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Patient-Reported Outcomes

Quality of Life of Older Adults Living With Dementia and Caregiver Strain in Benin

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ABSTRACT

Objectives: This study aimed at assessing the quality of life (QoL) of older adults living with dementia and caregiver strain in Benin, a West African country.

Methods: A cross-sectional study was conducted from October to November 2021, recruiting participants aged 60 and over and their caregivers from health facilities and a rural community in Benin. QoL of older adults and caregiver burden were collected using standardized instruments, namely the World Health Organization's dementia QoL and Zarit Burden Interview, respectively.

Results: A total of 114 older adults (mean age 73 ± 10 years, 51% female) and their primary caregivers (mean age 49 ± 16 years, 70% female) participated, of whom 73 were recruited from health facilities and 41 from rural communities. Fifty percent of older adults were diagnosed with mild to severe dementia. The overall QoL was good, with rural participants scoring higher in daily life and urban participants scoring higher in emotion. Factors associated with decreased QoL were higher disability levels and greater caregiver burden. The mean caregiver burden score was 17 ± 13, with higher scores among those caring for older men. Increased disability in older adults and lower socioeconomic status were linked to higher caregiver strain, whereas better QoL in older adults and higher socioeconomic status reduced caregiver burden.

Conclusion: Enhancing access to healthcare, strengthening social support systems, and providing caregiver training and support are crucial for improving the well-being and care of individuals living with dementia in Benin.

Keywords: burden, dementia, informal care, older adults, quality of life, sub-Saharan Africa.

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Introduction

According to the World Health Organization, the proportion of the world's population aged over 60 years, estimated at 12% in 2015, is expected to reach 22% in 2050.[1] This trend is the result of a reduction in mortality rates related to infectious diseases and an increase in life expectancy. Although high-income countries have experienced this shift in population aging for several decades, low- and middle-income countries (LMICs) are now experiencing the greatest changes.[1] Older age results in a range of health conditions, including hearing and visual impairments, depression, and dementia. The number of dependent older adults globally is expected to increase from 1.2 million in 2012 to 2.3 million by 2060, with dementia being one of the primary causes of dependence.[1-3] Dementia refers to a syndrome, usually of a chronic or progressive nature, in which cognitive function deteriorates beyond what might be expected from normal aging.[4] It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment.[4] In 2019, it was estimated that 54.7 million people worldwide were living with dementia and nearly 60% of them lived in LMICs. In sub-Saharan Africa, the age-standardized prevalence of dementia for all those aged ≥60 years was estimated at 6.38%.[3,5] In Benin, population-based studies on adults aged 65 years and older estimated the prevalence of dementia at 2.6% in rural and 3.7% in urban areas.[6,7]

Owing to neurodegeneration, people with dementia have an increased risk of mortality compared with those without dementia.[8,9] People with dementia also often experience a reduced quality of life (QoL) because of the loss of independence,[10,11] as well as their caregivers. A family caregiver is a person who takes care of a relative with loss of autonomy on a daily or regular basis. Caregiver strain, also known as caregiver burden, is the emotional, physical, and financial stress experienced by individuals who care for people with chronic illnesses such as dementia. Caregiver burden has been linked to increased psychological distress and reduced QoL among caregivers.[12-14] Studies have shown that 40%

to 75% of caregivers experience significant psychological morbidity,[15,16] and 15% to 32% meet the criteria for major depression.[17] In this context, assessing the QoL of older people and caregiver strain is crucial, particularly in low- and middle-income countries, such as Benin. This study aims to assess the QoL of older adults living with dementia and caregiver strain in Benin. We hypothesized that higher levels of disability in older adults with dementia are associated with lower QoL and higher caregiver burden.

Methods

Study Design

This cross-sectional study was conducted between October and November 2021 in Benin. Participants were recruited in 2 panels to consider the inclusion of older adults without a prior medical diagnosis of cognitive disorders and to allow comparison between urban and rural settings. The first panel was recruited from healthcare facilities. All the hospitals with a neurologist, geriatrician, or psychiatrist were visited. Where available, the medical files of people aged 60 years and above, who consulted from January 2015 to September 2021, were checked. Keywords were used to identify older adults with symptoms of dementia. Phone calls were made to contact people if they were still alive and book appointments for home visits. The second panel of participants was recruited from a rural community through door-to-door surveys conducted for screening of cognitive disorders. Screening was conducted using the Community Screening Interview for Dementia (CSI-D). Older people with CSI-D scores <24 were considered eligible. Community health workers assisted in identifying houses in the villages, and participants met directly at home.

Interviews were conducted in French, the official language in Benin, or in local languages (Fon and Dendi) and answers were entered in French.

Study Population

People aged ≥ 60 years with dementia symptoms or a CSI-D score <24 were included as index older person (IOP) with their relatives who appeared to be the most significantly involved in their routine care as primary caregivers (PCs). IOP unreachable by phone calls and those absent at the time of their home visit were excluded.

Data Collection

A comprehensive assessment of the sociodemographic and clinical characteristics of the older adults and their caregivers, dementia severity, functional and cognitive performances, disability, QoL, and caregiver burden was performed using different instruments:

- A structured questionnaire: designed to collect sociodemographic and clinical data on IOP and PC, including age, sex, marital status, formal education level, comorbidities, and features of memory complaints. The relationship between both participants was also explored. Data regarding housing, drinking water supply, electricity, and goods owned by the household were used to compute a score of socioeconomic status (ranging from 5 to 30, with the highest scores reflecting a better socioeconomic status).
- The Clinical Dementia Rating Scale[18]: a standardized scale used to evaluate functional and cognitive disorders to assess the presence and severity of dementia in a given subject.
- The Resource Utilization in Dementia instrument[19-21]: investigating the use of healthcare resources, including medical consultations, hospitalization, home aid, and caregiver time (activities of daily living [ADL], instrumental ADL, and supervision).
- The World Health Organization Disability Assessment Schedule 2.0[22]: a generic assessment instrument for health and disability used to measure functioning and level of disability. The 12-item version was used in this study, with total scores ranging from 12 to 60.
- The Dementia Quality of Life[23,24]: a standardized questionnaire for measuring QoL in people with dementia which contains 28 questions covering 3 domains (emotion, memory, and daily life) that the subject is asked to evaluate for the past week, on a 4-point Likert scale. A total score on a scale of 28 to 112 is generated, with higher scores indicating better health-related QoL. In the last question, respondents are asked to rate their overall QoL over the previous week.
- The Zarit Burden Interview (ZBI)[25]: a 22-item questionnaire to assess the caregiver's appraisal of the impact their involvement in the older person's care has on their lives. The final scores range from 0 to 88, with higher scores reflecting greater caregiver burden. Estimates of the level of burden can be made as follows: Little or no burden if $\text{ZBI} \leq 20$; mild to moderate burden if $20 < \text{ZBI} \leq 40$; moderate to severe burden if $40 < \text{ZBI} \leq 60$; and severe burden if $\text{ZBI} > 60$.

The assessment was digitized using KoboCollect, and data were collected through a dedicated application on an electronic tablet. The collected data were extracted and processed for analysis.

Statistical Analyses

Data were analyzed using R software version 4.2.3. Descriptive statistics were calculated for all the variables. Comparisons among participant subgroups were performed using Student's *t* test for quantitative variables and Fisher's exact test for qualitative variables. The Dementia Quality of Life Questionnaire score was treated as a dependent variable and analyzed using linear regression. The ZBI score was treated as a dependent variable and transformed into a binary outcome. Logistic regression was performed to identify factors associated with caregiver burden. Variables with $P < .2$ in univariate analysis were included in the multivariable model, selected using a stepwise approach to minimize the Akaike information criterion. Pearson's correlation coefficient was calculated to evaluate the correlation between caregiver strain and its associated factors. The significance threshold used for all statistical analyses was set at $P < .05$.

Ethics

This study was conducted in accordance with the principles of the Declaration of Helsinki. The survey protocol was approved by the Ethics Committee for Biomedical Research of the University of Parakou in Benin (REF:0402/CLERB-UP/P/SP/R/SA; March 15, 2021). The Ethics Advisory Committee for Research in partnership with the French National Research Institute for Sustainable Development (IRD, France) conducted an additional ethics review. All facilities provided authorization for data collection. An information notice was read and explained to all participants in French and local languages. Written informed consent (signature/fingerprint) from both the caregiver and the older person was obtained before the interview. Participants were assigned unique identifier codes. As compensation for their time, participants' blood pressure was measured, with appropriate advice provided when

Table 1. Characteristics of index older persons.

Characteristic	Overall (*N* = 114)	Community (*N* = 41)	Health facility (*N* = 73)	*P* value
Residency				<.001
Rural	46 (40.4%)	41 (100.0%)	5 (6.8%)	
Urban	68 (59.6%)	0 (0.0%)	68 (93.2%)	
Sex				.12
Female	58 (50.9%)	25 (61.0%)	33 (45.2%)	
Male	56 (49.1%)	16 (39.0%)	40 (54.8%)	
Age, (years)				.02
Mean (SD)	73.0 (9.69)	76.2 (12.1)	71.3 (7.58)	
Median [Min, Max]	71.0 [60.0, 109]	75.0 [60.0, 109]	70.0 [60.0, 90.0]	
Marital status				.4
Married monogamy	61 (53.5%)	19 (46.3%)	42 (57.5%)	
Married polygamy	12 (10.5%)	6 (14.6%)	6 (8.2%)	
Widow or separated	41 (36.0%)	16 (39.0%)	25 (34.2%)	
Formal education level				<.001
Never attended school	47 (41.2%)	35 (85.4%)	12 (16.4%)	
Primary or lower secondary education	25 (21.9%)	1 (2.4%)	24 (32.9%)	
Upper secondary education or more	29 (25.4%)	0 (0.0%)	29 (39.7%)	
Missing	13 (11.4%)	5 (12.2%)	8 (11.0%)	
Socioeconomic status, [5-30]				<.001
Mean (SD)	18.1 (5.18)	12.8 (1.58)	21.1 (3.92)	
Median [Min, Max]	18.0 [10.0, 30.0]	13.0 [10.0, 16.0]	21.0 [14.0, 30.0]	
Disability score, WHODAS [12-60]				.9
Mean (SD)	30.7 (14.8)	31.0 (15.3)	30.5 (14.7)	
Median [Min, Max]	27.5 [12.0, 60.0]	27.0 [12.0, 60.0]	28.0 [12.0, 60.0]	
Self-reported hypertension	65 (57.0%)	17 (41.5%)	48 (65.8%)	.02
Self-reported diabetes	10 (8.8%)	0 (0.0%)	10 (13.7%)	.01
Presence of visual or audio impairment	41 (36.0%)	14 (34.1%)	27 (37.0%)	.8
History of stroke	29 (25.4%)	2 (4.9%)	27 (37.0%)	<.001
Duration of memory disorders, years				.13
Mean (SD)	5.1 (3.6)	5.9 (4.4)	4.6 (3.1)	
Median [Min, Max]	5.0 [0.3, 20.0]	5.0 [1.0, 20.0]	4.2 [0.3, 13.3]	
Duration since last medical visit for memory disorders				<.001
Less than a year	29 (25.4%)	0 (0%)	29 (39.7%)	
One year or more	15 (13.2%)	0 (0%)	15 (20.5%)	
Long time ago	18 (15.8%)	8 (19.5%)	10 (13.7%)	
Never	38 (33.3%)	33 (80.5%)	5 (6.8%)	
Missing	14 (12.3%)	0 (0%)	14 (19.2%)	
Physicians in public hospitals	74 (64.9%)	8 (19.5%)	66 (90.4%)	<.001
Physicians in private hospitals	48 (42.1%)	7 (17.1%)	41 (56.2%)	<.001
Fetishists, diviners	22 (19.3%)	5 (12.2%)	17 (23.3%)	.2
Naturopaths, pharmacopoeia	11 (9.6%)	4 (9.8%)	7 (9.6%)	>.9
Priests, pastors, religious	2 (1.8%)	0 (0%)	2 (2.7%)	.5
Senior citizens' associations	1 (0.9%)	0 (0%)	1 (1.4%)	>.9
Dementia presence and severity (CDR)				.7
No dementia	15 (13.2%)	6 (14.6%)	9 (12.3%)	
Questionable dementia	42 (36.8%)	14 (34.1%)	28 (38.4%)	
Mild dementia	18 (15.8%)	7 (17.1%)	11 (15.1%)	
Moderate dementia	14 (12.3%)	7 (17.1%)	7 (9.6%)	
Severe dementia	25 (21.9%)	7 (17.1%)	18 (24.7%)	
DEMQOL Emotion domain score, [13- 52]				<.001
Mean (SD)	37.0 (8.28)	33.4 (8.50)	39.0 (7.47)	
Median [Min, Max]	38.0 [21.0, 52.0]	31.0 [21.0, 52.0]	41.0 [24.0, 52.0]	
DEMQOL Memory domain score, [6-24]				.3
Mean (SD)	16.3 (5.92)	15.5 (4.82)	16.7 (6.45)	
Median [Min, Max]	17.5 [6.0, 24.0]	14.0 [8.0, 24.0]	19.0 [6.0, 24.0]	

continued on next page

Table 1. Continued

Characteristic	Overall	Community	Health facility	*P* value
	(*N* = 114)	(*N* = 41)	(*N* = 73)	
DEMQOL Daily life domain score, [9-36]				.02
Mean (SD)	27.3 (7.02)	29.1 (4.67)	26.4 (7.91)	
Median [Min, Max]	28.5 [9.0, 36.0]	29.0 [19.0, 36.0]	28.0 [9.0, 36.0]	
DEMQOL total score, [28-112]				.2
Mean (SD)	80.6 (17.4)	78.0 (17.0)	82.1 (17.6)	
Median [Min, Max]	80.5 [43, 112]	73 [49, 109]	82 [43, 112]	
General appreciation of self QoL				<.001
Very Good	11 (9.6%)	5 (12.2%)	6 (8.2%)	
Good	28 (24.6%)	4 (9.8%)	24 (32.9%)	
Medium	50 (43.9%)	17 (41.5%)	33 (45.2%)	
Bad	25 (21.9%)	15 (36.6%)	10 (13.7%)	

CDR indicates clinical dementia rating scale; DEMQOL, Dementia Quality of Life Questionnaire; Max, maximum; Min, minimum; QoL, quality of life; SD, standard deviation; WHODAS, the World Health Organization Disability Assessment Schedule.

necessary, and COVID-19 prevention kits (surgical masks and hydro-alcoholic gel) were distributed.

Results

Characteristics of the Study Population

A total of 114 older adults and their main caregivers participated in this study: 73 from health facilities and 41 from community-based recruitment. All (100%) of the community participants were living in rural areas, and almost all (93%) of the health facility participants lived in urban areas of Benin. Table 1 shows the characteristics of the older adults and their caregivers. The mean age of the included IOP was 73 ± 10 years. The male-to-female ratio was 0.97, and 73 participants were married. Community IOP had a lower formal education level and lower socioeconomic status ($P < .001$). Although the mean duration of memory disorders was 5 years, one-third of the study population (80.5% of rural participants) did not seek any medical consultation for this specific problem. Fifty percent of older adults were found to have mild to severe dementia, and 37% had questionable dementia.

Among the caregivers (Table 2), 80 (70%) were female, with an average age of 49 ± 16 years. Spouses and children each represented 38% of the entire caregiver population; however, children represented 43% for health facilities compared with 29% for community ones. The type of relationship between older adults and caregivers was more diverse in the community. Family duties appeared to be the main reason for caregiving (71%), irrespective of the recruitment category or residency area. Caregiving time was highly variable, including 52 ± 74 min for ADL and 98 ± 90 min for instrumental ADL daily. About three-quarters of caregivers reported not doing any other activity during care time.

Older Adults' QoL of and Associated Factors

Older people reported a good QoL (81 ± 17); however, rural participants had significantly higher scores in the daily life domain (29 ± 5 vs 26 ± 8, $P = .02$), whereas urban participants' scores were highest in the emotion domain (39 ± 7 vs 33 ± 9, $P < .001$). Finally, when asked to give a general appreciation of their QoL, only 22% of rural elders declared good to very good QoL, compared with 43% in urban areas ($P < .001$) (Table 1).

Table 3 lists the factors associated with the QoL of IOP. Two major factors contributed to a decreased QoL in IOP: older adults' level of disability (-0.75, $P < .001$) and the caregiver burden (-9.41, $P < .001$).

Caregiver Strain and Associated Factors

Table 4 displays the features of the caregiver burden, all features of the 22 ZBI items are provided in the Appendix Table 1 in Supplemental Materials found at https://doi.org/10.1016/j.vhri.2025.101080. The total burden expressed by caregivers appeared to be relatively low (mean score 17 ± 13) and was significantly higher for older men than for females. The individual ZBI items caregivers mainly worried about were "do a better job in caring," "being afraid what the future holds for the relative," and "feeling one should be doing more." These concerns remain the top 3, regardless of the sex of the older person or caregiver. "Feeling one's health and privacy has suffered because involvement in care" was among the least frequently reported items. However, both items were reported significantly more often by female caregivers than by male caregivers.

Many factors were associated with the presence of caregiver strain (Table 5). The risk of strain for the caregiver increased with older adults' level of disability (OR = 1.13, $P = .002$). Meanwhile, increased socioeconomic status (OR = 0.73, $P = .006$) and older persons' QoL contributed to the reduction of strain (OR = 0.91, $P = .002$) and were the 2 main factors negatively related to caregiver burden. Finally, male caregivers were less likely to report strain compared with female caregivers (OR = 0.18, $P = .002$).

Overall, the burden expressed by caregivers was significantly correlated with older person's level of disability and QoL, as depicted in Figure 1.

Discussion

Caring for individuals living with dementia poses significant challenges and imposes a considerable burden on caregivers. This study aimed to assess the QoL of older adults with dementia and the associated strain on caregivers in Benin. These findings contribute to our understanding of the QoL, burden experienced by caregivers, and associated factors. Previous studies have also highlighted the impact of dementia on the QoL of older individuals and their caregivers. Research has shown that dementia-related impairments can significantly diminish the QoL, affecting emotional well-being, daily functioning, and overall satisfaction.[14,26]

Table 2. Characteristics of the primary caregivers.

Characteristic	Overall (*N* = 114)	Community (*N* = 41)	Health facility (*N* = 73)	*P* value
Sex				.3
Female	80 (70.2%)	26 (63.4%)	54 (74.0%)	
Male	34 (29.8%)	15 (36.6%)	19 (26.0%)	
Age				.9
Mean (SD)	49.3 (16.1)	49.0 (17.7)	49.5 (15.2)	
Median [Min, Max]	50.0 [17.0, 87.0]	45.0 [25.0, 87.0]	52.0 [17.0, 75.0]	
Marital status				.09
Married monogamy	90 (78.9%)	31 (75.6%)	59 (80.8%)	
Married polygamy	11 (9.6%)	7 (17.1%)	4 (5.5%)	
Single	11 (9.6%)	2 (4.9%)	9 (12.3%)	
Missing	2 (1.8%)	1 (2.4%)	1 (1.4%)	
Formal education level				<.001
Never attended school	42 (36.8%)	34 (82.9%)	8 (11.0%)	
Primary or lower secondary school	33 (28.9%)	7 (17.1%)	26 (35.6%)	
Upper secondary school or more	34 (29.8%)	0 (0%)	34 (46.6%)	
Missing	5 (4.4%)	0 (0%)	5 (6.8%)	
Relation to the older person				<.001
Spouse	43 (37.7%)	14 (34.1%)	29 (39.7%)	
Children	43 (37.7%)	12 (29.3%)	31 (42.5%)	
Children in law	13 (11.4%)	11 (26.8%)	2 (2.7%)	
Others	15 (13.2%)	4 (9.8%)	11 (15.1%)	
Motivation for caring				.11
Family duty	81 (71.1%)	31 (75.6%)	50 (68.5%)	
Obligation	17 (14.9%)	5 (12.2%)	12 (16.4%)	
Salary	7 (6.1%)	0 (0%)	7 (9.6%)	
Missing	9 (7.9%)	5 (12.2%)	4 (5.5%)	
Contribution level to total care				<.001
Less 50%	19 (16.7%)	7 (17.1%)	12 (16.4%)	
50 to 99%	31 (27.2%)	3 (7.3%)	28 (38.4%)	
100%	61 (53.5%)	30 (73.2%)	31 (42.5%)	
Missing	3 (2.6%)	1 (2.4%)	2 (2.7%)	
Daily ADL care duration, minutes				.02
Mean (SD)	51.8 (73.5)	33.7 (42.0)	62.1 (84.9)	
Median [Min, Max]	0 [0, 360]	0 [0, 120]	30 [0, 360]	
Daily IADL care duration, minutes				.6
Mean (SD)	98.2 (90.0)	92.2 (80.6)	102 (95.3)	
Median [Min, Max]	75 [0, 360]	120 [0, 360]	60.0 [0, 360]	
Daily supervision duration, minutes				<.001
Mean (SD)	74.8 (191)	8.05 (15.8)	112 (230)	
Median [Min, Max]	0 [0, 960]	0 [0, 60]	0 [0, 960]	
Caregiver burden level (ZBI)				.05
Null or low	69 (60.5%)	19 (46.3%)	50 (68.5%)	
Mild	41 (36.0%)	20 (48.8%)	21 (28.8%)	
Moderate	3 (2.6%)	2 (4.9%)	1 (1.4%)	
Severe	1 (0.9%)	0 (0%)	1 (1.4%)	

ADL indicates activities of daily living; IADL, instrumental activities of daily living; Max, maximum; Min, minimum; SD, standard deviation; ZBI, Zarit Burden Interview.

Study Findings

First, the study population consisted of older adults from both health facilities and community-based recruitment. The mean age of the surveyed population was 73 years, with a nearly equal distribution of males and females. Our findings revealed interesting differences between these populations. Rural participants were slightly older and had lower educational levels compared with their urban counterparts, consistent with previous research highlighting disparities in educational attainment and access to healthcare between rural and urban populations.[27,28] Additionally, deficiencies and comorbidities were more prevalent among urban participants, which can be attributed to the recruitment process involving health facilities. A substantial proportion of participants had mild to severe dementia including community participants, emphasizing the diagnosis gap previously mentioned by the literature.[29,30]

Overall, the IOP in this study reported a good QoL. Interestingly, rural participants reported higher scores in the daily life domain of QoL, whereas urban participants reported higher scores in the emotion domain. This is likely influenced by the perception and experience of QoL among individuals residing in different settings,[31] as well as by variations in access to healthcare services, social support, and environmental factors

Table 3. Factors associated with the quality of life of older adults, (DEMQOL total score).

Variable	Univariable model			Multivariable model		
	Estimate	Std. Error	*P* value	Estimate	Std Error	*P* value
Older adult age, years	−0.286	0.167	.089	-	-	-
Older adult sex (Male vs. Female)	4.751	3.240	.145	-	-	-
Socioeconomic status	0.693	0.310	.027	-	-	-
Older adult’s marital status	-	-	.056	-	-	-
Married monogamy (ref)	-	-	-	-	-	-
Married polygamy	9.634	5.397	.077	-	-	-
Widow or separated	−3.935	3.451	.250	-	-	-
Older adult’s disability level, (WHODAS)	−0.939	0.066	<.001	−0.750	0.078	<.001
Caregiver’s burden (Mild to Severe vs. Null or Low)	−23.183	2.529	<.001	−9.413	2.368	<.001
Informal care daily duration, minutes	−0.053	0.011	<.001	-	-	-
Caregiver’s marital status	-	-	.110	-	-	-
Married monogamy (ref)	-	-	-	-	-	-
Married polygamy	−0.605	5.488	.912	-	-	-
Single	11.486	5.488	.039	-	-	-

Ref indicates reference modality; Std, standard; WHODAS, the World Health Organization Disability Assessment Schedule.

unique to each setting. For example, in rural areas, most seniors had ongoing farming or selling activities, whereas, in urban areas, most were retired with no specific activity and therefore may have more spare time. Additionally, 55% of the interviewed caregivers declared achieving all care tasks alone—44% of urban caregivers and 71% of rural ones—suggesting that more people are involved in care in rural areas. This is probably because of the proximity of relatives because urban areas offer more transport facilities to visit relatives more frequently, whereas rural seniors live mostly with their spouses only and may have their younger relatives far from home for educational or employment reasons, which may affect their emotional stability. In line with previous findings, it is noteworthy that fewer rural elders in this study reported having good to very good QoL, compared with urban elders. This finding highlights the need for targeted interventions to improve the QoL of older adults living in rural areas, which could be supported by improvements in access to healthcare, social support systems, and leisure.

The sex distribution of caregivers in our study revealed a notable overrepresentation of women, consistent with previous

Table 4. Feature of caregiver strain as captures by the Zarit Burden Interview (ZBI) questionnaire.

Caregiver burden	Overall	Recruitment setting			Older person sex			Caregiver sex		
		Community	Health facility	*P* value	Female	Male	*P* value	Female	Male	*P* value
	(*N* = 114)	(*N* = 41)	(*N* = 73)		(*N* = 58)	(*N* = 56)		(*N* = 80)	(*N* = 34)	
Caregiver burden level (ZBI)				.03			.6			.2
Null or low, [0-20]	69 (60.5%)	19 (46.3%)	50 (68.5%)		37 (63.8%)	32 (57.1%)		45 (56.3%)	24 (70.6%)	
Mild to severe [21-88]	45 (39.5%)	22 (53.7%)	23 (31.5%)		21 (36.2%)	24 (42.9%)		35 (43.8%)	10 (29.4%)	
Caregiver burden score, ZBI [0-88]				.4			.04			.3
Mean (SD)	16.7 (13.2)	18.2 (14.4)	15.8 (12.5)		14.2 (11.9)	19.2 (14.1)		17.6 (12.6)	14.6 (14.5)	
Median [Min, Max]	15.5 [0, 63.0]	21.0 [0, 50.0]	13.0 [0, 63.0]		12.5 [0, 39.0]	17.5 [0, 63.0]		17.0 [0, 63.0]	11.0 [0, 52.0]	

Table 5. Factors associated with the presence of mild to severe strain in caregivers.*

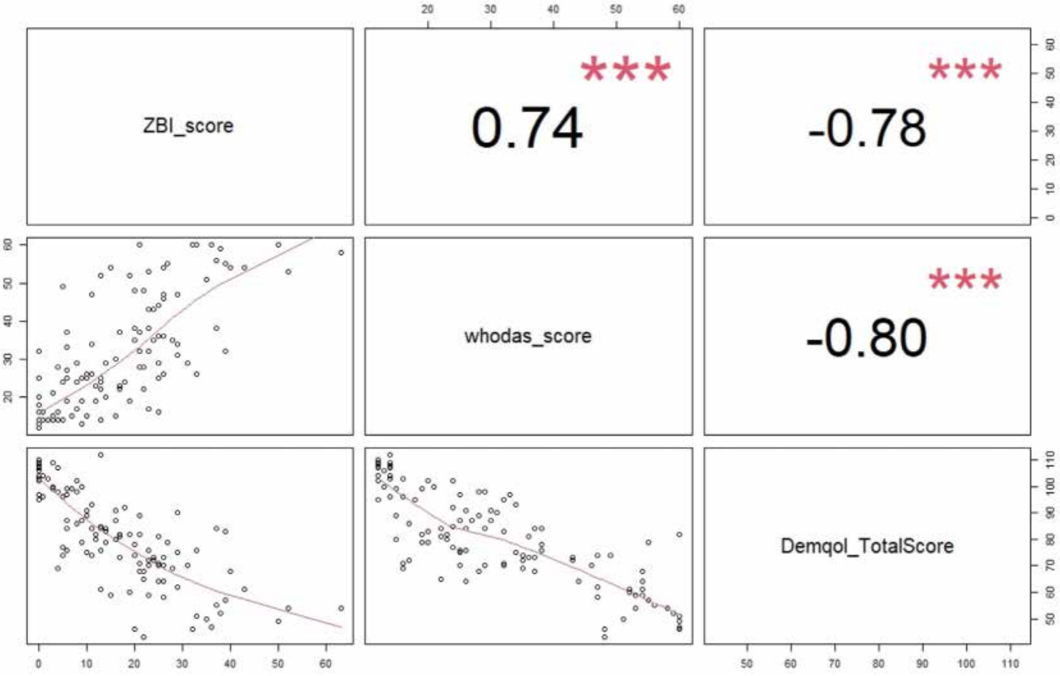
Characteristic	Univariable model			Multivariable model		
	OR	95% CI	*P* value	aOR	95% CI	*P* value
Older person age, years	1.01	0.97, 1.05	.669	0.92	0.83, 0.99	.027
Older person sex, Male | Female	1.28	0.59, 2.78	.535	-	-	-
Socioeconomic Status	0.86	0.78, 0.94	<.001	0.73	0.56, 0.92	.006
Disability level (WHODAS)	1.11	1.07, 1.16	<.001	1.13	1.04, 1.25	.002
Older person QoL (DEMQOL)	0.87	0.82, 0.91	<.001	0.91	0.84, 0.97	.002
Caregiver sex, Male | Female	0.49	0.19, 1.16	.115	0.18	0.03, 0.81	.034
Informal care daily duration, minutes	1.00	1.00, 1.01	.015	-	-	-
Caregiver formal educational level	-	-	.006	-	-	-
Never attended school (ref)	1.00	-	-	-	-	-
Primary or lower secondary education	0.24	0.08, 0.64	.005	-	-	-
Upper secondary education or more	0.31	0.12, 0.80	.017	-	-	-

CI indicates confidence interval; DEMQOL, Dementia Quality of Life Questionnaire; OR, odds ratio; QoL, quality of life; ref, reference modality; WHODAS, the World Health Organization Disability Assessment Schedule.
*Caregiver burden level (ZBI score): null or low [0-20]; mild to severe [21-88]

literature on dementia caregiving. This disparity in informal caregiving roles is a global phenomenon irrespective of the pathologies or country's resource level.[32-35] Highlighting sex inequities in caregiving responsibilities and their impact on female caregivers. In addition, female caregivers reported increased strain when caring for male seniors, suggesting potential challenges related to personal care tasks and the intersection of gender dynamics within the caregiving context. These sex-related challenges in dementia care should be a concern for policymakers in LMICs such as Benin, where cultural norms and gender roles may influence caregiving dynamics.[36,37]

This study found a relatively low level of burden among caregivers, with prominent concerns related to caregiving responsibilities and uncertainties for the future. This is lower than studies from Uganda, India, China, and other LMIC countries that have reported mild to moderate levels of caregiver burden.[38-40] However, it is well documented that caregiving for individuals living with dementia can have a significant impact on caregivers'

Figure 1. Correlation between the disability of older adults with their quality of life and caregiver burden. Numbers = Pearson correlation coefficient; *** $P < .001$.



DEMQOL indicates Dementia Quality of Life Questionnaire; WHODAS, the World Health Organization Disability Assessment Schedule; ZBI, Zarit Burden Interview.

physical, emotional, and social well-being.[16,17] Our findings can be partly attributed to the cultural norms that prioritize family support and caregiving, and the involvement of other family members in caregiving tasks may help alleviate the burden on primary caregivers. However, it is important to note that the interview setting, conducted in the presence of the older person, may have influenced the responses and potentially led to underreporting of caregiver burden. Then, sharing care tasks among multiple actors may help relieve strain on PCs and reduce their perceived burden.

Our study identified the level of disability experienced by older adults as the main factor associated with increased caregiver burden, corroborating previous research highlighting the impact of functional and cognitive impairments on caregiver strain. The increasing level of disability in older adults necessitates more time and attention from caregivers, leading to heightened strain and concern about the future. The severity of cognitive and functional impairments further compounded the challenges faced by caregivers, affecting their ability to provide care and support. Behavioral and psychological symptoms of dementia may exacerbate caregiver burden and negatively affect the well-being and QoL of both the caregiver and care recipient.

This study did not observe any significant correlation between caregiver burden and personal characteristics, such as age, sex, or relationship with older adults being cared for. This finding may be attributed to the cultural norms and practices in the study country, where caregiving is primarily driven by a sense of familial duty. In this context, caregivers prioritize the health and QoL of their relatives over their own well-being, which is consistent with the findings of a previous study conducted in Indonesia.[33]

Limitations and Strengths

Although this study provides valuable insights, it is important to acknowledge its limitations. First, it adopted a cross-sectional design, limiting the ability to establish causal relationships between variables. Longitudinal studies could provide more robust evidence on the dynamic nature of QoL and caregiver burden in dementia. Additionally, the use of convenience sampling may introduce selection bias and limit the generalizability of the findings to the broader Beninese older population with or without dementia. Future studies should strive to use more representative sampling methods. Additionally, the small sample size may have influenced the analyses, emphasizing the need for caution when interpreting the results. Despite these limitations, to our knowledge, this study represents the first assessment of the QoL of older individuals and caregiver strain in Benin. It utilized standardized instruments to assess various aspects of QoL, caregiver burden, and associated factors, ensuring reliable and comparable measurements. The inclusion of community participants from rural areas adds to the diversity of the sample and provides important insights into the situation of individuals who have not been previously diagnosed with or have had contact with healthcare facilities for cognitive disorders.

Conclusions

In conclusion, our study contributes to the growing body of knowledge regarding the burden experienced by informal caregivers of older adults living with dementia in resource-limited settings. Our findings highlight the need for comprehensive support and interventions to enhance the QoL of individuals with dementia and to reduce caregiver burden. Policymakers and healthcare stakeholders should consider these results in the development of targeted interventions, such as enhancing access to healthcare services, providing respite care, and promoting caregiver support programs. Furthermore, community-based awareness campaigns can help reduce the stigma associated with dementia and foster a supportive environment for the affected individuals and their caregivers.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section.

Supplemental Material

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