ORIGINAL ARTICLE

Factors and Concequences of Dementia Among Adults of Old Age in Karachi

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ABSTRACT

Dementia is one to the leading cause of mental impairment with 57.4 million individuals globally in 2019. This number is expected to increase up to 83.2 million by 2030 and 116 million by 2050[1]. In Pakistan however, an estimated 150,000–200,000 patients are living with dementia[2]. This study aims to find out the severity of dementia in patients and how this severity affects the quality of life of caretakers of dementia patients. Along with this study also aims to find out the factors involved in causing dementia.

Methodology: To find the association between dementia and quality of life, a cross sectionals. Study was conducted by through a questionnaire having CDR® scale (to find severity of dementia), Zarit Burden Interview (to assess burden on caregivers) and factors leading to dementia by targeting caregivers of dementia patients in different parts of Karachi. According to the sample size 383 responses were collected. Data was than analyzed by using SPSS version 27 using crosstabs, regression.

Results: Study revealed that dementia is associated with impaired life style of a care giver. ANOVA and regression was applied. Results of Regression analysis which showed that dementia does cause impaired lifestyle of caregiver as p value was 0.01(< 0.05). Different factors were assessed to find out if they lead to dementia or not. Among all only family history.

Conclusion: This study showed that quality of life of caregiver was affected by taking care of dementia patients and takes a huge toll on them, financially and mentally both. Both genders from different socioeconomic backgrounds were included in the study. Most of the participants were mild to moderately affected. Results implicate that most common factors, according to the caregiver that lead to dementia were family history and unhealthy eating habits. There were other rare factors that also came up during the data collection such as head injury.

Keywords: Dementia, Aging, QOL, Quality of life.

INTRODUCTION

Dementia is a syndrome in which there is a cognitive function beyond what might be expected from the usual consequences of biological agents[3][4]. It is an umbrella term, with Alzheimer's being its most prevalent type (60-70%)[5][6]. Dementia with Lewy bodies affects (1-2%) of the population aged over 65 years[7][8]. Memory loss, difficulty concentrating, hard to carry out everyday tasks, sleeping disorders, confusion, loss of correct words, and mood changes are some common symptoms observed in patients with dementia and can be used to differentiate them from the average old age population[9][8][10][11]. Alzheimer's is the most common type of dementia, involving plaques and tangles forming in the brain[9][12]. Symptoms that start gradually are most likely to include a decline in cognitive function and language ability[13][14][15]. For people aged between 65 and 69, around 2 in every 100 people have dementia. A person's risk increases as they age, roughly doubling every 5 years [16][17]. Dementia not only has an impact on the patient, but it also negatively affects the everyday life of his/her family, friends and especially caregivers[18][19].

More than 55 million people have dementia[3][4]. 7% of the Asian population is affected by it, with the fastest growth in the elderly population taking place in China, Pakistan and their South Asian and Western Pacific neighbors[9][20][21]. Dementia is a highly prevalent disease in the elderly in Pakistan with 6% of people over the age of 65 suffering from it[21].

A shortfall of research in Pakistan has made it compulsory to dig into beliefs, understanding, and attitudes towards dementia to promote practical and constructive policies and programs that may raise awareness about the welfare of patients and their caregivers.

Some studies focus on difficulties in everyday life. These include relatives or caregivers' ratings of day-to-day functioning[22]. The experiences of people with dementia are less often investigated because they are seen as a less reliable source due to insight problems[22][23]. One study that focuses on the strategies for managing their difficulties showed that they use their senses (sight, hearing, and touch) to compensate for declining cognition; they adapt their time and try to rely on old patterns and routines of everyday life[23][22]. It has been suggested that they use these strategies to gain a sense of control over their lives rather than be as effective as before. People with Alzheimer's disease have been found to be aware of their disease but unable to manage the practical and cognitive implications of their impairments in everyday life[22][23].

Therefore, we conducted this research to assess how much difficulty dementia patients face in performing everyday tasks, how it affects the lives of patients and caregivers, and if there are any factors leading to dementia because of which dementia is increasing worldwide.

MATERIAL AND METHODS

This was a cross-sectional study conducted by providing questionnaires in Karachi. Research was conducted in six months from February to July'22. Nonprobability Convenient Sampling Technique was used. Sample size of 380 was calculated manually and by using Epi Info v5.5.8.

Objective of the study was to determine an association between dementia and quality of life of caregivers. Secondary objective was to identify factors leading to dementia in study participants. Target population was caretakers of dementia patients, nursing home staff, nursing staff, and   people in hospitals who are taking care of such patients.

Questionnaire was formulated using 2 scales, clinical dementia rating scale, zarit burden scale. And data collection was done using two approaches. Google forms were circulated online and direct interview method was also used.

SPSS software will be used SPSS260 version was used. Frequencies of demographic data, Severity of dementia, quality of life (QOL) were computed using cross tabs and regression analysis was applied.

All subjects were asked to return a complete and informed consent form. The confidentiality of information given by participants was maintained. The study was also reviewed by an institutional ethical review board. The questionnaire was designed in both English and Urdu for the ease of use of the subject.

RESULTS

Sociodemographic characteristics of the study participants are shown in the table 1.1. 383 participants (caretakers of dementia

patients) were selected out of which 52% of the study population was between 20-30 years of age, with maximum duration with the patient around 5 years or less and 39.8% of the participants were children of the patient.

Table 1: Demographic Characteristics of the Participants

Demographics of caretaker	N = 383 (100%)
Age of the caretaker	
1. 20 – 30 years	199 (52)
2. 31 years and above	184 (48)
Duration with the patient	
1. 5 years or less	228 (59)
2. 10 years or more	154 (40)
Relationship with the patient	
1. Spouse	64 (16.9)
2. Child	151 (39.8)
3. Sibling	84 (22.2)
4. In-laws	80 (21.1)

In order to test the objectives, data was divided into 3 variables: Total dementia scale to calculate severity of dementia [24], quality of life to assess quality of life of the caretaker and factors of dementia assessing knowledge of the caretakers regarding the factors of dementia. Total dementia score was computed using Washington University CDR assignment logarithm by in putting CDR box score from the questions into the online calculator[7] and the frequencies of the patients are shown in the table 1.2 with 43.8% of the patients having mild cognitive impairment

Table 2: Severity of the Dementia calculated using CDR online calculator

Severity of dementia	N= 383 (100%)
No impairment	26 (12.9)
Questionable cognitive impairment	70 (34.8)
Mild cognitive impairment	
Moderate cognitive impairment	88 (43.8)
Severe cognitive impairment	
	15 (7.5)
	2 (1)

Quality of life (QOL) was assess through Zarit burden scale interview[9] and the total score was computed and burden of life of the caretaker of dementia patient was assessed. The frequency distribution of the quality of life score is in the table 1.3 where most of the care givers felt mild to severe burden (44.1%, 43.1%)

Table 3: Quality of life of the Caretaker

Quality of life	Score N=383 (100%)
Little or no burden	21 (5.6)
Mild to moderate burden	166 (44.1)
Moderate to severe burden	162 (43.1)
Severe burden	27 (7.2)

To find the association between quality of life of the caregiver (dependent variable) and severity of dementia of the patient (independent variable), linear regression was used and ANOVA was applied to see the significance of association and the result shown in the table 1.4 were found to be statistically significant p-value <0.05.

Table 4: Regression analysis showing significant association between Dementia and Quality of Life.

Independent variable	Dependent variable	R^2	P value	F	Beta coefficient
Severity of Dementia	Quality of life of the caretaker	0.53	0.01	10.936	0.230

Factors associated with dementia were calculated through the questionnaire by giving 1 to correct answer and 0 to the wrong answer and total score was computed. The questions and the frequencies are displayed in the table 1.5.Two of the factors most common in the patients were family history and unhealthy habbits.

Table 5: Factors of dementia identified

Factor of dementia	N = 383	
	Yes	No
Smoking	100 (26.1)	282 (73.6)
Head injuries	51(13.4)	331(86.4)
Family history	136(35.8)	244(64.2)
cholesterol	117(30.6)	265 (69.4)
Healthy eating habits	210(54.8)	173(45.2)
Physical inactivity	110 (28.9)	270 (71.1)
Obesity	90 (23.7)	290(75.7)

DISCUSSION

The goal of this study is to demonstrate that quality of life of caregivers depends on the severity of dementia. We used linear regression and ANOVA was applied to see the significance of association between two variables, where severity of dementia being independent and quality of life of caregiver being the dependent variable. As a result the P value was found to be significant (P=0.01) while severity of dementia predicts the outcome, which is quality of life of caregivers (R^2=0.53).

A total number of 383 participants took part in the study where 52% of the population was between age 20-30 and 48% were older than 30 years old. Among these participants 39.8% were the children of patients, 22.2% were siblings and the rest were spouse followed by in laws. We assessed the severity of dementia by using CDR online calculator and 34.8% had Questionable cognitive impairment while 43.8% had mild cognitive impairment. Then we assessed the quality of life of caregivers using Zarit burden scale and 44.1% caregivers felt mild to moderate burden while 43.1% felt moderate to severe burden on their quality of life. The statistics show a significant correlation between severity of dementia and burden on quality of life of caregivers.

We also assessed the knowledge of caregivers about factors that lead to dementia where the results were found showing head injuries were on top of the list followed by smoking and family history. One study also predicts that severity of dementia have negative effect towards the health of caregivers[19].While literature suggests that dementia have a negative effect on caregivers, a study was conducted to find out any positive effects on caregivers of patients with dementia but the results did not predict any positive affect[25]. Literature also suggests that caregivers are suffering from depression due to increased burden on their life[26]. The findings of our study are important as they provide quantitative data on how much negative impact severity of dementia possess over the quality of life of caregivers, where almost 78% participants suggesting that they had questionable to mild cognitive impairment and almost 88% caregivers facing moderate to severe burden on their quality life.

CONCLUSION

This study revealed significant association between severity of dementia and quality of life of caregivers, highlighting the burden faced by them. This study also highlights that how severe the cognitive impairment is and how much burden is faced by caregivers where most patients have questionable to mild cognitive impairment while burden on caregiver is assessed by a quantitative scale which suggests that most caregivers face mild to severe decrease in their quality of life while taking care of patients of dementia.

The strength of the study is that it was carried out in a representative sample with a reasonable sample size. Therefore, the results of the study can be used to understand the knowledge of general public about dementia across other areas of Pakistan as well. This will allow us to make policies and programs that can raise awareness among general population, patients and care givers about disease and ultimately improve the quality of life of the patients of dementia.

Limitations: Participants were recruited from only one geographical location (Karachi) and therefore may not represent

the views from Pakistan's residing in more deprived, rural areas or other cities.

Recommendations: Following from the results of questionnaires filled by persons living with dementia and their caregivers, the following recommendations can be made to further improve the study if it were to be conducted again:

1   Every effort was made to encourage participation from people with a range of economic and social backgrounds in Karachi. However, it is important to note that the participants were recruited primarily from one geographical location and therefore may not represent the views from those residing in a more deprived, rural areas or other cities of Pakistan. Hence, it's important to conduct the study on a larger scale including people from all across the country.

2   Despite having a diagnosis, a large number of participants did not have complete understanding of the meaning of diagnosis and the factors that may be responsible for causing it. Therefore, efforts should be made to raise awareness about the symptoms of dementia and its appropriate care.

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