aesthetics			
Cornell-Brown	Lucas-Carrasco et al (2013)	100	GDS-15	Emotion		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Barthel Index	Daily living		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			MMSE	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
			WHOQOL-BREF physical	QOL-Physical Health		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
	Ready et al (2002)	26	WHOQOL-BREF psychosocial	QOL-psychosocial		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			WHOQOL-BREF social	QOL- social		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			WHOQOL-BREF environment	QOL-environment	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			VADS rating	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
BASQID	Trigg et al (2007a)	41	WHOQOL-BREF – Physical	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		41	WHOQOL-BREF – Psychological	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		30	WHOQOL-BREF – Social	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		41	WHOQOL-BREF – Environmental	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		47	GDS-15	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		143	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
ADRQL	Kasper et al (2009)	146	SF-36 Mental health	Mental health	Correlations greater than or equal to (≥) |0.3| but less than

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					(<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 Vitality	Energy/vitality	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			SF-36 Social Functioning	Social function	correlations greater than (>) 0.3 but less than (<) 0.6 with instruments measuring related but dissimilar constructs
QOLAS	Selai et al (2001)	Mild-to-moderate (n=22)	COOP patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D mobility Patient	QOL-mobility	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D mobility Caregiver	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D self-care Patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D self-care Caregiver	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			EQ-5D usual activities Patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D usual activities Caregiver	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D pain/discomfort Patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D pain/discomfort Caregiver	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D anxiety/depression Patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D anxiety/depression Caregiver	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		Mild (n=12)	NPI-global Caregiver	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			IDDD Caregiver	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			COOP patient	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			EQ-5D mobility Patient	QOL- mobility	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D mobility Caregiver	QOL- mobility	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D self-care Patient	QOL- self-care	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D self-care Caregiver	QOL0 self care	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			EQ-5D usual activities Patient	QOL- usual activities	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D usual activities Caregiver	QOL- usual activities	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-5D pain/discomfort Patient	QOL- pain	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
			EQ-5D pain/discomfort Caregiver	QOL- pain		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			NPI-global Caregiver	Symptoms		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			IDDD Caregiver	Daily living		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
WHOQOL	Lucas-Carrasco et al (2011a)	104	Physical	DEM QOL-28	QOL	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Psychological			
			Social relations			
			Environment			
			Physical	GDS-15	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Psychological			We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Social relations			We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
			Environment			We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Physical	Barthel Index	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Psychological			
			Social relations			Correlations < |0.3| with instruments measuring unrelated constructs.
			Environment			
			Physical	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			Psychological			
			Social relations			
			Environment			
EQ-5D-3L	Kunz et al (2010)	335	NOSGER IADL PWD	Daily living		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		351	NOSGER IADL Caregiver	Daily living		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		336	MMSE PWD	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		351	MMSE caregiver	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
		369	QOLAD self-rating score	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		351	QOLAD proxy-rating score	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
	Michalowsky et al (2020)	498	EQ-VAS	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			QOLAD self-rating score	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
	Orgeta et al (2015)	478	CSDD (carer rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			RAID (self-rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			RAID (carer rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			BADLs (self-rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
			BADLs (carer rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			RSS (self-rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			RSS (carer rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			GHQ (carer rating)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
EQ-5D-3L	Michalowsky et al (2021)	77	GDS	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			EQ-VAS	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			QOLAD self-rating score	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
EQ-5D-5L		77	GDS	Emotion	Correlations greater than or equal to (≥) |0.3| but less than

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
	Michalowsky et al (2021)					(<) |0.6| with instruments measuring related but dissimilar constructs.
			CDR (carer rating)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
			CSDD (self-rating)	Emotion		Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
SF-36	Geschke et al (2013)	60	Physical function	QOL-AD	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
			Role-physical			
			Bodily pain			
			General health			
			Vitality			
			Social functioning			
			Role-emotional			
			Mental health			
	Machnicki et al (2009)	45	Physical function	Zarit	Burden scale	Correlations < |0.3| with instruments measuring unrelated constructs.
			Role-physical			
			Role-emotional			
			Social functioning			
			Mental health			
			Vitality			
			Bodily pain			
			General health			
			Physical function	MMSE	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			Role-physical			
			Role-emotional			
			Social functioning			
			Mental health			
			Vitality			
			Bodily pain			
			General health			
			Physical function			

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured		
			Role-physical	CDR	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			Role-emotional			
			Social functioning			
			Mental health			
			Vitality			
			Bodily pain			
			General health			
			Physical function	NPI	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Role-physical			
			Role-emotional			
			Social functioning			
			Mental health			
			Vitality			
			Bodily pain			
			General health			
HUI2	Karlawish et al (2008a)	30	MMSE (24-29)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		36	MMSE (20-23)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		27	MMSE (11-19)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		36	3MS (73-90)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		32	3MS (60-72)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.
		25	3MS (24-59)	Cognitive function		Correlations < |0.3| with instruments measuring unrelated constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
		28	QOL-AD (42-52)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		35	QOL-AD (37-41)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		30	QOL-AD (24-36)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		29	IADL-patient (8-10)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		31	IADL-patient (11-14)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		33	IADL-patient (15-27)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		34	IADL-caregiver (8-18)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		26	IADL-caregiver (19-24)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					measuring related but dissimilar constructs.
		26	IADL-caregiver (25-31)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		59	BADL-patient (6)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		34	BADL-patient (7-14)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		49	BADL-caregiver (6-7)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		37	BADL-caregiver (8-19)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		36	GDS (0-1)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
		26	GDS (2-3)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		31	GDS (4-11)	Emotion	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		29	SF-12 Mental functioning (56.0-67.5)	QOL- mental function	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		32	SF-12 Mental functioning (50.8-56.0)	QOL- mental function	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		32	SF-12 Mental functioning (28.9-50.8)	QOL- mental function	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		30	SF-12 Physical functioning (53.5-64.0)	QOL- physical function	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		30	SF-12 Physical functioning (44.0-53.5)	QOL- physical function	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		33	SF-12 Physical functioning (26.4-44.0)	QOL- physical function	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
	Karlawish et al (2008b)	28	MMSE (24-29)	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		37	MMSE (20-23)	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		35	MMSE (11-19)	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		34	3MS (73-90)	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		34	3MS (60-72)	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		32	3MS (24-59)	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
		34	QOL-AD (36-47)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		31	QOL-AD (33-35)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		35	QOL-AD (22-32)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		34	IADL (8-18)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments

Outcome measure	Study, year	Study sample (n)	Measure	Construct Measured	
					measuring related but dissimilar constructs.
		34	IADL (19-24)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		32	IADL (25-31)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		33	BADL (6)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		30	BADL (7-8)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		37	BADL (9-22)	Daily living	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
		36	SF-12 Mental functioning (51.7-66.4)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		31	SF-12 Mental functioning (40.7-51.7)	QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs

Outcome measure	Study, year	Study sample (n)	Measure		Construct Measured	
		33	SF-12 Mental functioning (8.6-40.6)		QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		34	SF-12 Physical functioning (53.5-64.0)		QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		32	SF-12 Physical functioning (44.0-53.5)		QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
		34	SF-12 Physical functioning (26.4-44.0)		QOL	We hypothesized correlations ≥ |0.6| with instruments measuring similar constructs
	Kavirajan et al (2009)	392 to 408	Sensation utility	Charlson Comorbidity Index	Comorbidity	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Mobility utility			
			Emotion utility			
			Cognition utility			
			Self-care utility			
			Pain utility			
			Multi-attribute utility			
			Sensation utility	Blessed dementia rating scale	Cognitive function	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Mobility utility			
			Emotion utility			
			Cognition utility			
			Self-care utility			
			Pain utility			
			Multi-attribute utility			
			Sensation utility		Symptoms	Correlations greater than or equal to (≥) |0.3| but less than

Outcome measure	Study, year	Study sample (n)	Measure		Construct Measured	
			Mobility utility	Composite Behavioral score		(<) |0.6| with instruments measuring related but dissimilar constructs.
			Emotion utility			
			Cognition utility			
			Self-care utility			
			Pain utility			
			Multi-attribute utility			
HUI3	Kavirajan et al (2009)	392 to 408	Vision utility	Charlson Comorbidity Index	Comorbidity	Correlations < |0.3| with instruments measuring unrelated constructs.
			Hearing utility			
			Speech utility			
			Ambulation utility			
			Dexterity utility			
			Emotion utility			
			Cognition utility			
			Pain utility			
			Multi-attribute utility			
			Vision utility	Blessed dementia rating scale	Cognitive function	Correlations < |0.3| with instruments measuring unrelated constructs.
			Hearing utility			
			Speech utility			
			Ambulation utility			
			Dexterity utility			
			Emotion utility			
			Cognition utility			
			Pain utility			
			Multi-attribute utility			
			Vision utility	Composite Behavioral score	Symptoms	Correlations greater than or equal to (≥) |0.3| but less than (<) |0.6| with instruments measuring related but dissimilar constructs.
			Hearing utility			
			Speech utility			
			Ambulation utility			

Outcome measure	Study, year	Study sample (n)	Measure		Construct Measured	
			Dexterity utility			
			Emotion utility			
			Cognition utility			
			Pain utility			
			Multi-attribute utility			

n, number; PWD, people with dementia; MMSE, Mini Mental State Examination; ADCS-ADL, Alzheimer's Disease Assessment Scale- Activities of Daily Living; NPI, Neuropsychiatric Inventory; HSQ, Health Status Questionnaire; HADS, Hospital Anxiety and Depression Scale; SPPB, Short Physical Performance Battery; BADLS-CZ, Bristol Activities of Daily Living Scale -Czech version; ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; HDRSPD; Hamilton Depression Rating Scale for Parkinson's Disease; GDS, Geriatric Depression Scale; PWD, People with dementia; SMQ, Short Memory Questionnaire; HADL, Hyogo Activities of Daily Living Scale; QOL, quality of life; QOL-AD, quality of life in Alzheimer's disease; PQOL, patient reports on own QOL; C-PQOL, caregiver reports on patients QOL; CQOL, caregiver report on own QOL; DEMQOL, Dementia Quality of Life Instrument; DQOL, Dementia Quality of Life Instrument; PSMS, Physical Self-Maintenance Scale; RMBPC, Revised Memory and Behavior Problems Checklist; GHQ, General Health Questionnaire; SAS, Simpson-Angus Scale, SDS, Self-Rating Depression Scale; CBD, caregiver burden questionnaire; WHOQOL, World Health Organization Quality of Life Scale ; WHOQOL-BREF, World Health Organization Quality of Life Scale Brief Version; NOSGER, Nurses' Observation Scale for Geriatric Patients; EQ-5D-3L, three-level version EuroQol-5 dimension; GDS-S-J, Geriatric Depression Scale Short-Form Japanese; J-ZBI_8, short version of the Japanese version of the Zarit Caregiver Burden Interview; WHO-5-J, Japanese version of the World Health Organization Five Well-being Index; CSDD, Cornell Scale for Depression in Dementia; RAID Rating of anxiety in dementia; BADLS, Bristol Activities of Daily Living Scale, RSS, Relative's Stress Scale; 3MS, Modified Mini Mental State Examination; CDR, Clinical Dementia Rating scale; IDDD, Performance Scale of the Interview of Deterioration in Daily Living Activities in Dementia; ADAS-cog, Alzheimer's Disease Assessment Scale – cognitive; BASQID, Bath Assessment of Subjective Quality of Life in Dementia; ADRQL, Alzheimer's Disease-Related Quality of Life; HUI, Health Utilities Index; QOLAS, Quality of Life Assessment Schedule; COOP, Dartmouth COOP charts

Appendix D: Modified GRADE

<table>
<tr><td>Quality of evidence</td><td>Lower if</td></tr>
<tr><td>High: confident that the true measurement property is close to the estimate (pooled/summarized result)</td><td rowspan="4">Risk of bias
-1 Serious
-2 Very serious
-3 Extremely serious

Inconsistency
0 Results are consistent (sufficient or insufficient)
-1 Serious (Results are inconsistent)

Imprecision
0 total n >100
-1 total n=50-100
-2 total n<50

Indirectness
Not Applicable. Definition for population was provided in the inclusion criteria.</td></tr>
<tr><td>Moderate: moderately confident in the estimate measurement property, though there is a chance that it could significantly deviate.</td></tr>
<tr><td>Low: limited confidence in the estimate measurement property; may significantly deviate from the true measurement property</td></tr>
<tr><td>Very low: very little confidence in the estimate; likely to significantly deviate from true measurement property</td></tr>
</table>

Prinsen, C. A., Mokkink, L. B., Bouter, L. M., Alonso, J., Patrick, D. L., De Vet, H. C., & Terwee, C. B. (2018). COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of life research*, *27*, 1147-1157.

Table 1: Study characteristics

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)	Outcome measure	Psychometric Properties
Akpinar et al., 2012	Türkiye	PWD 83	PWD 32	48	MMT score 19.38 ± 4.89	76.84 ± 7.51	QOL-AD	Language validity, Content validity, Internal consistency, Reliability
		Caregivers 83	Caregivers 36	65	NR	54.64 ± 12.13		
Brod et al., 1999	USA	PWD 99	PWD 95	56	MMSE score (n) Mild dementia (45) >19 Moderate dementia (50) 19-13	78.7 ± 7.43	DQOL	Internal consistency, Reliability, Convergent validity, Known group validity
Chua et al., 2016	UK	PWD 868	PWD 756	487	MMSE score 21.1 ± 5.1	78.7 ± 8.5	DEMQOL	Structural validity, Internal consistency, Convergent validity*
		Caregivers 909	Caregivers 679	426	MMSE score 20.8 ± 5.3	78.8 ± 8.1		
Coucill et al., 2001	UK	PWD 64	PWD 64	36	CDR score (n) CDR 0.5 (3) CDR 1 (36) CDR 2 (25)	76 (range 53-91)	EQ-5D	Reliability
		Caregivers 64	Caregivers 64	NR	NR	NR		
Geschke et al., 2013	Germany	PWD 60	PWD 60	38	MMSE score 20.2 ± 6.0	78.7 ± 6.4	SF-36	Internal consistency, convergent validity, Known group validity
Hoe et al., 2005	UK	PWD and caregivers 79	Able to complete 41	NR	MMSE score 7.0 ± 3.2	80.0 ± 8.8	QOL-AD	Internal consistency, Convergent validity
			Not able to complete 33	NR	MMSE score 2.2 ± 3.2	81.3 ± 7.6		

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)	Outcome measure	Psychometric Properties
Karim et al., 2007	UK	PWD 36	PWD 36	18	Self-perception of the severity of dementia Mild (6)/ Moderate (30)	78 (range 60-92)	D-QOL	Internal consistency, Reliability, Known group validity
Karlawish et al., 2008a	USA	PWD 110 Caregivers 110	PWD 93	42	MMSE score 21.3 ± 4.3	76.8 ± 2.7	HUI2, EQ-5D	Reliability, Convergent validity
Karlawish et al., 2008b	USA	PWD 110 Caregivers 110	Caregivers 100	70	MMSE score 28.76 ± 1.43	65.4±12.6	HUI2, EQ-5D	Reliability, Convergent validity
Kasper et al., 2009	USA	PWD community setting 146 / nursing homes 89/ assisted living 134	PWD in community setting 146	117+	MMSE score (n=111) < 18	60% of sample > age 80	ADRQL	Internal consistency, Convergent validity, Known-groups validity, Responsiveness
Kavirajan et al., 2009	USA	PWD 408 Caregivers 408	PWD 408 Caregivers 408	224	BDRS Score 5.9 ± 3.7	80±7	HUI2 & HUI3	Convergent Validity, Responsiveness
Kisvetrova et al., 2018	Czech	PWD and caregivers 212	212	135	MMSE score 22.6 ± 1.7	79.0 ± 7.5	QOL-AD	Internal consistency, Reliability, Convergent validity
Kunz et al., 2010	Germany	PWD and caregivers 390	PWD 390	264	MMSE score 18.6±3.8	80.2 ± 6.7	EQ-5D	Reliability, Convergent validity, Responsiveness
			Caregivers 357	261	NR	59.4 ± 13.4		

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)	Outcome measure	Psychometric Properties
Logsdon et al., 1999	United States	PWD and caregivers 77	PWD 77	36	MMSE score 17.1 ± 5.6	Patient 78.3 ± 6.1 Caregiver 69.8±13.8	QOL-AD	Internal consistency, Reliability, Convergent validity
Lucas-Carrasco et al., 2010	Spain	PWD and caregivers 119	102	67	MMSE score 19.49 ± 4.45	79.2 ± 7.0	DEMQOL	Internal consistency, Reliability, Convergent validity, Known group validity
Lucas-Carrasco et al., 2011a	Spain	PWD 104	PWD 104	65	MMSE score 18.3 ± 4.3	78.6 ± 7.2	WHOQOL	Internal consistency, Reliability, Convergent validity, Known group validity
Lucas-Carrasco et al., 2011b	Spain	PWD 120	PWD 101	68	MMSE score 19.4 ± 4.4	79.3 ± 7.0	DQoL	Internal consistency, Reliability, Convergent validity, Known group validity
Lucas-Carrasco et al., 2013	Spain	PWD 100	PWD 100	66	MMSE score 17.68 ± 4.19	79.18 ± 7.09	Cornell-Brown	Internal consistency, Convergent validity, Known group validity
Matsui et al., 2006	Japan	PWD 140	PWD 83	84	MMSE scores 20.3 ± 4.2	72.4 ± 7.3	QOL-AD	Internal consistency, Reliability, Convergent validity
		Caregivers 140	Caregivers 83	85	NR	61.7 ± 11.01		
Michalowsky et al., 2020	Germany	PWD 560 Caregivers 560	PWD 498	243	Functional deficits due to dementia 6.25 ± 1.0	PWD 79.03 ± 8.5	EQ-5D	Internal consistency, Convergent validity, Known group validity

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)	Outcome measure	Psychometric Properties
Michalowsky et al., 2021	Germany	PWD 77	PWD 77	47	MMSE 18.6 ± 7.4	80.2 ± 6.4	EQ-5D	Reliability, Convergent validity, Known group validity
Niikawa et al., 2019	Japan	PWD 87	PWD 87	60	CDR 0.5 (n) = 8 CDR 1 (n) = 53 CDR 2 (n) = 26	82.01 ± 7.27	DEMQOL	Internal consistency, Reliability, Convergent validity
		Caregivers 87	Caregivers 87	53	-	-		
Novelli et al., 2010	Brazil	PWD 60	PWD 60	42	MMSE scores Between 10-25	Mild dementia 75.5 ± 6.7	QOL-AD	Internal consistency, Convergent validity
						Moderate dementia 76.2 ± 6.2		
		Caregivers 60	Caregivers 60	44	-	Mild dementia 59.5 ± 15.4		
						Moderate dementia 60.1 ± 14.5		
Orgeta et al., 2015	UK	PWD and caregivers 488	PWD and caregivers 478	314	CDR Mild (%) 74.6	75.5 ± 7.3	EQ-5D	Reliability, Convergent validity
					CDR Moderate (%) 25.4	69.8 ± 11.6		
Ready et al., 2002	US	PWD and mild cognitive impairment 50	PWD and mild cognitive impairment 50	30	MMSE score 22.1 ± 5.4	75.9 ± 9.1	Cornell-Brown	Internal consistency, Reliability, Convergent validity
Schwab et al., 2018	Germany	PWD 201	PWD 201	88	MMSE scores 25.06 ±2.17	73.74 ± 7.92	DEMQOL	Structural validity, Internal consistency

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)	Outcome measure	Psychometric Properties
		Caregivers 201	Caregivers 201	143	-	64.82 ± 13.17		
Selai et al., 2001	UK	PWD 37	PWD 22	10	MMSE range 11-30	65 ± 8 (range 48-80)	QOLAS	Internal consistency, Convergent validity, Known-groups validity
		Caregivers 37	Caregivers 22	14		61 ± 13 (range 30-77)		
Smith et al., 2005	United Kingdom	PWD 130	PWD 101	59	MMSE scores 16.01 ± 8.53	78.65 ± 8.30	DEMQOL	Internal consistency, Reliability, Content validity, Convergent validity
		Caregivers 126	Caregivers 99	62	-	-		
Smith et al., 2007	United Kingdom	PWD 130	PWD 101	59	MMSE score (Mild/Moderate sample) 19.93 ± 4.84	Mild/Moderate sample 78.49 ± 8.32	DEMQOL	Internal consistency, Reliability, Content validity, Convergent validity
					MMSE score (Severe sample) 2.9 ± 3.6	Severe sample 79.23 ± 8.42		
		Caregivers 126	Caregivers 99	62	-	Mild/Moderate sample 67.96 ± 11.15		
						Severe sample 65.91 ± 13.21		
Stypa et al., 2020	Germany	PWD 30	PWD 30	19	MMSE scores 19.67 ± 4.78	77.30 ± 6.30	QOL-AD	Internal consistency, Convergent validity. Divergent validity
Trigg et al., 2007a	UK	Stage 1 PWD 60	53	32	MMSE Score 18.44±4.07	<65: 7	BASQID	Internal consistency, Reliability, Content validity, Convergent validity, Responsiveness
						65-74: 24		
						75-84: 19		
						>85: 10		
		Stage 2 PWD 150	143	88	MMSE Score 18.06±4.63	<65: 8		
						65-74: 29		
						75-84: 85		

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)		Outcome measure	Psychometric Properties
						>85	28		
Trigg et al., 2007b	UK	PWD 60	PWD 60	32	MMSE Score 18.44±4.07	<65	7	BASQID	Internal consistency, Reliability
						65-74	24		
						75-84	19		
						>85	10		
Voigt-Radloff et al., 2012	Germany	PWD 287	PWD 287	163	MMSE scores 20.8 ± 3.5	77.3 ± 7.2		DQoL	Internal consistency, Reliability, Convergent validity
Wolak et al., 2009	France	PWD 120	PWD 120	77	MMSE scores 20.8 ± 4.5	82.2 ± 6.0		QOL-AD	Internal consistency, Reliability, Structural validity, Convergent validity
		Caregivers 120	Caregivers 120	86	-	66 ± 15			
Wolak et al., 2010	France	PWD 155	PWD 155	98	MMSE score 20.8 ± 4.4	81 ± 6.0		DQOL	Internal consistency, Reliability, Convergent validity, Known group validity
Yamamoto-Mitani et al., 2002	Japan	PWD 36	PWD 36	26	Dementia Level +1 (early level) 4	79.9±7.1		QLDJ	Inter-rater reliability (Study B), reliability (study B), Internal consistency (Study C), Construct Validity (study C), Concurrent Validity (Study C)
					Dementia Level +2 (Middle-stage) 11				
					Dementia Level +3 (Severe dementia) 14				
					Dementia Level +4 (Very severe dementia) 7				

Study, year	country	Total Population (n)	Participants (n)	Gender (Female, n)	Disease severity Mean ± SD	Age at study Mean ± SD (y)	Outcome measure	Psychometric Properties
Yap et al., 2008	Singapore	PWD 67	PWD 3667	45	MMSE score 16.1 ± 5.4	78.4 ± 7.5	QOL-AD	Internal consistency, Reliability, Convergent validity
		Caregivers 67	Caregivers 67	44	-	51.4 ± 2.8		
Yu et al., 2013		PWD 200	PWD 195	NR	MoCA Score 7.26±5.51	73.6 ± 7.7	QOL-AD	Internal consistency, Reliability, Convergent validity
		Caregivers 100	Caregivers 87	NR	-	NR		

PWD, people with dementia; SD, Standard deviation; n, number; n, number; MMSE, Mini Mental State Examination; MOCA, Montreal Cognitive Assessment; QOL-AD, CDR, Clinical Dementia Rating scale; Quality of life in Alzheimer ’s disease; DQOL, Dementia Quality of Life Instrument; DEMQOL, Dementia Quality of Life Instrument; EQ-5D, EuroQoL-5 Dimension; SF-36, Short Form 36; HUI2, Health Utilities Index; HUI3, Health Utilities Index 3; ADRQL, Alzheimer's Disease-Related Quality of Life; WHOQOL, World Health Organization Quality of Life Scale; QOLAS, Quality of Life Assessment Schedule; BASQID, Bath Assessment of Subjective Quality of Life in Dementia; QLDJI, Quality of Life Instrument for Japanese Elderly with Dementia.

Chua et al., 2016: Did not evaluate convergent validity because authors used a multivariate model to look at associations between the DEMQOL and other variables.

Table 2: Structural Validity

Outcome measure	Study, year	Study sample (n)	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence
DEMQOL	Chua et al., 2016	868 PWD and 909 caregivers	CFA-DEMQOL: RMSEA = .062 (90 % CI .059–.065), CFI = .918	+	V	Sufficient	High
			CFA- DEMQOL-Proxy: RMSEA = .058 (90 % CI .055–.061), CFI = .932	+			
	Schwab et al., 2018	201 PWD and caregiver	DEMQOL (positive thought): H^s = 0.38	+	V		
			DEMQOL (negative emotions): H^s = 0.45	+			
			DEMQOL (physical and cognitive functioning): H^s = 0.42	+			
			DEMQOL (daily activities and social relationships): H^s = 0.46	+			
			DEMQOL-proxy (positive thought): H^s = 0.66	+			
			DEMQOL-proxy (negative emotions): H^s = 0.46	+			
			DEMQOL-proxy (physical and cognitive functioning): H^s = 0.50	+			
			DEMQOL-proxy (daily activities and social relationships): H^s = 0.42	+			

DEMQOL; Dementia Quality of Life Instrument.
CFA: CFI or TLI or comparable measure >0.95 OR RMSEA <0.08
H^S = Loevinger's H coefficient of scalability of the scale (> 0.50 = strong, > 0.40 = medium, > 0.30 = weak); The minimum requirement was 0.30 to meet the hypothesis for H^S.

Table 3: Summary of internal consistency findings

Outcome measure	Study, year	Study sample (n)	Statistical results	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
QOL-AD	Akpinar et al. (2012)	PWD (32)	Cronbach's α = 0.84	+	D	Sufficient	Moderate
		Caregivers (36)	Cronbach's α = 0.77	+			
	Hoe et al. (2005)	PWD and caregivers (41)	Cronbach's α = 0.78	+	D		
	Kisvetrová et al. (2018)	PWD and caregivers (212)	Cronbach's α (PWD) = 0.85	+	D		
			Cronbach's α (caregivers) = 0.85	+			
			Cronbach's α (composite) = 0.87	+			
	Logsdon et al (1999)	PWD (77)	Cronbach's α (PWD) = 0.88	+	D		
			Cronbach's α (caregivers) = 0.87	+			
	Matsui et al (2006)	PWD (83)	Cronbach's α = 0.84	+	V		
		Caregivers (83)	Cronbach's α = 0.82	+			
	Novelli et al (2010)	PWD and caregivers (120)	Cronbach's α (PQOL) = 0.80	+	V		
			Cronbach's α (C-PQOL) = 0.83	+			
	Stypa et al (2020)	PWD (30)	Cronbach's α = 0.79	+	D		
	Wolak et al (2009)	PWD (120)	Cronbach's α = 0.83	+	I		
		Caregivers (120)	Cronbach's α = 0.79	+			
		Composite	Cronbach's α = 0.84	+			
	Yap et al (2008)	PWD (67)	Cronbach's α = 0.9	+	D		
		Caregivers (67)	Cronbach's α = 0.81	+			
	Yu et al (2013)	PWD (195)	Cronbach's α = 0.66	-	V		
		Caregivers (87)	Cronbach's α = 0.87	+			
DEMQOL	Chua et al (2016)	PWD (756)	Omega index ω = 0.96	+	D	Sufficient	Moderate
		Caregivers (679)	Omega index ω = 0.96	+			

Outcome measure	Study, year	Study sample (n)	Statistical results	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Lucas-Carrasco et al (2010)	PWD (102)	Cronbach's α = 0.85	+	D		
		Caregivers (95)	Cronbach's α = 0.86	+			
	Niikawa et al (2019)	PWD (87)	Cronbach's α = 0.93	+	D		
		Caregivers (87)	Cronbach's α = 0.93	+			
	Schwab et al (2018)	PWD (201)	Cronbach's α = 0.72-0.83	+	V		
		Caregivers (201)	Cronbach's α = 0.81-0.87	+			
	Smith et al (2005)	PWD (75)	Cronbach's α = 0.87	+	V		
		Caregivers (98)	Cronbach's α = 0.89	+			
	Smith et al (2007)	PWD (68)	Cronbach's α = 0.87	+	D		
		Caregivers of mild moderate sample (77)	Cronbach's α = 0.87	+			
		Caregivers of Severe sample (21)	Cronbach's α = 0.92	+			
DQOL	Brod et al (1999)	PWD (95)	Cronbach's α (Self-esteem) = 0.80	+	V	Inconsistent	Moderate
			Cronbach's α (Positive affect) = 0.83	+			
			Cronbach's α (Negative affect) = 0.89	+			
			Cronbach's α (Feelings of belonging) = 0.67	+			
			Cronbach's α (Sense of Aesthetics) = 0.77	-			
	Karim et al (2008)	PWD (36)	Cronbach's α (Self-esteem) = range 0.73–0.74	+	V		
			Cronbach's α (Positive affect) = range 0.74–0.82	+			
			Cronbach's α (Negative affect) = range 0.76–0.80	+			
			Cronbach's α (Feelings of belonging) = range 0.56–0.71	-			
			Cronbach's α (Sense of Aesthetics) = range 0.79–0.78	+			
		PWD (101)	Cronbach's α (Self-esteem) = 0.62	-	V		
			Cronbach's α (Positive affect) = 0.76	+			

Outcome measure	Study, year	Study sample (n)	Statistical results	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Lucas-Carrasco et al (2011b)		Cronbach's α (Negative affect) = 0.83	+			
			Cronbach's α (Feelings of belonging) = 0.62	-			
			Cronbach's α (Sense of Aesthetics) = 0.79	+			
	Voight-Radloff et al., 2012	PWD (286)	Cronbach's α (Self-esteem) = 0.68	-	V		
		PWD (285)	Cronbach's α (Positive affect) = 0.84	+			
		PWD (285)	Cronbach's α (Negative affect) = 0.84	+			
		PWD (286)	Cronbach's α (Feelings of belonging) = 0.62	-			
		PWD (285)	Cronbach's α (Sense of Aesthetics) = 0.67	-			
	Wolak et al., 2010	PWD (155)	Cronbach's α (Self-esteem) = 0.69	-	V		
			Cronbach's α (Positive affect) = 0.84	+			
			Cronbach's α (Negative affect) = 0.87	+			
			Cronbach's α (Feelings of belonging) = 0.69	-			
			Cronbach's α (Sense of Aesthetics) = 0.74	+			
	Lucas-Carrasco et al (2013)	PWD (100)	Cronbach's α = 0.87	+	D		
	Ready et al (2002)	PWD (50)	Cronbach's α = 0.81	+	D		
BASQID	Trigg et al (2007a)	PWD (143)	Cronbach's α = 0.89	+	D	Sufficient	Moderate
	Trigg et al (2007b)	PWD (55)	Cronbach's α = 0.91	+	A		
ADRQL	Kasper et al (2009)	PWD (87)	Cronbach's α (Total) = 0.87	+	V	Inconsistent	Moderate
			Cronbach's α (Social interaction) = 0.84	+			
			Cronbach's α (Awareness of self) = 0.76	+			
			Cronbach's α (Feelings and mood) = 0.81	+			
			Cronbach's α (Enjoyment of activities) = 0.52	-			
			Cronbach's α (Response to surroundings) = 0.44	-			
QOLAS	Selai et al (2001)	PWD (22)	Cronbach's α = 0.78	+	V	Sufficient	Moderate
		Caregiver (22)					
EQ-5D-3L	Michalowsky et al (2020)	PWD and caregivers (498)	Cronbach's α = 0.98	+	V	Sufficient	Very good

Outcome measure	Study, year	Study sample (n)	Statistical results	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
SF-36	Geschke et al (2013)	PWD (60)	Cronbach's α (Physical functioning) = 0.92	+	V	Sufficient	Moderate
			Cronbach's α (Role-physical) = 0.789	+			
			Cronbach's α (Bodily pain) = 0.91	+			
			Cronbach's α (General health perceptions - Total) = 0.70	+			
			Cronbach's α (vitality) = 0.64	-			
			Cronbach's α (General health perceptions - social functioning) = 0.63	-			
			Cronbach's α (Role-emotional) = 0.86	+			
			Cronbach's α (Mental health) = 0.70	+			
WHOQOL	Lucas-Carrasco et al (2011a)	PWD (104)	Cronbach's α = 0.88	+	A	Sufficient	Moderate

n; number, PWD; People with dementia, QOL; quality of life, QOL-AD; Quality of life in Alzheimer's disease, PQOL; patient reports on own QOL, C-PQOL; caregiver reports on patients QOL, DEMQOL; Dementia Quality of Life Instrument, DQOL; Dementia Quality of Life Instrument, BASQID; Bath Assessment of Subjective Quality of Life in Dementia, ADRQL; Alzheimer's Disease Related Quality of Life, QOLAS; Quality of Life Assessment Schedule, EQ-5D-3L; Three-level version EuroQol-5 Dimension, SF-36; Short Form 36, WHOQOL; World Health Organization Quality-of-Life Scale

Table 4: Reliability

Outcome measure	Study, year	Study sample (n)	Type of reliability	Statistical information		Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
QOL-AD	Akpinar et al. (2012)	PWD (32)	Test- retest (12 months)	ICC	0.77	+	D	Test-retest reliability: Sufficient Inter-rater reliability: Insufficient	Test-retest reliability: Moderate Inter-rater reliability: Moderate
		Caregivers (36)		ICC	0.71	+			
	Kisvetrová et al (2018)	PWD and caregivers (212)	Inter-rater	ICC	0.60	-	D		
	Logsdon et al (1999)	PWD and caregivers (60)	Test-retest (1 week)	ICC (PWD)	0.76	+	V		
				ICC (Caregivers)	0.92	+			
	Matsui et al (2006)	PWD (83)	Test-retest (1 month)	ICC (PWD)	0.84	+	V		
				ICC (Caregivers)	0.91	+			
	Stypa et al (2020)	PWD (27)	Test-retest (5.56 ± 1.37 days)	Spearman's rho	$r = 0.75$	+	I		
	Wolak et al (2009)	PWD and caregivers (110)	Test-retest (2 weeks)	ICC (PWD)	0.89	+	A		
				ICC (Caregivers)	0.86	+			
	Yap et al. (2008)	PWD and caregivers (67)	Test-retest (1-2 weeks)	ICC (PWD)	0.72	+	A		
				ICC (Caregivers)	0.81	+			
	Yu et al (2013)	PWD and caregivers (100)	Test-retest (2 weeks)	ICC (PWD)	0.84	+	A		
				ICC (Caregivers)	0.90	+			
DEMQOL	Lucas-Carrasco et al (2010)	PWD (25)	Test-retest (2 weeks ± 3 days)	ICC	0.71	+	I	Sufficient	Low
	Niikawa et al (2019)	PWD (27)	Test-retest (2 weeks)	ICC (PWD)	0.942	+	I		
		Caregivers (27)		ICC (Caregivers)	0.942	+			
	Smith et al (2005)	PWD (17)	Test-retest (6 months)	ICC (PWD)	0.84	+	I		
		Caregivers (23)		ICC (Caregivers)	0.75	+			
	Smith et al (2007)	PWD (10)	Test-retest (2 weeks)	ICC	0.76	+	I		
		Caregivers (99) (mild/moderate=13 / severe=5)		ICC (mild/moderate)	0.67	-			
				ICC (severe)	0.84	+			
DQOL	Brod et al (1999)	PWD (18)	Test-retest (2 weeks)	ICC Self-esteem	0.68	-	I	Inconsistent	Low

Outcome measure	Study, year	Study sample (n)	Type of reliability	Statistical information		Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
				ICC Positive affect	0.90	+			
				ICC Negative affect	0.64	-			
				ICC Feelings of belonging	0.74	+			
				ICC Sense of Aesthetics	0.72	+			
	Karim et al (2008)	PWD (36)	Test-retest (2 weeks)	Spearman's rho Self-esteem	$r = 0.76$	+	D		
				Spearman's rho Positive affect	$r = 0.71$	+			
				Spearman's rho Negative affect	$r = 0.75$	+			
				Spearman's rho Feelings of belonging	$r = 0.71$	+			
				Spearman's rho Sense of Aesthetics	$r = 0.71$	+			
				Spearman's rho Quality of life	$r = 0.89$	+			
	Lucas-Carrasco et al (2011b)	PWD (28)	Test-retest (2 weeks ± 3 days)	ICC Self-esteem	0.58	-	D		
				ICC Positive affect	0.90	+			
				ICC Negative affect	0.81	+			
				ICC Feelings of belonging	0.67	-			
				ICC Sense of Aesthetics	0.76	+			

Outcome measure	Study, year	Study sample (n)	Type of reliability	Statistical information		Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Wolak et al (2010)	PWD (155)	Test-retest (2 weeks)	ICC Self-esteem	0.98	+	V		
				ICC Positive affect	0.99	+			
				ICC Negative affect	1.00	+			
				ICC Feelings of belonging	0.96	+			
				ICC Sense of Aesthetics	0.97	+			
BASQID	Trigg et al (2007a)	PWD (29)	Test-retest (2 weeks)	ICC	0.85	+	D	Sufficient	Very Low
	Trigg et al (2007b)	PWD (29)	Test-retest (2 weeks)	ICC	0.82	+	I		
QLDJ	Yamamoto-Mitani et al (2002)	PWD (36)	Inter-rater	Weighted kappa	0.73	+	A	Test-retest reliability: Sufficient Inter-rater reliability: Sufficient	Test-retest reliability: Low Inter-rater reliability: Low
			Test-retest (2 weeks)	Weighted kappa	0.94	+			
EQ-5D-3L	Coucill et al (2001)	PWD (64)	Inter-rater	Weighted kappa Mobility	0.28	-	I	Test-retest reliability: Insufficient Inter-rater reliability: Insufficient	Test-retest reliability: Low Inter-rater reliability: Low
		Caregivers (64)		Weighted kappa Self-care	0.26	-			
				Weighted kappa Usual Activities	0.09	-			
				Weighted kappa Pain/discomfort	0.35	-			
				Weighted kappa Anxiety/depression	0.19	-			
		PWD (81)	Test-retest	ICC	0.54	-	I		

Outcome measure	Study, year	Study sample (n)	Type of reliability	Statistical information		Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Karlawish et al (2008a)	Caregivers (83)	(2 weeks)	ICC	0.63	-			
	Karlawish et al (2008b)	Caregivers (82)	Test-retest (2 weeks)	ICC	0.63	-	I		
	Kunz et al (2010)	PWD and caregivers (333)	Inter-rater	ICC (utility score)	0.48	-	I		
				Weighted kappa Mobility	0.38	-			
				Weighted kappa Self-care	0.45	-			
				Weighted kappa Usual Activities	0.37	-			
				Weighted kappa Pain/discomfort	0.35	-			
				Weighted kappa Anxiety/depression	0.25	-			
	Orgeta et al (2015)	PWD and caregivers (478)	Inter-rater	ICC (utility score)	0.34	-	I		
				ICC (VAS)	0.22	-			
				Weighted kappa Mobility	0.49	-			
				Weighted kappa Self-care	0.25	-			
				Weighted kappa Usual Activities	0.09	-			
				Weighted kappa Pain/discomfort	0.25	-			
				Weighted kappa Anxiety/depression	0.20	-			
HUI2	Karlawish et al (2008a)	PWD (81)	Test-retest (2 weeks)	ICC (PWD)	0.65	-	I	Insufficient	Very Low
		Caregivers (83)		ICC (Caregiver)	0.66	-			
	Karlawish et al (2008b)	Caregivers (81)	Test-retest (2 weeks)	ICC	0.66	-	I		

Outcome measure	Study, year	Study sample (n)	Type of reliability	Statistical information		Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
WHOQOL	Lucas-Carrasco et al (2011a)	PWD (27)	Test-retest (2 weeks ± 3 days)	ICC Physical	0.70	+	A	Insufficient	Very Low
				ICC Psychological	0.51	-			
				ICC Social relations	0.59	-			
				ICC Environment	0.61	-			

n; number, PWD; People with dementia, QOL, quality of life, QOL-AD; quality of life in Alzheimer's disease, ICC; Intraclass correlation coefficient, DEMQOL; Dementia Quality of Life Instrument, DQOL; Dementia Quality of Life Instrument, HUI; The Health Utilities Index, BASQID; Bath Assessment of Subjective Quality of Life in Dementia, QLDJ; Quality of Life instrument for older Japanese people experiencing Dementia, WHOQOL; World Health Organization Quality-of-Life Scale

Table 5: Convergent validity

Outcome measure	Study, year	Study sample (n)		Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
QOL-AD	Hoe et al. (2005)	37		MMSE	$r = -0.02$	+	A	Insufficient	High
		37		ADCS-ADL	$r = 0.55$	+			
		37		Cornell	$r = -0.27$	-			
		37		NPI	$r = -0.11$	-			
		34		HSQ mental health	$r = 0.58$	+			
		35		HSQ role-mental	$r = 0.29$	-			
		36		HSQ role-physical	$r = 0.48$	+			
		31		HADS anxiety	$r = -0.05$	-			
		31		HADS depression	$r = 0.092$	-			
	Kisvetrová et al (2018)	212		SPPB	$r = 0.48$	-	A		
				BADLS-CZ	$r = -0.59$	-			
				GDS	$r = -0.66$	-			
	Logsdon et al (1999)	77		MMSE Composite	$r = 0.19$	+	A		
				ADL Composite	$r = -0.37$	-			
				IADL Composite	$r = -0.13$	-			
				HDRSPD Composite	$r = -0.43$	-			
				HDRSCD Composite	$r = -0.07$	-			
				GDS (patient report) Composite	$r = -0.49$	-			
				GDS (caregiver report) Composite	$r = -0.53$	-			
				Pleasant Event Scale-AD Composite	$r = 0.40$	+			
	Matsui et al (2006)	PWD (83)	MMSE score ≥ 21	MMSE	$r = 0.43$	-	A		
				SMQ	$r = -0.03$	+			
				HADL	$r = -0.18$	-			
				NPI Mood factor	$r = -0.30$	-			
				NPI Euphoria factor	$r = -0.12$	-			
				NPI Psychosis factor	$r = -0.00$	-			
			MMSE	MMSE	$r = 0.06$	+			
				SMQ	$r = -0.02$	+			

Outcome measure	Study, year	Study sample (n)		Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			score < 21	HADL	*r* =- 0.17	-			
				NPI Mood factor	*r* =- 0.33	-			
				NPI Euphoria factor	*r* =- 0.11	-			
				NPI Psychosis factor	*r* =- 0.31	-			
		Caregivers (83)	MMSE score ≥ 21	MMSE	*r* = 0.19	+			
				SMQ	*r* = 0.10	+			
				HADL	*r* =- 0.04	-			
				NPI Mood factor	*r* =- 0.56	-			
				NPI Euphoria factor	*r* =- 0.07	-			
				NPI Psychosis factor	*r* =- 0.05	-			
			MMSE score < 21	MMSE	*r* = -0.13	+			
				SMQ	*r* =- 0.17	+			
				HADL	*r* =- 0.21	-			
				NPI Mood factor	*r* =- 0.36	-			
				NPI Euphoria factor	*r* =- 0.00	-			
				NPI Psychosis factor	*r* =- 0.49	-			
	Novelli et al (2010)	120		MMSE Composite	*r* = 0.24	+	A		
				GDS (patient report) Composite	*r* = -0.61	-			
				Cornell scale	*r* = -0.67	-			
				NPI Composite	*r* = -0.58	-			
				IADL Composite	*r* = -0.58	-			
				ADL Composite	*r* = -0.22	-			
				Beck depression Composite	*r* = -0.38	-			
				PQOL Composite	*r* = -0.16	-			
				C-PQOL Composite	*r* = 0.91	+			
				CQOL Composite	*r* = 0.70	+			
	Stypa et al (2020)	28		DQOL Total	*r* = 0.47	-	V		
		30		GDS	*r* = -0.34	-			
		27		Adapted NPI	*r* = -0.22	-			
	Wolak et al (2009)	119		ADL Composite	*r* = -0.01	-	A		
				IADL Composite	*r* = 0.08	-			
				NPIc Composite	*r* = -0.21	-			

Outcome measure	Study, year	Study sample (n)	Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			NPId Composite	r = -0.21	-			
			Charlson Composite	r = 0.08	+			
			Zarit Composite	r = -0.10	+			
	Yap et al. (2008)	67	PSMS Patient	r = 0.05	-	V		
			PSMS Caregiver	r = 0.24	-			
			IADL Patient	r = −0.08	-			
			IADL Caregiver	r = 0.21	-			
			RMBPC memory Patient	r = −0.17	+			
			RMBPC memory Caregiver	r = 0.46	+			
			RMBPC disruption Patient	r = −0.04	+			
			RMBPC disruption Caregiver	r = 0.27	+			
			RMBPC depression Patient	r = 0.10	+			
			RMBPC depression Caregiver	r = 0.22	+			
			PAS-AD Patient	r = 0.01	+			
			PAS-AD Caregiver	r = 0.21	+			
			SF-36 physical functioning Patient	r = 0.13	-			
			SF-36 physical functioning Caregiver	r = 0.42	-			
			SF-36 physical role limitation Patient	r = −0.06	-			
			SF-36 physical role limitation Caregiver	r = 0.51	-			
			GHQ Patient	r = −0.02	-			
			GHQ Caregiver	r = 0.34	+			
			Zarit Caregiver Burden Patient	r = −0.10	+			
			Zarit Caregiver Burden Caregiver	r = 0.39	-			
	Yu et al (2013)	PWD (195) Caregivers (87)	ADL-Behavior competence Patient	r = -0.24	-	V		
			ADL-Behavior competence Caregiver	r = -0.18	-			
			SF-36 PF-Physical functioning Patient	r = 0.29	-			
			SF-36 PF-Physical functioning Caregiver	r = 0.13	-			
			SF-36 RP- Physical functioning Patient	r = 0.27	-			
			SF-36 RP- Physical functioning Caregiver	r = 0.21	-			
			GDS- Psychological status Patient	r = -0.21	-			
			GDS- Psychological status Caregiver	r = 0.14	-			
			SF-36 MH- Psychological status Patient	r = 0.29	-			

Outcome measure	Study, year	Study sample (n)	Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			SF-36 MH- Psychological status Caregiver	*r* = 0.11	-			
			SDS- Interpersonal environment Patient	*r* = 0.19	-			
			SDS- Interpersonal environment Caregiver	*r* = -0.27	-			
			SAS- Interpersonal environment Patient	*r* = 0.20	-			
			SAS- Interpersonal environment Caregiver	*r* = -0.16	-			
			CBS- Interpersonal environment Patient	*r* = 0.23	+			
			CBS- Interpersonal environment Caregiver	*r* = -0.14	+			
DEMQOL	Lucas-Carrasco et al (2010)	88	WHOQOL-BREF physical Patient	*r* =0.39	+	V	Insufficient	High
		92	WHOQOL-BREF physical Caregiver	*r* =0.22	-			
		87	WHOQOL-BREF psychosocial Patient	*r* =0.50	+			
		91	WHOQOL-BREF psychosocial Caregiver	*r* =0.42	+			
		88	WHOQOL-BREF social relation Patient	*r* =0.12	-			
		92	WHOQOL-BREF social relation Caregiver	*r* =0.04	-			
		88	WHOQOL-BREF environment Patient	*r* =0.31	+			
		92	WHOQOL-BREF environment Caregiver	*r* =-0.18	-			
		102	GDS-15 Patient	*r* =-0.56	-			
		95	GDS-15 Caregiver	*r* =-0.39	-			
		102	Barthel Index Patient	*r* =0.21	-			
		95	Barthel Index Caregiver	*r* =0.04	-			
	Niikawa et al (2019)	87	MMSE Patient	*r* =-0.12	+	V		
			MMSE Caregiver	*r* =-0.02	+			
			Barthel Index Patient	*r* =-0.03	-			
			Barthel Index Caregiver	*r* =0.03	-			
			GDS-S-J Patient	*r* =-0.75	-			
			GDS-S-J Caregiver	*r* =-0.54	-			
			NPI-Q severity Patient	*r* =-0.50	-			
			NPI-Q severity Caregiver	*r* =-0.65	-			
			NPI-Q distress Patient	*r* =-0.49	-			
			NPI-Q distress Caregiver	*r* =-0.59	-			
			J-ZBI_8 Patient	*r* =-0.24	+			
			J-ZBI_8 Caregiver	*r* =-0.49	+			
			QOL-AD Patient DEMQOL-J	*r* =0.68	+			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
				DEMQOL-P-J	*r* =0.50	-			
			QOL-AD Caregiver	DEMQOL-J	*r* =0.38	-			
				DEMQOL-P-J	*r* =0.64	+			
			EQ-5D 3L Patient	DEMQOL-J	*r* =0.50	-			
				DEMQOL-P-J	*r* =0.37	-			
			EQ-5D 3L Caregiver	DEMQOL-J	*r* =0.44	-			
				DEMQOL-P-J	*r* =0.56	-			
			WHO-5-J	DEMQOL-J	*r* =0.70	+			
				DEMQOL-P-J	*r* =0.47	-			
	Smith et al (2005)	PWD (16)	DQOL Self-esteem		*r* =0.40	+	V		
		PWD (16)	DQOL Positive effect		*r* =0.45	+			
		PWD (16)	DQOL Negative affect		*r* =0.40	+			
		PWD (15)	DQOL Feelings of belongings		*r* =0.29	-			
		PWD (18)	DQOL Sense of aesthetics		*r* =-0.40	-			
		PWD (36)	QOL-AD-PWD		*r* =0.55	-			
		Caregivers (55)	QOL-AD-Carer		*r* =0.44	-			
		PWD (54)	SF-12 PCS-PWD		*r* =0.24	-			
		Caregivers (30)	SF-12 PCS-Carer		*r* =0.06	-			
		PWD (54)	SF-12 MCS-PWD		*r* =0.67	-			
		Caregivers (30)	SF-12 MCS-Carer		*r* =0.41	+			
		PWD (69)	MMSE		*r* =-0.18	+			
		Caregivers (84)			*r* =-0.03	+			
		PWD (71)	GDS-30		*r* =-0.11	-			
		Caregivers (96)			*r* =-0.66	-			
		PWD (65)	Barthel Index		*r* =-0.28	-			
		Caregivers (87)			*r* =-0.01	-			
		Caregivers (90)	Carer GHQ-12		*r* =-0.21	-			
	Smith et al (2007)	PWD (33)	QOL-AD-PWD		*r* =0.54	-	V		
		Caregivers (38)	QOL-AD-Carer		*r* =0.52	-			
		PWD (16)	DQOL Self-esteem		*r* =0.40	+			
		PWD (16)	DQOL Positive effect		*r* =0.45	+			
		PWD (16)	DQOL Negative affect		*r* =0.40	+			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		PWD (16)	DQOL Feelings of belongings		*r* =0.29	-			
		PWD (16)	DQOL Sense of aesthetics		*r* =-0.40	-			
		PWD (50)	SF-12 PCS-PWD		*r* =0.28	-			
		Caregivers (38)	SF-12 PCS-Carer		*r* =0.20	-			
		PWD (50)	SF-12 MCS-PWD		*r* =0.65	-			
		Caregivers (28)	SF-12 MCS-Carer		*r* =0.32	+			
		PWD (64)	GDS-30		*r* =-0.17	-			
		Caregivers (75)			*r* =-0.61	-			
		PWD (58)	Barthel Index		*r* =-0.28	-			
		Caregivers (68)			*r* =-0.05	-			
DQOL	Brod et al (1999)	PWD 95	Self-esteem	GDS	*r* = -0.48	-	**A**	Insufficient	High
			Positive affect		*r* = -0.61	-			
			Negative affect		*r* = -0.64	-			
			Feelings of belonging		*r* = -0.42	-			
	Lucas-Carrasco et al (2011b)	101	Self-esteem	WHOQOL-BREF physical	*r* = 0.15	-	**V**		
			Positive affect		*r* = 0.34	+			
			Negative affect		*r* = 0.36	+			
			Feelings of belonging		*r* = 0.14	-			
			Sense of aesthetics		*r* = 0.20	-			
			Self-esteem	WHOQOL-BREF psychosocial	*r* = 0.32	+			
			Positive affect		*r* = 0.64	-			
			Negative affect		*r* = 0.56	+			
			Feelings of belonging		*r* = 0.42	+			
			Sense of aesthetics		*r* = 0.33	+			
			Self-esteem	WHOQOL-BREF social relation	*r* = 0.15	-			
			Positive affect		*r* = 0.14	-			
			Negative affect		*r* = 0.11	-			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			Feelings of belonging		*r* = 0.05	-			
			Sense of aesthetics		*r* = -0.05	-			
			Self-esteem	WHOQOL-BREF environment	*r* = 0.32	+			
			Positive affect		*r* = 0.33	+			
			Negative affect		*r* = 0.28	-			
			Feelings of belonging		*r* = 0.43	+			
			Sense of aesthetics		*r* = 0.09	-			
			Self-esteem	GDS-15	*r* = - 0.18	-			
			Positive affect		*r* = -0.54	-			
			Negative affect		*r* = -0.58	-			
			Feelings of belonging		*r* = -0.25	-			
			Sense of aesthetics		*r* = -0.09	-			
			Self-esteem	Barthel Index	*r* = 0.09	-			
			Positive affect		*r* = 0.04	-			
			Negative affect		*r* = 0.09	-			
			Feelings of belonging		*r* = 0.06	-			
			Sense of aesthetics		*r* = 0.06	-			
	Voigt-Radloff (2012)	150	QOL-AD self		*r* = 0.56	-	V		
		147	QOL-AD carer		*r* = 0.17	-			
		112	SF-12-physical self		*r* = 0.37	-			
		112	SF-12-mental self		*r* = 0.45	-			
		122	CSDD carer		*r* = -0.25	-			
		285	IDDD carer		*r* = 0.02	-			
		267	MMSE		*r* = 0.02	-			
		151	ADAS-cog		*r* = -0.14	-			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Wolak et al (2010)	155	Self-esteem	Duke- Physical health	*r* = 0.15	-	A		
			Positive affect		*r* = 0.20	-			
			Negative affect		*r* = -0.39	-			
			Feelings of belonging		*r* = 0.06	-			
			Sense of aesthetics		*r* = 0.06	-			
			Self-esteem	Duke- Mental health	*r* = 0.37	+			
			Positive affect		*r* = 0.32	+			
			Negative affect		*r* = -0.64	-			
			Feelings of belonging		*r* = 0.18	-			
			Sense of aesthetics		*r* = 0.15	-			
			Self-esteem	Duke- Social health	*r* = 0.19	-			
			Positive affect		*r* = 0.27	-			
			Negative affect		*r* = -0.07	-			
			Feelings of belonging		*r* = 0.20	-			
			Sense of aesthetics		*r* = 0.06	-			
			Self-esteem	Duke- General health	*r* = 0.34	+			
			Positive affect		*r* = 0.38	+			
			Negative affect		*r* = -0.57	-			
			Feelings of belonging		*r* = 0.21	-			
			Sense of aesthetics		*r* = 0.14	-			
			Self-esteem	Duke- Perceived health	*r* = 0.17	-			
			Positive affect		*r* = 0.23	-			
			Negative affect		*r* = -0.34	-			
			Feelings of belonging		*r* = 0.13	-			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			Sense of aesthetics		*r* = 0.18	-			
			Self-esteem	Duke- Self-esteem	*r* = 0.33	+			
			Positive affect		*r* = 0.28	-			
			Negative affect		*r* = -0.37	-			
			Feelings of belonging		*r* = 0.19	-			
			Sense of aesthetics		*r* = 0.03	-			
			Self-esteem	Duke- Anxiety	*r* = 0.25	-			
			Positive affect		*r* = 0.22	-			
			Negative affect		*r* = -0.48	-			
			Feelings of belonging		*r* = 0.04	-			
			Sense of aesthetics		*r* = 0.13	-			
			Self-esteem	Duke- Depression	*r* = 0.33	+			
			Positive affect		*r* = 0.30	+			
			Negative affect		*r* = -0.59	-			
			Feelings of belonging		*r* = 0.11	-			
			Sense of aesthetics		*r* = 0.12	-			
Cornell-Brown	Lucas-Carrasco et al (2013)	100	GDS-15		*r* = -0.54	-	**A**	Insufficient	Low
			Barthel Index		*r* = 0.02	-			
			MMSE		*r* = -0.17	-			
			WHOQOL-BREF physical		*r* = 0.54	+			
			WHOQOL-BREF psychosocial		*r* = 0.57	+	**I**		
			WHOQOL-BREF social		*r* = 0.20	-			
			WHOQOL-BREF environment		*r* = 0.20	-			
	Ready et al (2002)	26	VADS rating		*r* = 0.63	-			
BASQID		41	WHOQOL-BREF – Physical		*r* = 0.32	+	V	Sufficient	High

Outcome measure	Study, year	Study sample (n)	Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Trigg et al., (2007a)	41	WHOQOL-BREF – Psychological	$r = 0.39$	+			
		30	WHOQOL-BREF – Social	$r = 0.59$	+			
		41	WHOQOL-BREF – Environmental	$r = 0.34$	+			
		47	GDS-15	$r = 0.58$	+			
		143	MMSE	$r = -0.08$	+			
ADRQL	Kasper et al(2009)	146	SF-36 Mental health	$r = 0.02$	-	A	Insufficient	Moderate
			SF-36 Vitality	$r = 0.05$	-			
			SF-36 Social Functioning	$r = 0.15$	-			
QOLAS	Selai et al (2001)	Mild to moderate (n=22)	COOP patient	$r = 0.40$	-	V	Insufficient	Low
			EQ-5D mobility Patient	$r = 0.23$	-			
			EQ-5D mobility Caregiver	$r = 0.43$	+			
			EQ-5D self-care Patient	$r = -0.01$	-			
			EQ-5D self-care Caregiver	$r = 0.26$	-			
			EQ-5D usual activities Patient	$r = 0.41$	+			
			EQ-5D usual activities Caregiver	$r = 0.54$	+			
			EQ-5D pain/discomfort Patient	$r = 0.39$	+			
			EQ-5D pain/discomfort Caregiver	$r = -0.15$	-			
			EQ-5D anxiety/depression Patient	$r = 0.52$	-			
			EQ-5D anxiety/depression Caregiver	$r = 0.63$	-			
			NPI-global Caregiver	$r = 0.32$	+			
			IDDD Caregiver	$r = 0.42$	+			
		Mild (n=12)	COOP patient	$r = 0.47$	-			
			EQ-5D mobility Patient	$r = 0.26$	-			
			EQ-5D mobility Caregiver	$r = 0.59$	+			
			EQ-5D self-care Patient	$r = 0.48$	+			
			EQ-5D self-care Caregiver	$r = 0.39$	+			
			EQ-5D usual activities Patient	$r = 0.51$	+			
			EQ-5D usual activities Caregiver	$r = 0.57$	+			

Outcome measure	Study, year	Study sample (n)	Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			EQ-5D pain/discomfort Patient	$r = 0.62$	+			
			EQ-5D pain/discomfort Caregiver	$r = 0.47$	+			
			NPI-global Caregiver	$r = 0.70$	-			
			IDDD Caregiver	$r = 0.55$	+			
EQ-5D-3L	Kunz et al (2010)	335	NOSGER IADL PWD	$r = -0.40$	-	V	Insufficient	High
		351	NOSGER IADL Caregiver	$r = -0.57$	-			
		336	MMSE PWD	$r = 0.18$	+			
		351	MMSE caregiver	$r = 0.24$	+			
		369	QOLAD self-rating score	$r = 0.64$	+			
		351	QOLAD proxy-rating score	$r = 0.31$	-			
	Orgeta et al (2015)	478	CSDD (carer rating)	$r = -0.23$	-	V		
			RAID (self-rating)	$r = -0.17$	-			
			RAID (carer rating)	$r = 0.00$	-			
			BADLs (self-rating)	$r = -0.26$	-			
			BADLs (carer rating)	$r = -0.46$	-			
			RSS (self-rating)	$r = 0.10$	-			
			RSS (carer rating)	$r = -0.17$	-			
			GHQ (carer rating)	$r = -0.01$	-			
	Michalowsky et al (2020)	498	EQ-VAS	$r = 0.42$	-	V		
			QOLAD self-rating score	$r = 0.49$	-			
	Michalowsky et al (2021)	77	GDS	$r = -0.372$	-	A		
			EQ-VAS	$r = 0.488$	-			
			QOLAD self-rating score	$r = 0.397$	-			
EQ-5D-5L		77	GDS	$r = -0.311$	-	A	Insufficient	Low
			CDR (carer rating)	$r = 0.19$	+			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	Michalowsky et al (2021)		CSDD (self-rating)		*r* =-0.07	-			
SF-36	Geschke et al (2013)	60	Physical function	QOL-AD	*r* = 0.49	-	V	Insufficient	Moderate
			Role-physical		*r* = 0.49	-			
			Bodily pain		*r* = 0.60	+			
			General health		*r* = 0.51	-			
			Vitality		*r* = 0.50	-			
			Social functioning		*r* = 0.37	-			
			Role-emotional		*r* = 0.46	-			
			Mental health		*r* = 0.62	+			
HUI2	Karlawish et al (2008a)	30	MMSE (24-29)		*r* = 0.89	-	V	Insufficient	Moderate
		36	MMSE (20-23)		*r* = 0.85	-			
		27	MMSE (11-19)		*r* = 0.92	-			
		36	3MS (73-90)		*r* = 0.89	-			
		32	3MS (60-72)		*r* = 0.85	-			
		25	3MS (24-59)		*r* = 0.89	-			
		28	QOL-AD (42-52)		*r* = 0.96	+			
		35	QOL-AD (37-41)		*r* = 0.91	+			
		30	QOL-AD (24-36)		*r* = 0.77	+			
		29	IADL-patient (8-10)		*r* = 0.94	-			
		31	IADL-patient (11-14)		*r* = 0.89	-			

Outcome measure	Study, year	Study sample (n)	Measure	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		33	IADL-patient (15-27)	$r = 0.81$	-			
		34	IADL-caregiver (8-18)	$r = 0.90$	-			
		26	IADL-caregiver (19-24)	$r = 0.92$	-			
		26	IADL-caregiver (25-31)	$r = 0.83$	-			
		59	BADL-patient (6)	$r = 0.93$	-			
		34	BADL-patient (7-14)	$r = 0.80$	-			
		49	BADL-caregiver (6-7)	$r = 0.91$	-			
		37	BADL-caregiver (8-19)	$r = 0.85$	-			
		36	GDS (0-1)	$r = 0.95$	-			
		26	GDS (2-3)	$r = 0.90$	-			
		31	GDS (4-11)	$r = 0.79$	-			
		29	SF-12 Mental functioning (56.0-67.5)	$r = 0.91$	-			
		32	SF-12 Mental functioning (50.8-56.0)	$r = 0.91$	-			
		32	SF-12 Mental functioning (28.9-50.8)	$r = 0.82$	-			
		30	SF-12 Physical functioning (53.5-64.0)	$r = 0.97$	-			
		30	SF-12 Physical functioning (44.0-53.5)	$r = 0.90$	-			
		33	SF-12 Physical functioning (26.4-44.0)	$r = 0.79$	-			
	Karlawish et al (2008b)	28	MMSE (24-29)	$r = 0.76$	-	V		
		37	MMSE (20-23)	$r = 0.70$	-			
		35	MMSE (11-19)	$r = 0.71$	-			
		34	3MS (73-90)	$r = 0.76$	-			
		34	3MS (60-72)	$r = 0.71$	-			
		32	3MS (24-59)	$r = 0.70$	-			
		34	QOL-AD (36-47)	$r = 0.84$	+			
		31	QOL-AD (33-35)	$r = 0.72$	+			
		35	QOL-AD (22-32)	$r = 0.61$	+			
		34	IADL (8-18)	$r = 0.79$	-			
		34	IADL (19-24)	$r = 0.77$	-			
		32	IADL (25-31)	$r = 0.60$	+			
		33	BADL (6)	$r = 0.79$	-			
		30	BADL (7-8)	$r = 0.75$	-			
		37	BADL (9-22)	$r = 0.64$	-			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		36	SF-12 Mental functioning (51.7-66.4)		r = 0.79	-			
		31	SF-12 Mental functioning (40.7-51.7)		r = 0.75	-			
		33	SF-12 Mental functioning (8.6-40.6)		r = 0.61	-			
		34	SF-12 Physical functioning (53.5-64.0)		r = 0.78	-			
		32	SF-12 Physical functioning (44.0-53.5)		r = 0.72	-			
		34	SF-12 Physical functioning (26.4-44.0)		r = 0.66	-			
	Kavirajan et al (2009)	392 to 408	Sensation utility	Charlson Comorbidity Index	r = -0.07	-	D		
			Mobility utility		r = -0.20	-			
			Emotion utility		r = -0.10	-			
			Cognition utility		r = -0.00	-			
			Self-care utility		r = -0.08	-			
			Pain utility		r = -0.09	-			
			Multi-attribute utility		r = -0.12	-			
			Sensation utility	Blessed dementia rating scale	r = -0.40	-			
			Mobility utility		r = -0.56	-			
			Emotion utility		r = -0.19	-			
			Cognition utility		r = -0.66	-			
			Self-care utility		r = -0.71	-			
			Pain utility		r = -0.19	-			
			Multi-attribute utility		r = -0.69	-			
			Sensation utility	Composite Behavioral score	r = 0.26	-			
			Mobility utility		r = 0.13	-			
			Emotion utility		r = 0.71	-			
			Cognition utility		r = 0.18	-			
			Self-care utility		r = 0.11	-			
			Pain utility		r = 0.31	+			
			Multi-attribute utility		r = 0.44	+			
	Kavirajan et al (2009)	392 to 408	Vision utility	Charlson Comorbidity Index	r = -0.06	-	D	Insufficient	Low
			Hearing utility		r = -0.10	-			
			Speech utility		r = 0.05	-			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
HUI3			Ambulation utility		*r* = -0.20	-			
			Dexterity utility		*r* = -0.07	-			
			Emotion utility		*r* = -0.04	-			
			Cognition utility		*r* = -0.00	-			
			Pain utility		*r* = -0.13	-			
			Multi-attribute utility		*r* = -0.10	-			
			Vision utility	Blessed dementia rating scale	*r* = -0.23	-			
			Hearing utility		*r* = -0.05	-			
			Speech utility		*r* = -0.42	-			
			Ambulation utility		*r* = -0.57	-			
			Dexterity utility		*r* = -0.46	-			
			Emotion utility		*r* = -0.20	-			
			Cognition utility		*r* = -0.67	-			
			Pain utility		*r* = -0.22	-			
			Multi-attribute utility		*r* = -0.69	-			
			Vision utility	Composite Behavioral score	*r* = 0.25	-			
			Hearing utility		*r* = 0.16	-			
			Speech utility		*r* = 0.20	-			
			Ambulation utility		*r* = 0.13	-			
			Dexterity utility		*r* = 0.18	-			
			Emotion utility		*r* = 0.52	+			
			Cognition utility		*r* = 0.24	-			
			Pain utility		*r* = 0.26	-			
			Multi-attribute utility		*r* = 0.41	+			
WHOQOL	Lucas-Carrasco et al (2011a)	104	Physical	DEMQOL-28	*r* = 0.38	+	A	Insufficient	Moderate
			Psychological		*r* = 0.49	+			
			Social relations		*r* = 0.16	-			
			Environment		*r* = 0.35	+			
			Physical	GDS-15	*r* = -0.52	-			
			Psychological		*r* = -0.64	-			

Outcome measure	Study, year	Study sample (n)	Measure		Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			Social relations		*r* = -0.24	-			
			Environment		*r* = -0.45	-			
			Physical	Barthel Index	*r* = 0.46	+			
			Psychological		*r* = 0.21	-			
			Social relations		*r* = 0.29	-			
			Environment		*r* = 0.18	-			
			Physical	MMSE	*r* = -0.01	+			
			Psychological		*r* = 0.05	+			
			Social relations		*r* = 0.26	+			
			Environment		*r* = 0.30	-			

n, number; PWD, people with dementia; MMSE, Mini Mental State Examination; ADCS-ADL, Alzheimer's Disease Assessment Scale- Activities of Daily Living; NPI, Neuropsychiatric Inventory; HSQ, Health Status Questionnaire; HADS, Hospital Anxiety and Depression Scale; SPPB, Short Physical Performance Battery; BADLS-CZ, Bristol Activities of Daily Living Scale -Czech version; ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; HDRSPD; Hamilton Depression Rating Scale for Parkinson's Disease; GDS, Geriatric Depression Scale; PWD, People with dementia; SMQ, Short Memory Questionnaire; HADL, Hyogo Activities of Daily Living Scale; QOL, quality of life; QOL-AD, quality of life in Alzheimer's disease; PQOL, patient reports on own QOL; C-PQOL, caregiver reports on patients QOL; CQOL, caregiver report on own QOL; DEMQOL, Dementia Quality of Life Instrument; DQOL, Dementia Quality of Life Instrument; PSMS, Physical Self-Maintenance Scale; RMBPC, Revised Memory and Behavior Problems Checklist; GHQ, General Health Questionnaire; SAS, Simpson-Angus Scale, SDS, Self-Rating Depression Scale; CBD, caregiver burden questionnaire; WHOQOL, World Health Organization Quality of Life Scale ; WHOQOL-BREF, World Health Organization Quality of Life Scale Brief Version; NOSGER, Nurses' Observation Scale for Geriatric Patients; EQ-5D-3L, three-level version EuroQol-5 dimension; GDS-S-J, Geriatric Depression Scale Short-Form Japanese; J-ZBI_8, short version of the Japanese version of the Zarit Caregiver Burden Interview; WHO-5-J, Japanese version of the World Health Organization Five Well-being Index; CSDD, Cornell Scale for Depression in Dementia; RAID Rating of anxiety in dementia; BADLS, Bristol Activities of Daily Living Scale, RSS, Relative's Stress Scale; 3MS, Modified Mini Mental State Examination; CDR, Clinical Dementia Rating scale; IDDD, Performance Scale of the Interview of Deterioration in Daily Living Activities in Dementia; ADAS-cog, Alzheimer's Disease Assessment Scale – cognitive; BASQID, Bath Assessment of Subjective Quality of Life in Dementia; ADRQL, Alzheimer's Disease-Related Quality of Life; HUI, Health Utilities Index; QOLAS, Quality of Life Scale; COOP, Dartmouth COOP charts

Table 6: Known-groups validity

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
DEMQOL	Lucas-Carrasco et al (2010)	Self-perceived health Healthy vs. Unhealthy (DEMQOL 101/ DEMQOL-P 95)	Scores were significantly higher in Healthy group	$p = 0.021$	+	A	Insufficient	Moderate
		Depressed vs. non-depressed (DEMQOL 102/ DEMQOL-P 94)	Scores were significantly higher in non-depressed group	$p < 0.001$	+			
		Type of cognitive impairment (DEMQOL 96/ DEMQOL-P 87)	No significant differences in DEMQOL and DEMQOL-P scores according to type of cognitive impairment	$p = 0.481$ (DEMQOL)	-			
				$p = 0.139$ (DEMQOL-P)	-			
		MCI vs. dementia (DEMQOL 102/ DEMQOL-P 95)	No significant differences in DEMQOL and DEMQOL-P scores according to MCI vs. dementia	$p = 0.146$ (DEMQOL)	-			
				$p = 0.566$ (DEMQOL-P)	-			
		MMSE <18 vs. MMSE ≥18 (DEMQOL 102/ DEMQOL-P 95)	No significant differences in DEMQOL and DEMQOL-P scores according to severity of dementia	$p = 0.146$ (DEMQOL)	-			
				$p = 0.902$ (DEMQOL-P)	-			
	Smith et al (2005)	Mild/moderate subsample (77) vs Severe subsample (22)	DEMQOL-P people with severe dementia show marginally better HRQoL than those with mild/moderate dementia	Effect size –0.10	-	I		
DQOL	Brod et al (1999)	Possibly depressed group (15) vs non-depressed group (79)	Significantly higher mean scale scores for the nondepressed group compared with the possibly depressed group	Sense of Belonging ($p \leq 0.001$)	+	A	Insufficient	Low
				Negative Affect ($p \leq 0.001$)	+			
				Positive Affect	+			

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
			(Sense of belonging, Negative affect, Positive affect, and Self-esteem)	($p \leq 0.001$)				
				Self Esteem ($p \leq 0.001$)	+			
				Aesthetics scale ($p = 0.087$)	-			
	Karim et al 2007	Quality of life Very good (13) Good (18), and Fair (5)	Significant differences between groups for the DQOL were found for some of the scales	Sense of Belonging ($p = 0.109$)	-	A		
				Negative Affect (p = 0.070)	-			
				Positive Affect (p = 0.560)	-			
				Self Esteem (p = 0.020)	+			
				Aesthetics scale (p = 0.621)	-			
		Patient's general health Very good (8), Good (19), and Fair (8)		Sense of Belonging ($p = 0.006$)	+			
				Negative Affect ($p = 0.009$)	+			
				Positive Affect ($p = 0.153$)	-			
				Self Esteem ($p = 0.002$)	+			
				Aesthetics scale ($p = 0.765$)	-			
		Dementia severity Mild (6), Moderate (30)		Sense of Belonging ($p = 0.694$)	-			
				Negative Affect ($p = 0.520$)	-			

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
				Positive Affect (p = 0.371)	-			
				Self Esteem (p = 0.725)	-			
				Aesthetics scale (p = 0.020)	+			
	Lucas-Carrasco et al (2011b)	Male vs Female (101)	None of the DQOL scales were significantly associated with age, gender, marital status and education	NS	-	I		
		Married vs Widowed (101)						
		Primary school or more vs Less than primary school (101)						
		Healthy vs Unhealthy (101)	Scores were higher for all scales in health group. But significant differences were found only on the Negative Affect scale	Sense of Belonging (NS)	-			
				Negative Affect (p <0.001)	+			
				Positive Affect (NS)	-			
				Self Esteem (NS)	-			
				Aesthetics scale (NS)	-			
		GDS-15 (101) ≥ 6 vs < 6	Scores were higher in non-depressed than depressed, but significant differences were found on the Positive Affect and Negative Affect scales only	Sense of Belonging (NS)	-			
				Positive Affect (p <0.001)	+			
				Negative Affect (p <0.001)	+			
				Self Esteem (NS)	-			
				Aesthetics scale (NS)	-			

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		MMSE (101) ≤ 17 vs >17	No significant differences in scores between subjects with mild and moderate dementia	NR	-			
	Wolak et al (2010)	MMSE (155) ≥ 18 vs <18	No influence of cognitive status, depression status, presence of behavioural troubles, level of dependence and caregiver burden score on DQOL scores	Self-esteem ($p \leq 0.01$)	+	I		
				Positive Affects ($p \leq 0.001$)	+			
				Negative Affect (NS)	-			
				Feelings of belongings ($p \leq 0.01$)	+			
				Sense of aesthetics ($p \leq 0.01$)	+			
		Cornell's scale (155) <8 vs ≥8		Self-esteem ($p \leq 0.001$)	+			
				Positive Affects ($p \leq 0.01$)	+			
				Negative Affect ($p \leq 0.001$)	+			
				Feelings of belongings (NS)	-			
				Sense of aesthetics (NS)	-			
		NPI (155) <13 vs ≥13		Self-esteem (NS)	-			

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
				Positive Affects ($p \leq 0.05$)	+			
				Negative Affect ($p \leq 0.05$)	+			
				Feelings of belongings (NS)	-			
				Sense of aesthetics (NS)	-			
		IADL (155) <2 vs ≥2		Self-esteem (NS)	-			
				Positive Affects (NS)	-			
				Negative Affect (NS)	-			
				Feelings of belongings (NS)	-			
				Sense of aesthetics (NS)	-			
		Zarit (155) <21 vs ≥21		Self-esteem (NS)	-			
				Positive Affects (NS)	-			
				Negative Affect (NS)	-			
				Feelings of belongings (NS)	-			
				Sense of aesthetics (NS)	-			
Cornell-Brown	Lucas-Carrasco	Male vs Female (100)	No significant differences	$t = 0.899$ ($p = 0.371$)	-	A	Insufficient	Low

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
	et al (2013)	Healthy vs Unhealthy (100)	Scores were significantly higher in Healthy group	$t = 9.562$ ($p = 0.003$)	+			
		GDS-15 (100) ≥ 6 vs < 6	Scores were significantly higher in non depressed	$t = 5.354$ ($p < 0.001$)	+			
		No. self-reported chronic conditions (100) 4 vs ≥4	Scores were significantly higher in fewer chronic health conditions	$t = 2.388$ ($p = 0.019$)	+			
		MMSE (100) ≤ 17 vs >17	No significant differences	$t = 1.049$ ($p = 0.297$)	-			
ADRQL	Kasper et al (2009)	MMSE (100) <18 vs 18+	Significant lower mean scores (MMSE <18 group) Bonferroni adjustment for multiple comparisons	$P<0.05$	+	D	Sufficient	Moderate
		ADL difficulties (146) None, 1-2, 3-5	Significant high mean scores in none ADL difficulties group Bonferroni adjustment for multiple comparisons	$P<0.05$	+			
		Behavioral & psychological symptoms (146) No vs Yes	Significant high mean scores in 'No' group Bonferroni adjustment for multiple comparisons	$P<0.05$	+			
		Years since diagnosis (146) <1, 1-3, 3+	Significant high mean scores in <1 group	$P<0.05$	+			
		Survival (146) Died within 3years vs Survived	Significant lower mean scores in Died within 3years group Bonferroni adjustment for multiple comparisons	$P<0.05$	+			
		Nursing home entry (146) No vs Within 3 years	No significant differences	NR	-			
EQ-5D-3L	Michalowsky et al., 2020	General health status (560) Bad, average, above average	Significantly different among different stages of general health	$p < 0.001$	+			Moderate

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		Instrumental ADL (560) No problem. Moderate problems, Severe problems	Significantly different among different stages of IADL	$p < 0.001$	+	D	Insufficient	
		Functional impairment due to dementia (560) Moderate, severe	Not significantly different between stages of functional impairment due to dementia	NS	-			
		Depression (560) No hint for, Mild, Moderate to severe	Significantly different among different stages of depression	$p < 0.001$	+			
	Michalowsky et al., 2021	MMSE (139) No hint for, Mild, Moderate to severe	Not significantly different between stages of cognitive impairment	$p = 0.267$	-	A		
		General physical health (139) Very good, Good, Poor	Significantly different among different stages of general physical health	$p = 0.001$	+			
		General mental health (139) Very good, Good, Poor	Significantly different among different stages of general mental health	$p = 0.019$	+			
		Depression (139) No hint for, Hint for	Significantly higher scores in No hint for depression group	$p = 0.001$	+			
		Functional impairment (139) No problem, Moderate, Severe	Not significantly different between stages of functional impairment	$p = 0.084$	-			
		Pain (139) No problem, Moderate, Severe	Significantly higher scores in no Pain group	$p = 0.001$	+			
		Hospitalization (139) Yes, No	Significantly higher scores in no hospitalization group	$p = 0.002$	+			
EQ-5D-5L	Michalowsky et al (2021)	MMSE (139) No hint for, Mild, Moderate to severe	Not significantly different between stages of cognitive impairment	$p = 0.057$	-			Moderate

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		General physical health (139) Very good, Good, Poor	Significantly different among different stages of general physical health	$p = 0.040$	+	A	Insufficient	
		General mental health (139) Very good, Good, Poor	Not significantly different between stages of general mental health	$p = 0.396$	-			
		Depression (139) No hint for, Hint for	Significantly higher scores in No hint for depression group	$p = 0.001$	+			
		Functional impairment (139) No problem, Moderate, Severe	Not significantly different between stages of functional impairment	$p = 0.301$	-			
		Pain (139) No problem, Moderate, Severe	Significantly higher scores in no Pain group	$p = 0.001$	+			
		Hospitalization (139) Yes, No	Significantly higher scores in no hospitalization group	$p = 0.002$	+			
WHOQOL	Lucas-Carrasco et al (2011a)	Male vs Female (104)	None of the WHOQOL-BREF domains were significantly associated with sex, marital status, or education	Physical $t = 0.445$ (NS)	-	I	Insufficient	Very Low
				Psychological $t = 0.597$ (NS)	-			
				Social Relations $t = -0.917$ (NS)	-			
				Environment $t = -0.700$ (NS)	-			
		Married vs Widowed (104)		Physical $t = 0.809$ (NS)	-			
				Psychological $t = 0.243$ (NS)	-			
				Social Relations $t = 1.715$ (NS)	-			
				Environment $t = -0.838$ (NS)	-			

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
		Primary school or more vs Less than primary school (104)		Physical t = -0.231 (NS)	-			
				Psychological t = 0.076 (NS)	-			
				Social Relations t = -0.138 (NS)	-			
				Environment t = 0.673 (NS)	-			
		Healthy vs Unhealthy (104)	Scores were significantly higher in all domains, showing better QOL in PWD who perceived themselves to be healthy compared with unhealthy. A similar pattern was found for non depressed	Physical t = 3.278 (p <0.01)	+			
				Psychological t = 3.147 (p <0.01)	+			
				Social Relations t = 2.431 (p <0.05)	+			
				Environment t = 2.158 (p <0.05)	+			
		GDS-15 (104) ≥ 6 vs < 6		Physical t = -4.642 (p <0.01)	+			
				Psychological t = -6.849 (p <0.01)	+			
				Social Relations t = -2.065 (p <0.05)	+			
				Environment t = -4.720 (p <0.05)	+			
		MMSE (104) ≤ 17 vs >17	Scores were significantly higher in mild group in 2 domains: social and environmental	Physical t = - 0.583 (NS)	-			
				Psychological t = 0.125 (NS)	-			
				Social Relations	+			

Outcome measure	Study, year	Group (n)	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence (GRADE)
				$t = 2.637$ ($p < 0.05$)				
				Environment $t = 2.755$ ($p < 0.01$)	+			
		No. self-reported chronic conditions (104) 4 vs ≥4	Fewer chronic medical conditions had significant higher scores on the physical and psychological domains	Physical $t = 2.595$ ($p < 0.05$)	+			
				Psychological $t = 1.565$ (NS)	-			
				Social Relations $t = 1.134$ (NS)	-			
				Environment $t = 0.132$ (NS)	-			

n, number; PWD, people with dementia; DEMQOL, Dementia Quality of Life Instrument; DEMQOL-P, Dementia Quality of Life Instrument-proxy; MCI, Mild cognitive impairment; MMSE, Mini Mental State Examination; EQ-5D-3L, three-level version EuroQol-5 dimension; ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; NS, not significant; EQ-5D-5L, five-level version EuroQol-5 dimension; DQOL, Dementia Quality of Life Instrument; GDS, Geriatric Depression Scale; NR, not reported; NPI, Neuropsychiatric Inventory; ADRQL, Alzheimer's Disease-Related Quality of Life; WHOQOL, World Health Organization Quality of Life Scale

Table 7: Responsiveness

Outcome measure	Study, year	Study sample (n)	Time interval	Findings	Statistical information	Results of Hypotheses testing	Risk of Bias	Overall Rating	Quality of evidence
ADRQL	Kasper et al., 2009	146	1 year	Mean score significant decrease ($p < 0.05$) in increase ADL group. No change ADL group showed no significant difference		+	I	Insufficient	Very Low
BASQID	Trigg et al (2007a)	Clinical Global Change Rating Worse (3)	3 months	Significant correlations between clinician global	Effect size -0.67	+	A	Insufficient	Very Low

		Clinical Global Change Rating Same (23)			ratings of QoL change effect size statistics	Effect size 0.00	+			
		Clinical Global Change Rating Better (10)				Effect size 0.43	-			
EQ-5D-3L	Kunz et al (2010)	PWD (369/261)	Better Health	1 year		Effect size 0.12	-	D	Insufficient	Low
			Worse Health			Effect size 0.41	-			
		Caregiver (351/ 278)	Better Health			Effect size 0.01	-			
			Worse Health			Effect size 0.40	-			
HUI2	Kaviraja n et al., 2009	Large improvement (53)		1 year	With behavioral worsening, effective size was negative with magnitudes generally proportionate to magnitude of behavioral change	Effect size 0.04	-	A	Sufficient	Moderate
		Medium Improvement (42)				Effect size -0.30	-			
		Small improvement (43)				Effect size -0.01	+			
		No change (87)				Effect size -0.30	+			
		Small decline (35)				Effect size -0.48	+			
		Medium decline (31)				Effect size -0.65	+			
		Large decline (42)				Effect size -0.78	+			
		No Change–Remained in Home (240)			Effect size for subjects remaining at home indicated insignificant or small change	Effect size -0.30	+			
		Change From Home to Nursing Facility (29)				Effect size -0.76	+			

HUI3		Large improvement (53)	1 Year	With behavioral worsening, effective size was negative with magnitudes generally proportionate to magnitude of behavioral change	Effect size -0.06	-	A	Sufficient	Moderate
		Medium Improvement (42)			Effect size -0.16	-			
		Small improvement (43)			Effect size 0.06	+			
		No change (87)			Effect size -0.29	+			
		Small decline (35)			Effect size -0.48	+			
		Medium decline (31)			Effect size -0.67	+			
		Large decline (42)			Effect size -0.64	+			
		No Change–Remained in Home (240)		Effect size for subjects remaining at home indicated insignificant or small change	Effect size -0.27	+			
		Change From Home to Nursing Facility (29)			Effect size -0.50	+			

n, number; EQ-5D, EuroQol-5 dimension; PWD, people with dementia; ADRQL, Alzheimer's Disease-Related Quality of Life; ADL, Activities of Daily Living; HUI, Health Utilities Index; BASQID, Bath Assessment of Subjective Quality of Life in Dementia

Table 8: Summary table of quality of evidence and overall rating

Measure	How many studies	Structural Validity	Internal consistency	Test-retest Reliability	Known-groups validity	Convergent validity	Responsiveness
QOL-AD	10	Unidimensional	Moderate (+)	Moderate Test-retest: (+) Inter-rater: (-)		High (-)	
DEMQOL	6	High (+)	Moderate (+)	Low (+)	Moderate (-)	High (-)	
DQOL	5		Moderate (+/-)	Low (+/-)	Low (-)	High (-)	
BASQID	2		Moderate (+)	Very low (+)		High (+)	Very low (-)
CBS	2		Moderate (+)		Low (-)	Low (-)	
ADRQL	1		Moderate (+/-)		Moderate (+)	Moderate (-)	Very low (-)
QLDJ	1			Low Test-retest: (+) Inter-rater: (+)			
QOLAS	1		Moderate (+)			Low (-)	
EQ-5D-3L	1		Very good (+)	Low Test-retest: (-) Inter-rater: (-)	Moderate (-)	High (-)	Low (-)
EQ-5D-5L	1				Moderate (-)	Low (-)	
HUI2	2			Very low (-)		Moderate (-)	Moderate (+)
HUI3	1					Low (-)	Moderate (+)
SF-36	1		Moderate (+)			Moderate (-)	
WHOQOL	1		Moderate (+)	Very low (-)	Very low (-)	Moderate (-)	

(+) = Sufficient, (-) = Insufficient, (+/-) = Inconsistent, QOL-AD; quality of life in Alzheimer's disease, DEMQOL; Dementia Quality of Life Instrument, DQOL; Dementia Quality of Life Instrument, BASQID; Bath Assessment of Subjective Quality of Life in Dementia, ADRQL; Alzheimer's Disease Related Quality of Life, BASQID; Bath Assessment of Subjective Quality of Life in Dementia, CBS; Cornell-Brown Scale, ADRQL; Alzheimer's Disease Related Quality of Life, QOLAS; Quality of Life Scale, EQ-5D-3L; three-level version EuroQol-5 dimension, EQ-5D-5L; five-level version EuroQol-5 dimension, HUI2; Health Utilities Index 2, HUI3; Health Utilities Index 3, SF-36; Short-Form 36 Health Survey, WHOQOL; World Health Organization Quality-of-Life Scale.

CHAPTER 4:
Discussion

1.0 Thesis results

Quality of life (QOL) and health-related quality of life (HRQOL) measures are used to determine the health and well-being of individuals living with dementia (Martyr et al., 2017). In this thesis, we conducted a qualitative study asking caregivers what behaviours, symptoms, and activities they perceive are important in the assessment of dementia (Chapter 2) and conducted a systematic review to evaluate the psychometric properties of published QOL and HRQOL measures in people with dementia (PWD) living in the community (Chapter 3).

In Chapter 2, we conducted listening sessions to understand what caregivers for individuals with dementia consider important when assessing the QOL and HRQOL of individuals with dementia, specifically regarding their dementia progression and treatment. Using a qualitative approach, this study allowed us to identify key symptoms and behaviours that are important in the assessment of dementia from the perspective of caregivers. We found that everyday activities, changes in mood, cognitive difficulties and extrinsic factors were important for caregivers when evaluating QOL in PWD. The assessment of treatment impact on dementia progression often involves using cognitive measures such as the Mini-Mental State Examination (MMSE) and Montreal Cognitive Assessment (MoCA). (Garg et al., 2022; Harrison et al., 2016; Webster et al., 2017). Similarly, quality-adjusted life years are often used to include outcomes for health economic considerations (Whitehead & Ali, 2010; Shearer et al., 2012; Meeuwsen et al.,2013). Our results underscore the significance of considering not only cognitive or economic outcomes, but also examining outcomes such as alterations in mobility, feeding, social interactions, and emotions when assessing the impact of treatment or changes in dementia status. Most of these outcomes are assessed in commonly used QOL and HRQOL measures. Thus, the

results from Chapter 2 reinforced the importance of QOL and HRQOL measures as endpoints in clinical research and practice as well as how it affects family caregivers.

Hence, Chapter 3 was a systematic review on the measurement properties of QOL and HRQOL measures that are commonly used in PWD living in the community. This review revealed that there were 13 QOL or HRQOL measures tested for measurement properties such as reliability, validity and responsiveness. The results suggested that many commonly used measures may not be appropriate to use due their weak psychometric properties. Most of the measures evaluated in this review had moderate quality of evidence for internal consistency whereas they had moderate to low quality of evidence for convergent validity. Known-groups validity was evaluated for about half of the measures (six out of 13 measures) and they scored from moderate to very low quality of evidence. From the review, QOL-AD had the most studies included with only three psychometric properties assessed. However, DEMQOL had five psychometric properties assessed. Both did not assess responsiveness which is important because such measures need to capture changes in QOL over time (Mokkink et al., 2010). This may mean that PWD's QOL and HRQOL are not currently being captured adequately suggesting the need for future research to rigorously evaluate the psychometric properties (i.e. responsiveness) of these measures.

2.0 Impact of results

Findings from this thesis support the importance of including QOL and HRQOL measures when evaluating dementia progression and the effects of treatment. Caregivers reported the importance of outcomes such as mobility, social interactions, and emotions when assessing dementia impact. QOL and HRQOL measures provide an opportunity to assess such outcomes, and can be

included in research and clinical settings (Bowling et al., 2014; Banerjee et al., 2009). An interesting finding from Chapter 2 was that caregivers also discussed the importance of extrinsic factors such as financial decision-making, living situation, and communication barriers with health care professionals and others that can affect one's QOL. These domains are not present in most QOL and HRQOL measures. Caregivers reported these as being important to include because they can help inform their decision when it comes to PWD's dementia progression, interventions and treatment.

Furthermore, our findings showed the importance of evaluating the psychometric properties of dementia-specific measures as well as commonly used generic measures. The results of the systematic review suggest that caregivers, clinicians and researchers need to be aware that some of the measures may be limited and scores may not appropriately showcase the PWD's QOL or HRQOL. Many of the included measures had mixed evidence in support of their psychometric properties, and most were not evaluated for responsiveness. Hence, caregivers, healthcare workers and researchers need to be aware of such limitations when using QOL or HRQOL measures for dementia progression or evaluation. Results from Chapter 3's systematic review are similar to other reviews that have also suggested the need for further evaluation of dementia-specific QOL measures (Ettema et al., 2005; Perales et al., 2013; Bowling et al., 2015). Although generic QOL and HRQOL measures are also often used with PWD, they may not include domains that are specific to the disease of interest. Measures tailored to a specific disease can cover essential areas and may detect more noticeable changes in individuals as compared to generic measures (Guyatt, 1993).

3.0 Future direction

Results from Chapters 2 and 3 suggest the need to continue to evaluate psychometric properties of QOL and HRQOL measures (i.e. reliability, validity and responsiveness) as well as incorporate the caregiver's perspective in the evaluation of dementia. Many of the outcome measures had missing psychometric properties such as responsiveness. This may be due to the lack of longitudinal data collection needed for responsiveness which is important to see the changes in the patient-reported outcome over time or evaluate treatment's efficacy (Revicki et al., 2008; De Silva & Valentine, 2000). There is a need for more studies evaluating responsiveness in QOL and HRQOL measures. Chapter 3 also showed that some measures had higher quality of evidence and were evaluated more compared to other measures. Using QOL or HRQOL measures in PWD is important because they look at the overall well-being of the person (i.e. physical, mental and social well-being). This can help with taking a holistic approach and comprehensive look on the impact of treatment and dementia progression on PWD. Despite having various recommendations suggesting the use of QOL and HRQOL measures, Canada's dementia societies such as Alzheimer Society of Canada does not have any official recommendations on QOL or HRQOL measures in PWD. Other countries' dementia centers such as Australian Government's Dementia Centre for Research Collaboration, Alzheimer's Society of UK, Swedish Dementia Centre and have suggested various QOL and HRQOL measures to use (DCRC, 2023; Alzheimer's Society of UK, 2023; Svenskt Demenscentrum, 2023). For example, SveDem, the Swedish Dementia Registry uses Quality of Life in Late-Stage Dementia QUALID to assess QOL in PWD (Religa et al, 2015).

This thesis suggests that researchers and healthcare professionals need to include dementia caregivers' perspective to help better understand PWD's dementia progression. In Canada, one out of every five older adults suffering from dementia is admitted to a hospital. This is mainly because caregivers can no longer meet the needs of their loved ones at home, leading to the need for professional care (CIHI, 2022). These results could also be used to enhance education for clinicians who use dementia-specific measures when evaluating and monitoring dementia progression. Healthcare providers in Canada have expressed their restricted knowledge of dementia and neglecting caregivers' opinions (Dal Bello-Haas et al., 2014; Prorok et al., 2015; Livingston et al., 2010; VandeWeerd et al., 2006). These constraints reveal deficiencies in delivering proper care to those with dementia (Forbes et al., 2012; Pimlott et al., 2009 and Dal Bello-Haas et al., 2014). An approach that actively involves caregivers in discussions with healthcare providers can significantly improve the QOL of people with dementia.

Conclusions

The listening sessions from the qualitative study in Chapter 2 identified the importance of QOL and HRQOL measures when assessing dementia progression or treatment impact. The systematic review in Chapter 3 summarized the available measures and their psychometric measures used in PWD living in the community. The review demonstrated that dementia-specific measures and generic measures had a range of quality of evidence. Some of the measures are promising but further evaluation is needed. Future studies should focus on continuing to evaluate the measurement properties of dementia-specific measures in PWD as well as incorporate caregivers' perspectives in dementia progression evaluation.

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