



ASSESSMENT OF THE QUALITY OF LIFE CHANGES IN PATIENTS WITH ALZHEIMER'S DISEASE, AND THEIR CARE-GIVERS: AN OBSERVATIONAL CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Alzheimer's disease (AD) is a progressive neurologic disorder that causes the brain to shrink (atrophy) and brain cells to die, resulting in dementia- that is a continuous decline in thinking, behavioral and social skills that affect a person's ability to function independently. Caring for someone with AD is especially challenging as they lose the ability to communicate and comprehend. Quality of life (QoL) is the degree to which an individual is healthy, comfortable, and able to participate or enjoy life events. From an Occupational therapist's perspective, it is important to understand their perceived QoL to be able to provide a holistic, client-centered intervention.

OBJECTIVES: The objective of this study was to demonstrate that mild and moderate AD has a significant effect on the QoL of both, the patients, and their caregivers.

Study Design: An observational cross-sectional study was conducted.

METHODOLOGY: An assessment study was conducted in a private clinic at Mumbai, India, on 10 patients diagnosed with Mild AD (Group I) and 10 patients with Moderate AD (Group II) and on their care-givers. QoL was assessed by the QoL-AD scale on the patients, and by the Care-Giver Burden Questionnaire on their care-givers. The scores obtained from both the scales were compared between both the groups of patients and their care-givers.

Results: It was seen that the both the groups reported affectation in their QoL, but the QoL of the patients with Moderate AD was significantly higher than the QoL of patients with Mild AD ($P < 0.0001$). It was also seen that affectation in the QoL of the care-givers positively correlated (Pearson's correlation coefficient 0.824) with that of the patients.

Conclusion: The study showed that AD significantly affects the quality of life of individuals even in its mild and moderate forms. The patients with moderate AD had more affectation in their QoL as compared with those with mild AD. Also, it was found that the QoL of care-givers of the patients with moderate AD was more affected than the QoL of patients with mild AD, and the QoL of the care-givers and the patients were correlated.

KEYWORDS : Alzheimer's Dementia, Quality of Life, Care-giver

INTRODUCTION

Alzheimer's disease (AD), the most common cause of dementia, is a progressive, irreversible neurologic disorder that develops over a period of years.¹ AD is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills, and, eventually, the ability to carry out the simplest tasks. In most people with AD, symptoms first appear in their mid-60s. In the early stage of AD, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Symptoms may not be widely apparent at this stage, but family and close friends may take notice and a doctor would be able to identify symptoms using certain diagnostic tools.

Common difficulties include:

- Coming up with the right word or name.
- Remembering names when introduced to new people.
- Having difficulty performing tasks in social or work settings.
- Forgetting material that was just read.
- Losing or misplacing a valuable object.
- Experiencing increased trouble with planning or organizing.

According to the World Health Organization (WHO), quality of life (QoL) is defined as "the 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."²

Domains of Quality of Life (QoL) affected in patients with AD include competent cognitive functioning, the ability to perform activities of daily living and to engage in meaningful time use and social behavior, and a favourable balance between positive emotion and absence of negative emotion. AD can strip the person of normal indicators of personhood. The burden for informal caregivers and change in their quality of life can lead to patients being placed in nursing homes, day care centres or long term care homes. Factors found to worsen caregivers' quality of life include strained finances, poor family functioning, difficult patient behaviour, financial burdens and the amount of time caregivers spend caring for family members with AD.

Caring for someone with AD is especially challenging due to the fact that patients soon lose the ability to speak or otherwise communicate and seem unable to understand what is said to them.

As the disease progresses, with increasing cognitive impairment, the QoL is also seen to get affected proportionally.¹⁰

Therefore, this study explores the affectations in the QoL of patients with mild and moderate AD and their care-givers. It also attempts to correlate the QoL affectations of the patients and their care-givers.³

METHOD

Objective: The objective of this study was to demonstrate that mild and moderate AD has a significant effect on the QoL of both, the patients, and their caregivers.

Study Design: An observational cross-sectional study was conducted.

Study setting: The study was conducted at a private clinic in Navi Mumbai. The research was approved by the institutional ethics committee.

Participants: The patients and their care-givers were selected from a cohort of patients applying for treatment on an Out-patient basis at the D Y Patil Mental Health Clinic. A total of 20 patients were selected of which 10 belonged to the mild variety of AD and 10 belonged to the moderate variety, by non-probability based convenient sampling. They were joined by their primary caregivers (n = 20), which were their spouses. Criteria for inclusion in the study were a diagnosis of dementia of the Alzheimer's type performed by a general practitioner or neurologist/psychiatrist. Only patients living in one household with their primary care givers were included in the study.

All interviews took place in the domestic surroundings of the families after explaining the aim of the study and obtaining informed consent by both the patient and the care-giver. Assessments were carried out by specially trained research assistants. Patients and care-givers were interviewed separately to minimize bias and mutual influence on the responses.

PROCEDURE:

The QoL of the AD patients was assessed using the QOL-AD scale, while the QoL of the care givers was assessed using the Care Giver Burden scale. The participants were explained about the study and both verbal and written consent was taken. They were given an orientation about the scales that were administered.

DATA ANALYSIS:

The data were analysed using windows-based SPSS, Version 16.0, released 2007, Chicago, SPSS Inc. Unpaired *t*-test was used as statistical tests of significance. *P* value was set at 0.05 level of significance, and 95% confidence interval (CI) value were computed. Bivariate analysis for association was done using Pearson's correlation test.

RESULTS:

Data was generated by calculating the scores of the QOL-AD scale and the Care-giver Burden scale. Descriptive statistics including mean, standard error of mean, “t” and “P” value were computed on the basis of their answers on the scales. The QOL-AD scores were compared among the mild and moderate AD patient groups. The Care-Giver Burden scores were compared among the care-givers of the mild and moderate AD patients. All the groups showed affection in their QoL. The areas mostly affected on the QOL-AD scale were – Physical health, energy, memory, friends, ability to do chores and ability to do things for fun. Out of these, memory, and ability to do chores were significantly affected.

The areas that were troublesome or difficult for the caregivers, were caring for their relative and meeting other responsibilities for family or work and also fearing for what the future holds for their relative. Significant difficulty was met while maintaining a healthy relationship with other members of the family.

The demographics of the study participants was as follows:

	Patients		Care-givers	
	Mild AD	Moderate AD	Mild AD	Moderate AD
n	10	10	10	10
Age (median)	70	74	55	65
Age (range)	52 – 80	54 – 80	40 – 70	45 – 80
Male %	69.3	71.2	29.9	20.2
Female %	30.7	28.8	70.1	79.8

- Table 1 shows the comparison between the QoL of the patients with mild and moderate AD and their care-givers.
- Table 2 shows the correlation between the quality of life scores of the patients and care-givers.

DISCUSSION:

With progressing severity of AD, cognitive abilities of the patient, Physical health, leisure activities and activities of daily living are affected. This implies that the patient's autonomy is reduced. Neither is the patient able to uphold leisure activities on his or her own nor is the patient able to sustain functions to preserve living such as household chores or food preparation without help.⁴

In this study, it was found that the patients with mild and moderate AD reported affectations in their QoL. It was seen that patients with moderate AD showed significantly more affection in their QoL than those with mild AD. Which means that the QoL of the care-givers if more affected as the severity of AD increases. Rebecca E. Ready et al⁵ also revealed in their study that there was a correlation between the QoL of the patients with AD and their care-givers. Similar findings were reported by Pascalle R. Bosboom et al in their study.⁶

These findings correlated with QoL scores of the care-givers, i.e., the care-givers of patients with moderate AD reported significantly more affection in their QoL than those of mild AD. It was also seen that the QoL of the patients and their respective care-givers were significantly correlated. Marcela Moreira, in her study on the QoL of care-givers of patients with AD found that the spouse-caregivers' QoL is influenced by awareness of disease and PWD QoL.⁷

The findings from this study could be utilized for Occupational Therapy planning and interventions and focus on the development of adequate psycho-educational approaches to increase the patient's and caregivers' QoL, considering the specificities of their relationship.

The limitations of the study were that the study sample size was small

and so the results of the study cannot be effectively generalized. The study could have been conducted at the patients' home, to provide a familiar environment which would probably give different scores. Further recommendation is to conduct a longitudinal study that would include interventions to help improve the QoL. Future studies in the form of randomized controlled trials are also needed to validate the findings of the present study.

CONCLUSION:

The study showed that AD significantly affects the quality of life of individuals even in its mild and moderate forms. The patients with moderate AD had more affection in their QoL as compared with those with mild AD. Also, it was found that the QoL of care-givers of the patients with moderate AD was more affected than the QoL of patients with mild AD, and the QoL of the care-givers and the patients were correlated.

TABLES AND GRAPHS

Table 1: T – Test For Variables Of Caregiver Burden Scale And Qol-AD Scale

Measures	Mean ± SD		Mean Difference	95% CI of Mean Difference	P
	Mild AD	Moderate AD			
QOL – AD	38.6±2.58	31.1±4.05	7.5	1.42-4.73	<0.0001*
Care-Giver Burden Scale	32.7±1.05	42.5±1.26	9.8	0.70-1.90	<0.0001*

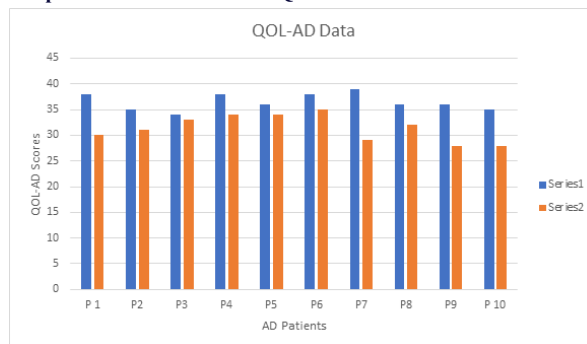
* Highly significant. QOL – AD: Quality of Life for Alzheimer's Disease Scale

Table 2: Correlation Between Variables of QOL-AD Score and Caregiver Score

		N	PEARSON Correlation
Pair 1	PATIENT'S SCORE & CAREGIVER'S SCORE	20 + 20	.824

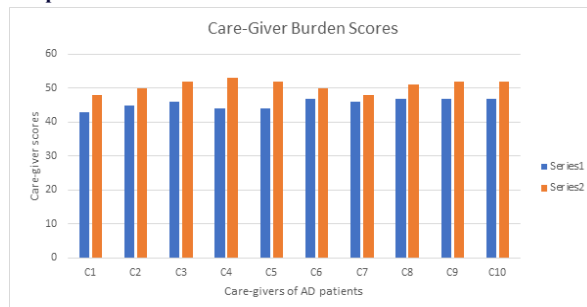
PEARSON CORRELATION of 0.824 indicates a fairly strong positive relationship between the patient score and the caregiver score.

Graph 1: Patient scores on the QOL-AD scale



Series 1 = Mild AD patients
Series 2 = Moderate AD patients

Graph 2: Care-Giver scores on the Care-Giver Burden scale



Series 1 = care givers of patients with Mild AD
Series 2 = care givers of patients with Moderate AD

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