

# Family Arrangements and Quality of Life in Mexican Patients with Dementia

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## Abstract:

**Introduction:** In the aging population, especially in subjects with dementia, the degree of dependence increases, as well as an increase in the needs of health services and social costs of care. The family is the main support network for a dependent older person. However, it leads to a different family structure.

**Objective:** To determine the influence of the types of arrangements of the caregiver family on the quality of life of the patient with dementia.

**Method:** Observational and cross-sectional study. Patients older than 65 years with dementia were included. The family arrangement and the quality of life of the patients, and the caregiver, were identified. The type of family arrangement was classified according to The Savvy Caregiver Trainer's Manual, and quality of life was measured using the Quality of Life in Alzheimer's disease [QOL-AD] scale.

**Results:** 200 patients with dementia and their main caregivers were included. The patients' median age was 80 [73-84] years, 125 [62.5%] women. The main family arrangement identified was the solitary caregiver [51.5%], followed by the collaborative caregiver [25.5%] and sequential caregiver [19%]. We found a lower score on the QOL-AD scale in patients with global intermediate phase dementia and patients with a solitary caregiver and collaborative caregiver compared to those in the initial phase. We found no difference in the score between the different types of caregivers globally or each phase of dementia.

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Conclusion: The type of family arrangement that the patient has does not influence the caregiver's quality of life or dementia. However, physicians can make a family focus on other factors related to a decrease in family burden.

**Keywords:** Quality of Life; Patients with Dementia

## **1. Introduction**

The population is aging due to the increase in people's life expectancy thanks to the improvement in the treatment of chronic diseases, surgeries, or interventional procedures. In the past, these patients would be treated for palliation, whose etiology not understood [1]. Patients over 60 years of age have been calculated of 901 million people in 2015, equivalent to 12% of the world population. An increase of up to 1.4 billion and 2.1 billion is projected in 2030 and 2050, respectively [2]. In Mexico, it is expected to increase from 7% of its population in 2000 to 28% [3].

Dementia is a syndrome that is defined as a decline in higher functions, such as memory, about the previous level of people, and psychological and behavioral alterations, producing a progressive disability in the subject [4]. Its prevalence is increasing exponentially, doubling every 5 to 6 years [5]. At present, despite the resources devoted to searching for curative treatment for dementia, the focus is on well-being and quality of life [6]. Improving the quality of life of the patient has become one of the primary objectives for dementia intervention. According to the World Health Organization [WHO], quality of life is "the perception that an individual has of his place in existence, in the context of the culture and value system in which he lives, and about their objectives, their expectations, their norms, their concerns", being a broad concept influenced in a complex way by the physical health of the subject, their psychological state, their level of independence, their social relationships, as well as their relationship with the elements essentials of their environment [7].

The perception of the quality of life has a subjective value, evaluated individually. Although dementia is thought to interfere with a person's ability to self-access and communicate, patients with mild to moderate dementia can adequately report their own quality of life [8]. It has been shown that patients with up to 10 points on the Mini-Mental State Examination [MMSE] can make approximate judgments about it [9].

In the aging population, especially in subjects with dementia, the degree of dependency increases, which translates into an increase in the needs for health services, and the social costs of formal and informal care. Informal support is the support provided by relatives, friends, and/or volunteers, characterized by its small size, the existence of affectivity in the relationship, and the provision of care through a commitment of a certain permanence or duration [10]. It is estimated that around 85% of the assistance provided to the elderly is provided by the family, especially by women [11].

The family is the main support network for a dependent older person. However, it leads to a different family

structure. According to The Savvy Caregiver Trainer's Manual, there are several types of family caregiver arrangements [12]:

1. The solitary caregiver: where one person does all the care work, despite other family members living in the area.
2. The observed caregiver: where, like the solitary caregiver, a person performs all the care work, and there are family members who act as vocals, expressing their thoughts about how to provide care.
3. Caregivers in a sequential team: where the family shares the care work sequentially and the responsibility of care is rotated among all the members at different times.
4. Caregivers with not easy alliance: where they have more than one member caring for the person with dementia simultaneously; members share work, even if they do not share the same goals or styles of providing care.
5. Collaborative caregivers: where each member takes part in the care of the person with dementia; all have a common goal, and members perceive help as support, even if they have the same care.

Because the family plays an important role in the care of patients with dementia, and this may have an impact on their quality of life, the objective of our study was to determine the influence of the types of arrangements of the caregiver family on the quality of life of the patient with dementia.

## **2. Methods**

An observational and cross-sectional study was carried out. Patients over 65 years of age with previously diagnosed dementia and their main caregiver were included to identify the family arrangement and the level of quality of life of the patients and the caregiver. Patients with mild to moderate dementia [MMSE > 10 points] were included according to the new NIA-AA criteria, which have the ability to complete the survey with the assistance or by them, who live in their home with a caregiver or caregivers, members of the family. In subjects with severe dementia, the survey was carried out only by the caregiver, omitting the subject's evaluation with dementia. The study was carried out in the Department of Family Medicine of the University Hospital at the end of 2019 and 2020. The Institutional Ethics and Research Committee approved the study, and the researcher informed consent was applied to recruit patients and their caregivers.

Through the survey, the socio-demographic data of the person with dementia, the main caregiver, family data, and characteristics of the dementia disease and care was carried out. For the evaluation of the type of family arrangement, the classification of The Savvy Caregiver Trainer's Manual [12] was used, identifying the family arrangement according to the presence of the solitary caregiver, the observed caregiver, caregivers in a

sequential team [sequential caregiver], caregivers with alliance not easy [problem caregiver] and collaborative caregivers. Quality of life assessment was carried out using the Quality of Life in Alzheimer's disease [QOL-AD] scale.

The QOL-AD has 13 items on a Likert-type scale from 1 [bad] to 4 [excellent], used to evaluate indicators such as physical health, energy, mood, family, memory, living conditions, marriage, social life, ability to perform tasks at home, general vision of oneself, financial situation and life in general; It has a version for the patient that can be used with people with dementia with MMSE > 10 points, with simple and direct language, in an approximate period of 10 minutes [13]. The score was evaluated in the patient with mild to moderate dementia and in the main caregiver of all patients, with the caregiver's version, with a maximum total score of 52 points. A higher score refers to a better quality of life.

Statistical analysis was carried out using the IBM SPSS version 25 package. Categorical variables were described in frequencies and percentages, and continuous variables as median and inter-quartile ranges. Scores on the QOD-AD scale were analyzed. Categorical variables were compared using Pearson's Chi-square test. A value of  $P < 0.05$  was considered statistically significant.

### **3. Results**

A total of 200 dementia patients and their primary caregivers were included.

The median age of the patients was 80 years, 62.5% women, the majority married [48.5%] or widowers [45%], housekeepers or retired [78%], Catholics [83.5 %]. Its main comorbidities were hypertension [36%] and diabetes mellitus [21%]. 26.5% were hospitalized one or more times in the last year.

Schooling of patients was mostly junior high [45%] and most of them retired [66%]

The median age of the caregivers was 60 [52-69] years, 76% women, 77% married, the majority housekeepers [41.5%], predominantly Catholic [83%]. Its main comorbidities were arterial hypertension [28%] and dyslipidemia [12%].

Most patients were not hospitalized in the last year and only 26.5% of them were hospitalized

The Disabilities of the patients were: Walking 57 [28.5%]; Hearing 45 [22.5%]; Vision 26 [13%]; Other 95 [47.5%].

Schooling of caregivers was mostly professional education [45%] and most of them retired [40%] and 75% of them have a good economic income

The main family arrangement identified was the solitary caregiver in 103 [51.5%], followed by the collaborative caregiver [25.5%, n = 51], sequential caregiver [19%, n = 38], observed caregiver [3.5%, n = 7] and problematic caregiver [0.5%, n = 1].

The median of people living in the home was 3 [2-4], this property more frequently was owned by the person with dementia or their spouse. Two types of the family were identified in the study population, nuclear [54%] and extended or extensive composite [46%]. According to the family life cycle, the most frequent life stage was some from a young couple without children to a family with teenagers [51.5%], followed by a family in retirement [37.5%].

The median evolution of the patient's dementia was 4 [2-6] years, 17% with less than one year of evolution. Two-thirds of the patients were found in the initial or intermediate stage of dementia, and the most frequent type of dementia was Alzheimer's disease [59%], followed by vascular dementia [20%]. The caregiver was often a child [57%] or spouse [31%], mainly women, caring for all or most of the time. We found that solitary and sequential caregivers were associated with patients with a greater evolution of dementia, while observed /problematic caregivers with a lower evolution [P < 0.001]. Observed /problematic caregivers were associated with fewer hours a day caring [P < 0.014], and these, together with solitary caregivers, were associated with caring every day of the week [P < 0.001]. We did not observe any difference in the rest of the family's characteristics, the care, and the type of support or resources available to the caregiver. [Table 1]

We found a lower score on the QOL-AD scale in patients with global intermediate phase dementia [P < 0.001] and in patients with a solitary caregiver [P < 0.005] and collaborative caregiver [P < 0.012] compared to those in the initial phase. We also observed a lower score as the evolution of dementia progresses in the QOL-AD score of the caregiver version globally [P < 0.001] and in solitary [P < 0.001] and sequential caregivers [P < 0.001]. We found no difference in the score between the different types of caregivers globally or each phase of dementia. [Table 2]

We found a moderate positive correlation between the QOL-AD score of patients with dementia and that of the caregiver, both generally [r = 0.667], and when excluding caregivers of patients with advanced dementia to whom the instrument [r = 0.667]. The scores between both subjects were statistically different, being lower in the caregiver, in general [26 vs. 33 points, P < 0.001], as well as excluding caregivers of patients with advanced dementia [27 vs. 33 points, P < 0.001].

#### **4. Discussion**

The dementia patient becomes more and more dependent on their caregivers for their daily living activities as the disease progresses, forcing the primary caregiver to make sacrifices. In many cases, the caregiver's

experiences are very stressful. And the burden of rigorous care activity, which impacts their quality of life [14], is associated with negative outcomes for the patient and the caregiver [15].

Given that the caregiver has criteria for working with families, it is crucial to identify the type of family arrangement that she presents to carry out the personalized approach associated with family dynamics. In our study, we found that the most prevalent type of arrangement in families with a patient with dementia was the solitary caregiver [51.5%], followed by collaborative caregivers [25.5%] and sequential team caregivers [19%]. This is not a surprising finding since it has been observed that the majority of older adults have only one main caregiver [64%], and 25% have several people as caregivers [16]. Also, most caregivers were female in our research [62.5%], with daughters being more often in charge of care, similar to reports in the literature [17,18].

We also observed that solitary and sequential caregivers were associated with a greater evolution of dementia, while observed or problematic caregivers with a lower evolution. This could suggest that in later stages of the evolution of dementia, caregivers who were left without support from the rest of the family or caregivers who reached a balance in the family dynamics for the care of the family member with dementia prevail, and that caregivers with a greater burden problematic family members present early in the illness, and the role of the primary caregiver will remain to be established. These same caregivers had less time in care per day, which could be related to the fact that disparities must be identified in the assignment of caregiver roles. In general, the main caregiver tends to take care of the patient with dementia most of the time, especially in the absence of people who support the care.

We found a lower score on the quality of life scale [QOL-AD], both in the patient with dementia and in the caregiver, according to the severity of dementia. The scores of both were moderately correlated. However, the caregiver with dementia tended to report lower QOL-AD scores than those reported by the patient with dementia. These findings suggest that the disease's evolution harms the quality of life; however, the caregiver has a higher level of affectation than that perceived by the patient with dementia.

One of the citrus sources of social support for the caregiver in the family: family members can offer instrumental and emotional support to caregivers and alleviate the burden associated with care demands. However, pre-existing family interactions and conflicts can exacerbate caregiver distress [19]. Furthermore, caring for a family member with dementia has been associated with family conflict, decreased social support, and social life limitations [20] associated with caring for oneself or pre-existing conflicts. Caregivers need both help and assistance from other family members, as well as words of encouragement and appreciation for the caregiver's work to lessen the burden [21]. As cognitive disability increases, caregivers perceive their family as more conflictive and less adaptable [22]. This may be an association of the predominance of the solitary caregiver over the rest of the types of family arrangements in our population.

In a statement from Canada, it is mentioned that people who live alone significantly reduce the quality of life in those over 65 years of age. In general, age, health status and social support [having friends / confidants] are better indicators of quality of life. [23]

It should also be taken into consideration that family dynamics are modified according to the family life cycle or the type of crisis that the family presents, generating centripetal or centrifugal forces so that the management of the roles of family members and pre-existing family conflicts can favor better communication, the establishment of alliances between members and a more enjoyable family dynamic. The type of family arrangement that the patient has does not influence the quality of life of the caregiver or the patient with dementia, nor is there a better family arrangement than another, since the family will decide it according to their needs and stages in which they are, however, a family approach can be carried out on other factors that could be related to a decrease in family burden.

## 5. Conclusion

The type of family arrangement that the patient has does not influence the caregiver's quality of life or the patient with dementia. However, a family approach can be made on other factors related to a decrease in family burden.

## 6. Limitations

Family members are reluctant to answer aspects related to their coexistence, especially men.

The questionnaires were sometimes answered by the husbands, but the one who knows the patient the most is the caregiver, who is mostly the woman.

## 7. Recommendations

Physicians must bear in mind that the caregiver of a patient with dementia is a person at high risk for a not so good quality of life.

**Table 1:** Types of family arrangements and their relationship with different variables

Variable	Global	Solitary caregiver	Sequential caregiver	Collaborative caregiver	Observed/ problematic caregiver	p
Number of people living at	3 [2-4]	3 [2-4]	4 [2-4]	3 [2-5]	3 [2-4]	0.144

home						
Home ownership		-				0.307
Person with dementia or spouse	134 [67%]	69 [67%]	28 [71.8%]	33 [64.7%]	4 [5.7%]	
Owner	49 [24.5%]	21 [20.4%]	10 [25.6%]	15 [29.4%]	3 [42.9%]	
Another	17 [8.5%]	13 [12.6%]	1 [2.6%]	3 [5.9%]	0 [0%]	
Type of family		-				0.28
Nuclear	108 [54%]	62 [60.2%]	17 [43.6%]	25 [34.9%]	4 [57.1%]	
Extended/extensive compound	92 [46%]	41 [39.8%]	22 [56.4%]	26 [51%]	3 [42.9%]	
Family life cycle		-				0.473
Young couple without	103 [51.5%]	49 [47.6%]	21 [53.8%]	28 [54.9%]	5 [71.4%]	
Empty nest	22 [11%]	10 [9.7%]	7 [17.9%]	5 [9.8%]	0 [0%]	
In retirement	75 [37.5%]	44 [42.7%]	11 [28.2%]	18 [35.3%]	2 [28.6%]	
Evolution of dementia	4 [2-6]	4 [3-8]	5 [2-6]	3 [1-6]	1 [0.8-3]	0.001
Time with dementia diagnosis		-				<0.001
One year or less	34 [17%]	11 [10.7%]	4 [10.3%]	14 [27.5%]	5 [71.4%]	
2-5 years	99 [49.5%]	51 [49.5%]	24 [61.5%]	22 [43.1%]	2 [28.6%]	
Currentst age of dementia		-				0.116
Inicial	52 [26%]	20 [19.4%]	12 [30.8%]	16 [31.4%]	4 [57.1%]	
Intermediate	84 [42%]	44 [42.7%]	14 [35.9%]	23 [45.1%]	3 [42.9%]	
Advanced	64 [32%]	39 [37.9%]	13 [33.3%]	12 [23.5%]	0 [0%]	
Clasification of the dementia		-				0.02
Alzheimer	118 [59%]	60 [58.3%]	26 [66.7%]	31 [60.8%]	1 [14.3%]	
Vascular	40 [20%]	16 [15.5%]	8 [20.5%]	14 [27.5%]	1 [28.6%]	
Parkinson	10 [5%]	5 [4.9%]	2 [5.1%]	1 [2%]	1 [28.6%]	
Another	32 [16%]	22 [21.4%]	3 [7.7%]	5 [9.8%]	1 [28.6%]	
Kinship of the caregiver		-				0.249
Child	114 [57%]	50 [48.5%]	30 [76.9%]	30 [58.8%]	4 [57.1%]	
Brother/sister	13 [6.5%]	8 [7.8%]	1 [2.6%]	4 [7.8%]	0 [0%]	



Spouse	62 [31%]	39 [37.9%]	6 [15.4%]	14 [27.5%]	3 [42.9%]	
Another	11 [5.5%]	6 [5.8%]	2 [5.1%]	3 [5.9%]	0 [0%]	
Hours a day		-				0.014
<12 hours	17 [8.5%]	3 [2.9%]	8 [20.5%]	5 [9.8%]	1 [14.3%]	
12-23 hours	46 [23%]	20 [19.4%]	9 [23.1%]	14 [27.5%]	3 [42.9%]	
24 hours	137 [68.5%]	80 [77.7%]	22 [56.4%]	32 [62.7%]	3 [42.9%]	
Days of the week		-				<0.001
<7 days	42 [21%]	2 [1.9%]	25 [64.1%]	15 [29.4%]	0 [0%]	
7 days	158 [79%]	101 [98.1%]	14 [35.9%]	36 [70.6%]	7 [100%]	
Number of people who help	1 [1-2]	1 [0-1]	2 [2-3]	2 [2-3]	1 [1-1]	
Belongs to a club or association	86 [43%]	39 [37.9%]	20 [51.3%]	25 [49%]	2 [28.6%]	0.315
Belongs to a religious group	48 [24%]	25 [24.3%]	9 [23.1%]	12 [23.5%]	2 [28.6%]	0.991
Vacation days per year		-				
0 days	140 [70%]	83 [80.6%]	23 [59%]	29 [56.9%]	5 [71.4%]	
1-14 days	40 [20%]	16 [15.5%]	8 [20.5%]	14 [27.5%]	2 [28.6%]	
>14 days	20 [10%]	4 [3.9%]	8 [20.5%]	8 [15.7%]	0 [0%]	
Has domestic help	62 [31%]	37 [35.9%]	9 [23.1%]	13 [25.5%]	3 [42.9%]	0.321

**Table 2.** Types of family arrangements and QoL-AD score of patients and caregivers.

Variable	n	Global	Solitary caregiver	Sequential caregiver	Collaborative caregiver	Observed/ problematic caregiver	P
<b>QOL-AD Patient with dementia</b>	136	33 [30-35]	33 [31-35]	35 [30.5-36]	32 [29-35]	35 [26-37]	0.517
Initial phase	52	34 [32.2-37]	34 [32.2-37]	35 [29.5-77.5]	34 [31.2-36.7]	35 [24.2-36.5]	0.797
Intermediate phase	84	32 [29.35]	32 [29-34.7]	33 [30.5-35.2]	31 [28-34]	26 [24-26]	0.515

P		<0.001	0.005	0.223	0.012	0.476	
<b>QOL-AD Caregiver</b>	200	26 [23-30]	26 [22-30]	27 [22-32]	26 [23-29]	28 [26-35]	0.367
Initial phase	52	29.5 [27-34]	30 [27-35]	31.5 [24.7-34]	28.5 [26-31.7]	30.5 [28-36]	0.598
Intermediate phase	84	26 [23-29]	26.5 [23-29.7]	24.5 [22.2-29]	26 [23-27]	26 [21-26]	0.707
Advanced phase	64	23 [20.2-26.7]	23 [20-26]	24 [21.5-30]	23.5 [20.5-25.7]	-	0.634
P		<0.001	<0.001	0.078	0.001	0.285	

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