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Improving Self-Report in Quality of Life Reporting for Individuals with Dementia

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IMPROVING SELF-REPORT IN QUALITY OF LIFE REPORTING FOR INDIVIDUALS WITH DEMENTIA

by

Elizabeth Redford

A Thesis Submitted in

Partial Fulfillment of the

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ABSTRACT

IMPROVING SELF-REPORT IN QUALITY OF LIFE REPORTING FOR INDIVIDUALS WITH DEMENTIA

by

Elizabeth Redford

The University of Wisconsin-Milwaukee, 2022
Under the Supervision of Dr. Heuer

People with dementia (PWD) are one of the fastest growing clinical populations for speech-language pathologists. Self-reported quality of life (QoL) assessments are critical patient-reported outcome measures that align with person-centered care principles. However, proxy-report is most often used due to assumptions that PWD cannot provide reliable self-report. Visual analogue scales (VAS) have been successfully used with people with expressive and cognitive deficits to measure subjective constructs, such as QoL, mood, and pain. The purpose of this project is to evaluate the feasibility and reliability of a VAS QoL assessment tool.

Twenty healthy older adults were assessed using the QoL-AD and the QoL-AD in combination with a VAS. Construct validity, internal consistency, and test-retest reliability of VAS and traditional QoL-AD were assessed by performing the QoL and VAS assessments twice, 4 weeks apart. Significant correlations between the overall VAS and the QoL-AD Likert scale ratings, between most of the QoL-AD and VAS subtests, and between first and second assessment scores were observed. Results indicated strong construct validity, internal consistency, and test-retest reliability of the VAS measures for QoL assessments in people without dementia. These results warrant further research into the development of a dementia-specific, self-reported VAS QoL scale for PWD.

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LIST OF ABBREVIATIONS

AD	Alzheimer’s Disease
BADLS	Bristol Activities of Daily Living Scale
CDR	Clinical Dementia Rating scale
CMAI	Cohen-Mansfield Agitation Inventory
CSDD	Cornell Scale for Depression in Dementia
DCM	Dementia Care Mapping
DEMQOL	Dementia Quality of Life
EQ-5D	EuroQol EQ-5D
GDS	Geriatric Depression Scale
HRQOL	Health Related Quality of Life
MCI	Mild Cognitive Impairment
MOCA	Montreal Cognitive Assessment
PCC	Person Centered Care
PWD	People With Dementia
QCL	Quality of Communication Life Scale
QoL	Quality of Life
QoL-AD	Quality of Life in Alzheimer’s Disease
QUALID	Quality of Life in Late-Stage Dementia
RAID	Rating of Anxiety in Dementia
R_s	Spearman’s Rho
SAQOL-39g	The Stroke and Aphasia Quality of Life Scale

SD	Standard Deviation
SLP	Speech-Language Pathologist
SSQ	Sydney Swallow Questionnaire
VAS	Visual Analogue Scale
VAMS	Visual Analogue Mood Scale

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INTRODUCTION

Dementia

Dementia is an umbrella term that encompasses a range of degenerative cognitive symptoms including changes in attention, behavior, problem-solving, memory, and language (Bayles & Kim, 2003; Bourgeois, Camp, Antenucci, & Fox, 2016; Bryan & Maxim, 2006; Nguyen, Terry, Phan, Vickers, & McInerney, 2019; Perry & Hodges, 1999). Communication deficits affecting retrieval of vocabulary and comprehension of longer more complex messages are common (Bayles & Kim, 2003; Bickel, Pantel, Eysenbach, & Schröder, 2000; Small & Gutman, 2002). Dementia types may be further classified based on the cluster of symptoms, pathology, etiology, or stage of the disease (Sachdev et al., 2014). The population of individuals with dementia has been steeply increasing over the last decade and is one of the fastest growing clinical populations for speech-language pathologists (SLP) nation-wide (Mahendra, Fremont, & Dionne, 2013). Speech-language pathologists are responsible for addressing the cognitive, communicative, and swallowing needs of people with dementia across the disease severity spectrum (Bourgeois, Brush, Douglas, Khayum, & Rogalski, 2016).

The Role of SLPs in Dementia Care

As our medical knowledge about dementia grows, it is possible to diagnose individuals earlier in the disease process; research advances using biomarkers indicate that soon diagnosis could occur before cognitive symptoms emerge (Bourgeois et al., 2016). Early or pre-symptomatic diagnosis allows SLPs to provide preventive strategies that can help individuals prepare for eventual symptom onset and maintain independent functioning for longer (Bourgeois et al., 2016). Speech-language pathologists can also provide counseling and education about the disease progression and treatment opportunities along the disease-continuum to maximize independence and engagement in meaningful activities (Douglas, Brush, & Bourgeois, 2018). Bourgeois et al., (2016) showed that family involvement and a highly engaged multidisciplinary team are key to increasing the effectiveness of early-stage treatment for individuals with mild cognitive impairment (MCI) or early-stage dementia. More frequent communication between persons with dementia and their caregivers indicates more positive relationships (Kwak, Park, Ingersoll-Dayton, & Spencer, 2015), and communication training for caregivers results in more meaningful engagement with individuals with dementia and a greater awareness of their perspective (Eggenberger, Heimerl, & Bennett, 2013).

For clients in the middle stages of dementia, SLPs provide evidence-based effective treatments that focus on maintenance of functional activities of daily life such as the implementation of memory and communication books (Burgio et al., 2001), spaced retrieval (Hopper et al., 2005) and environmental modifications that facilitate orientation to space and time (Bourgeois, Brush, Elliot, & Kelly, 2015). Speech-language pathologists address the needs of clients with moderate to severe dementia by encouraging the use of spared abilities, modifying the environment, and providing education and support while encouraging involvement from family members (Bourgeois et al., 2016). In order to make effective changes, SLPs need to understand their client’s values and interests and the relationship between their communication ability and environment (Bourgeois et al., 2016). Environmental modifications should compensate for deficits while allowing the individual as much independence as possible and ensuring that they have access to meaningful activities that contribute to their community (Bourgeois et al., 2016).

In summary, SLPs play a critical role by enhancing communication for individuals with dementia across the disease-continuum through assessment of communication abilities, provision of evidence-based intervention, training of caregivers and care team members in effective communication strategies, environmental modification to support deficits and encourage meaningful activity, advocating for their client's needs, and participating in research to improve and support evidence-based practices (Bourgeois et al., 2016; Hallowell, 2017).

Person-Centered Care

Person-centered care (PCC) is the evidence-based recommended care approach for people with dementia (Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018). Fazio et al., (2018) summarized recommendations to ensure person-centered care which include: a) recognizing that the person living with dementia is more than their disease and acknowledging the person, b) taking the perspective of the person living with dementia to understand their reality and promote opportunities for meaningful and purposeful engagement, c) building a supportive community where they are valued, and d) regularly evaluating care practices. Person-centered care considers the individual as a whole and shapes service around their health outcome priorities while maintaining autonomy and dignity (Douglas, Brush, & Bourgeois, 2018). Structuring an environment that maximizes independence in the context of memory loss and enabling the person with dementia to be a part of the decisions surrounding their daily care are key components of this approach (Douglas, Brush, & Bourgeois, 2018).

Speech-language pathologists have unique opportunities to use evidence-based services in the context of PCC to meet the complex communication needs of individuals with dementia. For example, SLPs can facilitate decision-making in PWD through caregiver training in supported communication strategies about valued daily activities, food, and clothing choices (Bourgeois, Camp, Antenucci, & Fox, 2016). Speech-language pathologists can also make changes to the environment to maximize engagement in valued activities by providing visual aids or compensatory strategies to ensure that the individual is able to participate (Douglas, Brush, & Bourgeois, 2018). Specifically, the Montessori approach which aligns with PCC principles provides evidence-based guidelines on how to select and adapt activities and structure the living environment to maximize participation (Douglas, Brush, & Bourgeois, 2018). Bourgeois et al., (2015) reported positive outcomes of the Montessori approach in dementia care including individuals showing increased independence, identifying with meaningful roles, and contributing to the community which resulted in higher levels of self-esteem.

In summary, SLPs provide a wide variety of evidence-based skilled services that align with PCC (Bourgeois, Camp, Antenucci, & Fox, 2016). The purpose of PCC is to improve QoL by adapting treatment to the individual’s priorities while maximizing independence (Fazio, Pace, Flinner, & Kallmyer, 2018). It is important to evaluate if provided SLP services improve QoL for people with dementia (Heuer & Willer, 2020), and to evaluate the effectiveness of care practices SLPs need tools that can clearly define and measure an individual's satisfaction with different aspects of their life. Quality of life measures can be integral patient-reported outcomes to identify and celebrate positive and unique aspects of an individual's life while also recognizing areas to optimize care (Ready & Ott, 2003).

Measuring the Impact of SLP Services

The World Health Organization defines quality of life as the way individuals perceive themselves and their position in life in relation to their culture and values, and how their standards, goals, concerns, and expectations are influenced (World Health Organization, 2021). This is a broad, generic definition applicable to people with and without disability across the age range. While there are a multitude of QoL definitions, many are abstract or underspecified and the challenges associated with the progressive nature of dementia are not always addressed (Missotten, Dupuis, & Adam, 2016). To identify these challenges, dementia-specific QoL definitions have been developed with varying emphasis on different aspects of QoL. For example, Ettema et al., (2005) focused on the role of environmental factors, highlighting the importance of a multidimensional assessment of environment through the perception of the PWD. Another definition discusses QoL as the enjoyment that the individual with dementia has with daily life, the quality of interactions that they have with their surroundings, and their overall sense of self (Yanamoto-Mitani et al., 2004). These QoL definitions are based on domains that have been identified to be most relevant to individuals with dementia including positive and negative affect, ability to communicate and engage in activities, and relationships with others (Terada et al,. 2002).

In summary, dementia-specific QoL is concerned with the experiences, personhood, support, and value that individuals with dementia perceive throughout the disease spectrum (Missotten, Dupuis, & Adam, 2016).

QoL Instruments

Just as there are generic and disease-specific QoL definitions, there are generic and disease-specific scales. Generic measures focus on factors such as general health and functional status, and how each contribute to general life satisfaction (Ettema et al., 2005). Dementia-specific scales attempt to tailor domains to those most important and relevant to individuals with dementia, taking the progressive nature of dementia into consideration (Ready & Ott, 2003). The most common dementia-specific QoL measures include items related to affect, mood, valued activities, and interactions with others (Ettema et al., 2005; Missotten, Dupuis, & Adam, 2016).

Subjective or Objective

The World Health Organization’s definition emphasizes the individual nature of QoL as a personal and subjective judgment of the individuals’ circumstances (World Health Organization, 2021). In contrast, there are definitions that attempt to quantify or objectively measure QoL through observational measures that rely on identifying the presence or absence of specific behaviors as indicators of QoL (Algar, Woods, & Windle, 2016). For example, Dementia Care Mapping (DCM) relies solely on observed behaviors, including activity and level of social withdrawal (Hubbard, Downs, & Tester, 2003). Lawton (1991) described a conceptual framework for QoL based on a multidimensional framework that includes observable indices of well-being and the individual's own subjective perception of their position in life. The model is comprised of four sectors: a) behavioral competence for social-normative functioning, b) perceived QoL for self-assessed social-normative functioning, c) objective environment for physical, economic, and social indicators, and d) psychological well-being for subjective evaluation of overall experience (Lawton, 1991). Many QoL scales have adapted this framework but with varying emphasis on subjective and objective content domains (Ettema et al., 2005). Common observable domains that are used in dementia-specific QoL measures include the presence or absence of behaviors, level of social interaction, and participation in activities, while common subjective domains include self-esteem, enjoyment of activities, and affect (Ettema et al., 2005).

The Quality of Life in Alzheimer's Disease (QoL-AD) scale assesses QoL related to the domains of affect, activities, interactions, self-concept, cognition, physical health, independence, relationships, and living conditions (Missotten, Dupuis, & Adam, 2016). The content domains of interactions, self-concept, and relationships address psychosocial well-being, and the domains of independence and living conditions address environmental factors (Heuer & Willer, 2020).

How QoL is Measured

The three most common methods used in dementia-specific QoL scales are self-report, proxy-report, and observational measures (Heuer & Willer, 2020). Self-report measures enable the person with dementia to judge their own QoL and are generally recommended where possible as QoL is a highly subjective and personal concept (Thorgrimsen et al., 2003). The use of self-report in QoL assessments closely aligns with the PCC principle related to participation of the individual in care decisions (Heuer & Willer, 2020). According to some authors, individuals across the dementia severity spectrum are capable of reliably discussing their wants and needs, and providing meaningful information related to QoL (Moyle, Murfield, Griffiths, & Venturato, 2011; Orrell et al., 2008). However, self-report in individuals with more severe dementia may be limited due to neurologic deficits, fatigue, language impairments, or medical problems (Hickey & Bourgeois, 2000).

Proxy-report measures are completed by a proxy-responder on behalf of the PWD and are usually a family member or caregiver of the individual (Gräske, Fischer, Kuhlmey, & Wolf-Ostermann, 2012). Advantages of proxy-report include reduction of cognitive burden on PWD, and the ability to provide an estimate of QoL for individuals who are not able to provide self-report due to the extent of their linguistic or cognitive impairments (Hickey & Bourgeois, 2000). However, proxy-report has been found to differ from self-report, with providers, caregivers and family members reporting lower QoL scores than the individual themselves (Carr & Higginson, 2001; Thorgrimsen et al., 2003). It has been suggested that discrepancies in proxy-report vs self-report may be due to the reporting caregiver focusing on physical aspects and impairments that influence the degree of care, or QoL assessments being based on the caregiver's judgement rather than attempting to substitute the judgement of the individual with dementia (Moyle, Murfield, Griffiths, & Venturato, 2011). Research has shown that proxy-report caregivers in care homes correlate QoL with the quality of care that they provide and the stage of the individual's dementia, while family members compare QoL to the individual's past before they were diagnosed (Griffiths et al., 2019). Additionally, the proxy-responder's relationship with the individual can influence their interpretation of QoL, and their perception of their own QoL can affect the proxy-report on another individual (Hickey & Bourgeois, 2002). Importantly, the use of proxy-report to assess QoL does not align with PCC principles (Heuer & Willer, 2020).

Observational measures allow for documentation of response in PWD in the moment while an intervention unfolds, based on observations of apriori defined behaviors (Algar, Woods, & Windle, 2016). Observational measures can be used to evaluate individuals or groups with a wide range of dementia severity, minimize exclusion criteria based on level of communication ability or cognition, and can be used across multiple time points throughout disease progression (Algar, Woods, & Windle, 2016). Observational scales like the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1991) assess the frequency and severity of agitated behaviors over a two-week period and allow care teams to track changes in these behaviors over time (Griffiths et al., 2020). Other observational measures like the Quality of Life in Late-Stage Dementia scale (QUALID) (Weiner et al., 2000) quantifies both positive and negative observable behaviors such as facial expressions, physical movements, and sounds into a total QoL score for individuals with severe dementia (Benhabib, Lanctôt, Eryavec, Li, & Herrmann, 2013). Observational measures are suitable for people who are not able to provide self-report and take important environmental factors into consideration as the person's immediate response to an activity or intervention is captured (Algar, Woods, & Windle, 2016).

This provides valuable information about environmental context and reflects PCC principles (Heuer & Willer, 2020). However, observational measures such as the CMAI that focus solely on the reduction of adverse behaviors do not align with PCC guidelines as they emphasize deficits rather than competence (Heuer & Willer, 2020). Observational measures require specialized training and vary in terms of time needed for assessment, number of individuals who can be observed, and degree of information that can be obtained (Algar, Woods, & Windle, 2016).

In summary, self-report measures are most accurate at capturing the subjective perspective of an individual's QoL (Moyle, Murfield, Griffiths, & Venturato, 2011; Orrell et al., 2008), and adhere to PCC principles by valuing the input of the PWD and centering them as an equal partner in their health care decisions (Heuer & Willer, 2020). The most significant barriers that keep self-report measures from being used for PWD are assumed unreliable self-report due to cognitive deficits, test-fatigue, medical issues, or language impairments (Hickey & Bourgeois, 2000).

Visual Analogue Scales

Visual analogue scales (VAS) are measurement tools that are used either alone or in conjunction with another assessment to measure subjective information (Wewers & Lowe, 1990). A VAS is a vertical or horizontal line that is typically 100mm in length with descriptors at each end noting extremes (Heller, Manuguerra, & Chow, 2016). Right-angle brackets on each end help to define the limits for placing marks while descriptions or anchors being placed on either side of the limit brackets keep the scale clear for response at any point (Wewers & Lowe, 1990). An individual is asked to answer a question by marking their perception at any point within the extremes (Heller, Manuguerra, & Chow, 2016). Visual analogue scales have been shown to identify small changes by allowing the respondent to interpret their position on the scale rather than having pre-set intervals to choose from (Williamson & Hoggart, 2005). Visual analogue scales are often used in pain assessments where patients are asked to mark their current level of pain with descriptors like 'no pain' and 'worst pain imaginable' at either end of the scale (Heller, Manuguerra, & Chow, 2016).

Speech-language pathologists have utilized VAS in valid and reliable assessments to address various disorders and domains including the Sydney Swallow Questionnaire (SSQ) to identify the symptoms and impact of oral-pharyngeal dysphagia (Szczesniak, Maclean, Zhang, Liu, & Cook, 2014), communication-related QoL using the ASHA Quality of Communication Life Scale (QCL) (Eadie et al., 2006), and HRQOL in individuals with aphasia due to a stroke using the Stroke and Aphasia Quality of Life scale (SAQOL-39g) (Hilari & Boreham, 2013). Visual analogue scales have been used with different populations including people with communication deficits due to stroke (Korner-Bitensky et al., 2006). One study that compared the ability to report varying levels of thermal stimuli using a VAS between individuals post-stroke, individuals with aphasia including a nonverbal subgroup, and a control group found that all participants were able to report the thermal stimuli using a VAS (Korner-Bitensky et al., 2006); this indicates that the individuals with severe expressive deficits benefited from the use of a VAS and were able to successfully report their subjective perception (Korner-Bitensky et al., 2006).

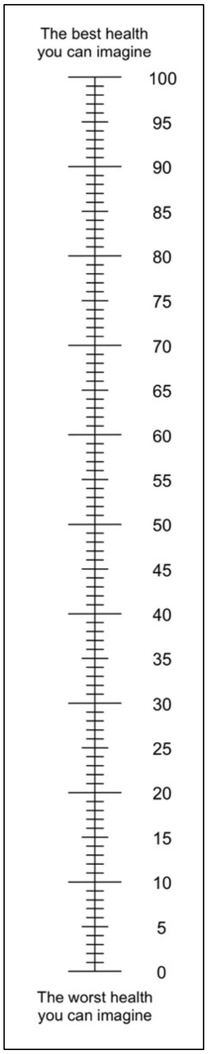

Figure 1: EQ-5D VAS

The EuroQol EQ-5D (EQ-5D) is a generic health-related quality of life (HRQOL) tool that assesses five dimensions including mobility, self-care, activity, pain or discomfort, and anxiety/depression using a VAS (Orgeta, Tudor Edwards, Hounsome, Orrell, & Woods, 2014). One study assessed the ability of individuals with mild to moderate dementia to report on their health-related quality of life (HRQOL) using the EQ-5D by comparing reports between the PWD and their caregivers, as well as participant and proxy scores on the Cornell Scale for Depression in Dementia (CSDD), the Rating of Anxiety in Dementia Scale (RAID), the Bristol Activities of Daily Living Scale (BADLS), and the Clinical Dementia Rating scale (CDR) (Orgeta et al., 2014). When completing the EQ-5D, participants were asked to mark their overall current health state on a 100-point VAS scale with 0 representing 'the worst health you can imagine', and 100 representing 'the best health you can imagine' (Orgeta et al., 2014). See Figure 1. The participants then wrote the number they selected on the scale in a box next to the VAS with the PWD completing the EQ-5D through interview format, and their caregivers completing the proxy-scale (Orgeta et al., 2014). The mean scores for PWD on the EQ-5D were higher than those reported by their caregivers but comparison scores between all assessments showed that individuals with mild to moderate dementia were able to accurately report on their HRQOL (Orgeta et al., 2014). When compared with dementia-specific scales including the QoL-AD and Dementia Quality of Life scale (DEMQOL) to assess inter-rater reliability, the EQ-5D performed the same with high consistency between scores for self- and proxy-report (Aguirre, Kang, Hoare, Tudor Edwards, &

Orrell, 2015). Results showed that the EQ-5D has good reliability and psychometric properties that are appropriate to be used with the dementia population (Aguirre, Kang, Hoare, Tudor Edwards, & Orrell, 2015).

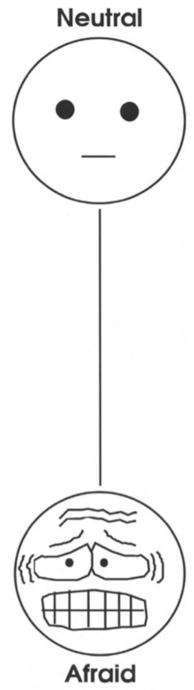

Figure 1. Sample item from the VAMS for anxiety.
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Figure 2: VAMS VAS

The Visual Analogue Mood Scale (VAMS) has been used to report individuals with Alzheimer's disease (AD) mood state (Ready, Carvalho, Green, Gavett, & Stern, 2011). Participants consisted of older adults who were comprehensively assessed and diagnosed as cognitively normal, having mild cognitive impairment (MCI) or diagnosed with AD (Ready et al., 2011). The VAMS consisted of a vertical 100mm line with a face depicting a neutral expression at the top, and a face depicting one of eight emotions including happy, sad, afraid, angry, confused, energetic, tired, and tense (Ready et al., 2011). See Figure 2. Participants placed their mark on the line based on their current mood state for each emotion (Ready et al., 2011). When comparing the affect between participants, the researchers determined that although they differed in their report of feeling confusion which they felt was attributable to their respective cognitive states, overall affect was similar across participants (Ready et al., 2011). Repeated completion of the VAMS indicated high test-retest reliability across participants (Ready et al., 2011). Convergent validity was demonstrated by significant positive correlations with the Geriatric Depression Scale (GDS) (Ready et al., 2011). This study showed that individuals with mild AD can reliably self-report their mood-state (Ready et al., 2011).

In summary, the use of visual supports in combination with a VAS enabled PWD to participate in self-report QoL assessments (Thomson & Chatterjee, 2014). The use of VAS minimizes verbal response requirements and supports self-report in populations who tend to be excluded from self-report (Arons, Krabbe, Jan van der Wilt, Olde Rikkert, & Adang, 2013). Currently there is no dementia-specific QoL scale that utilizes a VAS to maximize self-report.

Purpose Statement

Quality of life is often measured in PWD without their input using proxy-report due to concerns about cognitive and communicative deficits (Hickey & Bourgeois, 2000). This not only leads to incorrect perceptions of QoL (Carr & Higginson, 2001; Griffiths et al., 2019; Hickey & Bourgeois, 2000; Moyle, Murfield, Griffiths, & Venturato, 2011; Thorgrimsen et al., 2003), and thus incorrect assessment of satisfaction with delivered interventions, but also excludes PWD as active participants in their care (Heuer & Willer, 2020). Individuals with a range of dementia severities have been shown to accurately report on their mood state using VAS (Ready et al., 2011). The QoL-AD scale has a self-report option and is commonly used in dementia care (Heuer & Willer, 2020; Missotten, Dupuis, & Adam, 2016).

The purpose of this project is to determine whether performance on the QoL-AD is the same compared to using a VAS in combination with the QoL-AD in healthy older adults. The results could inform further research that determines if the use of VAS is suitable in maximizing reliable self-report in people with and without dementia.

METHODS

Approval for this research project was granted by the Institutional Review Board at the University of Wisconsin-Milwaukee. Eligible participants were provided an explanation of all study procedures including risks and benefits. The researcher answered all questions and then obtained written consent to participate in the study.

Participants and Recruitment

A total of 24 participants were recruited for this study through posting of research fliers at the Wauwatosa Public Library and the University of Wisconsin-Milwaukee Communication Sciences and Disorders department. Fliers were also emailed to senior community centers in Milwaukee for posting. Eligibility criteria included:

- Age of 60+ years
- The ability to participate in assessment at two time points, four weeks apart
- A score of 26 or higher on the Montreal Cognitive Assessment (MOCA)
- No current diagnosis of dementia or other neurodegenerative condition
- No severe hearing or visual impairments that cannot be resolved with the use of hearing aids or glasses

Participant's eligibility was assessed though a formal interview and cognitive screening with the examiner. Inclusion criteria were assessed through a questionnaire, followed by the completion of the MOCA. See Appendix A and Appendix B. Four participants were excluded during the screening because they did not pass the cognitive screening criterion consisting of a MOCA score of 26 or higher. Participant recruitment continued until a sample of 20 participants was obtained who met all eligibility criteria. All participants denied any current diagnosis of Alzheimer’s Disease, dementia, or other neurodegenerative condition and attended both meetings with researchers between 4 and 5 weeks apart.

The study cohort consisted of 10 females and 10 males, aged between 60 and 83. The mean age was 66.35 (4.96) years. See Table 1. Four participants reported a high school education or GED equivalent (1 female, 3 male), 1 participant reported an associate degree (1 female), 10 participants reported a bachelor's degree (7 female, 3 male), 4 participants reported a master’s degree (1 female, 3 male), and 1 participant reported a doctorate (1 male). See Table 2. All participants reported normal or corrected vision (10 females, 10 males), 16 participants reported normal or corrected hearing (9 female, 7 male), and 4 participants reported uncorrected hearing loss (1 female, 3 males). See Table 3. For participants with uncorrected hearing loss, strategies were implemented including increased speaking volume from researcher, decreased distance between participant and researcher, and ensuring the participant had a clear view of the researchers face while speaking. Scores on the MOCA ranged from a 26/30 to 29/30, with the mean score = 27.45. See Table 4.

Table 1: Breakdown of Age

Age	Frequency
60	1 (5%)
61	2 (10%)
63	2 (10%)
64	3 (15%)
65	3 (15%)
67	4 (20%)
69	2 (10%)
70	1 (5%)
73	1 (5%)
83	1 (5%)

Table 2: Breakdown Of Education

Level of Education	Frequency
High School or GED	4 (20%)
Associate Degree	1 (5%)
Bachelor’s Degree	10 (50%)
Master’s Degree	4 (20%)
Doctorate	1 (5%)

Table 3: Breakdown Of Hearing Status

Hearing Status	Frequency
Normal	16 (80%)
Corrected	4 (20%)

Table 4: Breakdown Of MOCA Scores

MOCA score	Frequency
26	5 (25%)
27	6 (30%)
28	4 (20%)
29	5 (25%)

Stimuli

The VAS consists of a 100mm horizontal line with brackets on each end. Horizontal lines have been found to be more reliable than vertical lines, and right-angle brackets on each end define the response limits (Wewers & Lowe, 1990). A face is located next to the bracket at each pole depicting happiness or satisfaction on the right side, and unhappiness or dissatisfaction on the left side. See Figure 3. for example.

Figure 3: VAS Used To Capture Responses Of QoL Assessment.

The QoL-AD scale is a dementia-specific QoL scale with good content validity and high reliability that assesses domains that are important to PWD (Thorgrimsen et al., 2003). The QoL-AD scale is commonly used with people across the dementia severity range as a self- or proxy-report measure (Heuer & Willer, 2020; Missotten, Dupuis, & Adam, 2016). The examiner and the participant each had a copy of a record sheet which listed each of the thirteen questions along with a section to circle or point to poor, fair, good, or excellent (Logsdon, Gibbons, McCurry, & Teri, 1999). The scale requires ten to fifteen minutes for the interview and self-report (Logsdon, Gibbons, McCurry, & Teri, 1999; 2002).

Procedure

Participants were assessed with both instruments two times, not less than 4 weeks apart, and not more than 5 weeks from initial assessment. Presentation sequence of VAS and QoL-AD response form were randomized for each participant at the first visit with the examiner recording the order of sequence and reversing the order at the second meeting.

Instructions

For each assessment, the examiner provided participants with a response form and a pen and read the standardized instructions aloud. When completing the QoL-AD, participants were asked to mark their response by circling one of four words indicating how they felt about each question. See Appendix C for standardized instructions. When completing the QoL-AD with VAS, the examiner explained the faces at the poles and brackets, and participants were asked to indicate their response by placing a mark at any point along the line. See Appendix D for standardized instructions.

Analysis

The QoL-AD assigns a point value to each of the four response possibilities on the questionnaire with poor = 1, fair = 2, good = 3, and excellent = 4 (Logsdon, 1996). According to scoring procedures, the examiner added the scores for all thirteen questions to generate the participant's overall QoL rating with a possible range of 13-52. VAS were scored by measuring the distance in millimeters between the end of the scale and the respondent's mark (Heller, Manuguerra, & Chow, 2016). The total VAS score was computed similar to the overall QoL-AD score as the sum of all 13 responses with a possible range of 0-1300.

Statistical Analysis

To determine the concurrent validity of the VAS, Spearman's rank order correlation coefficients between the overall QoL-AD score and the mean VAS score were computed. A high correlation coefficient would represent high validity of the VAS. Likewise, a low correlation coefficient would indicate less validity of the VAS. In addition, to compare performance across each item on the QoL-AD and the VAS, Spearman's rank order correlation coefficients were computed for each of the 13 items to identify if scores for each question correlate between the QoL-AD and QoL-AD with VAS. To measure test-retest reliability over time, performance on the VAS and the QoL-AD were collected two times, 4 weeks apart. Spearman's rank correlations between the scores of the first and the second assessment were conducted. Significance level and correlation coefficients were compared to determine the strength of the correlation between first and second QoL-AD and VAS assessment.

Research Question and Hypotheses

Research Question: Is there a difference in results between the QoL-AD self-report and QoL-AD self-report in combination with a supportive visual aid in healthy older adults?

H1: Concurrent validity: The overall scores of the QoL-AD will significantly correlate with the scores obtained from the VAS as indexed through Spearman's rank correlations

H2: Internal consistency: No significant differences in distribution of ratings for each of the 13 test items will be observed between the QoL ratings and the VAS scores, indexed through Spearman's rank correlations analysis for each of the thirteen questions.

H3: Test-retest reliability: Test-retest reliability will be assessed based on the comparison of Spearman's rank correlations between the scores of the first and second assessment. The effect sizes of Spearman's r (r_s) will be compared between the QoL-AD and the VAS correlation.

RESULTS

Concurrent validity was assessed using ranked Spearman correlation analyses between the overall scores of the QoL-AD the total VAS scores at the first and second assessment. Correlations were significant for the first assessment r_s (18) = .78, p <.001, and the second assessment r_s (18) = .73, p <.001. See Table 5 for descriptive data of VAS and QoL-AD results.

Table 5: Descriptive Statistics for Overall Scores

	N	Range	Minimum	Maximum	Mean	SD
VAS Meeting 1 Total Score	20	746.00	502.00	1248.00	1095.20	173.06
VAS Meeting 2 Total Score	20	745.00	520.00	1265.00	1093.95	175.23
QOL-AD Meeting 1 Overall Score	20	22.00	29.00	51.00	44.10	5.58
QOL-AD Meeting2 Overall Score	20	21.00	31.00	52.00	44.75	5.27

Internal consistency was assessed using Spearman's rank order correlation coefficients, computed for each of the 13 items to identify if scores for each question correlated significantly between QoL-AD and VAS. See Table 6 for correlation results for each question during the first and the second assessment.

Table 6: Correlation Results

Questions 1-13	Meeting 1 r_s	Meeting 2 r_s
1: Physical Health	.66**	.72**
2: Energy	.77**	.71**
3: Mood	.61**	.66**
4: Living Situation	.37	.35
5: Memory	.69**	.73**
6: Family	.69**	.40
7: Marriage	.69**	.35
8: Friends	.76**	.49*
9: Self as a whole	.44	.50*
10: Ability to do things like chores around the house	.78**	.79**
11: Ability to do things for fun	.58**	.51*
12: Money	.65**	.47*
13: Life as a whole	.45*	.51*
Key: ** = p <.01, * = p <.05		

Test-retest reliability was assessed based on the comparison of Spearman’s rank correlations between the scores of the first and the second assessment. The correlation for the VAS scale was significant: (r_s (18) = .86, $p < .001$). The correlation for the QoL-AD was also significant: (r_s (18) = .64, $p = .003$).

DISCUSSION

Interpretation of Results

Strong concurrent validity for the VAS was observed, reflected in significant, positive correlations of overall scores between VAS and QoL-AD at two assessment points.

Internal consistency was overall high. Spearman's rank order correlations on each of the 13 questions revealed the following pattern:

Correlation analyses of VAS and QoL-AD scores at the first meeting revealed 11 out of 13 positive, significant correlations for the questions about physical health, energy level, mood, memory, relationship with family members, marriage, relationship with friends, ability to do chores around the house, ability to do things for fun, financial situation, and life as a whole. Correlation analyses of scores at the second meeting showed 10 out of 13 significant, positive correlations for the questions about physical health, energy level, mood, memory, relationship with friends, whole self, ability to do chores around the house, ability to do things for fun, financial situation, and life as a whole. Across both assessments, analyses of 10 out of 13 questions revealed positive, significant correlations. For both assessments correlations were significant for questions about physical health, energy level, mood, memory, relationships with friends, ability to do chores around the house, ability to do things for fun, financial situation, and life as a whole. Further, 6 out of 13 questions showed the same level of significance at both assessment points.

Question 4 which assesses living situation showed a non-significant but consistent correlation across both time points. When visually inspecting the scatterplots for question 4, we found a relatively large spread of VAS ratings corresponding to each of the QoL-AD ratings. For example, when comparing responses on the QoL-AD and VAS at meeting 1, a rating of 3 on the QoL-AD corresponded to a range of VAS ratings of 60-93 instead of the expected range of 50-75. See Figure 4. Similarly, when comparing responses on the QoL-AD and VAS at meeting 2 for question 4, a rating of 3 on the QoL-AD corresponded to a range of VAS ratings of 43-89 instead of the expected range of 50-75. See Figure 5.

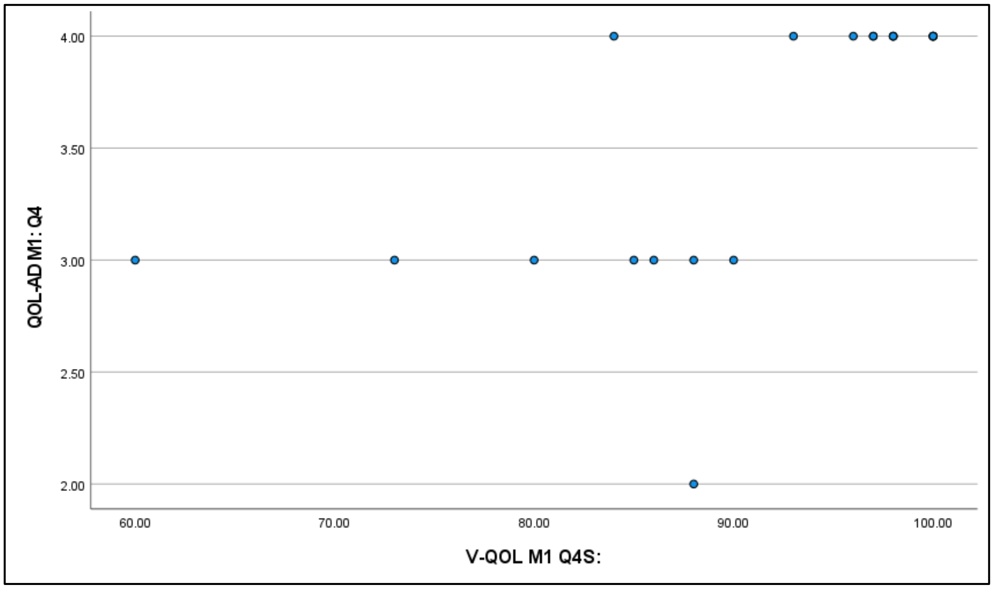


Figure 4: Comparison of QoL-AD and VAS Responses for Question 4 at Meeting 1

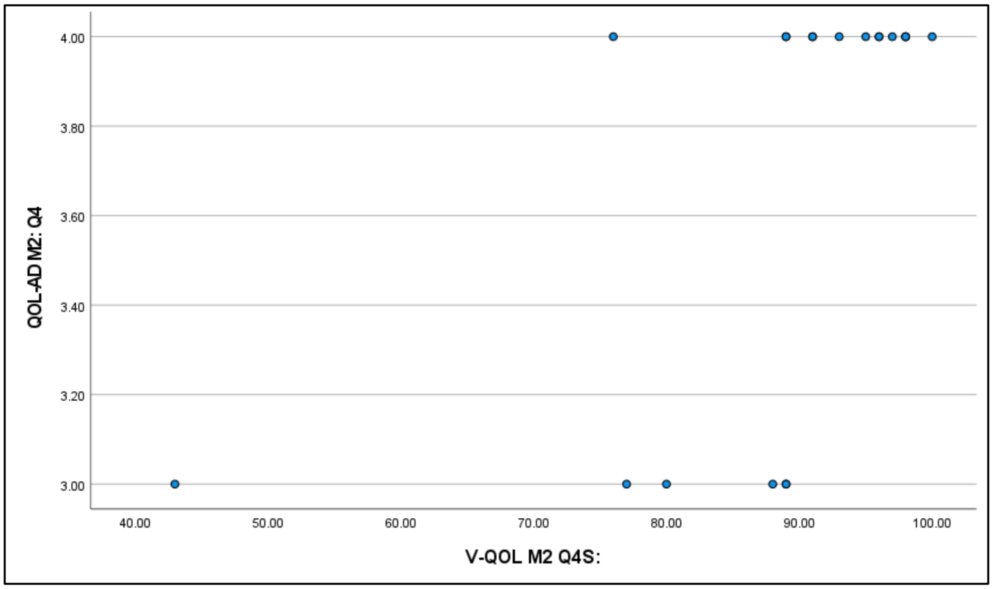


Figure 5: Comparison of QoL-AD and VAS Responses for Question 4 at Meeting 2

Further, out of the sample of 20 individuals, 12 participants (60%) provided the highest score of 4 on the QoL-AD at meeting 1, and 14 participants (70%) provided the highest score of 4 on the QoL-AD at meeting 2. This ceiling effect at both timepoints likely contributed to the lack of consistency found for question 4.

The initial validation study for the QoL-AD utilized a sample of community dwelling older adults with AD and their caregivers and performed an item analysis with Spearman correlations for each of the 13 questions (Logsdon, Gibbons, McCurry, & Teri, 1999). Similar to our own study, Logsdon et al., (1999) found a nonsignificant correlation for question 4 between individuals with AD and their caregivers. In contrast, another validation study with PWD and their caregivers found significant correlations for all 13 items between repeat assessments on the QoL-AD one week apart (Thorgrimsen et al., 2003). The researchers also surveyed PWD, medical professionals, and caregivers after completing the QoL-AD and received feedback that individuals felt the wording of some questions was vague while others thought the wording was too specific (Thorgrimsen et al., 2003). In this current study, the phrasing of question 4 may have left room for interpretation as participants may have considered the condition, location, or occupants of their home when responding to the question. See Appendix C and D for phrasing of all questions.

Lastly, the test-retest reliability assessment revealed significant, positive correlations between the two assessments for both measures of QoL-AD and VAS.

Implications of the Study

These findings are in line with existing research on VAS which shows that individuals with mild to moderate dementia are able to accurately report on their HRQOL (Orgeta et al., 2014), and individuals with mild AD are able to self-report on their mood-state (Ready et al., 2011). Our findings have demonstrated that self-reportedly healthy older adults report similar scores when using VAS as when using a Likert scale in QoL assessments, which supports VAS as a reliable and valid form of QoL reporting. These results align with Aguirre, Kang, Hoare, Tudor Edwards, and Orrell's (2015) findings which show that the EQ-5D VAS had high consistency and reliability when compared to dementia-specific QoL assessments. Our findings are unique in that this is the first time that a dementia-specific, as opposed to generic, VAS was implemented. We were able to show strong validity, internal consistency and test-retest reliability when compared with an existing dementia-specific assessment. This project is the first step towards development of a dementia-specific QoL assessment using a VAS for PWD to enable increased self-report and more accurate report of QoL; this would ultimately allow clinicians to measure the impact of person-centered care and intervention on their clients. In the context of existing evidence that demonstrates VAS can reduce verbal response requirements (Arons, Krabbe, Jan van der Wilt, Olde Rikkert, & Adang, 2013), and enable PWD to self-report on their own QoL (Thomson & Chatterjee, 2014), this is a promising finding that warrants further research.

Implications for Future Research

A logical next step would be to conduct this study with people who have mild cognitive impairment (MCI) and PWD. This future study would further explore the feasibility of using a VAS in the context of a dementia-specific QoL assessment and would provide important insights into the ability of people with dementia to self-report. This would also inform if VAS could reduce response confounds in those participants who exhibit more severe cognitive-linguistic deficits.

Our study demonstrated strong test-retest reliability over a 4-week time period. This could be due to the individuals experiencing similar life circumstances throughout the four weeks indicating no change in QoL, or due to the assessments (QoL-AD and VAS) not capturing change that did occur. Future research should determine whether VAS are sensitive to change over time by increasing the time interval between assessments.

Additionally, VAS could be compared to other standardized QoL measures that share content domains but are not identical in content such as the DEMQOL (BSMS, n.d.), to identify if change is reflected in all measures equally, and to determine if the VAS scores correlate with other measures of QoL.

For the current study, we randomized the presentation of VAS and QoL-AD at the first meeting and reversed the order at the second meeting. Future studies should explore any possible order or sequencing effects that could have occurred and assess whether the presentation sequence of VAS and QoL-AD had any effect on the results. If any order effects were present, a factorial design could be used including all possible presentation conditions (e.g., 2 assessment tools, x 2 meetings) in future studies.

Finally, future studies could include a post-assessment debrief asking participants if they preferred one scale over another, if they felt they responded similarly on all scales, and if one scale was more difficult to complete. This could provide insight from a participant perspective on ease of use and preference when completing QoL assessments.

Limitations of the Study

Efforts were made to recruit a diverse sample by strategically recruiting in senior centers across the metropolitan Milwaukee area. The researcher followed best practices to reduce barriers associated with recruiting a diverse sample including meeting with participants in locations and at times that were convenient to them in order to reduce barriers associated with travel.

However, a limited timeline resulted in an unrepresentative sample when compared to the greater Milwaukee population. While the sample had a well-balanced gender distribution and range in education levels, participants consisted of 19 White/Non-Hispanic individuals (9 female, 10 male), and 1 biracial, American-Indian and White/Non-Hispanic individual (1 female). See Table 7. Future studies could diversify samples by considering inclusion of non-native speakers of English and to explore diversity in the context of socio-economic status.

Table 7: Breakdown of Ethnicity

Ethnicity	Frequency
White/Non-Hispanic	19 (95%)
Biracial	1 (5%)

As previously mentioned, the 4-week timeline between meetings was determined by researchers apriori. Four weeks was considered long enough to not recall specific details about the first assessment, thus decreasing any learning effects. However, the time window was also chosen for pragmatic reasons related to deadlines and concerns about participant attrition. Wewers and Lowe (1990) reported in their systematic VAS review generally shorter time windows for reliability analyses than 4-weeks. However, a greater amount of time between meetings could influence the amount of change to be observed on a QoL measure.

SUMMARY AND CONCLUSION

We determined that the use of a VAS as a reporting method in healthy older adults produced very similar results to performance on the QoL-AD. Our results align with findings of VAS in the literature showing that people with cognitive-linguistic deficits can use VAS to report on a range of topics, including QoL. Our study is novel because we were able to demonstrate feasibility of a dementia-specific QoL assessment tool combined with a VAS. This distinction matters because it is those dementia-specific tools as opposed to generic QoL tools, that best serve as self-reported outcome measures of the impact of person-centered care on our clients with dementia.

References

Aguirre, E., Kang, S., Hoare, Z., Tudor Edwards, R., & Orrell, M. (2015). How does the EQ-5D perform when measuring quality of life in dementia against two other dementia-specific outcome measures? *Quality of Life Research, 25*(1), 45-49.

Algar, K., Woods, R. T., & Windle, G. (2016). Measuring the quality of life and well-being of people with dementia: A review of observational measures. *Dementia, 14*(4), 832-857.

Arons, A. M., Krabbe, P. F., Jan van der Wilt, G., Olde Rikkert, M. G., & Adang, E. M. (2013). Visual analogue scales: scale recalibration by patients with dementia and their proxies. *Quality of Life Research, 22*(5), 979-986.

Bayles, K. A., & Kim, E. S. (2003). Improving the functioning of individuals with Alzheimer's disease: emergence of behavioral interventions. *Journal of Communication Disorders, 36*(5), 327-343.

Benhabib, H., Lanctôt, K. L., Eryavec, G. M., Li, A., & Herrmann, N. (2013). Responsiveness of the QUALID to improved neuropsychiatric symptoms in patients with Alzheimer's disease. *Canadian Geriatrics Journal, 16*(4), 180-185.

Bickel, C., Pantel, J., Eysenbach, K., & Schröder, J. (2000). Syntactic comprehension deficits in Alzheimer's disease. *Brain and Language, 71*(3), 432-448.

Bourgeois, M. S., Brush, J., Elliot, G., & Kelly, A. (2015). Join the revolution: How Montessori for aging and dementia can change long-term care culture. *Seminars in Speech and Language, 36*(3), 209-214.

Bourgeois, M. S., Camp, C. J., Antenucci, V., & Fox, K. (2016). VoiceMyChoice: Facilitating understanding of preferences of residents with dementia. *Advances in Aging Research, 5*(6), 131-141.

Bourgeois, M., Brush, J., Douglas, N., Khayum, R., & Rogalski, E. (2016). Will you still need me when I'm 64, or 84, or 104? The importance of speech-language pathologists in promoting the quality of life of aging adults in the united states into the future. *Seminars in Speech and Language, 37*(3), 185-200.

Bryan, K., & Maxim, J. (2006). *Communication disability in the dementias.* London: Whurr Publishers.

BSMS. (n.d.). *DEMQOL: Dementia Quality Of Life Measure*. Retrieved July 2022, from BSMS: BSMS, n.d. DEMQOL: Dementia Quality Of Life Measure. [online] Bsms.ac.uk. Available at: <https://www.bsms.ac.uk/research/neuroscience/cds/research/demqol.aspx> [Accessed 2 May 2018].

Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., . . . Bankester, L. (2001). Come talk with me: Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist, 41*(4), 449-460.

Carr, A. J., & Higginson, I. J. (2001). Measuring quality of life; are quality of life measures patient centered? *British Medical Journal, 322*(7298), 1357-1360.

Cohen-Mansfield, J. (1991). *Cohen-Mansfield Agitation Inventory.* Research Institute of the Hebrew Home of Greater Washington.

Douglas, N., Brush, J., & Bourgeois, M. (2018). Person-centered, skilled services using a Montessori approach for persons with dementia. *Seminars in Speech and Language, 39*(3), 223-230.

Eadie, T. L., Yorkston, K. M., Klasner, E. R., Dudgeon, B. J., Deitz, J. C., Baylor, C. R., . . . Amtmann, D. (2006). Measuring communicative participation: a review of self-report instruments in speech-language pathology. *American Journal of Speech-Language Pathology, 15*(4), 307-320.

Eggenberger, E., Heimerl, K., & Bennett, M. I. (2013). Communication skills training in dementia care; a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics, 25*(3), 345-358.

Ettema, T. P., Dröes, R.-M., De Lange, J., Ooms, M. E., Mellenbergh, G. J., & Ribbe, M. W. (2005). The concept of quality of life in dementia in the different stages of the disease. *International Psychogeriatrics, 17*(3), 353-370.

Fazio, S., Pace, D., Flinner, J., & Kallmyer, B. (2018). The fundamentals of person-centered care for individuals with dementia. *The Gerontologist, 58*(S1), S10-S19.

Fazio, S., Pace, D., Maslow, K., Zimmerman, S., & Kallmyer, B. (2018). Alzheimer's association dementia care practice recommendations. *The Gerontologist, 58*(S1), S1-S9.

Gräske, J., Fischer, T., Kuhlmey, A., & Wolf-Ostermann, K. (2012). Quality of life in dementia care - differences in quality of life measurements performed by residents with dementia and by nursing staff. *Aging & Mental Health, 16*(7), 819-827.

Griffiths, A. W., Albertyn, C. P., Burnley, N. L., Creese, B., Walwyn, R., Holloway, I., . . . Surr, C. A. (2020). Validation of the Cohen-Mansfield agitation inventory observational (CMAI-O) tool. *International Psychogeriatrics, 32*(1), 75-85.

Griffiths, A. W., Smith, S. J., Martin, A., Meads, D., Kelley, R., & Surr, C. A. (2019). Exploring self-report and proxy-report quality-of-life measures for people living with dementia in care homes. *Quality of Life Research, 29*(2), 463-472.

Hallowell, B. (2017). *Aphasia and other acquired neurogenic language disorders; A guide for clinical excellence.* San Diego: Plural Publishing Inc.

Heller, G. Z., Manuguerra, M., & Chow, R. (2016). How to analyze the Visual Analogue Scale: Myths, truths, and clinical relevance. *Scandinavian Journal of Pain, 13*(1), 67-75.

Heuer, S., & Willer, R. (2020). How is quality of life assessed in people with dementia? A systematic literature review and a primer for speech-language pathologists. *American Journal of Speech-Language Pathology, 29*(3), 1702-1715.

Hickey, E. M., & Bourgeois, M. S. (2000). Health-related quality of life (HR-QOL) in nursing home residents with dementia: Stability and relationships among measures. *Aphasiology, 14*(5-6), 669-679.

Hilari, K., & Boreham, L.-D. (2013). Visual analogue scales in stroke: what can they tell us about health-related quality of life? *BMJ Open, 3*(9), e003309-e003309.

Hopper, T., Mahendra, N., Kim, E., Azuma, T., Bayles, K. A., Cleary, S. J., & Tomoeda, C. K. (2005). Evidence-based practice recommendations for working with individuals with dementia: Spaced-retrieval training. *Journal of Medical Speech-Language Pathology, 13*(4), xxvii-xxxiv.

Hubbard, G., Downs, M. G., & Tester, S. (2003). Including older people with dementia in research: challenges and strategies. *Aging & Mental Health, 7*(5), 351-362.

Korner-Bitensky, N., Kehayia, E., Tremblay, N., Mazer, B., Singer, F., & Tarasuk, J. (2006). Eliciting information on differential sensation of heat in those with and without poststroke aphasia using a visual analogue scale. *Stroke, 37*(2), 471-475.

Kwak, M., Park, S., Ingersoll-Dayton, B., & Spencer, B. (2015). Communication and relationship quality in later-life couples coping with dementia. *The Gerontologist, 55*(Suppl_2), 666-666.

Lawton, M. P. (1991). A multidimensional view of quality of life in frail elders. *The Concept and Measurement of Quality of Life in the Frail Elderly*, 3-27.

Logsdon, R. G. (1996). *Quality of life in Alzheimer's disease.*

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: Patient and caregiver reports. *Journal of Mental Health and Aging, 5*(1), 21-32.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64*(3), 510-519.

Mahendra, N., Fremont, K., & Dionne, E. (2013). Teaching future providers about dementia: the impact of service learning. *Seminars in Speech and Language, 34*(1), 005-017.

Missotten, P., Dupuis, G., & Adam, S. (2016). Dementia-specific quality of life instrumets: a conceptual analysis. *International Psychogeriatrics, 28*(8), 1245-1262.

Moyle, W., Murfield, J. E., Griffiths, S. G., & Venturato, L. (2011). Assessing quality of life of older people with dementia: a comparison of quantitative self-report and proxy accounts. *Journal of Advanced Nursing, 68*(10), 2237-2246.

Nguyen, H., Terry, D., Phan, H., Vickers, J., & McInerney, F. (2019). Communication training and its effects on carer and care-receiver outcomes in dementia settings: a systematic review. *Journal of Clinical Nursing, 28*(7-8), 1050-1069.

Orgeta, V., Tudor Edwards, R., Hounsome, B., Orrell, M., & Woods, B. (2014). The use of the EQ-5D as a measure of health-related quality of life in people with dementia and their carers. *Quality of Life Research, 24*(2), 315-324.

Orrell, M., Hancock, G. A., Galboda Liyanage, K. C., Woods, B., Challis, D., & Joe, J. (2008). The needs of people with dementia in care homes: the perspectives of users, staff and family caregivers. *International Psychogeriatrics, 20*(5), 941-951.

Perry, R. J., & Hodges, J. R. (1999). Attention and executive deficits in Alzheimer's disease: a critical review. *Brain; A Journal of Neurology, 122*(3), 383-404.

Ready, R. E., & Ott, B. R. (2003). Quality of life measures for dementia. *Health and Quality of Life Outcomes, 1*(1), 11.

Ready, R. E., Carvalho, J. O., Green, R. C., Gavett, B. E., & Stern, R. A. (2011). The structure and validity of self-reported affect in mild cognitive impairment and mild Alzheimer's disease. *International Psychogeriatrics, 23*(6), 887-898.

Sachdev, P., Kalaria, R., O'Brien, J., Skoog, I., Alladi, S., Black, S. E., . . . Prins. (2014). Diagnostic criteria for vascular cognitive disorders; A VASCOG statement. *Alzheimer Disease and Associated Disorders, 28*(3), 206-218.

Small, J., & Gutman, G. (2002). Recommended and reported use of communication strategies in Alzheimer's caregiving. *Alzheimer Disease and Associated Disorders, 16*(4), 270-278.

Szczesniak, M. M., Maclean, J., Zhang, T., Liu, R., & Cook, I. J. (2014). The normative range for and age and gender effects on the sydney swallow questionnaire (SSQ). *Dysphagia, 29*(5), 535-538.

Terada, S., Ishizu, H., Fujisawa, Y., Fujita, D., Yokota, O., Nakashima, H., . . . Kuroda, S. (2002). Development and evaluation of a health-realted quality of life questionnaire for the elderly with dementia in Japan. *International Journal of Geriatric Psychiatry, 17*(9), 851-858.

Thomson, L. J., & Chatterjee, H. J. (2014). Assessing well-being outcomes for arts and heritage activities: Development of a Museum Well-being Measures toolkit. *Journal of Applied Arts and Health, 5*(1), 29-50.

Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R. T., & Orrell, M. (2003). Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) Scale. *Alzheimer Disease & Associated Disorders, 17*(4), 201-208.

Weiner, M. F., Martin-Cook, K., Svetlik, D. A., Saine, K., Foster, B., & Fontaine, C. S. (2000). The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association, 1*(3), 114-116.

Wewers, M. E., & Lowe, N. K. (1990). A critical review of visual analogue scales in the measurement of clinical phenomena. *Research in Nursing & Health, 13*(4), 227-236.

Williamson, A., & Hoggart, B. (2005). Pain: a review of three commonly used pain rating scales. *Journal of Clinical Nursing, 14*(7), 798-804.

World Health Organization. (2021). *Measuring Quality of Life*. Retrieved from Health Topics: https://www.who.int/tools/whoqol

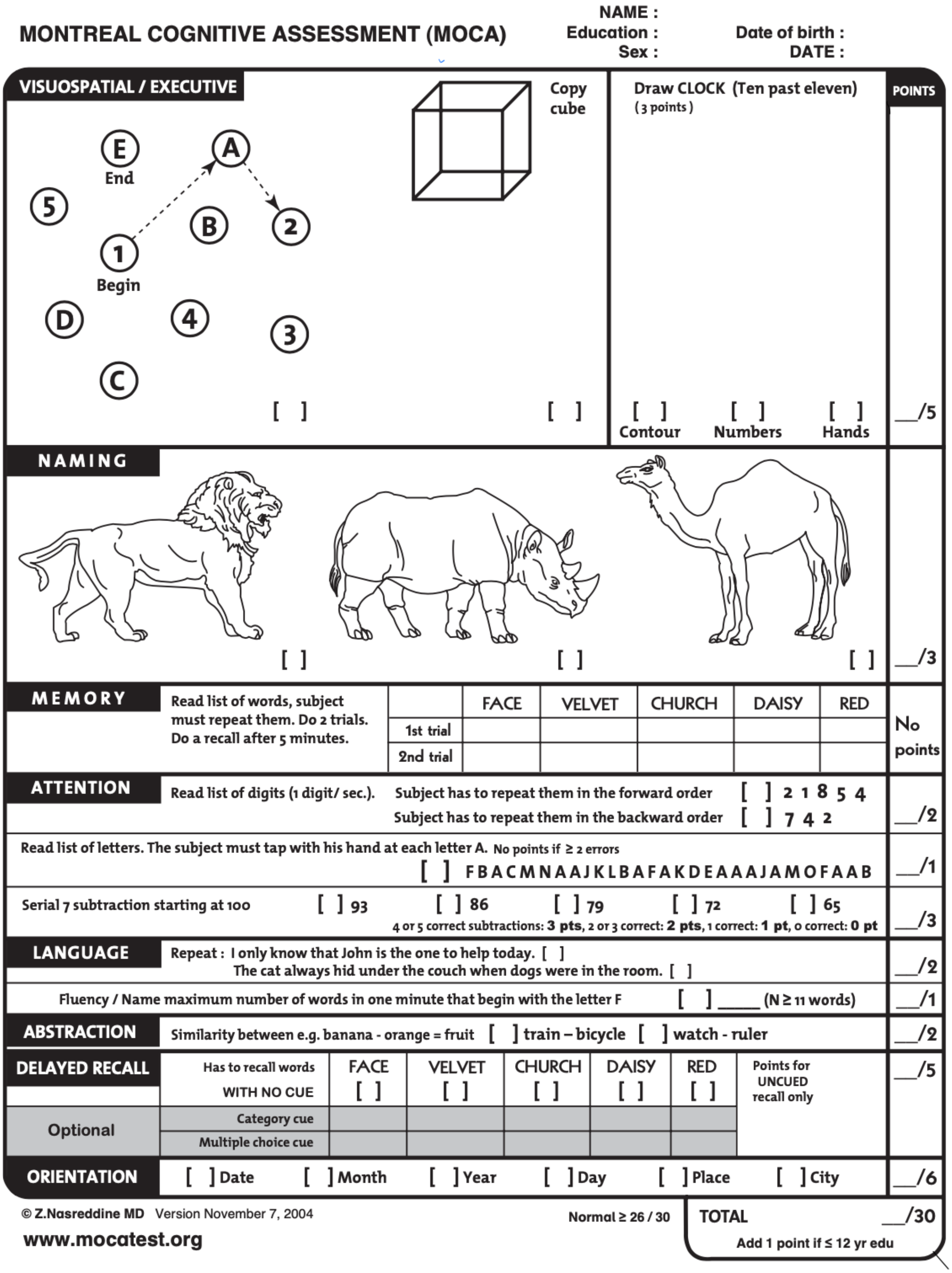
Yanamoto-Mitani, N., Abe, T., Okita, Y., Hayashi, K., Sugishita, C., & Kamata, K. (2004). The impact of subject/respondent characteristics on a proxy-rated quality of life instrument for the Japanese elderly with dementia. *Quality of Life Research, 13*(4), 845-855.

Appendix A: Screening Questions

Screening Questions:

1. Are you 60 years of age or older?
2. Do you have a current diagnosis of dementia, Alzheimer's disease, or any other neurodegenerative condition?
3. Are you able to participate in two meetings, 4 weeks apart?

Appendix B: Montreal Cognitive Assessment



MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME :
Education : Date of birth :
Sex : DATE :

		POINTS
VISUOSPATIAL / EXECUTIVE	[ ] Copy cube [ ] Draw CLOCK (Ten past eleven) (3 points) [ ] Contour [ ] Numbers [ ] Hands	__/5
NAMING	[ ] [ ] [ ]	__/3

MEMORY Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2 __/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B __/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** __/3

LANGUAGE Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ] __/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words) __/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler __/2

DELAYED RECALL

Has to recall words	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only
WITH NO CUE	[ ]	[ ]	[ ]	[ ]	[ ]	__/5
Optional: Category cue						
Optional: Multiple choice cue						

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City __/6

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Normal ≥ 26 / 30

TOTAL __/30
Add 1 point if ≤ 12 yr edu

Appendix B: Montreal Cognitive Assessment

Montreal Cognitive Assessment
(MoCA)

Administration and Scoring Instructions

The Montreal Cognitive Assessment (MoCA) was designed as a rapid screening instrument for mild cognitive dysfunction. It assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. Time to administer the MoCA is approximately 10 minutes. The total possible score is 30 points; a score of 26 or above is considered normal.

1. **Alternating Trail Making:**

Administration: The examiner instructs the subject: *"Please draw a line, going from a number to a letter in ascending order. Begin here* [point to (1)] *and draw a line from 1 then to A then to 2 and so on. End here* [point to (E)]."

Scoring: Allocate one point if the subject successfully draws the following pattern: 1 –A- 2- B- 3- C- 4- D- 5- E, without drawing any lines that cross. Any error that is not immediately self-corrected earns a score of 0.

2. **Visuoconstructional Skills (Cube):**

Administration: The examiner gives the following instructions, pointing to the **cube**: *"Copy this drawing as accurately as you can, in the space below".*

Scoring: One point is allocated for a correctly executed drawing.

- Drawing must be three-dimensional
- All lines are drawn
- No line is added
- Lines are relatively parallel and their length is similar (rectangular prisms are accepted)

A point is not assigned if any of the above-criteria are not met.

3. **Visuoconstructional Skills (Clock):**

Administration: Indicate the right third of the space and give the following instructions: *"Draw a* ***clock****. Put in all the numbers and set the time to 10 after 11".*

Scoring: One point is allocated for each of the following three criteria:

- Contour (1 pt.): the clock face must be a circle with only minor distortion acceptable (e.g., slight imperfection on closing the circle);
- Numbers (1 pt.): all clock numbers must be present with no additional numbers; numbers must be in the correct order and placed in the approximate quadrants on the clock face; Roman numerals are acceptable; numbers can be placed outside the circle contour;
- Hands (1 pt.): there must be two hands jointly indicating the correct time; the hour hand must be clearly shorter than the minute hand; hands must be centred within the clock face with their junction close to the clock centre.

A point is not assigned for a given element if any of the above-criteria are not met.

4. **Naming:**

Administration: Beginning on the left, point to each figure and say: *"Tell me the name of this animal".*

Scoring: One point each is given for the following responses: (1) camel or dromedary, (2) lion, (3) rhinoceros or rhino.

5. **Memory:**

Administration: The examiner reads a list of 5 words at a rate of one per second, giving the following instructions: *"This is a memory test. I am going to read a list of words that you will have to remember now and later on. Listen carefully. When I am through, tell me as many words as you can remember. It doesn't matter in what order you say them".* Mark a check in the allocated space for each word the subject produces on this first trial. When the subject indicates that (s)he has finished (has recalled all words), or can recall no more words, read the list a second time with the following instructions: "*I am going to read the same list for a second time. Try to remember and tell me as many words as you can, including words you said the first time."* Put a check in the allocated space for each word the subject recalls after the second trial.

At the end of the second trial, inform the subject that (s)he will be asked to recall these words again by saying, "*I will ask you to recall those words again at the end of the test."*

Scoring: No points are given for Trials One and Two.

6. **Attention:**

Forward Digit Span: Administration: Give the following instruction: "*I am going to say some numbers and when I am through, repeat them to me exactly as I said them".* Read the five number sequence at a rate of one digit per second.

Backward Digit Span: Administration: Give the following instruction: "*Now I am going to say some more numbers, but when I am through you must repeat them to me in the backwards order."* Read the three number sequence at a rate of one digit per second.

Scoring: Allocate one point for each sequence correctly repeated, (*N.B.:* the correct response for the backwards trial is 2-4-7).

Vigilance: Administration: The examiner reads the list of letters at a rate of one per second, after giving the following instruction: "*I am going to read a sequence of letters. Every time I say the letter A, tap your hand once. If I say a different letter, do not tap your hand".*

Scoring: Give one point if there is zero to one errors (an error is a tap on a wrong letter or a failure to tap on letter A).

Serial 7s: Administration: The examiner gives the following instruction: "*Now, I will ask you to count by subtracting seven from 100, and then, keep subtracting seven from your answer until I tell you to stop.*" Give this instruction twice if necessary.

Scoring: This item is scored out of 3 points. Give no (0) points for no correct subtractions, 1 point for one correction subtraction, 2 points for two-to-three correct subtractions, and 3 points if the participant successfully makes four or five correct subtractions. Count each correct subtraction of 7 beginning at 100. Each subtraction is evaluated independently; that is, if the participant responds with an incorrect number but continues to correctly subtract 7 from it, give a point for each correct subtraction. For example, a participant may respond "92 – 85 – 78 – 71 – 64" where the "92" is incorrect, but all subsequent numbers are subtracted correctly. This is one error and the item would be given a score of 3.

7. Sentence repetition:

Administration: The examiner gives the following instructions: "*I am going to read you a sentence. Repeat it after me, exactly as I say it* [pause]*:* ***I only know that John is the one to help today.***" Following the response, say: "*Now I am going to read you another sentence. Repeat it after me, exactly as I say it* [pause]*:* ***The cat always hid under the couch when dogs were in the room.***"

Scoring: Allocate 1 point for each sentence correctly repeated. Repetition must be exact. Be alert for errors that are omissions (e.g., omitting "only", "always") and substitutions/additions (e.g., "John is the one who helped today;" substituting "hides" for "hid", altering plurals, etc.).

8. Verbal fluency:

Administration: The examiner gives the following instruction: "*Tell me as many words as you can think of that begin with a certain letter of the alphabet that I will tell you in a moment. You can say any kind of word you want, except for proper nouns (like Bob or Boston), numbers, or words that begin with the same sound but have a different suffix, for example, love, lover, loving. I will tell you to stop after one minute. Are you ready?* [Pause] *Now, tell me as many words as you can think of that begin with the letter F.* [time for 60 sec]. *Stop.*"

Scoring: Allocate one point if the subject generates 11 words or more in 60 sec. Record the subject's response in the bottom or side margins.

9. Abstraction:

Administration: The examiner asks the subject to explain what each pair of words has in common, starting with the example: "*Tell me how an orange and a banana are alike*". If the subject answers in a concrete manner, then say only one additional time: "*Tell me another way in which those items are alike*". If the subject does not give the appropriate response (*fruit*), say, "*Yes, and they are also both fruit.*" Do not give any additional instructions or clarification.

After the practice trial, say: "*Now, tell me how a train and a bicycle are alike*". Following the response, administer the second trial, saying: "*Now tell me how a ruler and a watch are alike*". Do not give any additional instructions or prompts.

Scoring: Only the last two item pairs are scored. Give 1 point to each item pair correctly answered. The following responses are acceptable:

Train-bicycle = means of transportation, means of travelling, you take trips in both;
Ruler-watch = measuring instruments, used to measure.

The following responses are **not** acceptable: Train-bicycle = they have wheels; Ruler-watch = they have numbers.

10. Delayed recall:

Administration: The examiner gives the following instruction: "*I read some words to you earlier, which I asked you to remember. Tell me as many of those words as you can remember.* Make a check mark (✓) for each of the words correctly recalled spontaneously without any cues, in the allocated space.

Scoring: **Allocate 1 point for each word recalled freely without any cues**.

Optional:

Following the delayed free recall trial, prompt the subject with the semantic category cue provided below for any word not recalled. Make a check mark (✓) in the allocated space if the subject remembered the word with the help of a category or multiple-choice cue. Prompt all non-recalled words in this manner. If the subject does not recall the word after the category cue, give him/her a multiple choice trial, using the following example instruction, "*Which of the following words do you think it was, NOSE, FACE, or HAND?"*

Use the following category and/or multiple-choice cues for each word, when appropriate:

FACE:	category cue: part of the body	multiple choice: nose, face, hand
VELVET:	category cue: type of fabric	multiple choice: denim, cotton, velvet
CHURCH:	category cue: type of building	multiple choice: church, school, hospital
DAISY:	category cue: type of flower	multiple choice: rose, daisy, tulip
RED:	category cue: a colour	multiple choice: red, blue, green

Scoring: **No points are allocated for words recalled with a cue.** A cue is used for clinical information purposes only and can give the test interpreter additional information about the type of memory disorder. For memory deficits due to retrieval failures, performance can be improved with a cue. For memory deficits due to encoding failures, performance does not improve with a cue.

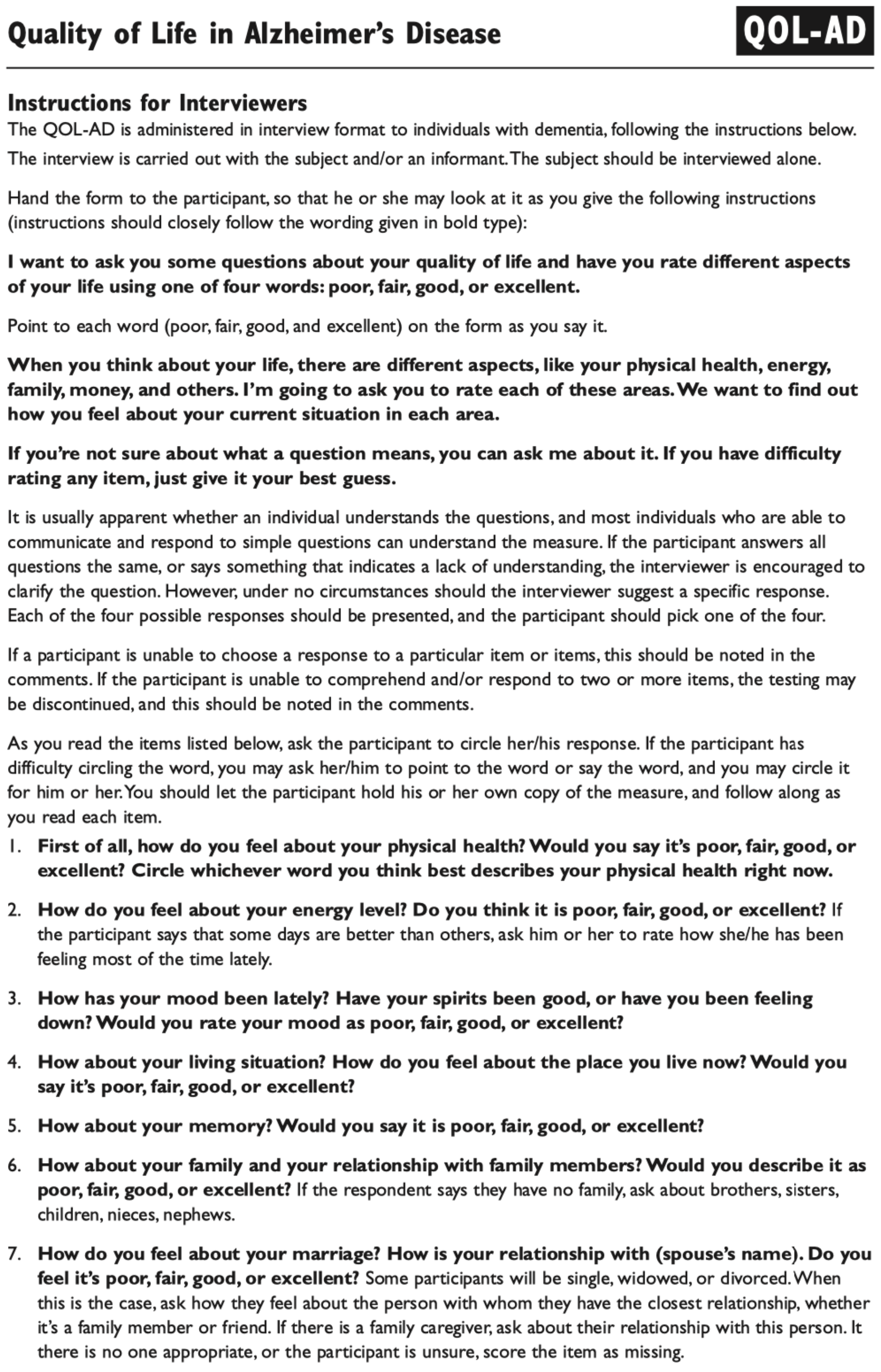
11. Orientation:

Administration: The examiner gives the following instructions: "*Tell me the date today"*. If the subject does not give a complete answer, then prompt accordingly by saying: *"Tell me the [year, month, exact date, and day of the week]."* Then say: *"Now, tell me the name of this place, and which city it is in."*

Scoring: Give one point for each item correctly answered. The subject must tell the exact date and the exact place (name of hospital, clinic, office). No points are allocated if subject makes an error of one day for the day and date.

TOTAL SCORE: Sum all subscores listed on the right-hand side. Add one point for an individual who has 12 years or fewer of formal education, for a possible maximum of 30 points. A final total score of 26 and above is considered normal.

Appendix C: Quality of Life in Alzheimer’s Disease



Quality of Life in Alzheimer’s Disease

QOL-AD

Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below. The interview is carried out with the subject and/or an informant. The subject should be interviewed alone.

Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.

Point to each word (poor, fair, good, and excellent) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I’m going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you’re not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

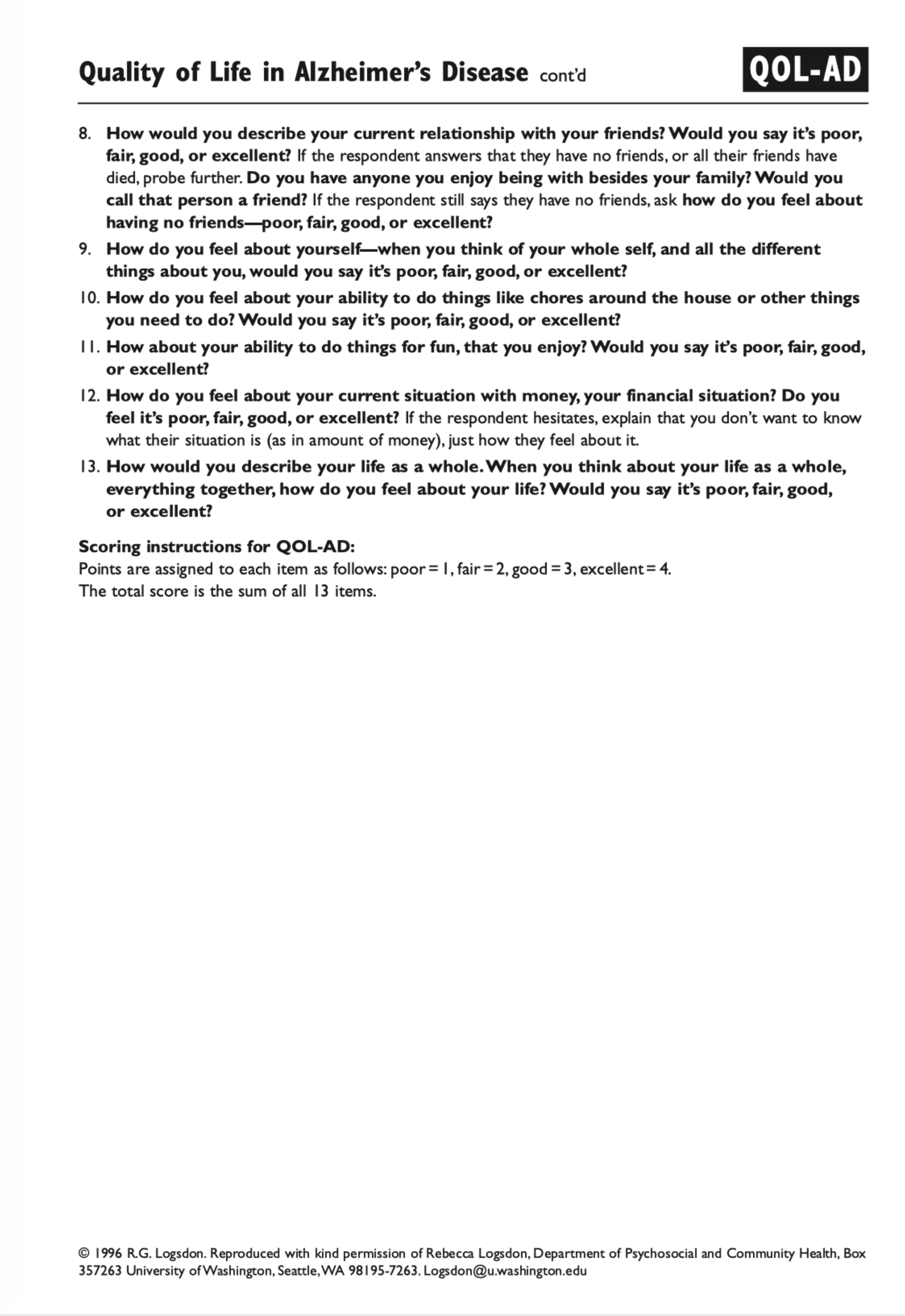
It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. **First of all, how do you feel about your physical health? Would you say it’s poor, fair, good, or excellent? Circle whichever word you think best describes your physical health right now.**
2. **How do you feel about your energy level? Do you think it is poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.
3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as poor, fair, good, or excellent?**
4. **How about your living situation? How do you feel about the place you live now? Would you say it’s poor, fair, good, or excellent?**
5. **How about your memory? Would you say it is poor, fair, good, or excellent?**
6. **How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent?** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.
7. **How do you feel about your marriage? How is your relationship with (spouse’s name). Do you feel it’s poor, fair, good, or excellent?** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it’s a family member or friend. If there is a family caregiver, ask about their relationship with this person. It there is no one appropriate, or the participant is unsure, score the item as missing.

Appendix C: Quality of Life in Alzheimer’s Disease

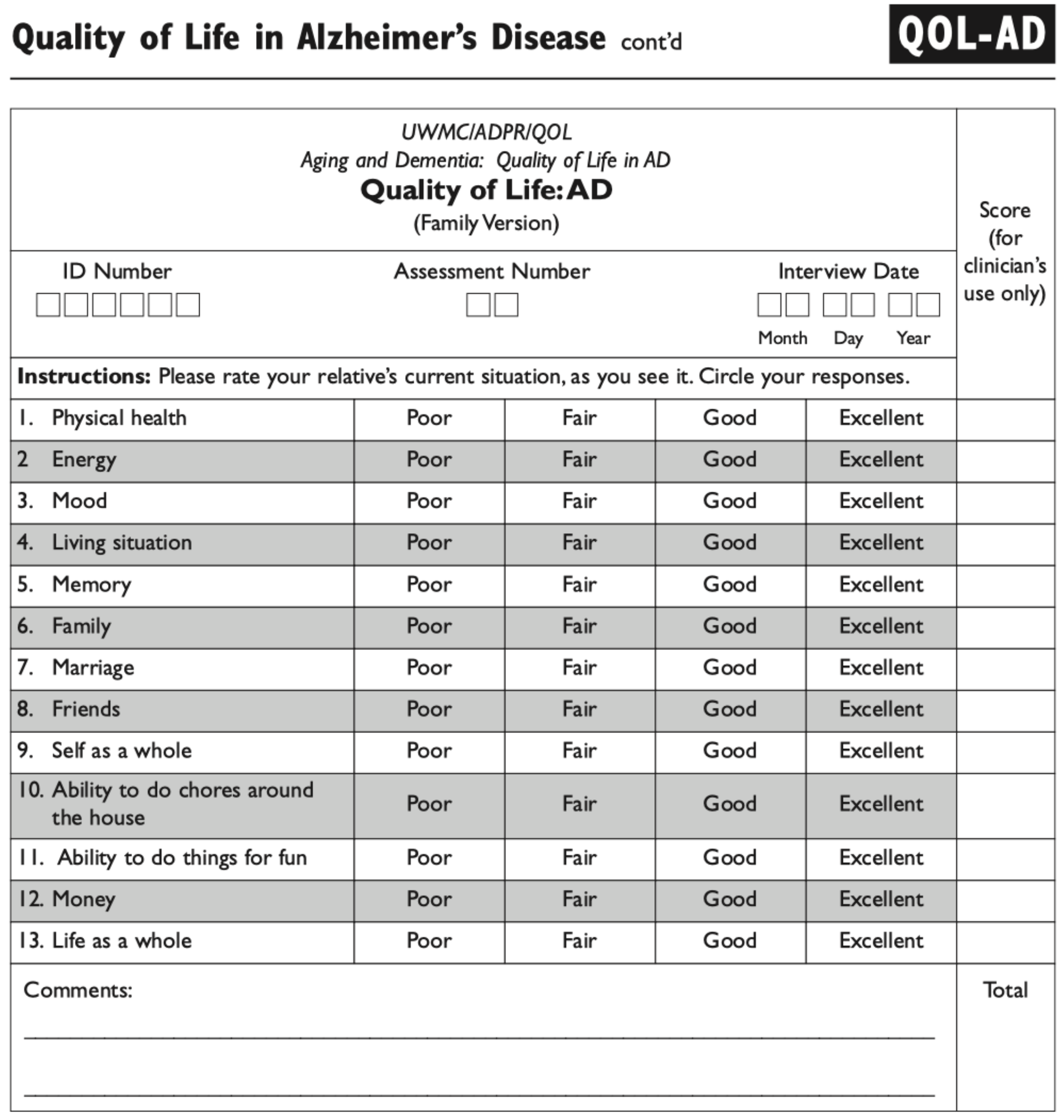


Quality of Life in Alzheimer’s Disease cont’d **QOL-AD**

8. **How would you describe your current relationship with your friends? Would you say it’s poor, fair, good, or excellent?** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**
9. **How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it’s poor, fair, good, or excellent?**
10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it’s poor, fair, good, or excellent?**
11. **How about your ability to do things for fun, that you enjoy? Would you say it’s poor, fair, good, or excellent?**
12. **How do you feel about your current situation with money, your financial situation? Do you feel it’s poor, fair, good, or excellent?** If the respondent hesitates, explain that you don’t want to know what their situation is (as in amount of money), just how they feel about it.
13. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it’s poor, fair, good, or excellent?**

Scoring instructions for QOL-AD:
Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4.
The total score is the sum of all 13 items.

Appendix C: Quality of Life in Alzheimer's Disease



Quality of Life in Alzheimer's Disease cont'd

QOL-AD

UWMC/ADPR/QOL
Aging and Dementia: Quality of Life in AD
Quality of Life: AD
(Family Version)

ID Number ☐☐☐☐☐☐

Assessment Number ☐☐

Interview Date ☐☐ ☐☐ ☐☐
Month Day Year

Score (for clinician's use only)

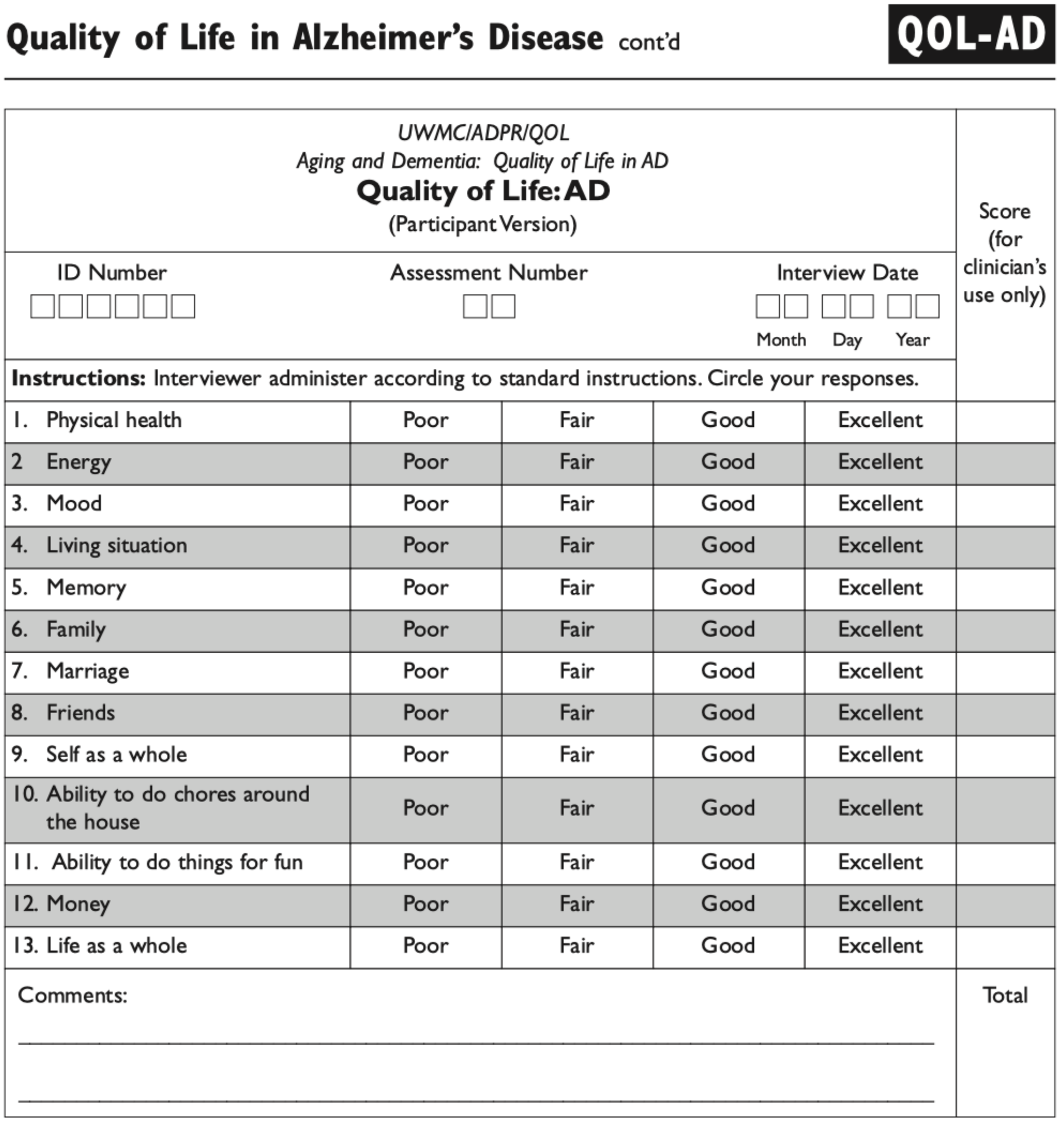
Instructions: Please rate your relative's current situation, as you see it. Circle your responses.

1. Physical health	Poor	Fair	Good	Excellent	
2 Energy	Poor	Fair	Good	Excellent	
3. Mood	Poor	Fair	Good	Excellent	
4. Living situation	Poor	Fair	Good	Excellent	
5. Memory	Poor	Fair	Good	Excellent	
6. Family	Poor	Fair	Good	Excellent	
7. Marriage	Poor	Fair	Good	Excellent	
8. Friends	Poor	Fair	Good	Excellent	
9. Self as a whole	Poor	Fair	Good	Excellent	
10. Ability to do chores around the house	Poor	Fair	Good	Excellent	
11. Ability to do things for fun	Poor	Fair	Good	Excellent	
12. Money	Poor	Fair	Good	Excellent	
13. Life as a whole	Poor	Fair	Good	Excellent	

Comments:

Total

Appendix C: Quality of Life in Alzheimer's Disease



Quality of Life in Alzheimer's Disease cont'd

QOL-AD

UWMC/ADPR/QOL
Aging and Dementia: Quality of Life in AD
Quality of Life: AD
(Participant Version)

ID Number ☐☐☐☐☐☐

Assessment Number ☐☐

Interview Date ☐☐ ☐☐ ☐☐
Month Day Year

Instructions: Interviewer administer according to standard instructions. Circle your responses.

					Score (for clinician's use only)
1. Physical health	Poor	Fair	Good	Excellent	
2 Energy	Poor	Fair	Good	Excellent	
3. Mood	Poor	Fair	Good	Excellent	
4. Living situation	Poor	Fair	Good	Excellent	
5. Memory	Poor	Fair	Good	Excellent	
6. Family	Poor	Fair	Good	Excellent	
7. Marriage	Poor	Fair	Good	Excellent	
8. Friends	Poor	Fair	Good	Excellent	
9. Self as a whole	Poor	Fair	Good	Excellent	
10. Ability to do chores around the house	Poor	Fair	Good	Excellent	
11. Ability to do things for fun	Poor	Fair	Good	Excellent	
12. Money	Poor	Fair	Good	Excellent	
13. Life as a whole	Poor	Fair	Good	Excellent	
Comments: ____________________________________ ____________________________________					Total

Appendix C: Quality of Life in Alzheimer’s Disease

Quality of Life in Alzheimer’s Disease cont’d

QOL-AD

Score Summary Sheet

Informant’s score of subject’s QOL ☐ (maximum 52)

Subject’s own QOL rating ☐ (maximum 52)

Instructions for Interviewers: QoL-AD with VAS

Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

If administering the QoL-AD with VAS first: **I want to ask you some questions about your quality of life and have you rate different aspects of your life using a line scale.**

If administering the QoL-AD with VAS after the QoL-AD: **I want to ask you the same questions about your quality of life but have you rate them using a line scale instead of the rating scale we used before.**

Point to the VAS and show that a mark can be made anywhere along the continuum. Point to each end bracket and face while discussing the poles.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area. For each question I want you to make a mark along the line that shows how you feel about each question. You can place a mark anywhere along this line in between the brackets on either end. The left side is total dissatisfaction, and the right side is complete satisfaction.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. A VAS should be presented for each question and the participant should make a mark on the line that corresponds to their feelings about the question being discussed.

If a participant is unable to record a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to place a mark on the VAS that corresponds to their feelings about each question.

1. **First of all, how do you feel about your physical health? Mark on the scale how your health is today. *Point to the sad face saying,* this is the worst health you can imagine. *Point to the happy face saying,* this is the best health you can imagine.**
2. **How do you feel about your energy level? Mark on the scale how your energy is today. *Point to the sad face saying,* this is the worst energy level you can imagine. *Point to the happy face saying,* this is the best energy level you can imagine.** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.
3. **How has your mood been lately? Have your spirits been good, or have you been feeling down? Mark on the scale how your mood is today. *Point to the sad face saying,* this is the worst mood you can imagine. *Point to the happy face saying,* this is the best mood you can imagine.**

4. **How about your living situation? How do you feel about the place you live now? Mark on the scale how you feel about your living situation today.** ***Point to the sad face saying,*** **this is the worst situation you can imagine.** ***Point to the happy face saying,*** **this is the best situation you can imagine.**
5. **How about your memory? Mark on the scale how your memory is today.** ***Point to the sad face saying,*** **this is the worst memory you can imagine.** ***Point to the happy face saying,*** **this is the best memory you can imagine.**
6. **How about your family and your relationship with family members? Mark on the scale how your relationship is today.** ***Point to the sad face saying,*** **this is the worst relationship you can imagine.** ***Point to the happy face saying,*** **this is the best relationship you can imagine.** If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.
7. **How do you feel about your marriage? How is your relationship with (spouse's name)? Mark on the scale how you feel about your marriage today.** ***Point to the sad face saying,*** **this is the worst relationship with your spouse you can imagine.** ***Point to the happy face saying,*** **this is the best relationship with your spouse you can imagine.** Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. It there is no one appropriate, or the participant is unsure, score the item as missing.
8. **How would you describe your current relationship with your friends? Mark on the scale how your relationships with your friends today.** ***Point to the sad face saying,*** **this is the worst relationship with your friends you can imagine.** ***Point to the happy face saying,*** **this is the best relationship with your friends you can imagine.** If the respondent answers that they have no friends, or all their friends have died, probe further. **Do you have anyone you enjoy being with besides your family? Would you call that person a friend?** If the respondent still says they have no friends, ask **how do you feel about having no friends—poor, fair, good, or excellent?**
9. **How do you feel about yourself—think of your whole self, and all the different things about you. Mark on the scale how you feel about yourself today.** ***Point to the sad face saying,*** **this is the worst feeling about yourself you can imagine.** ***Point to the happy face saying,*** **this is the best feeling about yourself you can imagine.**
10. **How do you feel about your ability to do things like chores around the house or other things you need to do? Mark on the scale how you feel about your ability today.**
11. **How about your ability to do things for fun, that you enjoy? Mark on the scale how you feel about your ability today.** ***Point to the sad face saying,*** **this is the worst ability to do things you can imagine.** ***Point to the happy face saying,*** **this is the best ability to do things you can imagine.**
12. **How do you feel about your current situation with money, your financial situation? Mark on the scale how you feel about your financial situation today.** ***Point to the sad face saying,*** **this is the worst financial situation you can imagine.** ***Point to the happy face saying,*** **this is the best financial situation you can imagine.** If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.
13. **How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Mark on the scale how you feel about your life today.** ***Point to the sad face saying,*** **this is the worst feeling about your life you can imagine.** ***Point to the happy face saying,*** **this is the best feeling about your life you can imagine.**