

Original Article

Correlates of Quality of Life of Older Adults with Dementia, Alexandria, Egypt

Zeinab N. Shata¹, Heba M. El-Kady², Hala K. Ibrahim³

¹Lecturer of Mental Health, Family Health Department, High Institute of Public Health, Alexandria University, Egypt

²Assistant Professor of Geriatric Health, Family Health Department, High Institute of Public Health, Alexandria University, Egypt

³Assistant Professor of Public Health Nursing, Family Health Department, High Institute of Public Health, Alexandria University, Egypt

Abstract

Objective(s): To determine factors associated with quality of life (QoL) of older adults with dementia in Alexandria, Egypt.

Methods: A total of 102 dementia patient-caregiver participated in a cross-sectional study at the psychogeriatric outpatient clinic in Almaamora Psychiatric Hospital in Alexandria (2013). Community dwelling older adults (≥ 60 years), and having scores of 10-20 on the Mini Mental State Examination (MMSE), were recruited. They were assessed using Quality of Life-Alzheimer's Disease (QoL-AD)-combined report, Patient Health Questionnaire-9 (PHQ-9) for depression, and Katz Index for Activities of Daily Living (ADL).

Results: The higher scores on the QoL-AD correlated significantly with younger ages of patients ($r = -0.270$, $p < 0.001$) and caregivers ($r = -0.254$, $p = 0.01$), higher scores on the MMSE ($r = 0.208$, $p = 0.03$) and ADL ($r = 0.551$, $p < 0.001$), and lower PHQ-9 scores ($r = -0.506$, $p < 0.001$). Better QoL associated significantly with adequate monthly income ($p = 0.04$), AD type of dementia ($p = 0.002$), absence of co-morbid physical diseases ($p < 0.001$), and caregivers not living with the patient in same residence ($p = 0.02$). Regression analysis revealed only two predictors of QoL namely the person's level of independence in ADL, and lower depressive symptoms ($B = 0.644$, $B = -0.303$, respectively, $p < 0.001$).

Conclusion: QoL of patients with moderate dementia was significantly predicted by the severity of depressive symptoms and level of functional dependence. Dementia care plans should include regular screening and early management of depression, as well as patient and caregiver psycho-education to increase patients' functional independency.

Keywords: ADL, community dwelling older adults, dementia, depression, QoL-AD.

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✉Correspondence:
Email: zeinab.shata@yahoo.com

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INTRODUCTION

The rapidly growing number of older adults in Egypt and worldwide as a result of increased life expectancy,⁽¹⁾ will be reflected in the prevalence rates of dementia. In 2015, the worldwide prevalence rate of dementia was estimated to be 5.2%, and it is projected to double every 20 years. Among all people living with dementia, 58% of them live in low or middle income countries, and this proportion is expected to rise to 63% in 2030.⁽²⁾ Dementia surveys conducted in Egypt reported a wide range of prevalence rates from 1.4% to 21.95% in different age groups for older adults aged 60 and above.⁽³⁾ Dementia is a neurocognitive disorder characterized by impairment in a person's cognitive abilities such as memory and language, eventually affecting the individual's ability to

carry out activities of everyday life independently.⁽⁴⁾ In 1998, the World Health Organization (WHO) defined quality of life (QoL) as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns". This definition takes into account both individual perception and the relationship with the environment.⁽⁵⁾ In recent years, research examining the factors that contribute to QoL has broadened our understanding of quality of care for community-dwelling patients with dementia. Previous studies have identified several disease-related determinants that influence QoL in people with dementia; these include the presence of neuropsychiatric symptoms, activities of daily living (ADL), cognition, and comorbid conditions. Depression has consistently been found to be negatively correlated

with patient-reported QoL.^(6, 7) Given no available medications have proved effective in terminating the progression of damage caused by Alzheimer's Disease, making it a non-curable fatal disorder in most types,⁽⁴⁾ the maximization of QoL among people living with dementia has emerged as the most important outcome measure in the management of dementia.⁽⁷⁾ Consequently, assessing factors that may increase or decrease the QoL of persons with dementia is a mandatory contribution to our understanding of the QoL in dementia to help achieve the maximum QoL.⁽⁸⁾

Although several studies investigated QoL among people with dementia worldwide, however, the few studies conducted in Egypt targeted mainly health-related QoL of older adults, with no known studies that targeted disease-specific QoL of community dwellers with dementia.^(9, 10) The authors in a previous study reported validation of an Arabic-version of QoL-AD.⁽¹¹⁾ The current work aimed to identify factors associated with the QoL among persons with dementia in Alexandria, Egypt.

METHODS

A cross-sectional study took place in the psychogeriatric out-patient clinic of Al-Maamora Psychiatric Hospital in Alexandria; a governmental hospital which provides a tertiary level mental health services for the residents of Alexandria Governorate and two other governorates. During the period of the study, which lasted from July to December 2013, patients with dementia attending the above-mentioned clinic, and their main caregivers were recruited. Inclusion criteria included community dwelling older adults diagnosed with dementia by the hospital psychiatrist, with both the patient and caregiver being able to complete the QoL-AD (older adults with no communication problems), having a Mini Mental State Examination (MMSE) score of 10 to 20, and the presence of the main caregiver accompanying the patient at the time of interview. The sample size was calculated using QoL-AD mean scores and standard deviations of both older adults (31.58 ± 5.88) and their caregivers (27.08 ± 5.85),¹² at a 95% confidence level, a power of 95%, and an equal care recipients/caregivers ratio. The minimum required sample size was 90 patient-caregiver dyad. To overcome any drop in response rate, the size of the sample was increased by 10%. The clinic was working two days per week. It was visited during working days to recruit the required sample size. The total participants included 102 patient-caregiver dyads. Data were collected from both persons with dementia and their caregivers through an interview by a psychologist, who was well trained by the first author. Basic data included socio-demographic characteristics of both persons with dementia and their caregivers.

Other data collected from persons with dementia included social, medical, and behavioural items. The following tools were used: 1. The Arabic Version of Quality of Life-Alzheimer's Disease Scale (QoL-AD). This scale was developed originally by Logsdon et al.⁽¹³⁾ It is a brief 13-item scale used to assess the QoL among people with dementia and completed by the patient, caregiver, or both. The scale assesses physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores around the house, and the ability to do things for fun, money, and life quality as a whole. The scale is rated on a 4-point scale from 1 (poor) to 4 (excellent) and the total score is calculated by summing all items. Total possible scores range from 13–52, with higher scores indicating higher QoL. Three forms of the scale are available based on the patient's self-report, the caregiver report, or a combined one. The combined report is obtained by multiplying the patient's scores by 2, and then adding the caregiver's scores, and finally dividing the sum of both by 3. This combined report gives more weight to the patient reports as they are the main target for evaluation. An Arabic version of this tool was adapted and validated as a separate and preparatory part of this work. Further details on validation were published in a previous study.⁽¹¹⁾ The validated Arabic version was applied to persons with a MMSE score of 10 to 20.

2. The Arabic Version of the Mini Mental State Examination (MMSE). It is a clinician administered assessment of cognitive functions (registration of new information, orientation, attention, calculation, recall, language, and construction skills). The total score ranges between 0 and 30. A score below 20 indicates the presence of dementia. The lower scores indicate higher cognitive impairment.⁽¹⁴⁾

3. Katz Index for Activities of Daily Living (ADL) The Katz Index for Activities of Daily Living (ADL) was used to assess the ability of older adults to perform the activities of daily living independently, as an indicator of their functional status. The ADL assesses performance in six functions (bathing, dressing, toileting, transferring, continence, and feeding). Each item receives either 'Yes' or 'No' for independence with a score of one for each 'Yes' and zero for each 'No'. The total score ranges from 0 to 6, with the higher scores indicating functional independence.⁽¹⁵⁾

4. The Patient Health Questionnaire-9 (PHQ-9)–Arabic Version. The original PHQ-9 is the depression module that includes 9 items used to assess depressive symptoms in the last 2 weeks, on a Likert-scale from 0 to 3. It is based on the 9 DSM-IV criteria of depression⁽¹⁶⁾ and is used effectively in medical populations, including people with cognitive impairments and older adults to assess their depressive symptoms.⁽¹⁷⁾ An Arabic version was validated in an

earlier Egyptian study and showed acceptability and good psychometric properties.⁽¹⁸⁾ The total scores range between 0 and 27 where the severity of depressive symptoms increases with higher scores.

Statistical Analysis

The Statistical Package for Social Sciences (SPSS, version 16; SPSS Inc, Chicago, USA) was used. Percentage, range, mean, and standard deviation (SD) were used as descriptive statistics. Tests of significance included Chi-square (X^2), and Fisher's exact tests. The independent sample t-test was used to compare the means of QoL-AD combined scores between two groups of cases. The one-way ANOVA procedure was used to compare several means. Correlations were conducted using Pearson's correlation coefficient (r). Multivariate analysis was carried out using linear regression analysis to determine factors independently associated with QoL-AD. Only variables significantly associated with QoL-AD scores in the univariate analysis were included in the linear regression. The effect of predictor variables was explained in terms of regression coefficient (B). A p-value of 0.05 or less was considered significant.

Ethical Considerations

The study was approved by the Ethics Committee of the High Institute of Public Health (HIPH), Alexandria University on the basis of the Declaration of Helsinki. As Al-Mammora Psychiatric Hospital is affiliated to the General Secretary of Mental Health, approval of its Ethics Committee was obtained before conducting the research. In addition, written informed consents were obtained from the participants and the objectives of the study were explained to them at the beginning of the interview and confidentiality of the information was confirmed.

RESULTS

Table 1 shows the socio-demographic characteristics of the sample. The mean age of patients with dementia was 67.46 ± 6.53 years. Females outnumbered males (55.9%) and 32.4% were married. The majority of the sample (69.6%) were illiterates or could just read and write, while only 5.9% were university graduates. Most of the patients (92.2%) reported an adequate income. Regarding caregivers, their mean age was 44.3 ± 10.5 years, nearly half of them (52.9%) were females and more than two-thirds (69.6%) were living with the patient in the same residence. Caregivers had evidently higher level of education compared to their care recipients, as 75% had completed basic or higher education.

As shown in table 2, the majority of persons with dementia (83.4%) received the diagnosis of AD. Their mean score on the MMSE was 11.87 ± 1.95 . The mean total score on ADL was 4.65 ± 1.95 . Regarding the QoL-AD, total mean scores of persons with dementia, caregivers', and

combined reports were 26.38 ± 3.03 , 25.88 ± 3.30 , and 26.41 ± 2.94 , respectively. Nearly half of the persons with dementia (45.1%) complained of chronic physical morbidity, and about two-thirds of them (67.6%) had behavioural symptoms. The mean total score of the PHQ-9 was 5.07 ± 3.46 .

Table (1): Socio-demographic characteristics of persons with dementia and their caregivers

Characteristics of the sample (n=102)	No. (%)
Persons with dementia characteristics	
Age (range)	51–84 years
Mean \pm SD	67.46 ± 6.53
Gender	
Male	45 (44.1)
Female	57 (55.9)
Marital status	
Single	28 (27.5)
Married	33 (32.4)
Widowed	33 (32.4)
Divorced	8 (7.7)
Current working status	
Working	2 (1.9)
Not working	100 (98.1)
Education	
Illiterate or just read & write	71 (69.6)
Basic education	18 (17.6)
Secondary education	7 (6.9)
University or higher	6 (5.9)
Total monthly income	
Not adequate	8 (7.8)
Adequate	94 (92.2)
Engagement in social activities^a	
	2 (1.9)
Caregivers' characteristics	
Age (range)	16–72 years
Mean \pm SD	44.3 ± 10.5
Gender	
Male	48 (47.1)
Female	54 (52.9)
Education	
Illiterate or just read & write	25 (24.5)
Basic education	43 (42.2)
Secondary education	25 (24.5)
University or higher	9 (8.8)
Caregiver living with care recipient in the same residence	
	71 (69.6)

According to table 3, persons with dementia who reported that their monthly income is adequate had significantly higher scores on the QoL-AD compared to those whose income was inadequate ($p = 0.04$). Significant differences in QoL-AD scores were found for different types of dementia ($F = 6.72$, $p = 0.002$). Persons who received a diagnosis of AD reported significantly higher mean total scores on the QoL-AD compared to persons with vascular dementia (VD) (26.82 ± 2.61 versus 23.37 ± 2.98 , $p < 0.01$). Persons who had chronic diseases had significantly lower scores on the QoL-AD than those with no chronic diseases ($t = 2.68$, $p < 0.001$). Persons with dementia who were not living with their caregivers had significantly higher scores on the QoL-AD than those who lived with their caregivers in the same place ($t = 2.35$, $p = 0.02$).

Table 4 shows weak negative significant relation between QoL and patient's age ($r = -0.270$, $p < 0.001$), caregiver's age ($r = -0.254$, $p = 0.01$), and PHQ-9 total score ($r = -0.506$, $p < 0.001$). On the other hand, QoL-AD combined total scores showed significant moderate positive correlations with the total scores of MMSE ($r = 0.208$, $p = 0.03$), and ADL ($r = 0.551$, $p < 0.001$). Table 5 shows the results of a stepwise linear regression analysis

regarding the predictors of QoL-AD scores. The scores of ADL significantly predicted higher scores on the QoL-AD ($B = 0.644$, $p < 0.001$). On the contrary, depressive symptoms were found to be significant negative predictor of QoL-AD scores ($B = -0.303$, $p < 0.001$). Independence in ADL showed a higher effect on the QoL-AD scores than the depressive symptoms.

(2): Neuropsychiatric characteristics and functioning of persons with dementia

Characteristics	No. (%)	Range	Mean \pm SD
Type of dementia			
AD	85 (83.4)		
Vascular dementia	9 (8.8)		
Mixed	8 (7.8)		
Duration of Treatment received			
Pharmacological	74 (72.5)	4–48 months	15.04 \pm 10.87
Psychosocial	17 (16.7)		
Both	11 (10.8)		
MMSE			
		10–18	11.87 \pm 1.95
ADL Total Score			
		0–6	4.65 \pm 1.95
QoL-AD patient report			
		17–35	26.38 \pm 3.03
QoL-AD caregiver report			
		18–38	25.88 \pm 3.30
QoL-AD combined report			
		18–34.5	26.41 \pm 2.94
Presence of chronic diseases			
	46 (45.1)		
Presence of behavioural symptoms			
	69 (67.6)		
PHQ-9 total score			
		0–22	5.07 \pm 3.46

Table (3): Mean QoL-AD combined scores according to persons with dementia and caregiver-related variables

Variables	Mean QoL-AD scores (SD)	Test of significance (p)
Gender		
Male	26.02 (2.84)	$t = -1.18$ (0.23)
Female	26.71 (3.01)	
Total monthly income		
Not adequate	24.41 (2.56)	$t = -2.02$ (0.04)*
Adequate	26.58 (2.92)	
Type of dementia		
AD	26.82 (2.61) ^a	$F = 6.72$ (0.002) **
VD	23.37 (2.98) ^a	
Mixed	25.45 (4.26)	
Treatment received		
Pharmacological	26.44 (3.17)	$F = 1.26$ (0.28)
Psychosocial	25.62 (2.35)	
Both	27.42 (1.75)	
Having chronic diseases		
No	27.10 (2.39)	$t = 2.68$ (0.000) ***
Yes	25.57 (3.34)	
Presence of behavioural symptoms		
No	27.13 (3.13)	$t = 1.72$ (0.08)
Yes	26.06 (2.81)	
Caregiver living with the person in the same residence		
No	27.43 (3.28)	$t = 2.35$ (0.02)*
Yes	25.96 (2.69)	

^a Post hoc test: significant difference between AD and VD at $p < 0.01$, * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Table (4): Correlations of QoL-AD combined report scores with person's and caregiver's age, duration of illness, MMSE, ADL, and PHQ-9 scores

Variables	Pearson correlation r (p)
Person's age	-0.270 (0.000) **
Caregiver's age	-0.254 (0.01)*
Duration of illness	0.023 (0.81)
MMSE	0.208 (0.03)*
ADL	0.551 (0.000) **
PHQ-9	-0.506 (0.000) **

*p < 0.05, **p < 0.001

Table (5): Results of the stepwise linear regression analysis of the predictors of QoL-AD scores

Independent variables (Predictors)	B Coefficient	Standard Error	Beta Coefficient	P-value
Independence in ADL ^a	0.644	0.070	0.427	000*
Level of depressive symptoms ^b	-0.303	0.124	-0.356	000*

R² = 0.415, F = 35.158, p < 0.001, ^a based on Katz Index for ADL, ^b based on PHQ-9, *p < 0.001

DISCUSSION

Dementia is currently recognized as a major public health challenge in both developed and developing countries attributed to the increased ageing of populations. Enhancing QoL among them is the best priority care that could be provided, since no specific cure has been proved effective in treating dementia. Findings from the systematic review conducted by Banerjee et al., supported the absence of clear or consistent associations between health-related QoL and socio-demographic variables in dementia.⁽¹⁹⁾ When a disease-specific QoL measure, such as the QoL-AD was used, age, gender, socio-economic status, and years of education showed no association with QoL-AD ratings.^(20,21) The demographic variables in the current work were not associated with the QoL except for the person's age, which negatively correlated with the QoL and the economic status of the patient, that was positively associated with it. The relationship with age may be explained on the basis of being mediated by the cognitive functions of the patient (i.e., cognitive functions worsen with advancing in age). In the current work, this explanation is supported by the presence of a significant positive correlation between the QoL and MMSE scores. Controlling for the mediator will help to examine this relationship accurately. On the other hand, adequate monthly income can play a vital role in a developing country like Egypt, where healthcare services are overburdened and may not be able to meet

all patients' needs. The role of patients' resources, including the financial aspect, in enhancing the QoL was indicated by Keating and Gaudet.⁽²²⁾ The significant negative association between QoL-AD scores and the MMSE in the current work is partially consistent with the findings of other studies. Some studies consistently showed no association between cognitive functions (as measured by the MMSE) with the QoL in dementia,^(23,24) while many other studies indicated such negative association.^(19,21,25) In the current study, the QoL increased when the persons with dementia were not living with their caregivers in the same residence. An explanation may include that the effect of living arrangements of caregivers is mediated through the level of patient independence. Patients with satisfactory level of independence in daily activities were those who were more likely to live in a separate residence. In support of this explanation, the regression analysis revealed that after controlling for other confounders, level of independence in ADL emerged as a significant predictor of QoL. One of the important findings of this study is that the QoL among persons with dementia who received a diagnosis of AD was significantly higher compared to those with VD. Several explanations should be viewed in the light of the sample characteristics; in which the majority of cases were AD cases and all of them were not in severe stages. Explanations may include moderators, such as depression, functional impairment, and caregiver burden. Findings of the current study are

consistent with those indicated in several studies that reported a strong correlation between depression and the QoL in dementia.^(19,21,25) Depression may act as a moderator, as it is often noted that mood changes occur earlier and are more severe in VD than AD.⁽²⁶⁾ Likewise, as many studies correlated functional impairment in daily living with the QoL,^(21,27) it is possible that functional impairment may be more predictive of the QoL in VD than AD because neurologic functions are more impaired, and because of the greater medical comorbidity in VD.⁽²⁶⁾ This explanation is further supported in this current study by the findings that ADL and having chronic physical morbidity were significantly associated with the QoL. In support to our findings, Gitlin et al., found significant negative association between the number of health conditions in persons with dementia and their perceived QoL.⁽²⁸⁾ Caregiver burden and stress may be associated with the QoL in VD. In addition, AD and VD have different effects on caregiver burden, depending on the stage of dementia severity. Persons with VD are more burdensome to caregivers than AD in the early and middle stages of dementia, and the reverse is reported for severely impaired patients where AD was more burdensome than VD.⁽²⁶⁾ Greater caregiver burden and distress in the early to middle stages of VD may contribute to lower perceptions of care recipients' QoL during these times, relative to patients with AD. Kawasky et al., indicated that caregivers' mental health had its effect on rating the QoL among people with dementia.⁽²⁹⁾ This explanation needs further research based on the assessment of caregiver burden and on the stage of severity of dementia.

Consistent with many other studies, the present work revealed that the level of dependence in activities of daily living and depression were significantly associated with the QoL in patients with dementia. What was added in this research is that among all the factors that showed a significant association with the QoL, results of the multiple linear regression analysis pointed only to activities of daily living and depression as predictors of the QoL. In their research, Andersen et al., found that dependency in ADL was the main factor affecting health-related QoL in patients with dementia.⁽⁷⁾ Other studies conducted based on the QoL-AD revealed similar results.^(21,30) In a recent Egyptian study (2016), depressed mood and dependence in instrumental activities of daily living were significantly associated with low health-related QoL.⁽¹⁰⁾ In addition, the findings of many studies pointed to depression as the most common predictor of low QoL for patients with dementia.^(21,25,30)

Strengths and limitations of the study

The strength of this work comes from the methodology applied, in which the combined report of

the QoL-AD was used to overcome one of the points of debate that have been associated with QoL assessment in people with dementia. Some authors considered subjective QoL to be sufficient to evaluate QoL in all aspects, while others viewed it as a component of QoL that should be further evaluated by proxy due to cognitive impairment that can affect one's ability to assess QoL.^(31,32) On the other hand, other researchers indicated that impairment in cognitive function does not affect QoL self-assessment.^(20,33) Currently, the majority of opinions suggest that QoL assessment in dementia should include a subjective assessment in addition to proxy evaluations,⁽³⁴⁾ which was achieved in this work, using the combined report score.

Some limitations of the present study should be addressed. Only persons with a MMSE score equal to or more than 10 were included, which means that the findings do not apply to persons with severe dementia. Moreover, this study focused mainly on factors related to persons with dementia, while caregiver-related factors such as caregivers' perceived burden, emotional status and their relationship with their care recipients were not addressed. Finally, the cross-sectional design did not allow assessment of temporal relations, which are better investigated through longitudinal studies.

CONCLUSION & RECOMMENDATIONS

Several factors showed significant association with QoL; however, only activities of daily living and severity of depression could predict the QoL among persons with moderate dementia. Several implications are related to these findings. Early identification and treatment of depression and co-morbid physical conditions should be highly prioritised in care plans designed for persons with dementia. In addition, conducting educational programmes for people with dementia and their caregivers to help them increase functional independence of patients is highly needed. Provision of social supportive services to patients with dementia and their families to ensure fulfilling their basic financial needs is among the recommended actions. Further longitudinal studies, including patients with severe dementia, and addressing other caregiver-related factors as well as the patient-caregiver relationship are highly needed to narrow the gap in our knowledge regarding factors that could affect the QoL in people with dementia.

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