

## Burden of Carers for Elderly People in Greece. Proposals to Alleviate it through Restructuring of the Care Model

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Received: November 10, 2019; Published: December 10, 2019

### Abstract

**Aim:** The aim of this study was the assessment of Alzheimer patients carers burden in order illustrate the need of actions to alleviate this burden from the carers and also to describe some of these actions as they are suggested in National Action Plan for Dementia-Alzheimer's Disease.

**Method:** The assessment of Dementia patients carers as well as Non Dementia elderly carers in various sites in Greece from urban and rural areas regarding their burden and quality of life using Zarit and SF-36 scales retrospectively as well as checking for various demographic data regarding these two groups

**Results:** Overall 164 carers were assessed. Out of them 93 dementia cares and 71 non-dementia carers. Carers with patients suffering from dementia have a decrease quality of life  $p = 0,009$ . It was shown that the carers age for both groups was correlated significantly with increased burden and decreased quality of life  $p = ,002$  and  $p = ,012$  retrospectively. It was also shown that there is a greater burden for the male carers  $p = ,033$  as well as greater decrease in quality of life if the patient with dementia was male  $p = ,002$ . Finally, there was statistically significant difference regarding residence. Elderly suffering from dementia is more likely to live in an urban environment  $p = ,003$ .

**Conclusion:** Carers burden is a complicated and multifactorial phenomenon. It seems that male gender of the patient, age of the carer and male gender of carer increase carers burden and decrease quality of life. It is also discussed in the paper that due to the fact that dementia care decreases quality of life for the carers and since carers themselves gradually are more stressed by patients care a number of measures to reduce these burden are proposed in the National Action Plan for Dementia-Alzheimer's Disease. The most important of them are legislation changes, treatment protocols and guidelines in order for them to be more prepared to deal with the later stages of disease. Restructuring of the care home framework that will allow respite and short admissions for the patients as well as easy access for every one and also end of life units in order to support the patients and their carers at the end stages of the disease.

**Keywords:** Elderly; Carers; Burden; Dementia; Care Homes

### Introduction

The current study's aim is to access the degree in witch diagnosis of dementia and its course in a patient is experienced as a burden and also affects the quality of life of patient's carers.

In this study dementia was approached from the view of social psychiatry, studying the implication that this disease can have to the family environment. We believe that through this approach we could detect with better accuracy the specific needs of the carers regarding burden alleviation and improvement of their quality of life. This can help the policy makers to design and implement better policies in order to help the carers and to reduce the overall social impact of the dementia in the various stages of its course [1,2].

### Method

#### Type of the study and sampling sites

It is a multicenter cohort study. Sample was gathered from various geographic regions of Greece in order to have a more representative sample. The following sites were involved:

1. 'Laiko' General Hospital Athens
2. Psychogeriatric Association Athens
3. Psychogeriatric Clinic University General Hospital of Alexandroupolis
4. Regional medical center Didimoticho Municipality
5. General population in Evros and Thessaloniki from 'Open Elderly Care Centers'

In order to gain access to the above-mentioned sites a permission from Democritus University of Thrace ethics comity was granted and each one of the sites was informed and gave its consent.

#### Participants-Sampling procedure

Main carers of patients with dementia from the above-mentioned sites that had no mental disorder and were under no medication for mental disorders were the sample of the study. Main carers of at least an elderly person that was not suffering from dementia which had no mental disorder and was under no medication for mental disorders were the control group of this study.

Study was conducted between June and October of 2010. Random sampling procedure was used. All the carers that were present and fulfilled the inclusion criteria in a certain day of the week in each site and accepted to participate were included.

All the participants were informed about the study and participated with their own free will signing the informed consent document as it was approved by the ethics comity of Democritus University of Thrace.

#### Tools

1. Zarit Burden Interview: This questionnaire is a useful and handy tool. It is easy to be completed accurate enough and not time consuming. It takes 5 to 7 minutes to be completed. It consists of 22 questions in a Likert type questionnaire. These questions help to detect the burden of the carer's difficulties. Zarit questionnaire is standardize in Greek [3].
2. 36 item Sort Form Survey (Sf-36) quality of life Questionnaire. It consists from 8 different questions categories about overall health, activities and quality of life of the interviewed persons. It is in a scale from 0-100. This is a questionnaire widely used in public health finances. Sf-36 is standardize in Greek [4].
3. An ad hoc questionnaire was created from the writers of this study in order for us to assess possible factors that can alter or modify the burden and quality of life of elderly person's carers.

#### Interview procedure

Each participant was firstly assessed with the demographic questionnaire and then was administered the other two questionnaires. These were completed with the help of the researcher if the participant asked for it. The whole procedure had duration of about 20 - 30 minutes.

**Statistical methods**

All the constant variables we assessed were following normal distribution. Thus the method that was used for simple sample comparisons was t-test and Pearson’s Correlation was used for correlations. Crosstabs and x<sup>2</sup> was used for distinct variables [5].

SPSS for windows in its 10<sup>th</sup> version was used.

**Results**

A total of 164 carers were assessed. Out of them 93 were carers for people suffering from dementia and 71 were carers for people not suffering from dementia.

Carers of elderly with dementia score lower in SF-36 in comparison with the control group SF 36 = 82,89 vs SF 36 = 85,48 (p = 0,009). That is not the case though for Zarit questionnaire that there is no significant difference.

Male cares score higher than females in Zarit questionnaire Zarit = 40, 69 vs Zarit = 30, 59 (p = 0,033) but there is no significant difference in SF 36 score. There was also a statistically significant difference between carers of male and female patients suffering from dementia SF 36 = 79,76 vs SF 36 = 84,62 (p = 0,002) but there was no statistical difference in Zarit score (Table 1).

t-test			
	Healthy elder	Elder suffering from Dementia	p
Zarit Score	30,13 (S.D. 13,97)	32,47 (S.D. 15,51)	P = 0,363
SF-36 Score	85,48 (S.D. 5,43)	82,89 (S.D. 5,84)	P = 0,009
	Dementia carer male	Dementia carer female	
Zarit Score	40,69 (S.D. 15,54)	30,59 (S.D. 25,14)	P = 0,033
SF-36 Score	82,75 (S.D. 6,34)	82,97 (S.D. 5,83)	P = 0,908
	Male patient	Female patient	
Zarit Score	35,92 (S.D. 14,79)	30,44 (S.D. 15,82)	P = 0,150
SF-36 Score	79,76 (S.D. 6,31)	84,62 (S.D. 4,9)	P = 0,002

Table 1

Correlations demonstrated that there is a statistically significant correlation regarding burden increase (Pearson correlation 0,200 p = 0,002) as well as quality of life decline (Pearson correlation -0,250 p = 0,013) with carers’ age. This is a finding for the total number of the participants. In dementia carers group thought this does not apply regarding burden increase (Pearson correlation 0,004 p = 0,978) but still applies regarding quality of life decline (Pearson correlation -0,317 p = 0,006) (Table 2).

Pearson Correlation		
<b>Whole sample</b>		
Age of the Carer/ Zarit Score	P.C. = 0,250	p = 0,002
Age of the Carer/ SF-36 Score	P.C. = -0,200	p = 0,013
<b>Carers of patients with dementia</b>		
Age of the Carer/ Zarit Score	P.C. = 0,004	P = 0,978
Age of the Carer/ SF-36 Score	P.C. = -0,317	P = 0,006

Table 2

Regarding demographic data no statistical differences were detected between the two groups with the exception of residence were more elderly suffering from dementia were living in urban areas than in rural areas 82,7% vs 17,3% retrospectively. This is a statistically significant difference (p = 0,003) (Table 3).

	Healthy Elder				Elder suffering from dementia				p
Elderly Sex	31,1% (Mail)		68,9% (Female)		35,1% (Mail)		64,9% (Female)		,715
Carers Sex	31,1% (Mail)		68,9% (Female)		17,6% (Mail)		82,4% (Female)		,071
Elders Age	76,87 (S.D. 8,67)				76,27 (S.D. 8,08)				,679
Carers Age	47,18 (S.D. 11,47)				50,4 (S.D. 11,63)				,109
	Urban		Rular		Urban		Rular		
Residence	59,3%		40,7%		82,7%		17,3%		,003
	Same house	Close proximity	Foot distance	Car distance	Same house	Close proximity	Foot distance	Car distance	
Carers Distance	34,5%	15,5%	17,2%	32,8%	48,6%	9,5%	20,3%	21,6%	,242
	Primary	Preliminary	Higher		Primary	Preliminary	Higher		
Carers education	8,3%	38,3%	53,3%		11,1%	34,7%		54,2%	,828

Table 3

There were no other statistical differences.

**Discussion**

These findings also show greater decline in quality of life in carers with elderly suffering with dementia in comparison with the cares of elderly that do not suffer from dementia. This is expected since dementia symptoms create great stress to the carer especially neuro-psychiatric symptoms of the disease like agitation and these add up to the rest of burden that a carer of an elder experiences. This finding illustrates more the need for help for the patients suffering from dementia as well as their carers too. Since this pattern leads to the collapse of supporting system for the dementia patients if the carer remains unsupported [6].

An important finding is also that male gender as a carer suffers more burden. It is also worth mentioning than male carers are much fewer than female carers although it does not reach statistical significance in our sample. These findings are backed from the literature regarding the fact that male carers tend to leave the person that they have the responsibility to care for earlier and also spend less time weekly for their caring role [7].

The other finding that has also to do with gender is the fact that male patients cause greater decline in quality of life than female patients do. It is possible that decrease of quality of life has to do with also with that women, most of the time wife, have to take decisions that was usually taken by their husband or father and in this way their stress increases. Equally important is the fact that it is more difficult to handle a male patient in episodes of agitation or to help him for his self care especially if you are a woman. This has often as a result increased physical burden regarding their muscle and joints. In contrast it is possible that they do not feel that restrained caring for their relative since this care fulfils a role and a sense of duty. There is indeed some evidence that shows and increase in cares stress and sense of emptiness after the admission of their relative in a care home [8].

Another significant finding is the fact burden increases and quality of life decreases for the carer as older as he or she gets. This is in accordance with the literature [9] as well as with the common sense that the older a couple gets the more need for support has. Although

some can argue the main cause for increased burden and decrease of quality of life is carers' age and not the carers' role, in our study it was shown that the main decrease was between carers for the patients with dementia and not the other carers. So there is a strong chance that carers role is more difficult to bare with the increase of age and not old age by its own for the carers.

Another finding is the fact that dementia patients were found more frequent in urban environment in comparison with the rural environment. This is an important finding although its cause is most likely complicated and has many factors. We can argue that elderly that are unable to support themselves in their home towns or villages follow their children in larger cities. Another cause can be that their health problems do not allow them to stay any more in remote areas and they prefer to live in a city to feel safer. There is of course the fact that this can be a methodological error since a great deal of the sample was gathered from specialized centers in big cities so it is not that representative. Sample analysis though does not support this argument.

The current study had some limitations.

This study includes a relatively small number of patients, especially since there is a need to divide them in smaller groups for statistical analysis. Despite this fact though in most of the cases even in sub groups the number of participants was adequate to perform reliable testing [10].

There are relative few differences if we take into amount the number of participants. It is most likely that although we checked for many parameters there are others like patients physical health problems like incontinence that cause significant burden or the time that the carer spends at elders home and not only its presence in the house that adds to overall burden [11].

Another limitation was the fact the stage of dementia of the elderly was not assessed in order to search for any possible correlations between the stage of the disease and carers burden and quality of life [12].

Since dementia is not possible to be reversed or stopped, most of the burden of the disease will fall in patients carers at it shown in this study. Thus they will require support in their effort.

In US and UK the number of patients with dementia that die in terminal care units increases during the last years [13,14]. This is indicative of the above mentioned reality.

Of course each culture has different cultural sensitivities regarding the place that patients with dementia die. In a multicentre European study it was shown that in Netherlands 92% of the elderly die in Care homes in Wales this percentage drops to 50% while in Belgium to 11% there are no data in this study for Southern Europe including Greece [15].

In the National Strategy for Dealing with Dementia that was developed by the Greek Ministry of Health in its 3<sup>rd</sup> axis 'Axis 3: Support of caregivers of people with dementia' is described the need to developed an adequate network of standardized elderly care units for patients with dementia that can support the patient who cannot stay at home any more.

This network will be able to:

1. Increase quality of life for the elderly in advanced stages of the disease
2. Improve the care for the elderly that already stay in care homes
3. Give the option of admission in care units of people with physical health issues that cause delirium as an alternative to home treatment or hospital admissions
4. Provide short respite stays in care homes in order to alleviate some of the burden for their carers
5. Provide care of people without adequate social support (poor or homeless) or people with legal issues like capacity to consent for their treatment.

The aims of these approaches are

1. Covering nursing home care of people with dementia in a balanced way throughout the country when there is no way for the patient to stay at home any more.
2. Increase quality of life for patients with dementia where ever they stay
3. Decrease the burden for the carers with multiple benefits for them and the patients
4. Reduction in hospital admissions [16].

It is equally important though to create appropriate protocols, guidelines and care units for the final stages of the disease. These protocols can help to create a unified strategy for the end stages of the disease regardless where the patient might be treated. In training for these protocols nursing staff, primary care practitioners as well as carers should participate in order to customize themselves with the end of life issues [17,18]. Main aim is the right handling of the patient as well as the right timing for the admission of a patient in terminal care units [19].

Timing is crucial since these are short stay and not long stay units. In US the average stay in these units are 90 days [20]. There are appropriate tools to assess the proper time for admission in such units like AHOPE (Alzheimer's-Hospice Placement Evaluation Scale) which gives an approximately six months prognosis [21].

These units are better to be small in order to provide better quality of care and to be better distributed. They must have properly trained staff that is accustomed to life expectancy of the residence [22] and their need for palliative care [23] and to spend great effort to deal with the patient [24] his needs and their end of life decisions [25].

Quality of care in terminal care units must be constantly assessed in order to achieve the highest possible quality of life in the terminally ill patients. There are proper psychometric tools in order to help in this goal like MV QOLI Missoula-VITAS Quality of life Index [26].

Another important part that has to be addressed in caring for the dementia patients is capacity and decision making. This is a great burden for the carers as well as medical staff in order not be accused for negligence.

National Strategy for Dealing with Dementia Plan in its fifth axis 'Axis 5: Legislation – Rights of people with dementia and their caregivers' mentions the need for advance directive orders [27]. There is some experience from countries with similar family culture like Israel and model of change in their legislation that can have great interest [28].

An interesting model of terminal care unit which in fact has significant results and is also cost effective, is the Extra Sheltered Housing scheme in Shore Green in UK.

In this model patient and his carer live small apartments in the same compound with the hospital where patient has medical and nursing care until the end of his life.

This Scheme has shown significant results in reduction of hospital admissions and hospital stay [29].

### Conclusion

Caring for a person with dementia decreases further the quality of his life. This is getting worse as the carer is getting older.

Furthermore caring for the elderly increases carer burden and decreases quality of life for their carers.

Male carers seem to experience more burden when they care for people with dementia. Male gender in patients with dementia is linked with more decrease of quality of life for the carer.

Care homes that function in a modern framework, terminal care units, and proper protocols of care for elderly with dementia and appropriate legislation changes, can alleviate much of the carers and society's burden of the disease.

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**Volume 9 Issue 1 January 2020**

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