The Burden and Quality of Life of Dementia Caregivers: Exploring the Roles of Care Recipients' Social Cognition, Memory, and Executive Functioning

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List of Abbreviations

Abbreviation	**Definition**
AD	Alzheimer’s Disease
ADL	activities of daily living
CB	caregiver burden
CG(s)	caregiver(s)
CVA	cerebrovascular accident
CQoL	caregivers’ quality of life
DR	delayed recall
EF	executive functions
EFT	Ekman 60 Faces Test
FEEST	Facial Expressions of Emotion – Stimuli and Tests
FTD	frontotemporal dementia
iADL	instrumental activities of daily living
IR	immediate recall
LBD	Lewy body dementia
MCI	mild cognitive impairment
MMSE	Mini-Mental State Examination
MoCA	Montreal Cognitive Assessment
NIP	Netherlands Institute of Psychology
PwD	people with dementia
QoL	quality of life
QoL-AD	Quality of Life – Alzheimer Disease Scale
RAVLT	Rey Auditory Verbal Learning Test
SC	social cognition
SPSS	Statistical Package for the Social Sciences
TBI	traumatic brain injury
TMT	Trail Making Test
UMCG	University Medical Center Groningen
VaD	vascular dementia
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life
ZBI	Zarit Burden Interview

“To love a person is to learn the song in their heart

and sing it to them when they have forgotten.”

Arne Garborg

Abstract

Dementia is a major healthcare challenge, currently affecting 55 million individuals worldwide. As the disease progresses, people with dementia (PwD) increasingly rely on external support, usually necessitating that spouses or children take on the roles of informal caregivers (CGs). This responsibility is time-consuming and can place strain on CGs, resulting in increased burden and reduced quality of life. While research has established various factors that contribute to such adverse outcomes of dementia caregiving, the role of the care recipients' cognitive decline – a defining characteristic of dementia – remains a subject of debate. In the present study, a cross-sectional design was employed to explore the roles of PwDs' social cognition, memory, and executive functioning in caregiver burden (CB) and CGs' quality of life (CQoL). The sample included 48 PwD and their respective close ones. PwDs' emotion recognition (Ekman 60 Faces Test [EFT]), episodic memory (Rey Auditory Verbal Learning Test [RAVLT]), and cognitive flexibility (Trail Making Test [TMT]), as well as CGs' self-reported burden (Zarit Burden Interview [ZBI]) and quality of life (Quality of Life – Alzheimer's Disease Scale [QoL-AD]), were measured. Using multiple linear regression and analysis of variance, it was found that neither the combined nor isolated effects of social cognition, memory, and executive functioning were significantly related to CB and CQoL. However, when examining these constructs more in-depth, a significant positive correlation was found between PwDs' emotion recognition and CGs' psychological well-being, an underlying factor of CQoL. This finding highlights the importance of social reciprocity in the early stages of dementia caregiving. Theoretical and practical implications as well as areas for further research are discussed.

Keywords: Alzheimer's Disease, caregiver burden, cognitive functioning, dementia, executive functions, memory, social cognition, quality of life

The Burden and Quality of Life of Dementia Caregivers: Exploring the Roles of Care Recipients' Social Cognition, Memory, and Executive Functioning

Dementia is a major global cause of disability and burden (WHO, 2023) and one of the greatest healthcare challenges of the 21st century (Scheltens et al., 2021). Presently, approximately 55 million individuals worldwide are affected, a number projected to triple by 2050 (Alzheimer's Disease International, 2018). Dementia is a syndromal term encompassing a spectrum of diseases that are characterized by a significant decline in cognitive abilities interfering with a person's ability to perform everyday activities (McKhann et al., 2011). This decline, combined with the current absence of a cure, makes dementia one of the most widely feared diagnoses worldwide (Werner et al., 2021). Most types of dementia involve progressive neurodegeneration, resulting in a loss of cerebral volume and structural integrity (Harper et al., 2017). Alzheimer's Disease (AD), primarily marked by episodic memory impairment (Begali, 2020), represents the most prevalent type of dementia, accounting for 60 to 70% of cases (WHO, 2023). Vascular dementia (VaD), caused by progressive vascular brain damage like small vessel disease or cerebral infarctions (Wolters & Ikram, 2019), is the second most common type. Other frequent types of dementia include frontotemporal dementia (FTD), associated primarily with personality and behavior changes, and Lewy body dementia (LBD), hallmarked by hallucinations and visuospatial dysfunction (Begali, 2020). Despite variations in symptom expressions and disease trajectories, all types share the perception of dementia as being “a loss of the mind and self” (Moniz-Cook et al., 2006, p. 385).

The Role of the Support System in Dementia Care

The impact of dementia extends beyond the diagnosed individuals themselves, as the immediate social environment plays a crucial role in the care process (Charalambous, 2023). Nearly 80% of people with dementia (PwD) require assistance with activities of daily living (ADL), such as bathing and dressing, as well as with instrumental activities of daily living (iADL), like transportation and managing finances (Alzheimer's Association, 2020a). Typically, these responsibilities are taken on by informal caregivers (CGs). Informal care refers to the provision of usually untrained and unpaid care to a relative or friend with a chronic illness or disability (Revenson et al., 2016). In the Netherlands, informal dementia CGs are on average 64 years old, with 71% being female (Alzheimer Nederland 2022). Most CGs are family members of the individual with dementia; 46% are spouses and 47% are children(-in-law). They dedicate an average of 39 hours per week to caregiving. Nearly half of the CGs are retired (47%), while 43% are employed, balancing their care responsibilities with work (Alzheimer Nederland, 2022).

Compared to CGs of individuals with other conditions, such as cancer or depression, dementia CGs face an elevated risk of experiencing burden (Leinonen et al., 2001; Spatuzzi et al., 2022). They often strive to maintain a “bubble of normalization” by refraining from seeking help, which can exacerbate the strain (Parker et al., 2022, p. 717). Moreover, as age represents the most significant risk factor for dementia (e.g., Santos et al., 2014), dementia CGs are frequently elderly individuals themselves (Farina et al., 2017), dealing with their own physical and psychological challenges. Furthermore, the progressive nature of the disease implies an increasing reliance on external support. Consequently, caregiving responsibilities become progressively more challenging and time-consuming as the disease advances (Haro et al., 2014; Wolff et al., 2016).

The Burden and Quality of Life of Dementia CGs

Research on dementia care has historically focused on measuring the burden and strain experienced by CGs. In the late 20th century, attention was primarily directed toward understanding *caregiver burden* (CB; Matthew et al., 2021), a term introduced to capture the demanding nature of caring for PwD (Montgomery et al., 1985). CB is defined as “the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time" (Liu et al., 2020, p. 442). Factor analysis on measures of CB has identified two predominant factors: personal strain and role strain (Bédard et al., 2001). Longitudinal studies indicate that 47% of dementia CGs experience clinical levels of burden at baseline, increasing to 57% over a period of three years (Connors et al., 2020). Among CGs in the Netherlands, 59% rate the stress of caregiving as high or very high (Alzheimer's Association, 2020b), and 13% report feeling severely burdened (Alzheimer Nederland, 2022).

In the current century, the research focus has shifted from CB towards an adjacent construct: *caregivers' quality of life* (CQoL). This shift acknowledges the complex reality of caregiving, where positive and negative effects can coexist (Matthew et al., 2021). Quality of life (QoL) is understood as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHOQOL Group, 1995, p. 1405). Factor analysis on measures of CQoL has identified three predominant factors: physical well-being, social well-being, and psychological well-being (Torisson et al., 2016). Numerous studies have explored the relationship between CB and CQoL, consistently reporting a direct negative correlation between the two constructs (e.g., Contreras et al., 2021; Oba et al., 2018; Torlaschi et al., 2022), with effect sizes ranging from moderate (Spearman's r = -0.36; e.g., Oba et al., 2018) to large (Spearman's r = -0.52; e.g., Torlaschi et al., 2022). Research has also suggested an indirect connection through the caregiver's mental health state (Paredes et al, 2017).

Increased CB and diminished CQoL are adverse outcomes of dementia caregiving with far-reaching consequences for both CGs as well as care recipients. CGs may experience depression and anxiety (e.g., Lippe et al., 2021; McAuliffe et al., 2020), mental fatigue (Nagatomo et al., 1999), sleep disturbances (Lippe et al., 2021), functional and cognitive impairment (Torisson et al., 2016), and physical health issues such as hypertension, diabetes, and heart disease (Kovaleva et al., 2018; Lippe et al., 2021). Depressive symptoms are particularly prevalent, affecting 30 to 40% of dementia CGs (Alzheimer's Association, 2020b). PwD under the care of highly burdened individuals are at elevated risk of experiencing elder abuse (Beach et al., 2005; Wiglesworth et al., 2010) and premature nursing home placement (Martin et al., 2022; Stephan et al., 2015).

PwD Factors Contributing to Increased CB and Reduced CQoL

Due to the serious implications of adverse outcomes for dementia CGs, extensive research has been conducted to gain a better understanding of their development. This is a challenging issue because the experience of dementia caregiving is multidimensional and, thus, intercorrelations of different factors occur (Bédard et al., 2000). With regard to the PwD, established contributing factors include older age (e.g., Santos et al., 2014), male gender (e.g., Abdollahpour et al., 2015; Nagatomo et al., 1999), a diagnosis of FTD or AD (D'onofrio et al., 2015; Mioshi et al., 2013), greater dementia severity (Mioshi et al., 2013), a longer time since diagnosis (Santos et al., 2014), a higher level of dependency (Abdollahpour et al., 2015; Serrano-Aguilar et al., 2006), impaired functioning in ADL and iADL (e.g., Connors et al., 2020; Torlaschi et al., 2022; van den Kieboom et al., 2020), and – most influentially – the presence of neuropsychiatric symptoms, specifically disruptive and aberrant behavior, which includes agitation, aggression and disinhibition (e.g., Cheng, 2017; Connors et al., 2020; Contreras et al., 2021; Rosdinom et al., 2013).

The Role of Cognitive Functioning

The impact of PwDs' cognitive decline, the hallmark symptom of dementia, on outcomes for CGs remains a debated subject, due to inconsistent findings: Some studies have identified relationships between global cognitive functioning – usually assessed with single screening tests like the Mini-Mental State Examination (MMSE; Folstein et al., 1975) or the Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) – and CB or CQoL (e.g., Kamiya et al., 2014; Lethin et al., 2020; Paredes et al., 2017; Torlaschi et al., 2022; Tulek et al., 2020). Conversely, other studies have not found such associations (e.g., Borsje et al., 2016; Brodaty et al., 2014; Connors, 2020; Kajiwara et al., 2018; Rosdinom et al., 2013). Miller et al. (2013) reported no effect of screened global cognitive functioning but did find associations between increased CB and declines in PwDs’ anterograde memory, impulse control, and emotion processing. The researchers suggested that assessing the functioning of specific cognitive domains might reveal effects that global cognition screening overlooks.

Memory

A significant body of research has explored which cognitive domains are most affected in dementia and how impairments in these domains impact CGs. A frequently impaired cognitive domain, particularly in AD, is memory. Research has reported correlations between increased CB and self-reported memory problems (Yoshino & Takechi, 2023), anterograde memory performance (Miller et al., 2013), and autobiographical memory impairment (Kumfor et al., 2016) in PwD. Another study found a positive impact of memory strategy training for PwD on reducing burden and depression in their CGs (McAuliffe et al., 2021), suggesting a crucial role of memory functioning. As an explanatory note, memory impairments might result in repeated conversations, questions, and potential safety concerns, thereby elevating caregiving demands and stress. Similarly, witnessing the fading of shared memories and a decline in recognition might lead to emotional distress.

Executive Functions

Another often impaired cognitive domain in dementia is executive functioning. Executive functions (EF) are higher-order cognitive processes that enable individuals to manage and regulate thoughts, behaviors, and emotions to achieve goals and adapt to changing circumstances (Diamond, 2013). These skills are crucial for various aspects of daily life, such as problem-solving, decision-making, organizing, planning, and self-control. Research has linked increased CB to reduced impulse control (Miller et al., 2013) and impaired problem-solving skills (Yoshino & Takechi, 2023) in PwD. The researchers suggested that impairments in these EF may necessitate higher levels of supervision and intervention from CGs, thereby increasing workload and stress.

Social Cognition

Social cognition (SC) was recognized as a formal cognitive domain in the latest edition of the Diagnostic and Statistical Manual of Mental Disorders ([DSM-5]; American Psychiatric Association [APA], 2013). SC refers to “a complex set of mental abilities underlying social stimulus perception, processing, interpretation, and response”, including emotion recognition, joint attention, empathy, moral processing, and theory of mind (Beaudoin & Beauchamp, 2020, p. 255). Multiple studies have established a relationship between dementia progression and dysfunction in SC (e.g., Cosentino et al., 2014; Kemp et al., 2012; Kumfor et al., 2014). AD has been linked to impairments in theory of mind (Kessels et al., 2021; Le Bouc et al., 2012), empathy (Fernandez-Duque et al., 2010), and emotion recognition (Kessels et al., 2021; Phillips et al., 2010; Torres et al., 2015). FTD was associated with impairments in empathy, social interest, affection and warmth, and responsiveness to the feelings of others (Dermody et al., 2016; Fernandez-Duque et al., 2010). Findings regarding the role of PwDs’ SC in adverse outcomes for CGs are mixed: Increased CB has repeatedly been associated with impaired emotion recognition (Martinez et al., 2018; Miller et al., 2013; Spitzer et al., 2019). In contrast, Daley et al. (2018) found the opposite effect; a link between increased CB and preserved emotion recognition in PwD. As an explanatory note, they proposed that emotional engagement in the presence of cognitive impairment may lead to negative interactions and a greater sense of burden.

The Current Study

Understanding the development of adverse outcomes for dementia CGs is essential, given the extensive implications for all involved. Previous studies have identified numerous factors contributing to increased CB and reduced CQoL. However, the role of the cognitive functioning of PwD remains a subject of debate due to inconsistent findings. The current study aimed to investigate the relationships between PwDs' SC, memory, and EF – cognitive domains that are commonly impaired in dementia – and the burden and QoL experienced by CGs. While research on the isolated effects of SC, memory, and EF on outcomes for caregivers is scarce, the combined effect of these domains has not been explored at all, representing a significant knowledge gap. This is relevant, as in clinical practice dementia typically presents itself with a complex interplay of impairments across several cognitive domains rather than isolated deficits. The findings obtained from this study contribute to a better understanding of the role of PwDs' cognitive functioning in the caregiving experience. This information can aid in developing interventions tailored to meet the needs of families affected by dementia.

Hypothesis 1: The Roles of PwDs' SC, Memory, and EF in CB and CQoL

The first research question concerned the roles of PwDs' SC, memory, and EF in experienced CB and CQoL. Using multiple linear regression analyses, potential relationships between PwDs' cognitive performances and CGs' burden and QoL were investigated. Based on the scientific evidence presented previously, it was hypothesized that CB would be related to PwDs' SC. Although prior research reported mixed findings on the direction of the relationship, a predominant portion suggested a negative correlation with emotion recognition abilities (Martinez et al., 2018; Miller et al., 2013; Spitzer et al., 2019). Therefore, higher CB was predicted to be associated with lower SC functioning. Negative correlations were also expected between CB and PwDs' memory and EF, meaning that lower functioning in these domains would be associated with increased CB. This prediction was based on the fact that multiple aspects of memory and EF have been found to relate to CB (Kumfor et al., 2016;

Miller et al., 2013; Yoshino & Takechi, 2023), although the specific aspects examined in the present study, episodic memory and cognitive flexibility, have not been directly investigated.

While the effect of PwDs’ cognitive functioning on CQoL is less explored, indirect evidence suggests potential effects. Given the consistently reported moderate to large negative correlations between CB and CQoL across multiple studies, it was hypothesized that factors negatively related to increased CB would also correlate with a decrease in CQoL. Therefore, positive associations between CQoL and the three examined cognitive domains of PwD were anticipated: Better functioning in SC, memory, and EF was expected to be linked to higher QoL in dementia CGs, and vice versa.

Exploratory Analysis 1: PwDs’ SC, Memory, and EF and Distinct Factors of CB and CQoL

The second research question examined the relationships of SC, memory, and EF in PwD and the distinct factors of CB and CQoL. Established CB factors include personal and role strain, whereas CQoL consists of physical, social, and psychological well-being. To our knowledge, no studies have yet investigated whether the underlying factors of CB and CQoL relate to the cognitive functioning of PwD. Hence, this analysis was exploratory.

Exploratory Analysis 2: PwDs’ Profiles of SC, Memory, and EF at Different Degrees of CB

The third and last research question concerned the cognitive functioning of PwD at different degrees of CB. Specifically, it was investigated whether PwD of mildly and severely burdened CG groups display different SC, memory, and EF profiles. To our knowledge, no prior research has examined this issue. Therefore, this analysis was also exploratory.

Methods

Design

This study was part of the ‘Vesta study’ conducted between August 2012 and February 2020 at the Geriatrics Department of the University Medical Center Groningen (UMCG) in The Netherlands. The primary objective of the Vesta study was to explore SC and behavioral changes among individuals in the early stages of dementia or with mild cognitive impairment (MCI). A cross-sectional study design was employed, involving a sample of 75 individuals who were referred to the memory clinic for assessment, and their close ones. The study was approved by the local ethics committee.

Procedure

Referred individuals were asked to bring a close person with them to the appointment. Upon arrival at the memory clinic, eligible dyads received information about the study (Appendix A). After being given time to consider their participation, the dyads provided written informed consent (Appendix B) and subsequently followed the planned appointment procedure. Referred individuals underwent an extensive neuropsychological assessment and, meanwhile, their close ones completed questionnaires. The collected data were added to a dataset, where all data were handled anonymously. The dyads did not receive compensation for their study participation.

Participants

The current study consisted of a subset of participants from the Vesta cohort who had received a diagnosis of dementia subsequent to their assessment (N=48; hereafter referred to as “PwD”) and their respective close ones (N=48; hereafter referred to as “CGs”). The dementia diagnosis was established through a comprehensive evaluation, including physical, neurological, psychiatric, and cognitive assessments, and was confirmed by an expert panel. Exclusion criteria included conditions that could affect cognitive functioning other than dementia: vision or hearing problems interfering with the neuropsychological assessment, a cerebrovascular accident (CVA) within the last six months, a delirium within the last three months, neurological or psychiatric disorders (e.g., epilepsy, brain tumor, or schizophrenia), moderate to severe traumatic brain injury (TBI), and alcohol or drug dependence.

Measures

CG Measures

CB. Experienced CB was assessed utilizing the Dutch version of the 12-item version (Bédard et al., 2001) of the Zarit Burden Interview (ZBI; Zarit & Zarit, 1987; Appendix C). This questionnaire has demonstrated moderate construct validity and high internal consistency (α = .90; Ojifinni & Uchendu, 2018). Items such as “Do you feel that your social life has suffered because you are caring for your relative?” are rated on a Likert scale from 0 (*never*) to 4 (*nearly always*), resulting in total scores between 0 and 48. According to established cutoffs, a ZBI total score of less than 3 indicates low burden, 3 to 8 moderate, 9 to 18 high, and over 18 severe burden (Hébert et al, 2000). Recent research has identified a score of 19 as a more robust indicator of severe burden (Yu et al., 2019); therefore, this cutoff was used in the current analyses. In the dataset, one item score was missing and substituted with the mean score of the respective item.

CQoL. Experienced CQoL was measured using the Dutch version of the Quality of Life – Alzheimer’s Disease (QoL-AD) scale (Logsdon et al., 1999; Appendix D). This self-report questionnaire has shown moderate content validity, moderate concurrent validity, high interrater reliability, and high internal consistency (α = .82; Thorgrimsen et al., 2003). 13 items concerning well-being in various areas of life, including mood, family and friends, health, and finances are rated on a Likert scale from 1 (*poor*) to 4 (*excellent*). Total scores range from 13 to 52, with higher scores indicating greater CQoL. Missing item scores in the dataset (N=4) were substituted with the mean score of the respective item.

PwD Measures

SC. Emotion recognition was chosen as a measure of SC due to the relative independence of other cognitive functions and the availability of well-researched neuropsychological tests and established norms (Kelly et al., 2022). Emotion recognition was assessed using the Dutch version of the Ekman 60 Faces Test (EFT) of the Facial Expressions of Emotion Stimuli and Tests (FEEST; Young et al., 2002). The FEEST has shown moderate split-half reliability (r = .62) and high concurrent validity (r = .81; Young et al., 2002), alongside high diagnostic accuracy for different conditions, including FTD (Diehl-Schmid et al., 2007). Participants are presented with 60 photographs of faces of men and women and are asked to identify the expressed emotions: anger, disgust, sadness, happiness, fear, or surprise. Each of the six emotions appears ten times, resulting in a total score ranging from 0 to 60. To account for age, sex, and education, the EFT scores were standardized to Z-scores using the norms provided by the Netherlands Institute of Psychology ([NIP], Schmand et al., 2012).

Memory. Memory functioning was assessed using the Dutch version of the Rey Auditory Verbal Learning Test (RAVLT; Rey, 1964), an auditory test measuring verbal encoding and episodic memory. The RAVLT has shown adequate divergent and convergent validity and high internal consistency (α = .82; de Sousa Magalhães et al., 2012). Participants are instructed to memorize a list of 15 words presented five times. After each presentation, they are asked to recall as many words as possible. Summation of the trial scores results in a total immediate recall (IR) score, ranging from 0 to 75. After a 20-minute interval, the delayed recall (DR) is assessed by asking the participants to recall as many words as possible. To control for the influence of the IR performance, an adjusted DR score was computed by using the formula RAVLT-DR / (RAVLT-IR / 5). These adjusted scores were standardized based on the mean and standard deviation (*SD*) of the healthy control group (HC) of the Vesta study (Strijkert et al., submitted); using the formula Z = (RAVLT-DR adj. score – mean HC

RAVLT-DR) [.8852] / *SD* HC RAVLT-DR [.23962]. The range of *Z*-scores was set between 2.6 and -2.6. In cases where cognitive limitations prevented participants from completing the test (N = 4), an alternative version with only eight words was administered. Analysis of these performances suggested that the participants would have scored in the impaired range on the RAVLT. Consequently, the missing values were imputed with *Z*-scores of -2.6.

EF. Cognitive flexibility, the ability to switch thinking between different concepts, was utilized as an indicator of executive functioning. Cognitive flexibility was assessed using the Dutch version of the Trail Making Test (TMT; Reitan, 1955), a widely used instrument in clinical practice that has shown high construct validity (Sánchez-Cubillo et al., 2009). The TMT comprises two parts: TMT-A requires participants to sequentially connect numbered circles in ascending order as quickly as possible, assessing basic visuomotor speed. TMT-B extends this task by alternating between numbers and letters, thereby placing demands on EF like self-regulation and inhibition. The ratio of TMT-B to TMT-A scores (TMT B/A index) is a relatively pure measure of cognitive flexibility (Sánchez-Cubillo et al., 2009). TMT B/A indexes were computed and standardized into *Z*-scores using the NIP norms (Schmand et al., 2012). In instances where cognitive limitations prevented participants from completing TMT-B (N = 10), the test was discontinued. As an inability to perform the task indicated impairment in the required cognitive functions, these missing values were substituted with the maximum observed time in the dataset (523 seconds).

Data Analyses

Statistical analyses were conducted using IBM Statistical Packages for the Social Sciences (SPSS) version 27. Initially, descriptive analyses were performed to summarize participants' sociodemographic characteristics and to provide overviews of PwDs' and CGs' scores. Prior to hypothesis testing, it was verified that the assumptions for the statistical analyses were met. For the analyses, PwDs' measures – EFT *Z*-scores, TMT B/A *Z*-ratios, and

RAVLT-DR adjusted *Z*-scores – were defined as independent variables, while CGs' measures – ZBI and QoL-AD total scores – were defined as dependent variables. Two multiple linear regression analyses were conducted to explore the relationships between PwDs' test performances and CGs' questionnaire scores. Specifically, ZBI and QoL-AD total scores were regressed on EFT *Z*-scores, TMT B/A *Z*-ratios, and RAVLT-DR adjusted *Z*-scores. Subsequently, five regression analyses were performed to investigate the relationships between PwDs' test performances and CGs' distinct questionnaire factor scores. Specifically, ZBI factor scores, as well as QoL-AD factor scores were regressed on EFT *Z*-scores, TMT B/A *Z*-ratios, and RAVLT-DR adjusted *Z*-scores. The multiple correlation coefficient R^2 was used as an indicator of the overall model fit, providing information about the percentage of variance of the dependent variable that is explained by all independent variables together. The isolated contribution of each independent variable was interpreted based on the semipartial correlation coefficient (*sr*), which indicates how much total variance of the dependent variable is uniquely explained by an independent variable. Finally, an ANOVA was performed to explore group differences between mildly and severely burdened CGs with regard to PwDs' cognitive functioning. Effect sizes were interpreted based on Eta squared (η^2), which measures the proportion of variance associated with each main effect and interaction effect.

All analyses utilized standardized *Z*-scores. In accordance with the norms provided by the NIP (Schmand et al., 2012), *Z*-scores of -2.1 or lower were interpreted as indicative of impairment in the measured cognitive function. Since the independent variables did not exhibit significant intercorrelation, missing values were managed through pairwise exclusion of cases, ensuring maximal utilization of available data. The significance level was set at $\alpha < .05$. Corrections for multiple comparisons were applied when appropriate. Simple bootstrapping with 1000 samples was performed whenever feasible to validate the robustness and reliability of the observed findings.

Results

Data analyses were conducted on a total of 96 individuals, comprising 48 PwD and 48 CGs. The PwD were aged between 55 and 89, with a mean of 73.9 ± 7.5 years. Nearly two-thirds were male (60.4%). The mean education level, based on the Dutch Verhage classification system ranging from 1 (*low*) to 7 (*high*), was 4.9 ± 1.3. PwDs' MMSE scores ranged between 16 and 29, with a mean of 25.7 ± 3.6. The majority of the PwD had a differential diagnosis of AD (58.7%), 15.2% had VaD, and the remainder had a mixed form of both, LBD, or other dementia diagnoses. The sample did not include individuals with FTD. The CGs were aged between 42 and 86, with a mean age of 66.8 ± 10.3 years. Three-quarters were female (75%). The CGs' mean education level was 5.2 ± 1. Their MMSE scores ranged from 26 to 30, with a mean of 29.4 ± 1. Thirty-eight CGs were spouses to the PwD, one was an ex-spouse, and nine were (in-law) children. The duration of care was, on average, 22.2 ± 33.5 months, with 16.8 ± 33.5 weekly hours dedicated to caregiving responsibilities.

Seven PwD (14.6%) exhibited impairment on the EFT, 17 PwD (42.5%) scored in the impaired range on the RAVTL, and 31 (73.8%) on the TMT. Regarding the CGs, the majority (54.3%) scored 38 points or higher on the QoL questionnaire. Four CGs reported low burden

Table 1

Overview of PwDs' Performances on the Test Measures

Measure	N	*M*	*SD*	Range	*Z*
EFT (total score)	48	38.8	7	24 – 53	-1
RAVLT-IR (total score)	37	23.7	8.2	11 – 57	-2.1
RAVLT-DR (total score)	36	3.3	2.8	0 – 14	-.6
RAVLT-DR adj.	36	.6	.4	0 – 1.4	-1.1
TMT-A (time in seconds)	41	69.6	40.2	29 – 187	-.8
TMT-B (time in seconds)	41	279.6	166	89 – 523	-1.6
TMT B/A ratio	42	4.1	1.7	1.4 – 8.2	-1.6

Note. adj. = adjusted; DR = delayed recall; EFT = Ekman 60 Faces Test; IR = immediate recall; *M* = mean; N = number of available records; PwD = people with dementia; RAVLT = Rey Auditory Verbal Learning Test; *SD* = standard deviation; TMT = Trail Making Test; *Z* = standardized mean score.

(score <3), seven moderate burden (score 3-8), 20 high burden (score 9-19), and 17 severe (score >19) burden. PwDs' test performances and CGs' questionnaire scores are reported in Tables 1 and 2, respectively.

Assumption Checks for Parametric Testing

The independence of observations was naturally fulfilled by the sampling procedure. Linearity assumptions were met between all independent and dependent variables. There was no significant multicollinearity among the independent variables (see correlation matrix in Appendix E). Q-Q plots of standardized residuals indicated equality of variances among all three independent variables, verifying assumptions of homoscedasticity. The independence of errors was confirmed by residual plots and non-significant Durbin-Watson scores. Q-Q plots of standardized residuals indicated that normality assumptions were satisfied for both total questionnaire scores and all factor scores, except for the ZBI factor 'role strain', which displayed slight skewness due to one outlier. Since all other assumptions were met, the consequences were evaluated as marginal. Therefore, parametric tests were deemed appropriate and conducted accordingly.

Table 2

Overview of CG Scores on the ZBI and QoL-AD Questionnaires

Instrument	N	*M*	*SD*	Range
ZBI (total score)	48	15.6	8.6	0 – 45
Personal strain[a]	48	11.4	6.9	0 – 34
Role strain[a]	48	4.2	2.5	0 – 11
QoL-AD (total score)	46	38.1	5.6	27 – 51
Physical well-being[b]	46	11	2.2	6 – 16
Social well-being[b]	46	18.6	2.7	13 – 24
Psychological well-being[b]	46	8.5	1.6	5 – 12

Note. CG = caregiver; *M* = mean; N = number of available records; QoL-AD = Quality of Life – Alzheimer Disease Scale; *SD* = standard deviation; ZBI = Zarit Burden Interview.

[a] factor of the ZBI questionnaire.

[b] factor of the QoL-AD questionnaire.

Hypothesis 1: The Roles of PwDs' SC, Memory, and EF in CB and CQoL

The relationships between PwDs' test performances and CGs' questionnaire scores were investigated by regressing ZBI and QoL-AD total scores on EFT *Z*-scores, TMT B/A *Z*-ratios, and RAVLT-DR adjusted *Z*-scores. The multiple linear regression analyses showed no significant effect of the regression model on either the ZBI ($F(3, 36) = .351$, $p = .789$, $R^2 = .028$) or the QoL-AD ($F(3, 34) = 1.374$, $p = .267$, $R^2 = .108$), indicating that PwDs' test performances taken together accounted for 2.8% of the variance in ZBI scores and 10.8% of the variance in QoL-AD scores. Examination of the isolated contributions of the independent variables showed no significant effect of any of the PwD measures on either CG questionnaire (see Table 3). The observed non-significant results were supported by bootstrapping.

Table 3

Multiple Linear Regression Analyses for PwDs' Test Performances Predicting CGs' Scores

Model A: Dependent variable ZBI total scores (N = 48)							
Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R^2
(Constant)	14.335	2.929	8.394 - 20.275	.000			
EFT total scores	-1.346	1.448	-4.282 - 1.590	.359	-.153	-.153	
RAVLT-DR adj. scores	.258	.916	-1.600 - 2.117	.780	.047	.046	
TMT B/A ratios	-.118	1.492	-3.144 - 2.909	.938	-.013	-.013	
Explained variance							.028
Model B: Dependent variable QoL-AD total scores (N = 46)							
Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R^2
(Constant)	38.135	1.863	34.349 - 41.922	.000			
EFT total scores	1.643	.921	-.228 - 3.515	.083	.293	.289	
RAVLT-DR adj. scores	-.657	.583	-1.842 - .528	.268	-.190	-.183	
TMT B/A ratios	-.557	.949	-2.487 - 1.372	.561	-.100	-.095	
Explained variance							.108

Note. Unstandardized coefficient (B) with standard error of B (*SE*) and 95% confidence interval (CI), probability (*p*), partial correlation coefficient (*pr*), semipartial correlation coefficient (*sr*), and multiple correlation coefficient (R^2) for the overall model fit.
Abbreviations: adj. = adjusted; DR = delayed recall; EFT = Ekman 60 Faces Test; PwD = people with dementia; QoL-AD = Quality of Life – Alzheimer Disease Scale; RAVLT = Rey Auditory Verbal Learning Test; TMT = Trail Making Test; ZBI = Zarit Burden Interview.

Exploratory Analysis 1: PwDs’ SC, Memory, and EF and Factors of CB and CQoL

The relationships between PwDs’ test performances and CGs’ distinct questionnaire factor scores were investigated by regressing the ZBI factor scores and the QoL-AD factor scores on EFT *Z*-scores, TMT B/A *Z*-ratios, and RAVLT-DR adjusted *Z*-scores. Regarding the ZBI, the multiple linear regression analyses did not yield significant effects for the model on either the factor personal strain (F(3, 36) = .502, *p* = .684, R^2 = .040) or the factor role strain (F(3, 36) = .155, *p* = .926, R^2 = .013), indicating that the test performances of the PwD taken together accounted for 4% of the variance in the factor personal strain and 1.3% of the variance in the factor role strain. The results are presented in Table 4.

Table 4

Multiple Linear Regression Analyses for PwDs’ Test Performances Predicting ZBI Factor Scores

Model C: Dependent variable ZBI factor personal strain (N = 48)

Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R^2
(Constant)	10.331	2.316	5.634 - 15.027	.000			
EFT total scores	-1.195	1.145	-3.516 - 1.126	.303	-.171	-.170	
RAVLT-DR adj. scores	.373	.725	-1.096 - 1.843	.609	.086	.084	
TMT B/A ratios	-.161	1.180	-2.554 - 2.232	.892	-.023	-.022	
Explained variance							.040

Model D: Dependent variable ZBI factor role strain (N = 48)

Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R^2
(Constant)	4.008	.871	2.242 - 5.775	.000			
EFT total scores	-.145	.431	-1.018 - .728	.738	-.056	-.056	
RAVLT-DR adj. scores	-.151	.273	-.704 - .402	.583	-.092	-.092	
TMT B/A ratios	.079	.444	-.821 - .979	.860	.030	.030	
Explained variance							.013

Note. Unstandardized coefficient (B) with standard error of the estimate (*SE*) and 95% confidence interval (CI), probability (*p*), partial correlation coefficient (*pr*), semipartial correlation coefficient (*sr*), and multiple correlation coefficient (R^2) for the overall model fit.
Abbreviations: adj. = adjusted; DR = delayed recall; EFT = Ekman 60 Faces Test; PwD = people with dementia; RAVLT = Rey Auditory Verbal Learning Test; TMT = Trail Making Test; ZBI = Zarit Burden Interview.

Regarding the QoL-AD, the regression analyses revealed non-significant effects for the model on all three factors: physical well-being (F(3, 34) = .645, *p* = .592, R^2 = .054), social well-being (F(3, 34) = 1.568, *p* = .215, R^2 = .122), and psychological well-being (F(3, 34) = 2.060, *p* = .124, R^2 = .154). These results indicated that PwDs' test performances taken together accounted for 5.4% of the variance in physical well-being, 12.2% of the variance in social well-being, and 15.4% of the variance in psychological well-being. The results are presented in Table 5. Bootstrapping supported the non-significant effects on all five factors.

Upon examination of the isolated contributions of the independent variables, a significant positive relationship was found between PwDs' EFT *Z*-scores and the QoL-AD factor psychological well-being (*pr* = .373, *sr* = .369, *p* = .025), indicating that EFT *Z*-scores uniquely explained 36.9% of the variance in CGs' psychological well-being. With bootstrapping applied, the relationship remained significant, with a slightly increased effect size (*pr* = .404, *sr* = .400, *p* = .015). To investigate this relationship further, the effects of EFT *Z*-scores on the components of the factor psychological well-being were analysed. It includes three items: mood, memory, and self as a whole. Correlational analysis showed a significant relationship of moderate effect size between EFT *Z*-scores and self as a whole (*r* = .355, *p* = .016), but no association with mood (*r* = .278, *p* = .061) or memory (*r* = .138, *p* = .362).

Exploratory Analysis 2: PwDs' SC, Memory, and EF at Different Degrees of CB

CGs were categorized into four groups based on established cutoffs related to the degree of experienced burden: low, moderate, high, and severe. Since the low-burden group consisted of only four participants, it was decided to combine the lowest two groups into a single category of mildly burdened CGs (N=11) to increase the power of the analysis. This group was then compared with severely burdened CGs (N=17). The middle group, consisting of highly burdened CGs (N = 20), was excluded from the analysis to focus the comparison on CGs at opposite ends of the burden spectrum and enhance the visibility of any potential effects. Between the compared groups, no significant differences existed regarding relevant characteristics: age (F(1, 26) = .034, $p = .855$, $\eta^2 = .001$), sex (χ^2(1, N = 28) = .368, $p = .544$, $w = .115$), education (F(1, 26) = .081, $p = .779$, $\eta^2 = .003$), or MMSE-scores (F(1, 24) = 2.905, $p = .101$, $\eta^2 = .108$).

Table 5

Multiple Linear Regression Analyses for PwDs' Test Performances Predicting QoL-AD Factor Scores

Model E: Dependent variable QoL-AD factor physical well-being (N = 46)

Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R²
(Constant)	10.874	.761	9.327 - 12.421	.000			
EFT total scores	.487	.376	-.278 - 1.251	.205	.216	.216	
RAVLT-DR adj. scores	-.092	.238	-.576 - .392	.701	-.066	-.065	
TMT B/A ratios	-.316	.388	-1.105 - .472	.420	-.139	-.136	
Explained variance							.054

Model F: Dependent variable QoL-AD factor social well-being (N = 46)

Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R²
(Constant)	18.849	.886	17.048 - 20.651	.000			
EFT total scores	.551	.438	-.340 - 1.441	.217	.211	.202	
RAVLT-DR adj. scores	-.470	.277	-1.034 - .093	.099	-.279	-.273	
TMT B/A ratios	.151	.452	-.767 - 1.069	.740	.057	.054	
Explained variance							.122

Model G: Dependent variable QoL-AD factor psychological well-being (N = 46)

Independent variables	B	*SE*	95% CI	*p*	*pr*	*sr*	R²
(Constant)	8.424	.521	7.364 - 9.483	.000			
EFT total scores	.603	.258	.079 - 1.127	.025*	.373	.369	
RAVLT-DR adj. scores	-.094	.163	-.425 - .238	.569	-.098	-.091	
TMT B/A ratios	-.383	.266	-.923 - .157	.158	-.240	-.228	
Explained variance							.154

Note. Unstandardized coefficient (B) with standard error of the estimate (*SE*) and 95% confidence interval (CI), probability (*p*), partial correlation coefficient (*pr*), semipartial correlation coefficient (*sr*), and multiple correlation coefficient (R²) for the overall model fit.

Abbreviations: adj. = adjusted; DR = delayed recall; EFT = Ekman 60 Faces Test; PwD = people with dementia; QoL-AD = Quality of Life – Alzheimer Disease Scale; RAVLT = Rey Auditory Verbal Learning Test; TMT = Trail Making Test.

* = significant at $p < .05$.

A one-way ANOVA was conducted to compare mildly and severely burdened CG groups in terms of the effects of PwDs' EFT *Z*-scores, RAVLT-DR adjusted *Z*-scores, and TMT B/A *Z*-ratios. The analysis revealed no significant differences between the two CG groups across any of the PwDs' test measures: the EFT *Z*-scores ($F(1, 26) = .086$, $p = .774$, $\eta^2 = .003$), the RAVLT-DR adjusted *Z*-scores ($F(1, 26) = .594$, $p = .449$, $\eta^2 = .026$), and the TMT B/A *Z*-ratios ($F(1, 26) = .095$, $p = .761$, $\eta^2 = .004$). The results are reported in Table 6. The observed non-significant effects were supported by bootstrapping.

Table 6

One-Way ANOVA Comparing CG Groups on PwD Measures

Measure	Mildly burdened CGs (N=11)		Severely burdened CGs (N=17)		$F(1, 26)$	p	η^2
	M	*SD*	*M*	*SD*			
EFT total scores	-.882	1.3460	-1.012	1.0234	.084	.774	.003
RAVLT-DR adj. scores	-.896	1.7450	-.378	1.5518	.594	.449	.026
TMT B/A ratios	-1.736	.7890	-1.854	1.0373	.095	.761	.004

Note. adj. = adjusted; CGs = caregivers; DR = delayed recall; EFT = Ekman 60 Faces Test; *F* = F-statistic; *M* = mean; η^2= Eta-squared; *p* = probability; PwD = people with dementia; RAVLT = Rey Auditory Verbal Learning Test; *SD* = standard deviation; TMT = Trail Making Test.

Discussion

Caring for PwD is a demanding task, involving a multitude of responsibilities that can strain informal CGs. Increased CB and reduced CQoL can lead to serious repercussions, including mental and physical health issues (Kovaleva et al., 2018; Lippe et al., 2021; McAuliffe et al., 2020), as well as elder abuse and premature nursing home placement for PwD (Beach et al., 2005; Martin et al., 2022; Stephan et al., 2015; Wiglesworth et al., 2010). This study aimed to contribute to a more comprehensive understanding of the dementia caregiving experience by exploring the roles of PwDs' functioning in SC, memory, and EF. We hypothesized that lower functioning in these cognitive domains would be associated with adverse outcomes for CGs. To evaluate this hypothesis, we explored potential correlations with CB and CQoL, both overall and in terms of their underlying factors. Additionally, we investigated whether care recipients of CGs on opposite ends of the burden spectrum displayed different performance profiles in SC, memory, and EF.

We found that the cognitive functioning of PwD across all examined domains was not significantly related to either the burden or the QoL experienced by CGs, whether considered combined or separated by domain. Furthermore, no significant associations were found between PwDs' functioning in SC, memory, and EF and the underlying factors of CB and CQoL – with one notable exception: PwDs' emotion recognition abilities were positively correlated with CGs' psychological well-being, explaining 37% of the variance, particularly in terms of CGs' sense of self. When comparing mildly and severely burdened CG groups, no significant differences in PwDs' performance profiles of SC, memory, and EF were observed.

Theoretical Implications

The observed absence of relationships between PwDs' SC, memory, and EF and outcomes for CGs underscores the complex nature of dementia caregiving beyond the cognitive decline of the care recipients. This finding suggests that the cognitive functioning of

PwD may not play a critical role in outcomes for CGs, but that there may be mediating or moderating factors. One potentially influential factor is the severity of dementia, which has previously been linked to increased CB (Mioshi et al., 2013). The neurodegenerative nature of dementia implies that symptoms worsen over time. Our assessments took place at an early stage of the disease, during the diagnostic process. At this point, the cognitive symptoms of the PwD were likely still comparatively mild compared to those in more advanced stages. Therefore, it cannot be ruled out that, at a later stage of the disease, a relationship between the cognitive functioning of the PwD in our sample and outcomes for their CGs may well be found. A related factor that may have influenced the results is the duration of care, which has also been linked to increased CB (D'onofrio et al., 2015). It is plausible that, at the time of the assessments, some CGs might not yet have perceived themselves as such.

Concluding, our results suggest that the cognitive functioning of PwD in the early stages of the disease does not relate to adverse outcomes for CGs. This finding addresses a gap in the literature as previous studies on dementia caregiving have predominantly focused on the manifestation of the disease at later stages. Therefore, our findings might not be directly comparable to other studies in the field, but provide valuable insights into the subtle cognitive and behavioral changes occurring at the onset of dementia. Further research is needed to assess how the relationships between PwDs' functioning in SC, memory, and EF and outcomes for CGs manifest at more advanced stages, where cognitive dysfunctions are more pronounced, and the burden experienced by CGs is likely higher.

The Role of SC

Prior research has repeatedly associated PwDs' emotion recognition abilities with CB, although evidence exists for both directions of the relationship, positive (Daley et al., 2018) and negative (Martinez et al., 2018; Miller et al., 2013; Spitzer et al., 2019). The fact that the present study did not find a significant relationship implies that the role of emotion recognition in PwD in CB and overall CQoL may be minimal or non-existent in the early stages of dementia. On top of that, the relationship might depend on other factors such as the differential diagnoses presented in the sample. For instance, the study of Miller et al. (2013), which has linked PwDs' emotion recognition to increased CB, predominantly included individuals with FTD, a form of dementia where impairments in SC are most pronounced and are part of the diagnostic criteria (Begali, 2020). In contrast, our sample did not include participants with FTD, thereby providing insights into the manifestation of CB and CQoL in the non-FTD dementia caregiving context. Furthermore, findings from Spitzer et al. (2019) and Martinez et al. (2018) indicated that CGs' subjective evaluations of their relatives' emotion recognition abilities – a factor not considered in the present study – played a mediating role in the relationship between objective emotion recognition in PwD and CB. The researchers proposed that CGs' heightened awareness of emotion recognition deficits in PwD might mitigate adverse outcomes of dementia caregiving.

The observation that PwDs' emotion recognition independently contributes to CGs' psychological well-being is a novel finding, as the relationship between PwDs' functioning in SC and factors of CQoL has not been investigated before. Our finding suggests that the ability of PwD to process and respond to emotional cues plays a significant role in maintaining CGs' psychological health, emphasizing the importance of social reciprocity in dementia caregiving. A possible explanation is that care recipients' recognition of their CGs' emotions provides them with a sense of validation, which might benefit their self-perception. Conversely, impaired emotion recognition could negatively affect the psychological well-being of CGs through social behavioral problems in PwD, which have been linked to impaired emotion recognition (Strijkert et al., 2023).

The Role of Memory

As prior research has reported relationships between increased CB and various aspects of memory, including self-reported memory problems (Yoshino & Takechi, 2023), anterograde memory performance (Miller et al., 2013), and autobiographical memory (Kumfor et al., 2016), we anticipated that PwDs' functioning in episodic memory might similarly relate to adverse outcomes for CGs. However, our findings did not support this hypothesis. The discrepancy between our results and those of the referenced studies may be attributable to differences in sample characteristics and study methodologies. Specifically, the participants in the samples of Miller et al. (2013) and Kumfor et al. (2016) were in more advanced stages of dementia, with average disease durations of 3 to 5 years. Consequently, memory impairments were likely more pronounced in these studies. Furthermore, the methodologies used to assess memory functioning varied significantly: while we employed an objective measure of verbal episodic memory, Yoshino and Takechi (2023) used a self-report questionnaire and Kumfor et al. (2016) conducted qualitative interviews. Miller et al. (2013) focused on visual memory functioning. This suggests that varying aspects of memory (e.g., visual anterograde vs. verbal episodic) may differently relate to dementia caregiving. Further research is needed for clarification.

The Role of EF

We proposed that cognitive flexibility in PwD would significantly correlate with adverse outcomes for CGs, based on documented links between increased CB and dysfunctions in the EF of impulse control (Miller et al., 2013), and problem-solving abilities (Yoshino & Takechi, 2023). However, our findings did not support such a relationship. Here too, the differences in findings could be attributed to the higher severity of dementia in the other samples, as well as methodological differences. It is also important to recognize the diversity within EF, warranting caution against assuming uniform relationships between

PwDs' EF and outcomes for CGs. For instance, problems of PwD in impulse control, as assessed by Miller et al. (2013), might affect CGs differently than impairment in cognitive flexibility. Further research is necessary to investigate the differential effects of various EF on dementia CGs.

Practical Implications

The observed significant relationship between PwDs' emotion recognition abilities and the psychological well-being of CGs is novel and presents relevant implications for clinical practice and opportunities for further research. When considered alongside the non-significant correlations of other cognitive domains with outcomes for CGs, our finding suggests that interventions specifically tailored to address the quality of emotional communication within the CG-care recipient dyad could improve CGs' well-being and, thereby, indirectly also benefit the care recipients. Such interventions might involve teaching practical strategies to compensate for deficits in emotion recognition or providing psycho-education for CGs to help them better understand the nature and consequences of SC deterioration in dementia. This information could assist CGs in setting realistic expectations about communication and social interaction with care recipients and in preparing for future challenges that might arise in this area. However, empirical support for such interventions is currently lacking. Longitudinal studies are necessary to verify their effectiveness.

Limitations

Unexpected study results may be related to limitations of our research. Firstly, we assessed PwDs' cognitive functioning with only one test per domain. Given the complexity of cognition, performance on a single test may not provide a comprehensive reflection of the functioning of an entire cognitive domain. Thus, it may be more accurate to interpret our findings in terms of the specific functions of emotion recognition, episodic memory, and cognitive flexibility, rather than the superordinate domains of SC, memory, and EF.

Additionally, while our multiple linear regression analyses demonstrated sufficient statistical power to detect small or moderate effects (86-99%), the statistical power of the ANOVA was more limited. Excluding highly burdened CGs from the analysis enabled a comparison of CG groups at both ends of the burden spectrum but it also reduced the sample size to a level possibly too low to detect the presence of effects. A post-hoc power analysis using G*Power version 3.1.9.7 (Faul et al., 2009) revealed moderate power for detecting moderate-sized effects (72%) and low power for detecting small effects (17%). Therefore, it is plausible that small effects may have gone undetected. Further research with larger sample sizes is needed to validate our findings, preferably employing longitudinal designs to also allow for inferences about causality – something that was not feasible in the present study due to the cross-sectional design.

Conclusion

This study aimed to explore the roles of PwDs' functioning in SC, memory, and EF in the burden and QoL experienced by CGs. Our findings do not support the hypothesis that the functioning in these cognitive domains relates to adverse outcomes for CGs, at least not in the early stages of dementia. Neither the combined nor the individual effects of emotion recognition, episodic memory, and cognitive flexibility were significantly related to CB and overall CQoL. These results underscore the complexity of dementia caregiving and suggest the presence of mediating factors. However, the significant association we identified between PwDs' emotion recognition abilities and the psychological well-being of CGs introduces an area for potentially beneficial interventions. Since this is a novel finding, empirical support for corresponding intervention programs is currently lacking. Further studies with larger sample sizes, longitudinal designs, and comprehensive cognitive assessments are required to further elucidate the complexities of dementia caregiving.

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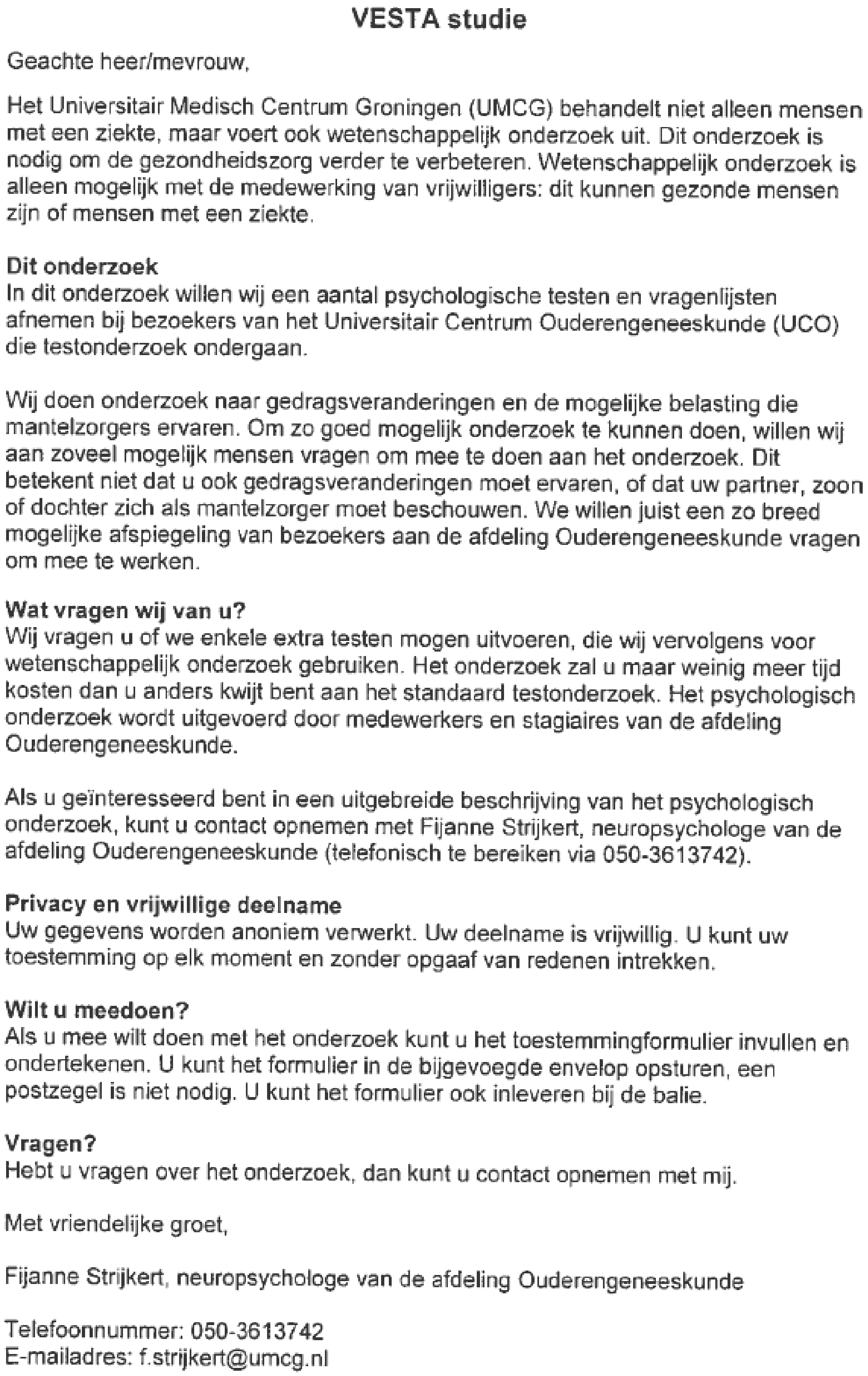
Appendix A

Letter with Study Information for Eligible Participants



VESTA studie

Geachte heer/mevrouw,

Het Universitair Medisch Centrum Groningen (UMCG) behandelt niet alleen mensen met een ziekte, maar voert ook wetenschappelijk onderzoek uit. Dit onderzoek is nodig om de gezondheidszorg verder te verbeteren. Wetenschappelijk onderzoek is alleen mogelijk met de medewerking van vrijwilligers: dit kunnen gezonde mensen zijn of mensen met een ziekte.

Dit onderzoek
In dit onderzoek willen wij een aantal psychologische testen en vragenlijsten afnemen bij bezoekers van het Universitair Centrum Ouderengeneeskunde (UCO) die testonderzoek ondergaan.

Wij doen onderzoek naar gedragsveranderingen en de mogelijke belasting die mantelzorgers ervaren. Om zo goed mogelijk onderzoek te kunnen doen, willen wij aan zoveel mogelijk mensen vragen om mee te doen aan het onderzoek. Dit betekent niet dat u ook gedragsveranderingen moet ervaren, of dat uw partner, zoon of dochter zich als mantelzorger moet beschouwen. We willen juist een zo breed mogelijke afspiegeling van bezoekers aan de afdeling Ouderengeneeskunde vragen om mee te werken.

Wat vragen wij van u?
Wij vragen u of we enkele extra testen mogen uitvoeren, die wij vervolgens voor wetenschappelijk onderzoek gebruiken. Het onderzoek zal u maar weinig meer tijd kosten dan u anders kwijt bent aan het standaard testonderzoek. Het psychologisch onderzoek wordt uitgevoerd door medewerkers en stagiaires van de afdeling Ouderengeneeskunde.

Als u geïnteresseerd bent in een uitgebreide beschrijving van het psychologisch onderzoek, kunt u contact opnemen met Fijanne Strijkert, neuropsychologe van de afdeling Ouderengeneeskunde (telefonisch te bereiken via 050-3613742).

Privacy en vrijwillige deelname
Uw gegevens worden anoniem verwerkt. Uw deelname is vrijwillig. U kunt uw toestemming op elk moment en zonder opgaaf van redenen intrekken.

Wilt u meedoen?
Als u mee wilt doen met het onderzoek kunt u het toestemmingformulier invullen en ondertekenen. U kunt het formulier in de bijgevoegde envelop opsturen, een postzegel is niet nodig. U kunt het formulier ook inleveren bij de balie.

Vragen?
Hebt u vragen over het onderzoek, dan kunt u contact opnemen met mij.

Met vriendelijke groet,

Fijanne Strijkert, neuropsychologe van de afdeling Ouderengeneeskunde

Telefoonnummer: 050-3613742
E-mailadres: f.strijkert@umcg.nl

Appendix B

Informed Consent Sheet

VESTA studie Controle proefpersonen

Deelnemernummer: __ __ __ __ __

Toestemmingverklaring
deelname aan wetenschappelijk onderzoek

VESTA studie

Ik ben naar tevredenheid over het onderzoek geïnformeerd. Ik heb de informatiebrief goed gelezen. Ik heb vragen kunnen stellen over het onderzoek. Ik heb voldoende bedenktijd gehad en goed kunnen nadenken over mijn deelname.

Mijn deelname aan dit onderzoek is geheel vrijwillig. Ik weet dat ik het recht heb om op elk moment en zonder opgave van reden mijn toestemming weer in te trekken.

Ik geef mijn toestemming aan deelname aan het onderzoek en geef toestemming tot het gebruiken van de gegevens voor wetenschappelijk onderzoek en publicaties in wetenschappelijke tijdschriften. Ik begrijp dat de onderzoeksgegevens anoniem opgeslagen en gebruikt zullen worden.

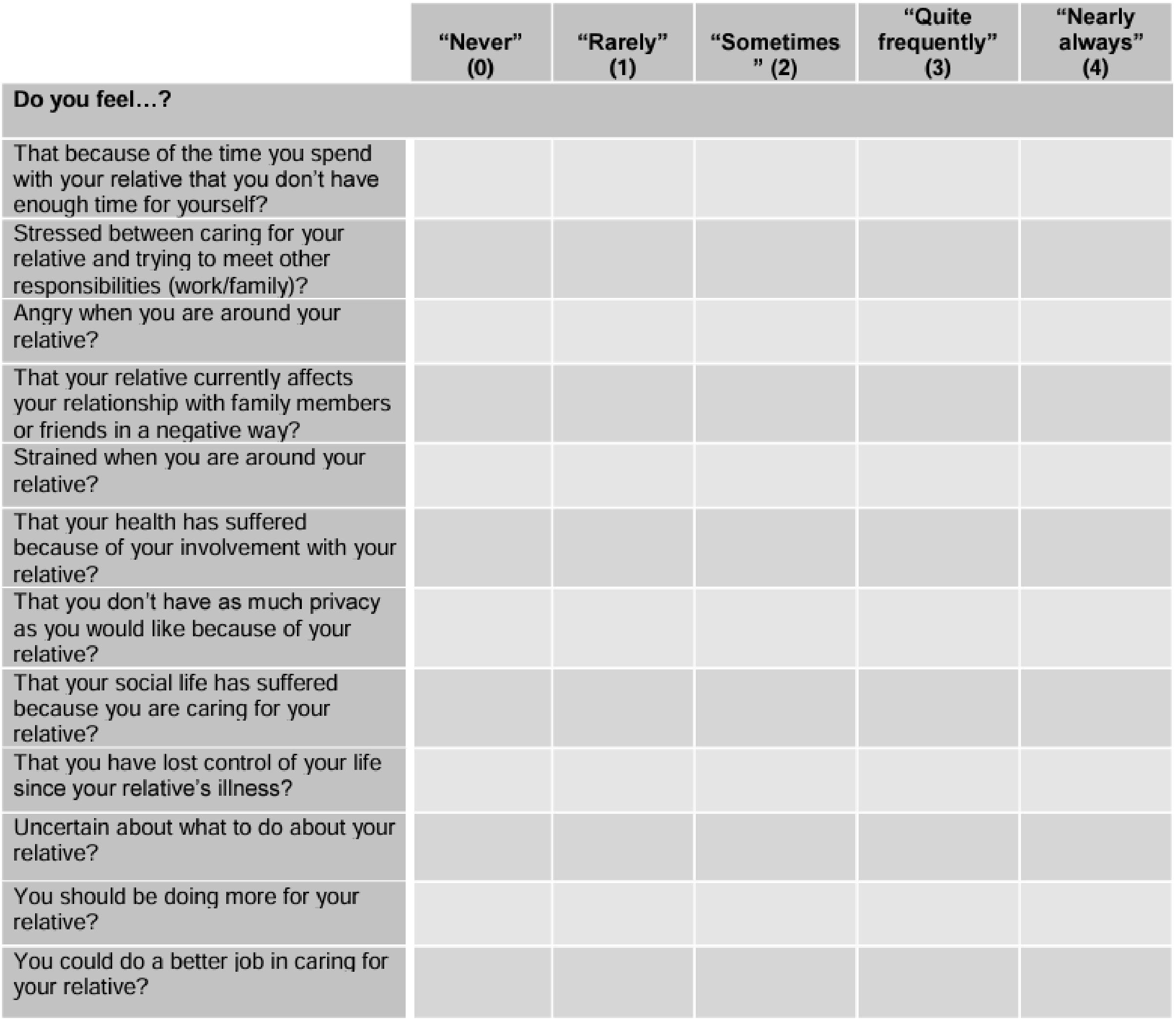
Naam:

Geboortedatum:

Handtekening: **Datum:**

Appendix C

ZBI Form – 12-Item Version



	“Never” (0)	**“Rarely” (1)**	**“Sometimes” (2)**	**“Quite frequently” (3)**	**“Nearly always” (4)**
Do you feel…?					
That because of the time you spend with your relative that you don’t have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don’t have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative’s illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

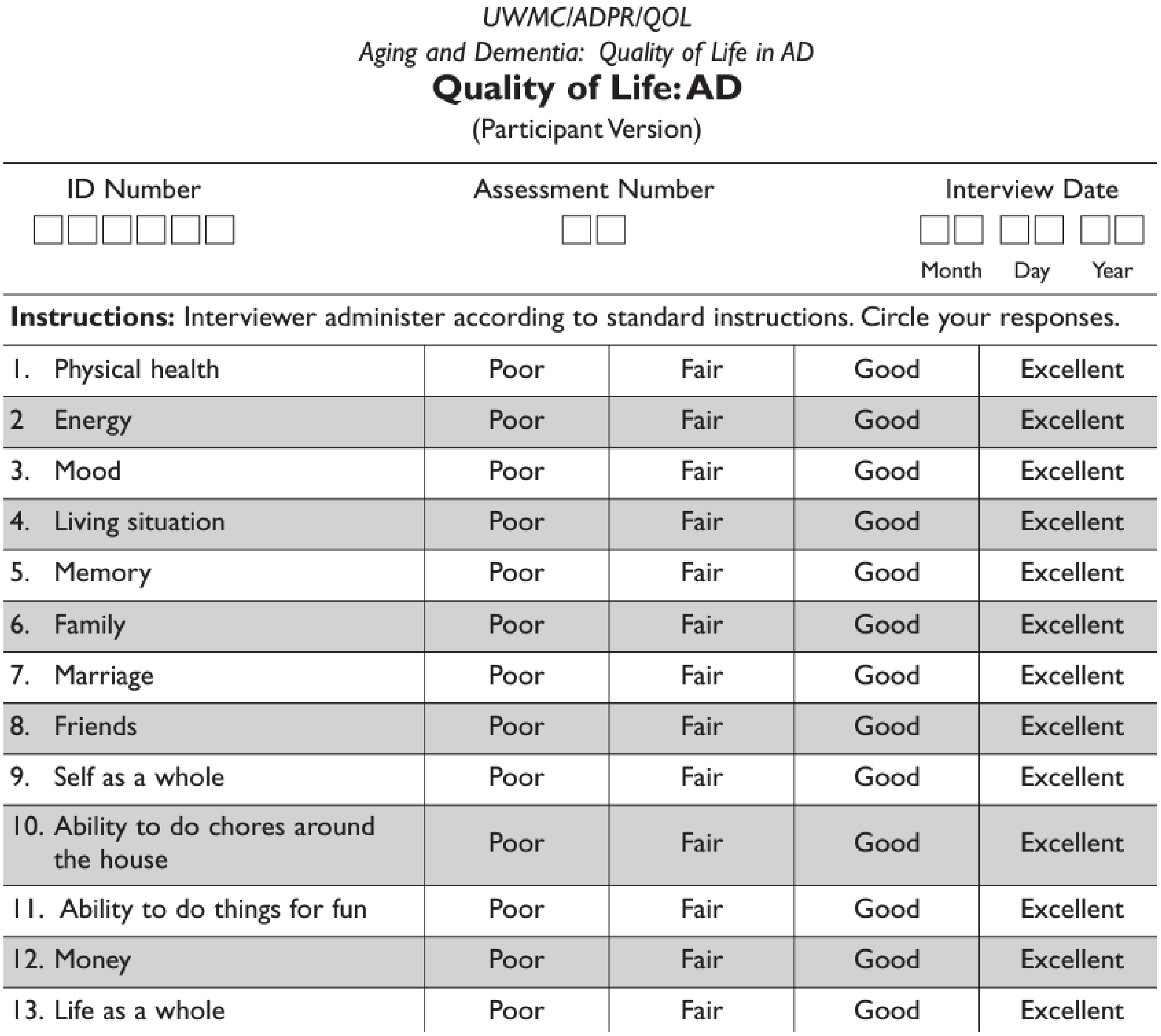
Center to Advance Palliative Care (n.d.). *Short Form Zarit Burden Interview (ZBI-12)* [PDF]. Retrieved February 14, 2024, from: https://www.oncozine.com/wp-content/uploads/2018/11/ZBI-12_Form.pdf

Factors of the ZBI (Bédard et al., 2001):

- Personal strain: Items 1, 2, 3, 4, 5, 6, 7, 8, 9
- Role strain: Items 10, 11, 12

Appendix D

QoL-AD Form



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.

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

Cogs Clubs (n.d.). *Quality of Life in Alzheimer's Disease* [PDF]. Retrieved February 14, 2024, from: https://www.cogsclub.org.uk/professionals/files/QOL-AD.pdf

Factors of the QoL-AD (Torisson et al., 2016):

- Physical well-being: items 1, 2, 10, 11
- Social well-being: items 4, 6, 7, 8, 12, 13
- Psychological well-being: items 3, 5, 9

Appendix E

Correlation Matrix of the Independent Variables

Measure	EFT	RAVLT-DR adj.
EFT	–	
RAVLT-DR adj.	.083	–
TMT B/A ratio	.313	-.010

Note. Reported values are Pearson Correlations