

Evaluating well-being: Quality of life in elderly dementia patients in Mayo hospital Lahore

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Abstract

Objective: To determine the quality of life and its association with sociodemographic variables in elderly people suffering from dementia.

Method: The cross-sectional study was conducted at the Neurology Department of Mayo Hospital, Lahore, Pakistan, from July 15 to November 20, 2024, and comprised diagnosed dementia patients of either gender aged at least 65 years. The patients were categorised into early, middle and late stages based on their symptomatology as per the World Health Organisation guidelines. The quality of life was determined by using the short version of World Health Organisation Quality of Life questionnaire. The association between stages of dementia and quality of life scores was explored. Data was analysed using SPSS 24.

Results: Of the 120 patients with mean age 70.74 ± 5.7 years, 66(55%) were males, 50(41.7%) were illiterate, 68(56.7%) had early-stage dementia, 28(23.3%) had middle-stage dementia and 24(20%) had late-stage dementia. Stages of dementia had a significant association with quality of life ($p=0.001$) and health satisfaction ($p=0.001$).

Conclusion: Dementia significantly impacted quality of life across all stages.

Keywords: Quality of life, Dementia, Stages of dementia, elderly population, WHOQOL-BREF. (JPMA 76: 716; 2026)

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Introduction

Dementia is a syndrome leading to impairment in cognitive function affecting remembering things, thinking, making decisions, behaviour, calculation, learning and judgment. This interferes with the performance of activities of daily living (ADLs).¹ The most common form of dementia is Alzheimer's disease that affects 60-70% of all cases.² Pakistan has an estimated 150,000-200,000 patients with dementia, and it is expected that the prevalence of dementia will rise from 2% to 6% over the next 30 years among people aged >65 years due to increase in average life expectancy.³ Worldwide, around 50 million people have dementia, with over 60% living in low- and middle-income countries (LMICs).⁴ Dementia mostly affects older people, but it is not a normal part of aging.⁵ The most common risk factors for developing dementia are physical inactivity, obesity, smoking, alcohol consumption, high cholesterol, family history of dementia, diabetes mellitus (DM), mid-life hypertension (HTN), social isolation and cognitive inactivity.⁶ People with dementia may experience different problems, like forgetfulness, time disorientation, difficulty in communication, reasoning, independently performing

tasks and self-care.⁷ Among older people, dementia is the major culprit of disability and dependency, and the seventh leading cause of death. A multi-centre, cross-sectional study conducted during 2016-2018 in Pakistan to document current prevalence proportions of all patients presenting to neurological and psychiatric departments showed that the prevalence of dementia was 2.5% among all age groups.⁸ A 2018 study in Norway found that the mean Quality of life in elderly patients with dementia (QUALID) sum score ($n=298$) with mean age 85.5 ± 6.8 years at baseline and after a follow-up of one year was 22.7 ± 7.2 and 21.5 ± 7.2 , respectively.⁹

To our knowledge, Pakistan is lacking evidence regarding the quality of life (QOL) of dementia patients. The current study was planned to determine the QOL of elderly patients suffering from dementia.

Subjects and Methods

The cross-sectional study was conducted at the Neurology Department of Mayo Hospital, Lahore, Pakistan, from July 15 to November 20, 2024. After approval from the institutional ethics review board of King Edward Medical University (KEMU), Lahore, the sample size was calculated using absolute precision (d) 0.13, population standard deviation (σ) 7.2 and anticipated population mean (μ_{-a}) 22.7.9, The sample was raised using non-probability consecutive sampling technique. Those included were diagnosed dementia patients of either gender aged at least 65 years. The subjects were enrolled based on clinical

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history and examination by a physician after taking informed consent from each of them. Patients were excluded if they were blind, deaf, dumb, mentally retarded and having a current or past history of drug abuse except nicotine. Also excluded were patients of cerebral vascular accident having weakness or paralysis in any part of the body, and those with diagnosed psychiatric illnesses, like depression, anxiety, mania, obsessive-compulsive disorder (OCD), bipolar disorder and schizophrenia.

The enrolled patients were categorized into early, middle and late stages of dementia based on their signs and symptoms in line with the World Health Organisation (WHO) guidelines,¹⁰ according to which, early-stage dementia is characterised by forgetfulness, confusion about time, and losing track of familiar places; middle-stage dementia is marked by increasing difficulty with communication, help for personal care, wandering and repeated questioning; and late-stage dementia is marked by difficulty recognising friends and relatives, aggression and poor orientation of time and place.

The QOL was assessed using the brief 26-item version of WHOQOL questionnaire (WHOQOL-BREF), which is a self-administered questionnaire, having 2 general items related to QOL rating and health satisfaction. The questionnaire has 4 domains of QOL; physical, psychological, social relationships, and environment. Each item is rated on a Likert scale ranging 1--5, with 1 indicating worst QOL and 5 indicating best QOL. Three of the remaining 24 items are negatively framed (Nos. 3, 4 and 26), and their scores are reversed for data analyses. Each domain score is transformed into a 0-100 scale, linearly, for easier comparability with literature. The minimum score 0 indicates the poorest QOL and the maximum score of 100 indicates the best QOL. The responses in early-stage cases were collected from patient themselves, while in late-stage cases, caregiver-proxy ratings were used.¹¹

Data was analysed using SPSS 24. Mean±standard deviation was calculated for continuous variables. Normality of continuous variables was checked with Shapiro-Wilk test, and, as the data was not normally distributed, median with interquartile range (IQR) values were calculated. Frequency and percentages were calculated for qualitative variables. Effect modifiers, like age, gender, residence, education, severity and income, were controlled through stratification. Chi-square test was used to find the association between stages of dementia and two general items; "How would you rate your QOL", and "How satisfied are you with your health". As the data was skewed and had more than two groups, Kruskal-Wallis-H test was used to correlate stages of dementia with QOL domain scores. Post stratification, chi-square and Kruskal-

Wallis-H test were applied, taking $p < 0.05$ as significant. Post-hoc analysis was conducted for pairwise comparisons related to the stages of dementia using Mann Witney U test with Bonferroni correction to reduce the risk of type 1 error, taking $p < 0.016$ as significant.

Results

Of the 120 patients with mean age 70.74 ± 5.7 years, 66(55%) were males, 50(41.7%) were illiterate, 68(56.7%) had early-stage dementia, 28(23.3%) had middle-stage dementia and 24(20%) had late-stage dementia (Table).

Stages of dementia had a significant association with QOL ($p=0.001$) (Figure 1) and health satisfaction ($p=0.001$) (Figure 2).

Table: Sociodemographic characteristics of the patients.

	n (%)
Age (years)	
65-70	76 (63.3)
71-80	32 (26.7)
81-85	5 (4.2)
86-90	3 (2.5)
91-95	3 (2.5)
96-100	1 (0.8)
Gender	
Male	66 (55)
Female	54 (45)
Educational level	
Illiterate	50 (41.7)
Primary	32 (26.7)
Middle	23 (19.2)
Matric & above	15 (12.5)
Monthly income (PKR)	
<25000	31 (25.8)
25000-75000	62 (51.7)
>75000	27 (22.5)
Residence	
Rural	43 (35.8)
Urban	77 (64.2)
Stage of dementia	
Early stage of dementia	68 (56.7)
Middle stage of dementia	28 (23.3)
Late stage of dementia	24 (20.0)

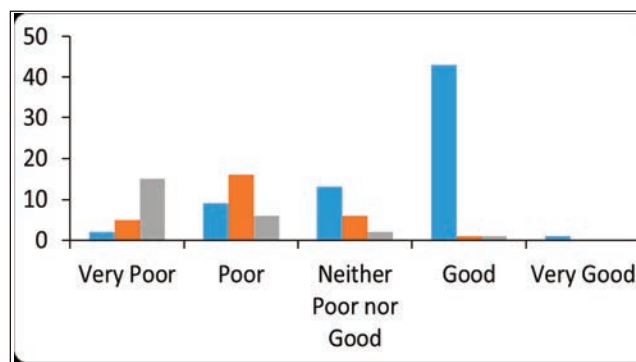


Figure-1: Comparison of quality of life (QOL) with regard to the stage of dementia.

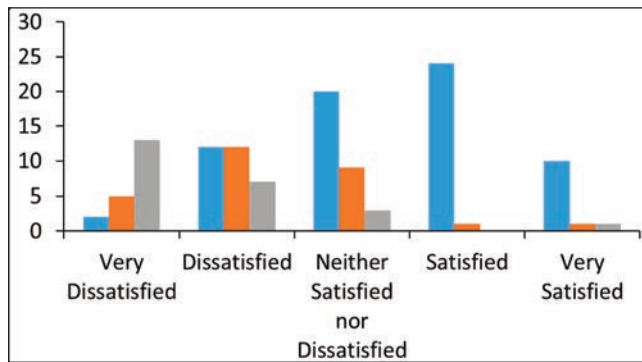


Figure-2: Comparison of health satisfaction with regard to the stage of dementia. Post-stratification analysis showed that all QOL domains had significant association with gender, residence and monthly income across all the three stages of dementia ($p < 0.05$). For age, all QOL domains were significantly associated only with age 65-70 years and 71-75 years ($p < 0.05$). For educational level, all QOL domains were significantly associated with all stages of dementia ($p < 0.05$) except social and environmental QOL domain in those with matric ($p = 0.14$) and above-matric ($p = 0.18$) educational levels.

Pairwise comparisons for all QOL domains across all dementia stages showed significant results ($p < 0.016$) except for social and environmental QOL across middle-stage ($p = 0.47$) and late-stage ($p = 0.02$) of dementia.

QOL score declined sharply in later stages of dementia; most pronounced in those aged 65-75 years, but the association was weaker among those aged ≥ 75 years. Very poor QOL score was observed in late-stage dementia in females 7/9 (77.8%), rural residents 5/7 (71.4%), low-income individuals 4/6 (66.7%) and illiterate individuals 7/11 (63.6%). Comparatively better QOL scores were observed in late-stage dementia in males 8/13 (61.5%), urban residents 10/15 (66.7%), higher-income individuals 1/3 (33.3%), and matric & above educated individuals 1/2 (50%). Health satisfaction also declined sharply in late-stage dementia; most pronounced in those aged 65-75 years. Very dissatisfied status was observed in late-stage dementia in females 5/8 (62.5%), rural residents 5/5 (100%), low-income individuals 3/6 (50%) and individuals who were illiterate 5/9 (55.6%). Comparatively better health satisfaction was observed in late-stage dementia in males 8/12 (66.7%), urban residents 8/15 (53.3%), higher-income individuals 1/4 (25%), and higher-educated individuals 1/3 (33.3%).

Discussion

The current study revealed a progressive decline in QOL with dementia advancement, and there were marked reductions across all domains. Significant variations were

also observed in health satisfaction and overall QOL ratings, with satisfaction levels being notably higher in the early stages, and declining sharply in the middle and late stages. Moreover, sociodemographic factors, such as age, gender, educational level, residence and income, influenced QOL outcomes, underscoring the complex interplay of personal and disease-specific factors on health-related QOL among dementia patients.

QOL scores significantly varied across stages of dementia ($p = 0.001$). Most early-stage dementia patients rated their QOL as good (63.2%), while most late-stage dementia patients rated their QOL as very poor (62.5%). Similar findings were also reported in an earlier study.¹²

Satisfaction with health also varied significantly across dementia stages ($p < 0.001$). In the early stage, most participants were satisfied (35.3%). Conversely, in the late stage, dissatisfaction was most prevalent 54.2%. These results suggest a marked decrease in satisfaction with health as dementia progressed. A study in Taiwan reported the increasing trend of emergency department visits and hospitalisations as dementia progressed from early to late stage, which could be attributed to declining cognitive function, decreased health satisfaction, and increasing physiological symptoms.¹³

Significant declines ($p < 0.001$) in all domains of QOL were observed across all dementia stages, with highest scores being reported in early stages, and significant difference between each stage. It was evident from a study, which was in accordance with the current study, that better QOL was linked to independence in ADLs mediated by physical fitness.¹⁴ A study reported that mildly-impaired elderly people with dementia outperformed the moderately-impaired people with dementia in terms of language skills, and experienced less social loneliness. In addition, as dementia progresses to later stages, there was more enhanced decline in social and emotional loneliness.¹⁵ These findings were consistent with the current findings that environmental QOL decreased with advancing dementia. Similar to the current study, a study found that a friendlier and more caring environment had a more positive impact on QOL of elderly dementia patients. The patients residing in a small homelike setting reported a better QOL compared to those residing in large-scale institutions owing to the fact that they had higher levels of homelike environment, better social interactions with friends and family members, spent time in social gatherings, did not have to follow structured activity programmes, had lesser frequency of agitated behaviour, and received more personal attention and empathy from the staff.¹⁶ Kim B et al. categorised behavioural and psychological symptoms (BPSD) of elderly dementia

patients into three symptom clusters (hyperactivity, psychosis, and physical behaviour) and found that as the dementia stage advanced, these symptoms became more pronounced, leading to increased caregiving burden and stress.¹⁷

In the current study, relatively younger patients of early-stage dementia had higher satisfaction, with a consistent decline in middle-stage and late-stage dementia. Significant differences in all QOL domains were noted only in younger age groups. Unlike the current study, Bally EL et al. found that longer institutional stay rather than advancing age was responsible for lower QOL as the patients felt helpless and suffered loneliness.¹⁸

Males rated QOL and health satisfaction higher compared to females, and male scores were higher in all QOL domains. This consistency of objective and subjective reporting can be explained by cultural norms peculiar to Pakistan where women show greater emotional resilience, yet they report comparatively lower QOL owing to more domestic responsibilities.¹⁹ Consistent to the finding, a study reported lower QOL in females of LMICs where women have less access to healthcare, low income, and limited social cohesion and independence.²⁰

Significant impact of income on health satisfaction and QOL scores was observed in the current study, indicating the moderating effect of income between dementia and QOL, which may be due to better access to resources and support system. Mar J et al. also found that older women with dementia having low socioeconomic status had lower QOL.²¹

Poor QOL was reported by rural residents, particularly in late-stage dementia in the current study, which was contrary to the findings of Besser LM et al. who found better QOL in rural caregivers due to their better social networks, but in Pakistan, lower healthcare access, limited resources and financial constraints contribute to lower QOL among rural patients.^{22,23}

Lower education status was found to be associated with lower QOL in the current study, especially illiterate patients reported lowest QOL in late-stage dementia. As noted in literature, literate patients have better resilience, good understanding of disease, better ability to cope with emotional and practical challenges, and thus have higher QOL.²⁴

The current study has limitations as the cross-sectional design limited the ability to assess the temporal changes and causality in the association between stages of dementia and QOL. Also, the use of consecutive non-probability sampling technique may have limited the

generalisability of the findings as the sample may not fully represent patients from diverse backgrounds. Exclusion of patients unable to communicate might have resulted in under-representation of late or more severe dementia stages. Self-reported data by patients or caregiver-proxies may have allowed recall bias and response bias to creep in, especially in the case of caregivers having limited knowledge of the disease or the patients. Also, there may be inconsistencies in responses due to the subjective nature of QOL assessment. Further, the sample size of 120 patients might have limited the generalisability of the findings. Finally, other sociodemographic features that have the potential to influence the outcomes were not accounted for in the study, such as caregiver burden and comorbidities.

Despite the limitations, however, the current study found that younger age, male gender, higher education, higher income level, and urban residence were the positive influencing factors contributing to better QOL, highlighting the need for targeted interventions by having a good knowledge of these factors. Also, more attention is needed to be paid to middle-stage and late-stage dementia patients, particularly in social and environmental QOL domains, to better address their unmet needs.

Policymakers and health professionals have to prioritise strategies for early diagnosis and interventions to slow dementia's progression, which can help reduce the caregiver burden and lessen the cost of healthcare. Community-based rehabilitation programmes, easy access to healthcare facilities, and good social support are bound to be helpful.

The current findings have the potential to act a guide for future research to find comprehensive care models and preventive measures to target modifiable risk factors, like social deprivation, low educational level and low economic status, which will ultimately uplift the living standards of dementia patients and enable them to live a happy and productive life.

Conclusion

The QOL of early-stage dementia patients was comparatively better than those with middle-stage and late-stage dementia. Significant associations found between dementia stages and QOL scores as well as health satisfaction level were also noted.

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Author Contribution:

SA, MA, NB, MS, IH, AR, AWK & HM: Concept, design, data acquisition, analysis, interpretation, drafting, revision, final approval and agreement to be accountable for all aspects of the work.