

Caregiver Burden in a Culturally Diverse Memory Clinic Population: The Caregiver Strain Index-Expanded

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Keywords

Culturally competent care · Cross-cultural comparison · Caregivers · Caregiver burden · Dementia care · Ethnicity and race

Abstract

Introduction: Although qualitative studies have highlighted substantial barriers to dementia diagnosis and care in culturally diverse populations in Europe, quantitative studies examining the level of caregiver burden in these populations have been lacking thus far and are urgently needed. **Methods:** We compared the caregiver burden levels on the Caregiver Strain Index (CSI)-Expanded of 63 culturally diverse patient-caregiver dyads from a multicultural memory clinic with 30 native Dutch patient-caregiver dyads and examined the association between caregiver burden and determinants of burden. **Results:** Informal caregivers in the multicultural memory clinic cohort experienced a high level of caregiver burden (mean CSI-score multicultural cohort: 6.1 [SD: 3.3]; mean CSI-score native Dutch cohort: 4.8 [SD: 3.2]). Burden was significantly associated with impairment on proxy-rated and objective measures of cognitive functioning, such as the Informant Questionnaire on Cognitive Decline and the Rowland Universal Dementia Assessment Scale, and with instru-

mental activities of daily living. Burden was the highest in spousal caregivers. The positive subscale of the CSI-Expanded provided limited additional information. **Conclusion:** Caregivers of culturally diverse patients experience a high level of caregiver burden, in particular at more advanced disease stages. This study highlights the need to screen culturally diverse caregivers in European memory clinics on caregiver burden to identify those in need of caregiver support.

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Introduction

Over the past century, European countries have become increasingly diverse. In these diverse populations – particularly in migrant populations from Asia and Africa – the prevalence of dementia is higher than in older adults born in Europe [1], likely due to a higher prevalence of risk factors for dementia, such as cardiovascular disease, diabetes, and limited cognitive reserve. Dementia care in these groups is often viewed as a responsibility of the family [2, 3], and caregivers may fear losing the respect of the wider family or social network if they do not provide care to the person with dementia [4]. In addition, there are numerous barriers to dementia diagnosis and

care in these populations [2, 5, 6]; therefore, formal dementia care services are often accessed only when the level of caregiver burden becomes exceptionally high [2].

Traditional caregiver burden instruments mainly focus on aspects of care that can increase the level of burden, such as increased emotional strain; however, preliminary studies in culturally diverse caregivers of persons with dementia in the Netherlands suggest that positive aspects of taking care of a family member – such as appreciation expressed by the wider social network – may balance out some of the “negative” effects in these culturally diverse populations [3, 4]. An instrument is therefore needed that covers both these positive and “negative” aspects. To that end, Al-Janabi et al. [7] developed an extended version of the Caregiver Strain Index [8], adding 5 items measuring “positive” aspects of care that may decrease caregiver burden. Some factors that may influence burden scores are caregiver characteristics [9, 10], patients’ neuropsychiatric symptoms [11–13], functional impairment – particularly in instrumental activities of daily living (iADL [11, 12, 14]) – and objective cognitive impairment.

Given the increasing numbers of culturally diverse individuals with dementia in Europe, the goal of this study was to determine the level of caregiver burden in these caregivers and examine the relationship with these potential determinants of burden.

Materials and Methods

Participants

We included 63 caregiver-patient dyads from the outpatient multicultural memory clinic of the Erasmus MC University Medical Center in Rotterdam, the Netherlands. The patients were first-generation immigrants from Turkey ($n = 27$), Morocco ($n = 14$), Suriname ($n = 7$), Cape Verde ($n = 4$), and other countries ($n = 11$). In addition, we included 30 native Dutch patient-caregiver dyads from the outpatient memory clinic of the Erasmus Medical Center.

Procedure

All patients were referred to the memory clinic for cognitive evaluation and underwent a comprehensive clinical evaluation, after which they were discussed in a multidisciplinary meeting (see [15]). Patients were diagnosed according to established research criteria for dementia subtypes [16–18] or the 5th Edition of the Diagnostic and Statistical Manual of Mental Disorders for primary psychiatric disorders [19]. Imaging biomarkers (CT or MRI) to support the diagnosis were collected in 73% (46/63) of the culturally diverse patients; imaging data were available less often in culturally diverse individuals diagnosed with primary psychiatric disorders (3/9 patients, 33%) and subjective memory complaints (SMC; 8/13 patients, 61%). Lumbar punctures were only used on indication (5%). Based on the intake interview with the informant,

the clinician scored the level of functional impairment in basic activities of daily living (ADL [20]) and iADL [21]. The CSI-Expanded and other informant-based measures were administered to the caregivers in a separate room while the patients underwent neuropsychological testing. Caregivers could choose between the Dutch or an adapted Moroccan-Arabic or Turkish version of the CSI-Expanded. Caregiver-patient dyads were included between January 2019 and January 2021. The majority of the native Dutch caregivers (90%) was recruited as part of a study about neuropsychiatric symptoms in memory clinic patients with specific requirements on the minimum amount of time the caregiver spent with the patient.

Measures

Caregiver Strain Index-Expanded

The CSI-Expanded [7] is an extended version of the original 13-item Caregiver Strain Index [8]. The original 13-item instrument covers aspects such as emotional strain, physical demands, and time constraints, with a cutoff score of $\geq 7/13$. The CSI-Expanded contains 5 additional items that focus on aspects of caregiving that may decrease burden, such as the patient showing appreciation of the care provided by the informal caregiver. Although the original study totaled the subscale scores (i.e., with a total score between -5 and 13), we followed Kruithof et al. [22] in analyzing both scales separately to determine the added value of the positive subscale.

The Dutch CSI-Expanded was previously translated and validated [7]; in the current study, Moroccan-Arabic and Turkish versions were developed following the translation recommendations by the International Test Commission [23], with forward and backward translation and a subsequent evaluation and revision by a team of bicultural, bilingual native speakers to evaluate the cultural and linguistic appropriateness of the translations.

Other Informant-Based Measures

Caregivers of the multicultural memory clinic cohort (as well as a subset of caregivers in the native Dutch cohort) filled out the short version of the Informant Questionnaire on Cognitive Decline (IQCODE [24]); the IQCODE aims to capture cognitive decline and consists of 16 items rated on a 5-point Likert scale. The average score on all items is calculated, resulting in a final score ranging from 1 (marked improvement in cognitive functioning) to 5 (marked decline). For older first-generation immigrants in the Netherlands, a cutoff score of 3.8 was determined to be optimal [25]. In addition, we collected information on the caregivers’ sex and the type of relationship to the patient.

Cognitive, Functional, and Neuropsychiatric Measures (Patients)

All patients in the multicultural memory clinic underwent a neuropsychological assessment, which consisted predominantly of cognitive and behavioral measures that have been validated in culturally diverse populations in the Netherlands, such as the Cross-Cultural Dementia screening (CCD [26]), modified Visual Association Test (mVAT [15]), and Rowland Universal Dementia Assessment Scale (RUDAS [27]). The CCD covers the domains of memory (Objects tests A and B), mental speed (Dots test A and Sun-Moon test A), and executive functioning (Dots test B and Sun-Moon test B). The modified Visual Association Test is a test of visual association memory consisting of colored photographs. The RUDAS is a cognitive screening test specifically designed for use in culturally, linguistically, and educationally diverse populations

Table 1. Caregiver characteristics and scores on the Caregiver Strain Index-Expanded

	Multicultural memory clinic cohort (n = 63)	Native Dutch cohort (n = 30)	Significance
CSI-Expanded informant, n (%)			
Spouse	8 (13)	24 (80)	<i>p</i> < 0.001
1 or more adult child(ren)	49 (78)	3 (10) ¹	
Others ²	6 (10)	3 (10)	
Sex, males, n (%)	18 (29) ³	6 (20)	ns
CSI-Expanded score			
Score on the negative items (original scale)	6.1 (3.3)	4.8 (3.2)	<i>p</i> = 0.01*
Score on the positive items ⁴	-5.0 (1)	-5.0 (1.25)	ns
Distribution of positive subscale scores			
	-5: 67%	-5: 53%	
	-4: 13%	-4: 23%	
	-3: 17%	-3: 20%	
	-2: 3%	-2: 3%	
	-1: 0%	-1: 0%	

Values are displayed as mean (standard deviation) unless otherwise specified. * *p* value after correcting for sample differences. ¹ One adult child verified his answers with the spouse of the patient. ² For example, second-degree relative, friend, neighbor, and parent. ³ Two CSI-Expanded were filled out by 2 informants of different sexes (e.g., brother and sister). ⁴ Median (IQR); a “yes” on an item of the original scale is scored as 1, and a “yes” to an item on the positive subscale is scored as -1; a “no” is scored as 0 on both scales.

and similar to the MMSE in its scope and administration time, with an optimal cutoff of <22/30 for culturally, linguistically, and educationally diverse individuals in the Netherlands [27]. In addition, patients filled out the Dutch, Turkish, or Moroccan-Arabic 15-item Geriatric Depression Scale (GDS-15 [28, 29]). Acculturation was measured with a shortened, adapted Short Acculturation Scale for Hispanics (SASH [30]), consisting only of the 4 “Language use” items, in which we substituted “Spanish” with the first language of the patient and “English” with “Dutch.” Clinicians rated patients on the ADL and iADL scales. Patients in the native Dutch cohort were administered a different neuropsychological test battery which included the MMSE [31].

Statistical Analysis

Differences in demographic characteristics between native Dutch and multicultural memory clinic participants were analyzed in *R* with χ^2 tests for nominal data and *t* tests for continuous data. To compare burden levels on the original CSI, we ran a robust linear regression in which we corrected for sample differences in patients’ sex and relationship status. We did not correct for differences in the patients’ educational attainment as these reflect existing disparities in educational attainment in the general population [32]. As the positive subscale showed substantial skewness and the native Dutch cohort was modest in size, no meaningful group comparison could be carried out on the positive subscale while correcting for sample differences in sex and relationship status. We therefore used a Mann-Whitney U test (uncorrected for sex and relationship status) to analyze group differences on the CSI-Expanded positive subscale. We used Pearson correlations (or nonparametric equivalents) to determine the relationship between caregiver burden and its possible determinants. We corrected for multiple testing using the false discovery rate (FDR)

based on Benjamini-Hochberg adjusted *p* values. ANOVA (or a non-parametric equivalent) was used to compare caregiver burden levels by relationship type and across dementia stages – SMC, mild cognitive impairment, and dementia.

Results

Fifty-eight culturally diverse caregivers filled out the Dutch version of the CSI-Expanded, while 4 preferred the Turkish version and 1 the Moroccan-Arabic version. Three culturally diverse caregivers were accidentally administered the original CSI – these caregivers remained in the analyses of the original CSI, but were excluded from the analyses of the CSI-Expanded positive subscale. The native Dutch cohort contained relatively more spousal caregivers compared to the multicultural memory clinic cohort (see Table 1). Table 2 shows the characteristics of the patients included in the sample. The patients from the multicultural memory clinic had a lower education level than native Dutch patients. In addition, the native Dutch sample contained more male patients. The patient groups did not differ in age or diagnoses.

Level of Caregiver Burden

In the multicultural memory clinic cohort, 29 (46%) caregivers scored above the original CSI cutoff score of ≥ 7

Table 2. Patient demographic characteristics, cognitive test scores, and diagnosis of the patients

	Multicultural memory clinic cohort (n = 63)	Native Dutch cohort (n = 30)	Significance
Age	70.9 (10.5)	73.1 (8.4)	ns
Education level, n (%)			
0 years of education/illiterate	17 (27)	0 (0)	p < 0.001
1 year of education up to primary education	27 (43)	0 (0)	
> primary education	19 (30)	30 (100)	
Sex, males, n (%)	25 (40)	23 (77)	p = 0.001
Years in the Netherlands	41.6 (10.6)	–	–
RUDAS	21.2 (5.0; n = 57)	–	–
IQCODE	4.0 (0.6; n = 55)	3.7 (0.5; n = 14)	–
MMSE	19.4 (3.8; n = 17)	23.9 (5.7; n = 21)	–
Diagnosis, n (%)			
Subjective memory complaints	13 (21)	5 (17)	ns
Mild cognitive impairment	9 (14)	8 (27)	
Dementia	19 (30)	12 (40)	
Primary psychiatric disorder (e.g., depression)	9 (14)	1 (3)	
Cognitive disorder due to other known medical conditions (e.g., epilepsy)	4 (6)	2 (7)	
Could not be determined	9 (14)	2 (7)	

Values are displayed as mean (standard deviation) unless otherwise specified. RUDAS, Rowland Universal Dementia Assessment Scale; IQCODE, Informant Questionnaire on Cognitive Decline; MMSE, Mini Mental State Examination.

based on the 13 original items, in comparison with 8 (27%) native Dutch caregivers. After correcting for sample differences in relationship type and patients' sex, caregivers in the multicultural cohort experienced significantly higher levels of caregiver burden (original CSI) than the native Dutch cohort ($t = 2.48, p = 0.01$). The native Dutch and multicultural memory clinic cohort did not differ in their CSI-Expanded positive subscale score ($U = 795.0, p = 0.30$). A substantial proportion of the caregivers showed a maximum score on this subscale (multicultural memory clinic $n = 43$ [67%] and native Dutch cohort $n = 16$ [53%]). Ceiling effects were particularly present for items 14 and 18 of the positive subscale ("I am happy to care for him/her" and "Taking care of him/her is important to me"). In the multicultural cohort, the positive and negative scales were highly correlated ($r = -0.58$, unadjusted $p < 0.001$). There was a medium to large correlation in the Dutch cohort ($r = -0.39$, unadjusted $p = 0.03$), which remained significant after adjusting for FDR.

Relationship of CSI-Expanded with Patient Demographics, Cognitive and Functional Impairment, and Depression

In the multicultural cohort, there were no correlations between the original CSI and patient demographics (education level, sex, years living in the Netherlands, and

SASH acculturation score) or self-reported depressive symptoms (GDS-15). The scores on the original CSI showed moderate positive correlations with the level of impairment in iADL ($r = 0.38, p < 0.01$), but not with impairment in basic ADL ($r = 0.22, p = 0.10$). In terms of cognitive impairment, higher scores on the original items of the CSI were strongly associated with more severe cognitive impairment on the short IQCODE ($r = 0.59, p < 0.001$) and moderately with more impaired general cognitive functioning (RUDAS, $r = -0.33, p = 0.01$) and memory performance (mVAT, $r = -0.40, p = 0.02$, CCD Objects test B, $r = -0.28, p = 0.04$). There were no significant correlations with CCD measures of mental speed or executive functioning. After correcting for FDR, only the associations with the IQCODE and iADL remained statistically significant. The positive subscale did not show any significant correlations after correcting for FDR.

Caregiver Strain Index in Relation to Relationship Type and Patient Diagnosis

Spousal caregivers, adult children, and "other" caregivers of culturally diverse patients experienced different levels of caregiver burden on the original CSI (see Fig. 1; $F = 4.4, p = 0.02$). Post hoc analyses (corrected for FDR) revealed a higher level of spousal caregiver burden (mean

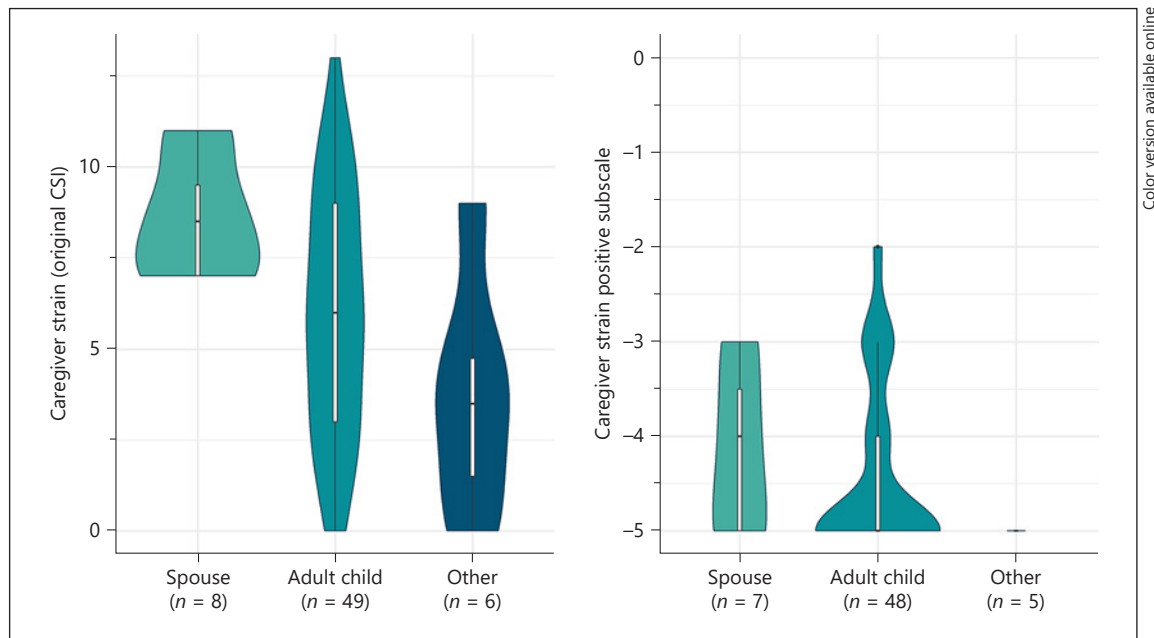


Fig. 1. Scores on the original CSI and positive subscale by relationship type in the multicultural cohort. CSI, Caregiver Strain Index.

CSI: 8.6, SD: 1.7) in comparison with both adult children (mean CSI: 5.9, SD: 3.3; $p = 0.04$) and “other” caregivers (mean CSI: 3.7, SD: 3.2; $p = 0.02$). The scores on the positive subscale were similar across relationship types ($H = 3.7$, $p = 0.16$).

There were also significant differences in caregiver burden by dementia stage (Fig. 2; $F = 5.9$, $p = 0.02$). Post hoc analyses (corrected for FDR) revealed that caregiver burden was higher in caregivers of persons with dementia than persons with SMC (mean difference: -3.07 , $p = 0.04$), while the other comparisons were not significant. The scores on the positive subscale were similar across dementia stages ($H = 0.5$, $p = 0.8$).

Discussion

In this study, we found that informal caregivers of culturally diverse patients experience a high level of caregiver burden as evidenced by the substantial number of individuals scoring above the cutoff on the CSI; these burden levels were associated with dementia severity on proxy-rated and objective cognitive measures, as well as functional measures, and with relationship type. Contrary to our expectation, the positive subscale of the CSI-Expanded provided little additional information.

This study demonstrated that caregiver burden levels in caregivers of culturally diverse patients are high, in line with other studies investigating caregiver burden in neurodegenerative disease (e.g., [33–36]). Several factors may contribute to these high levels of burden. In the early stages of dementia, it is common for 1 person in culturally diverse families to serve as the primary caregiver [3]. As dementia symptoms progress, this primary caregiver may increasingly dedicate their time to caring for the person with dementia, giving up on their own personal activities and social life, which can subsequently result in isolation of the caregiver [37]. The strong feelings of filial or religious duty experienced by these primary caregivers may motivate them to continue to provide informal care despite increasing levels of burden [37]. We therefore recommend general practitioners and memory clinics to routinely monitor caregiver burden and arrange subsequent intercultural caregiver support if necessary.

We found associations between burden levels and (proxy-rated and objective) measures of cognitive functioning, functional impairment, dementia stage, and relationship type. This is in line with previous studies, although some studies in less culturally diverse populations have found weak or no correlations between objective measures of cognition and caregiver burden [38] – pos-

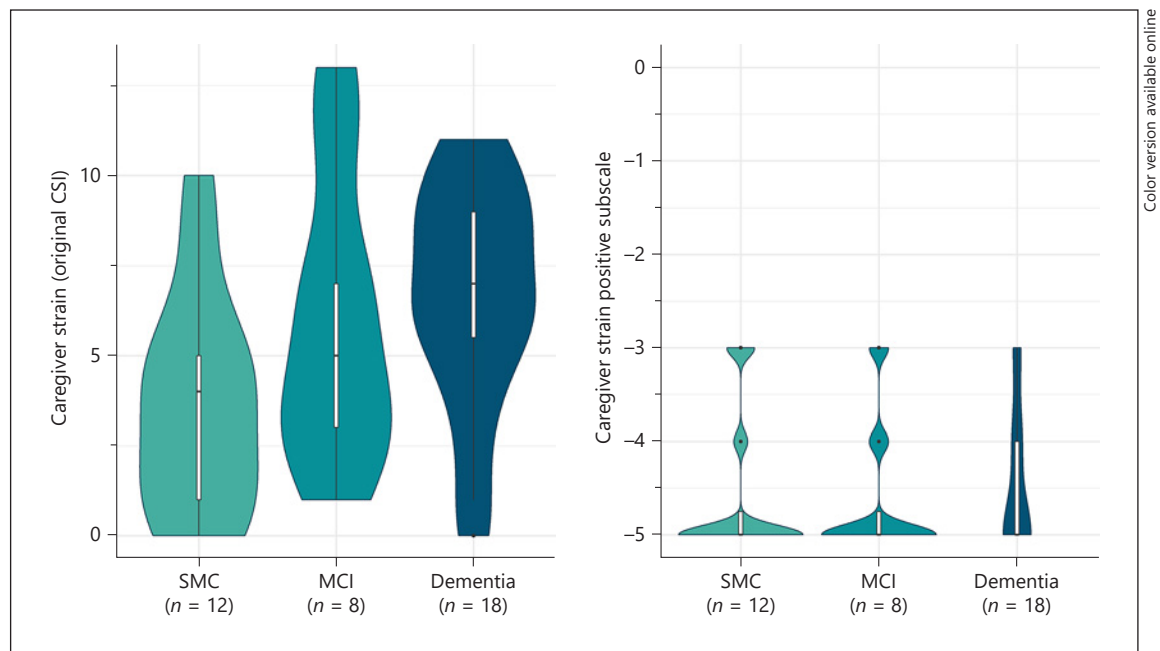


Fig. 2. Scores on the original CSI and positive subscale by dementia stage in the multicultural cohort. CSI, Caregiver Strain Index; SMC, subjective memory complaints; MCI, mild cognitive impairment.

sibly due to the inclusion of more severely cognitively impaired patients in these study samples (e.g., [9, 39]). Regarding relationship type, spousal caregivers experienced significantly higher levels of burden than adult children and “other” caregivers. The levels of burden in adult children showed substantial variation. Previous studies in less culturally diverse populations suggest that burden may be influenced by different mechanisms across different caregiver roles; for example, adult children may experience particular uncertainty over the future, such as “increased worry over how long they can maintain their level of caregiving in addition to other responsibilities” [40]. Such differences require further study and should be addressed in caregiver support strategies.

Somewhat contrary to our expectation, there was little variation in the scores on the positive subscale and no clear correlations with possible determinants of caregiver strain. Kruihof et al. [22] similarly found limited added value of the positive subscale in a sample of caregivers of stroke patients and suggested modifications to the items or answer format or the use of a different instrument. It may also be interesting to examine whether the addition of this subscale may improve the overall user experience of caregivers filling out this questionnaire – for example, caregivers may feel more comfortable discussing burden-

some aspects of care if such topics are alternated with more positive factors.

This study has several strengths. It was carried out in a specialized multicultural memory clinic, in which the staff has ample experience in assessing patients with culturally diverse backgrounds. In addition, we were able to include individuals from a wide variety of cultural, educational, and linguistic backgrounds. For example, over two-thirds of the patients included in the study received little formal education. We used several instruments and questionnaires that were previously validated in culturally, linguistically, and educationally diverse elderly in the Netherlands, such as the IQCODE, RUDAS, CCD, and mVAT, ensuring a valid assessment of cognitive impairment. Some limitations should be acknowledged. This was a retrospective analysis of data collected in routine clinical care, and the study lacked information on some potential determinants of caregiver burden (e.g., caregivers’ education level). Furthermore, it was not possible to examine the association between caregiver burden and neuropsychiatric symptoms other than depression in our multicultural memory clinic cohort, given that no validation studies have been carried out on instruments such as the Neuropsychiatric Inventory [41] in culturally diverse populations in the Netherlands. Last, although both na-

tive Dutch and culturally diverse caregivers on average scored close to the cutoff score for dementia on the MMSE and the RUDAS, respectively – indicating that they likely had similar levels of cognitive impairment – we could not formally compare the level of cognitive and functional impairment in these 2 populations because of the different instruments used across groups. Therefore, we were unable to examine whether or not the differences in caregiver burden between native Dutch and culturally diverse individuals are perhaps in part attributable to differences in the level of cognitive and functional impairment between these groups.

In conclusion, this study highlights that caregiver burden levels in caregivers of culturally diverse patients in the multicultural memory clinic are high, and general practitioners and memory clinics should actively monitor and subsequently arrange support for those caregivers experiencing severe levels of caregiver burden.

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Statement of Ethics

IRB approval was obtained from the IRB of the Erasmus MC University Medical Center in Rotterdam (MEC-2019-0036 and MEC-2020-0341). The procedures used in this study adhere to the

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tenets of the Declaration of Helsinki. Dutch native caregivers provided written informed consent, while written informed consent was waived for culturally diverse individuals by the IRB of the Erasmus MC University Medical Center.

Conflict of Interest Statement

The authors have no relevant financial or nonfinancial interests to disclose.

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Author Contributions

S.F., J.M.P., and W.S.E. designed the study. S.F., L.C.J., E.B., J.H., and W.S.E. contributed to the data collection. S.F. drafted the manuscript; all authors critically revised and approved the final version of the manuscript.

Data Availability Statement

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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