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Exploring Factors Contributing to Caregiver Burden in Family Caregivers of Congolese Adults with Suspected Dementia

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Abstract

Introduction: Predicting caregiver burden in individuals with suspected dementia – is critical due to the debilitating nature of these disorders and need for caregiver support. While some examination of the factors affecting burden has been undertaken in Sub-Saharan Africa, each country presents with its own unique challenges and obstacles. This pilot study investigates predictors of caregiver burden in family caregivers of individuals with suspected dementia living in the Democratic Republic of the Congo (DRC).

Methods: Linear and multiple regression analyses were conducted to explore factors associated with caregiver burden in 30 patient-caregiver dyads with the Zarit Burden Interview (ZBI) for caregiver burden evaluation. Cognitive impairments of patients were assessed using the Community Screening Instrument for Dementia (CSID), Alzheimer's Questionnaire (AQ), the African Neuropsychology Battery (ANB), and the Neuropsychiatric Symptoms Inventory (NPI).

Results: Average caregiver burden on the ZBI was 36.1 (SD=14.6; range=12–58). Greater impairments in patient cognition (orientation, visuospatial, memory, executive functioning), fragility, and neuropsychiatric symptoms (delirium, agitation, depression) were predictive of caregiver burden. After controlling for AQ scores and caregiver gender, greater symptoms of depression, and worse performances on verbal memory and problem solving were associated with greater caregiver burden.

Conclusion: Worsening patient fragility, cognition, functioning, and neuropsychiatric symptoms influenced caregiver burden in caregivers of individuals with suspected cognitive impairment in the DRC. These findings are consistent with the prior literature. Future studies may wish to explore supportive factors and caregiver specific characteristics that buffer against perceived burden.

Introduction

Caregiving burden has been broadly defined as psychological distress associated with providing care that effects a caregiver's emotional, social, financial, physical, and spiritual functioning [1]. Caregivers of individuals with dementia have been shown to experience a greater burden compared to other non-diverse and western caregivers [2]. Thus, identifying the determinants of care recipients is critical for identifying individuals at increased risk, and developing interventions aimed at mitigating caregiver burden.

A conceptual framework for studying caregiver burden has been proposed that implements the stress process model [2–4]. This model categorizes predictors of caregiver burden into contextual factors (caregiver and care recipient factors), primary stressors (associated with the patient's disease), and secondary stressors. A wealth of studies across different medical conditions have identified predictors of caregiver burden including the socio-demographical status of care recipient (e.g., older age, female sex, low educational attainment, relationship to the care recipient/patient, lack of supportive resources, and disease-related factors) [3, 5–7]. Outcomes of caregiver burden include mental health problems (depression, anxiety, suicide), adverse health effects, poor physical health, isolation, and increased risk of death for caregiver [6]. Further, studies have shown that the experience of caregiving burden varies by ethnicity and that culture plays a role in the expression of caregiving burden and associated depression [8–10].

Given the progressive nature of neurodegenerative diseases, emphasis has been placed on identifying factors associated with caregiver burden among individuals caring for patients living with Alzheimer's disease and related dementias. In a systematic review, Chiao et al. divided patient characteristics associated with caregiver burden into behavioral factors, disease-related factors, and patient socio-demographical factors [7]. Disease-related factors including the severity of dementia, type of dementia [11, 12], and longer disease

duration were all associated with higher caregiver burden. Poorer functional status [13, 14], behavioral disturbances [3, 11, 15], and the presence of psychiatric symptoms [7, 13] were associated with greater caregiver burden given the increase in oversight and caregiver responsibilities. Lastly, caregiver-related characteristics associated with increased burden include lower income, lower education attainment, female sex, and cohabitation [6].

Despite a burgeoning literature investigating the factors associated with caregiver burden, studies identifying factors associated with caregiver burden in sub-Saharan Africa are more limited [16–21]. Notably, caregiver burden can be exacerbated in low-income countries due to lack of health services [22], cultural health beliefs [17], lack of training and education about the disease, underdeveloped care systems [23], and poor health outcomes [17]. The number of older adults in sub-Saharan Africa is expected to triple by 2050 and thus the prevalence of dementia is also predicted to increase [23]. There is a critical need to explore the challenges that caregivers face in this culturally non monolithic region to inform current efforts in developing resources for caregivers.

To the best of our knowledge, there are no studies investigating the factors associated with caregiver burden in the Democratic Republic of Congo (DRC). In this study, we investigate predictors of caregiver burden in primary caregivers of individuals with suspected dementia living in the DRC. Specifically, we explore the relationship between caregiver burden and caregivers' and patients' demographics, patient's cognitive performance using the African Neuropsychology Battery (ANB), and neuropsychiatric symptoms. We hypothesize that greater caregiver burden will be associated with poorer cognitive performance more severe neuropsychiatric symptoms, and patient and caregiver characteristics. Given that this is the first study examining caregiver burden in the DRC, we explore cultural factors that may be unique to this population, including gender of the caregiver and their relationship to the patient.

Methods

Participants

Participants were care recipient older adult Congolese with suspected dementia and their caregiver. Care recipients were drawn from a parent study of cognitive markers and biomarkers of Alzheimer's disease in the Democratic Republic of Congo (DRC), including from the city of Kinshasa and nearby rural villages near Kinshasa. Recruitment took place at churches, clinics, hospitals, older adult associations and gatherings, and door-to-door. Based on previous Central African Countries (Congo Brazzaville) research with Community Screening Instrument for Dementia (CSID) reporting the score of 18.6 (SD 5.6) for suspected dementia [24], care recipients classified as suspected dementia in this study were those who obtained a score on the CSID < 19 and a score on the Alzheimer's questionnaire (AQ) of >13. They also needed (1) to be age 50 or older (2) have a family member or close friend to serve as a collateral informant or care partner (3) to have no current or past history of neurodevelopmental, mental disability or other neurodegenerative diagnosis than Alzheimer's disease, (4) no current psychiatric diagnosis. The caregiver was considered as a spouse, relative, child or a friend who has been living with or taking care of the subject with suspected dementia for at least 5 years. The study was approved by the Ethics Committee of

the University of Kinshasa. The final sample included (n=30) care recipients with suspected dementia and (n=30) caregivers enrolled.

Instruments

Screening Measures for Suspected Dementia:

Community Screening Instrument for Dementia (CSID) [25]: care recipients were screened using the Community Screening Instrument for Dementia (CSID). The CSID has been extensively used in many international dementia studies and has been shown to be a sensitive instrument for screening dementia [24, 26]. The CSID consists of cognitive assessment interviews with the subject and with the informant or caregiver. The cognitive assessment is based on the following domains: orientation (place and time), attention and calculation, language (naming and fluency), constructional apraxia, learning and memory (3 trials of 10 words each and a delayed recall trial). The CSID has been used in two central African capitals for prevalence of dementia and the score of 18.6 (SD 5.6) was the cutoff for suspected dementia [24].

Alzheimer's Questionnaire (AQ): Caregivers evaluated cognitive and functional abilities of care recipients using the Alzheimer's Questionnaire (AQ), which is a yes/no informant or caregiver-based screening instrument [26–28]. AQ evaluates five domains which includes memory, orientation, function ability, visuospatial and language of the participants. Based on previous literature [25], care recipients were assigned to the suspected dementia group with an AQ score of 13 or higher. The AQ has sensitivity of 98.55 and specificity of 96 for AD [28] and has not yet been tested in this cohort.

Neuropsychological Measures:

African Neuropsychology Battery (ANB): Care recipients were also tested with the ANB. ANB is a culturally appropriate battery of cognitive tests developed by Ikanga and Stringer and validated in the Democratic Republic of Congo [29]. For the current study, two memory (one verbal and one visuospatial) and two executive functioning measures (African Card Game Test and African Proverb Test) on the ANB were included. Learning and Memory measures included the African List Memory Test (ALMT) and the African Visuospatial Memory Test (AVMT). Each memory measure consists of 3 learning trials, an interference trial, a short delay recall, a 20-minute long-delay recall trial, and a recognition trial. The ALMT scores range from 0–12 in each trial. AVMT score ranges between 0 to 20 points in each trial. Psychometrically, the ALMT and AVMT have good test-retest reliability, respectively. Intraclass correlation stability coefficients have been found to be .80 and .53 [30].

The African Card Game Test is a variant of a card game played in many African countries, which evaluates problem solving ability through organization and strategy. The strategy score ranges from 0–64 points. This test has an excellent internal consistency and reliability with .93 Cronbach's alpha [30]. The African Proverb Test requires abstract interpretation of traditional African proverbs, drawn from a number of Sub-Saharan countries. Each proverb earns a score of 2, 1, or 0 depending upon the degree of abstraction. A total score ranges

between 0 and 18. This test also has an excellent internal consistency and reliability with .86 Cronbach's alpha [30].

Neuropsychiatric Symptoms Questionnaires:

Geriatric Depression Scale (GDS): Care recipients were also evaluated with the GDS. The 15-item GDS is a self-report questionnaire used to evaluate depression in older adults [31], which is common in late life among adults [32]. Total scores range from 0 to 15, with higher scores indicating greater levels of depressive symptoms. A cutoff score > 5 suggests the presence of depression [31]. The GDS has an α coefficient of 0.745 [33] and has not yet been tested in this cohort.

Beck Anxiety Inventory (BAI): Care recipients were examined with the BAI. The BAI is a 21-item questionnaire measuring anxiety symptoms [34]. The BAI has a total score which ranges from 0–63. A score of < 9 indicates normal anxiety while the score of >10 indicate the presence of an anxiety disorder [35]. The BAI has a good internal consistency of alpha = 0.89 [36].

Individual Fragility Questionnaire (IFQ): Care recipients were also tested with the IFQ. This questionnaire evaluates risk factors resulting in functional decline in an older adult. This profile of risk of fragility is based on different gerontological aspects of life (number of medications, falls, activities of daily living, urinary incontinence, nutrition, perception of health, etc.). The score ranges between 0–48 points, with higher score indicating greater individual fragility [37]. This test has a sensitivity of 75.9, specificity of 59.4% and negative predictive value of 82.9 [38]. This test has not been tested within this cohort.

Neuropsychiatric Inventory (NPI): Care recipients were evaluated with the NPI. The NPI is an informant or caregiver based brief assessment of neuropsychiatric symptomatology [39, 40]. The NPI assesses the presence/absence and severity of 12 neuropsychiatric symptoms in patients with dementia. For each domain, the NPI evaluates the presence, frequency, severity, frequency and severity composite, and the impact of symptoms. The NPI scores range between 0–12 for the presence of symptoms, 0–48 for the frequency of symptoms, and 0–36 for the severity of symptoms. The NPI has an internal consistency reliability of alpha=0.67 [41] and has not been tested within this cohort.

Demographic information and medical history—Care recipients completed demographic and medical history.

Questionnaires to caregivers about participants:

Caregiver Burden Assessment: Caregivers of those with a diagnosis of suspected dementia were interviewed using the Zarit Burden Interview (ZBI), a popular caregiver self-report measure [42]. The ZBI is a 22-item instrument where the caregiver is asked to endorse statements related to caregiver burden using a 5-point scale. The total score ranges from 0 to 88 items with higher scores meaning greater endorsement of burden. The ZBI has Cronbach's α of 0.93 [43] and has not yet been used in this cohort.

Procedure

Care recipients were administered the dementia screening measures to assign them to the group of those with suspected dementia. Informed consent was obtained from participants meeting study participation criteria. Care recipients were administered demographic, medical history, questionnaires, and the ANB in a single session lasting 2.5–3 hours. Their caregivers were requested to fill out demographic information, questionnaires, and ZBI. While performance in CSID (score <19) and the AQ (Score >13) were used to classify care recipients as suspected dementia, the ANB scores were used mostly to predict the association between caregiver burden and cognitive performance in care recipients.

Statistical analysis

Descriptive statistics of socio-demographics for care recipients and their caregivers, neuropsychiatric symptoms and neuropsychological test scores for care recipients were generated. Because most of the care recipients could not correctly recall a word, the ALMT and AVMT delayed total recall were dichotomized into two categories, namely, at least one word recalled and no words recalled. Mean, standard deviation, median and interquartile range were presented for the continuous variables, while counts and proportions were calculated for the categorical variables. Due to the exploratory nature of the paper, we have used basic statistics and did not use any adjustment methods for multiple comparisons.

Because the continuous test scores were measured on different scales, we standardized the scores to make them comparable. Each test score was standardized by subtracting it from its mean and by dividing the difference by its standard deviation. To select a subset of effects among all the possible predictors to build a predictive model for caregiver burden, GLMSELECT procedure was used to perform model selection as caregiver burden is a continuous response. The GLMSELECT procedure performs effect selection in the framework of general linear models with a variety of model selection methods as well as selection and stopping criteria. It extends traditional significance-level-based method by incorporating information criteria to determine what effects to add or drop at any step. For the present analysis, we used backward elimination with Schwarz Bayesian Information Criterion, Akaike's information criterion, and adjusted R-square statistic to select variables. The final models were determined by clinical judgement and the automated variable selection method. The relationship between caregiver burden and selected predictors was analyzed via both simple and multiple linear regressions. The regression coefficients were compared between unadjusted and adjusted analyses. The assumptions of linear regression were examined.

Statistical analyses were performed using SAS 9.4 and R 4.1.2. All tests of statistical significance were 2-tailed, and a p value <0.05 was considered significant.

Results

Care recipient and caregiver sociodemographic characteristics

The average age of the care recipients was 71.2 years, 46.7% were female, 80% had a less than a high school education, and two-thirds resided in an urban area. The average age of

the caregivers was 53.3 (spouses: 62.1, kids: 42.6) years, with two-thirds being female, half of them having received above high school education, and a majority of them being spouses (43.3%) or kids (46.7%) living with patients (see Table 1).

Care recipients' cognitive performance and neuropsychiatric symptoms

The median score of AQ, African Proverb Test and African Card Game Test were 18, 2 and 18, respectively, suggesting more than half of the care recipients had cognitive impairment. Only 36.7% and 26.7% of patients, respectively, could correctly recall a word after a 20-minute delay on the ALMT and AVMT. Eighty percent of the care recipients had a GDS score greater than 5 – indicating that the majority had at least mild depression (See Table 1). According to NPI-Q, approximately 60% of the patients demonstrated irritability, 46.7% depression, 40% anxiety, 30% nighttime behavioral disturbances, 26.7% appetite/eating disturbances, 13.3% delirium, hallucinations, and agitation and aggression, 10% euphoria and disinhibition, and 6.7% aberrant motor behaviors.

Relationship between caregiver burden and care recipients or caregiver characteristics

The average caregiver burden on the ZBI was 36.1 (SD=14.6), with scores ranging from 12 to 58 – indicating little to moderate burden. Using clinical judgement and backward elimination techniques, care recipient and caregiver socio-demographics, care recipient cognitive scores, and neuropsychiatric symptoms were selected for the regression analyses. Table 2 presents both the unadjusted and adjusted relationship of caregiver burden with selected predictors. Bivariate analysis (Model 1) suggested that higher AQ total scores (i.e., orientation, functionality and visuospatial domain scores); NPI scores (i.e., presence of delirium, agitation and depression symptoms); as well as individual fragility scores were significantly associated with greater caregiver burden ($p<0.02$). After controlling for AQ total score and caregiver gender, as the strongest predictors in univariate analysis, effects of cognitive performance, neuropsychiatric scores and symptoms and fragility were attenuated, while the effects of gender and AQ scores became stronger (Model 2). With adjustment of AQ total score and caregiver gender, caring for care recipient with depression symptoms made caregiver burden increase by 10.6 point ($p=0.02$); one-standard deviation increase in fragility score was associated with 5.8-point increase in caregiver burden ($p=0.01$). Caregiver burden score dropped by 15.9 or 6.3 when a patient correctly recalled at least one word after a long delay on ALMT or with every additional problem solving ability in African Card Game Test, respectively ($p<0.003$). Adjusting for AQ total score, female caregivers experienced 9.0 points more stress than their male counterparts ($p=0.0448$). Adjusting for caregiver gender, an increase of one-standard deviation in AQ score, orientation, functionality and visuospatial subscales led to 9.4, 10.5, 6.4 and 8.5-point elevation in caregiver stress, respectively ($p<0.02$). Statistically significant findings in Model 2 were summarized in Figure 1. Effects above the reference line indicate positive correlation, while those under the line suggest negative association.

Discussion

The current study sought to identify factors associated with caregiver burden for individuals providing care to older adults with suspected dementia in the DRC. Overall, caregivers

in the sample reported mild to moderate burden. This was an intermediate degree of caregiver burden reported on the ZBI when compared to samples of other African caregivers of individuals with cognitive impairment [17] with the degree of burden across samples possibly varying by the quality of healthcare infrastructure within respective regions. Findings indicated that care recipient fragility was a significant predictor of caregiver burden and may contribute to burden via increased physical demands. Frailty may also contribute to caregiver burden in cognitively impaired populations due to lack of insight or appreciation of risk associated with physical limitations/frailness (e.g., fall risk). Other studies have shown that even pre-frailty, or the accumulation of smaller physical limitations, is linked to increased caregiver burden for those providing care to individuals with cognitive impairments [44].

Higher scores on the informant-based Alzheimer's screening predicted greater caregiver burden in the study sample. This is particularly salient as a brief yes/no screening instrument initially developed for use in primary care settings may have dual utility; not only does the AQ have strong sensitivity in detecting Alzheimer's disease in certain demographic groups [28], but findings from the current sample suggest AQ scores may additionally reflect the severity of caregiver burden given its reliance on informant report. Questions regarding cognitive orientation, followed by visuospatial abilities and functional abilities were most strongly associated with caregiver burden. Collectively, these questions provide insight into the degree of a patient's functional independence. Reduced functioning in these domains may require greater oversight by the caregiver and contribute more strongly to perceived burden.

The presence of neuropsychiatric symptoms in the current sample predicted caregiver burden. More specifically, symptoms of depression, delirium, and agitation/aggression scales of the NPI were associated with higher burden. This is consistent with extant literature which has shown that neurobehavioral and neuropsychiatric symptoms most strongly predict burden irrespective of dementia etiology, and across several cultures, caregiver burden is greatest with neurobehavioral/neuropsychiatric symptoms [18, 45–47]. Our findings indicate that both “positive” and “negative” neuropsychiatric symptoms contribute to caregiver burden. Further investigation is needed to determine how specific clusters of symptoms may differentially relate to dimensions of burden. Notably, the mechanisms of strain in the caregiver-care recipient relationship may differ for individuals in the DRC. Social ostracization and stigmatization of care recipients is common and may provide an additional layer of complexity in addition to delayed treatment seeking to avoid social exclusion [48].

Little is known about factors that contribute to caregiver burden in the DRC where healthcare resources for individuals living with cognitive impairment and behavioral symptoms are limited. With institutionalization of people living with dementia being less common in the DRC, the caregiving role is typically assumed by family members. Dementia caregivers in the DRC are often not provided psychoeducation about dementia, trained in caregiving, or compensated for their efforts. Further, dementia misconceptions and stigmatization are prevalent and may result in misattribution of dementia to non-neurological factors - such as witchcraft. The perception of the caregiver's role can vary; perceptions can range from being a positive, supportive experience to being a significant barrier resulting in

social exclusion of the person living with dementia [48, 49]. These cultural and contextual factors may increase the strain of the caregiver beyond routine care demands and warrant deeper investigation.

While neuropsychiatric symptoms are traditionally most challenging for caregivers to manage, cognitive symptoms reflect an additional contributor to stress. In the current sample, deficits in higher level cognitive functions, such as verbal memory and executive functioning, were also associated with burden. These aspects of cognition are linked to instrumental activities of daily living and functional autonomy [50], and even mild cognitive deficits in these domains require a greater care oversight which may be internalized as burden by the caregiver.

Additional analyses revealed gender differences in overall caregiver burden such that women caregivers in the sample reported higher burden. This is consistent with findings that women caregivers of older adults tend to experience greater role strain and role conflict relative to male caregivers and corresponds with gender roles reflected in the DRC [51]. The current findings may also come as a byproduct of the demands on women to uphold multiple role responsibilities including maintaining domestic work, childcare, and social connections. Data show that women caregivers to older adults spend more time in a caregiver role [51, 52], another factor that may contribute to gender-differences in caregiver burden.

Overall, the findings of the present study fit within the context of the stress process model (i.e., how individuals in adverse environments are impacted by the accumulation of chronic stress) [4]. Based on this model, it appears that some of the contextual factors measured in the study (namely, conditions associated with caregiver gender) play a small role in caregiver burden. However, the primary stressors - that is, the conditions, experiences, and behaviors that are problematic and related to the disease-process - appear most strongly linked to caregiver burden in the sample. Cognitive impairment, frailty, and neuropsychiatric symptoms, all of which were identified as predictors of burden in the present study, can be subsumed under the category of primary stressor. These characteristics are linked to the direct needs of the care recipient and may be taxing to a caregiver attempting to manage them. Based on this model, cognitive decline or progression of disease may result in an increase in the aforementioned symptoms and contribute to secondary stress. While not measured directly in the present study, secondary stress is often related to caregiver role strain, difficulty managing outside work, financial strain, and reduced social functioning. Future work should explore the links between primary and secondary stressors and their relationship to caregiver burden in a similar sample.

Additionally, given that caregiver burden is a multi-dimensional construct and encompasses psychological, physical, social, and economic stressors encompassed by the caregiving experience [5], researchers should consider the impact of burden beyond a global composite score [45]. Future directions should examine what additional domains of caregiving for individuals with cognitive impairment are most cumbersome as interventions may be targeted to offer structured support. Burden may also differ by urbanicity - as the availability of resources for caregivers, degree of collectivism/family structure, and perspectives of

elderly in the DRC has been shown to differ based on whether a person is living in a rural or urban region of the country [53].

Overall, the current study extends our knowledge of predictors dementia caregiver burden within the DRC. While the study is one of the first of its kind within the DRC, it does not come without limitations including small sample size and a cross-sectional design. Future work should replicate the present findings in a larger sample and with a longitudinal component to examine the evolution of burden with progression of dementia symptoms. Additionally, burden was assessed in a sample of individuals who have suspected dementia. It is possible that burden may differ across axes of dementia subtype (e.g., behavioral variant of frontotemporal dementia vs. AD) and caregiving domain (psychological, economic, etc.) because the clinical manifestation of dementia differs drastically by etiology and the type of support needed may vary. Thus, extending the present work to include other suspected dementia subtypes is important. Another limitation is the possibly circular relationship of worse caregiver stress leading to over-endorsement of functional limitations on the AQ. Lastly, the current study focused solely on aspects that predicted negative caregiver outcome. Future studies may wish to explore supportive factors and caregiver specific characteristics that buffer against perceived burden. Additionally, identifying causal pathways through which intermediate factors may influence caregiver burden, such as psychological coping strategies and social support, is critical to further advancing our understanding of the nuanced experiences of dementia caregivers in the DRC. Finally, this paper was exploratory and statistical analysis prioritized effect estimates and confidence intervals given the limited sample size, rather than statistical significance. Future studies with larger sample sizes are needed to provide more precise estimates.

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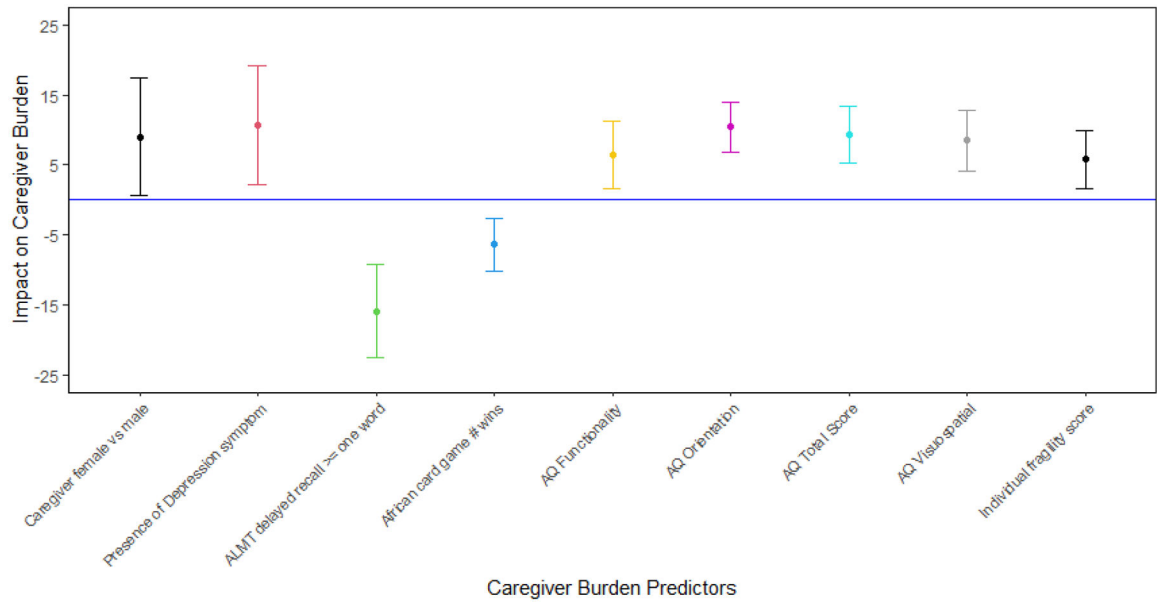


Figure 1:
Impact of Patient Cognitive Performance, Symptoms and Caregiver Gender on Caregiver Burden.
AQ: Alzheimer’s Questionnaire & ALMT: African List Memory Test.

Table 1**Patient and Caregiver Demographics, Patient Neuropsychological Test Scores and Neuropsychiatric Symptoms**

Patient (n=30)	
Age, years	71.2 ± 8.7
Female, n (%)	14 (46.7)
Education, years	9.0 (6.0 – 12.0)
Education years categories, n (%)	
0 years of education	2 (6.7)
1–6 years of education (primary school)	9 (30.0)
7–12 years of education (secondary school)	13 (43.3)
13–17 years of education (Postgraduate)	6 (20.0)
Urban residence, n (%)	20 (66.7)
Patient Neuropsychological Test Scores	
Community Screening Instrument for Dementia	31.0 (24.0 – 37.0)
Alzheimer's Questionnaire	18.0 (13.0 – 20.0)
Memory	6.0 (5.0 – 7.0)
Orientation	3.0 (2.0 – 4.0)
Functional abilities	6.0 (3.0 – 7.0)
Visuospatial abilities	0.0 (0.0 – 3.0)
Language	2.0 (1.0 – 4.0)
Geriatric Depression Scale	
Total score	8.0 (5.0 – 12.0)
Total score 5	24 (80.0)
Individual fragility	12.0 (10.0 – 17.0)
African List Memory Test	
Three trials recall total	11.0 (8.0 – 14.0)
Long delay recall at least one word, n (%)	8 (26.7)
African Visuospatial Memory Test	
Three trials recall total	4.0 (3.0 – 9.0)
Long delay recall at least one word, n (%)	11 (36.7)
African Proverb Test	2.0 (1.0 – 4.0)
African Card Game	18.0 (16.0 – 24.0)
Neuropsychiatric Inventory	
Presence of symptoms	3.0 (2.0 – 4.0)
Frequency of symptoms	6.0 (2.0 – 9.0)
Severity of symptoms	4.0 (2.0 – 6.0)
Composite (frequency × severity)	8.0 (2.0 – 12.0)
Impact of symptoms	4.0 (2.0 – 8.0)
Caregivers (n= 30)	
Age, years	53.3 ± 14.9

Female, n (%)	20 (66.7)
Education, years	12.0 (8.0 – 15.0)
Duration living with the patient, years	21.5 (8.0 – 40.0)
Relationship with the patient, n (%)	
Spouse	13 (43.3)
Child	14 (46.7)
Other	3 (10)
Caregiver helped by another person, n (%)	28 (93.3)

* Values are mean \pm standard deviation, median (interquartile range) or count (%).

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Table 2

Association of Patient and Caregiver Characteristics with Caregiver Burden

	Model 1*		Model 2**	
	β Coefficient and CI	p value	Parameter estimate and CI	p value
Patient demographics				
Age, years	0.9 (-4.5, 6.3)	0.75	0.9 (-3.2, 5.0)	0.68
Female vs male	0.6 (-10.1, 11.2)	0.92	-2.7 (-11.0, 5.7)	0.54
Education, years	-1.2 (-6.5, 4.2)	0.67	1.2 (-3.1, 5.6)	0.58
Caregiver demographics				
Caregiver age, years	3.8 (-1.4, 9.0)	0.17	3.0 (-1.0, 6.9)	0.15
Caregiver female vs male	7.4 (-3.5, 18.3)	0.19	9.0 (0.6, 17.4)	0.0448 [†]
Caregiver education, years	-1.0 (-6.4, 4.4)	0.72	-2.3 (-6.5, 2.0)	0.31
Years caregiver Live with patient	0.2 (-5.2, 5.6)	0.94	1.8 (-2.3, 6.0)	0.39
Caregiver spouse of patient	1.3 (-10.1, 12.7)	0.83	2.4 (-5.7, 10.6)	0.56
Patient Neuropsychological Test Scores				
Community Screening Instrument for Dementia score	-2.8 (-8.0, 2.5)	0.31	-1.1 (-5.4, 3.2)	0.61
Alzheimer's Questionnaire				
Total Score	9.0 (4.8, 13.2)	0.0003	9.4 (5.3, 13.4)	<0.0001 [‡]
Memory subscale	2.2 (-3.2, 7.5)	0.43	2.3 (-3.0, 7.5)	0.40 [‡]
Orientation subscale	10.3 (6.5, 14.1)	<0.0001	10.5 (6.9, 14.0)	<0.0001 [‡]
Functionality subscale	6.3 (1.4, 11.1)	0.0178	6.4 (1.7, 11.2)	0.0135 [‡]
Visuospatial subscale	8.8 (4.6, 13.1)	0.0004	8.5 (4.1, 12.9)	0.0008 [‡]
Language subscale	1.7 (-3.7, 7.1)	0.54	2.1 (-3.2, 7.4)	0.44 [‡]
African List Memory Test				
Three trials total recall	-4.6 (-9.7, 0.5)	0.09	-1.4 (-5.9, 3.0)	0.53
Delayed recall	-16.6 (-26.8, -6.5)	0.0033	-15.9 (-22.5, -9.2)	<0.0001
African Visuospatial Memory Test				
Three trials total recall	-6.6 (-11.4, -1.8)	0.0117	-3.6 (-7.8, 0.6)	0.11
Delayed recall	-10.4 (-20.6, -0.1)	0.06	-6.6 (-14.7, 1.4)	0.12
African Proverb Test score				
African card game wins	-3.4 (-8.8, 2.1)	0.24	-0.6 (-5.0, 3.8)	0.80
Neuropsychiatric Inventory Scores				
Presence of symptoms	9.1 (4.8, 13.4)	0.0003	4.9 (-0.1, 9.9)	0.07
Frequency of symptoms	9.7 (5.6, 13.8)	<0.0001	5.5 (-0.2, 11.2)	0.07
Severity of symptoms	8.6 (4.2, 13.0)	0.0007	3.7 (-1.8, 9.1)	0.20
Composite (frequency \times severity)	9.3 (5.1, 13.5)	0.0002	4.7 (-0.9, 10.3)	0.11
Impact of symptoms	7.7 (3.1, 12.4)	0.0030	2.9 (-2.1, 8.0)	0.27
Neuropsychiatric Symptoms				
Delirium	19.9 (6.5, 33.2)	0.0069	7.0 (-7.6, 21.6)	0.35
Hallucination	0.1 (-15.1, 15.4)	0.99	-5.6 (-17.9, 6.8)	0.39

	Model 1*		Model 2**	
	β Coefficient and CI	p value	Parameter estimate and CI	p value
Agitation and aggressivity	15.2 (1.1, 29.4)	0.0445	6.9 (-5.6, 19.5)	0.29
Depression symptom	14.9 (5.9, 23.8)	0.0030	10.6 (2.1, 19.1)	0.0221
Anxiety symptom	1.3 (-9.3, 12.0)	0.81	2.6 (-5.9, 11.0)	0.56
Euphoria	2.6 (-14.7, 19.8)	0.77	-1.9 (-15.6, 11.9)	0.79
Disinhibition	11.5 (-5.3, 28.2)	0.19	11.7 (-1.1, 24.5)	0.09
Irritability	10.4 (0.3, 20.5)	0.05	5.2 (-3.6, 14.0)	0.26
aberrant motor behavior	16.8 (-3.0, 36.6)	0.11	1.7 (-16.4, 19.9)	0.85
sleep issues	1.5 (-9.8, 12.9)	0.79	-3.2 (-12.4, 5.9)	0.49
appetite issues	7.8 (-3.7, 19.2)	0.19	1.0 (-9.1, 11.0)	0.85
Individual fragility score	9.2 (5.0, 13.4)	0.0002	5.8 (1.7, 9.9)	0.0108

* Simple linear regression

** Multiple linear regression controlling for Alzheimer's Questionnaire total score and caregiver gender

[†] Adjusted for Alzheimer's Questionnaire total score only

[‡] Adjusted for caregiver gender only