



# CARING FOR DEMENTIA PATIENTS IN CYPRUS

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# RESEARCH EVIDENCE FROM THE FAMILY PERSPECTIVE

*Research informs practice and contributes  
to the formulation of policy*



# THE CHALLENGE

- A 2012 report by the World Health Organisation recognised that dementia is a global health challenge and called on countries to recognise this challenge and include dementia in public health planning.



# WHY DEMENTIA IS A CHALLENGE?

- Currently estimated at 35.6 million people worldwide. This number will double by 2030 and more than triple by 2050
- More than 6 million people with dementia in Europe
- A significant public health challenge because of:
  - The high global prevalence
  - Economic impact on families, caregivers and communities
  - The associated stigma and social exclusion



# THE EVIDENCE

- The majority of people with dementia live in the community (70% to 81%) and for approximately 75% of these individuals, care is provided by family and friends
- Effects of caring
  - Increased risk of stress, burden and psychiatric morbidity in the form of depression
  - subjective wellbeing, physical health and quality of life is significantly lower, in dementia caregivers than in other caregivers

# THEORETICAL BACKGROUND

- FACTORS LEADING TO CAREGIVER STRESS
- *Poulshock and Deimling model*
  - burden of care can be **exacerbated** by behavioral disturbances of the care-receiver
  - or **ameliorated** by support and mature coping



# The *Pearlin and colleagues' model (1990)*

## FACTORS LEADING TO CAREGIVER STRESS

The background context (level of support and impact of other life events)

Intrapsychic strains such as personality, competence, and role captivity of the caregiver

Secondary role strains such as family conflict and social life

The primary stressors of the illness (the level of help required by the patient, behavioral and psychological problems in dementia)

# THE CY PROFILE



- Population: 839,751 (2011)
  - <http://appsso.eurostat.ec.europa.eu/nui/print.do?print=true>
- Life expectancy at birth m/f (years) **78/83** is among the highest in the EU
- Age structure
  - 0-14 years: 16.2% (male 93,280/female 88,022)
  - 15-64 years: 73.4% (male 427,752/female 394,578)
  - **65 years and over: 10.4%**
  - <http://www.who.int/countries/cyp/en/>
- In Cyprus there are no detailed data on the prevalence of dementia but according to international data the **risk of developing dementia** according to the age is
  - 65-69 years: 1 in 100
  - 70-79 years: 1 in 25
  - 80+ years: 1 in 6
- **Health systems in transition (European observatory 2012)**



# DEMENTIA IN CYPRUS

- A growing challenge since it affects the lives of a great number of Cypriots, who either suffer from this disease or care for someone who does.
- 14,000 persons older than 60 years suffer from different types of dementia
- The number of these cases is expected to expand rapidly in the coming years, thus increasing the burden the disease places on individuals and families.
- Less appreciated are the economic impact and the pressure for the health system and society in general, which will only increase as the prevalence rates of dementia rise.



# GERONTOLOGICAL CARE IN CYPRUS

- The family as the primary caregiver
- Residential care
- Government geriatric homes
- Old people's homes
  - Private
  - Municipalities
- Community care (day centres)
- Home care
- Voluntary organizations care



# THE NATIONAL STRATEGIC PLAN FOR DEMENTIA

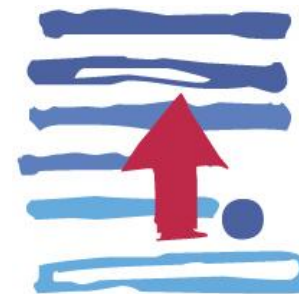
- Developed by the Multidisciplinary Committee for Alzheimer's and related dementias
- Consisted of professionals, academics, patients organisations
- To be submitted to the ministry of Health shortly



# RESEARCH FOR THE ELDERLY IN CYPRUS



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NEUROLOGY & GENETICS



Ίδρυμα  
Πρώθισης  
Έρευνας

# RESEARCH PROJECTS

- The social aspects of ageing in Cyprus
  - Positive (family support, increased social network) and negative aspects (ageism, lack of information and communication from the health care agencies) (Fellas C., 2009)
- Evaluation of home care nursing for the elderly in Cyprus
  - Type of care and work framework (care, counselling, promotion of self-care) (Kouta Ch. 2009)

# FAMILY CARE IN THE CYPRUS CULTURE

- Strong bonds, culture and filial obligation
- Parental responsibility based on ancient Greek cultural and traditional roots
- The Aeneas myth

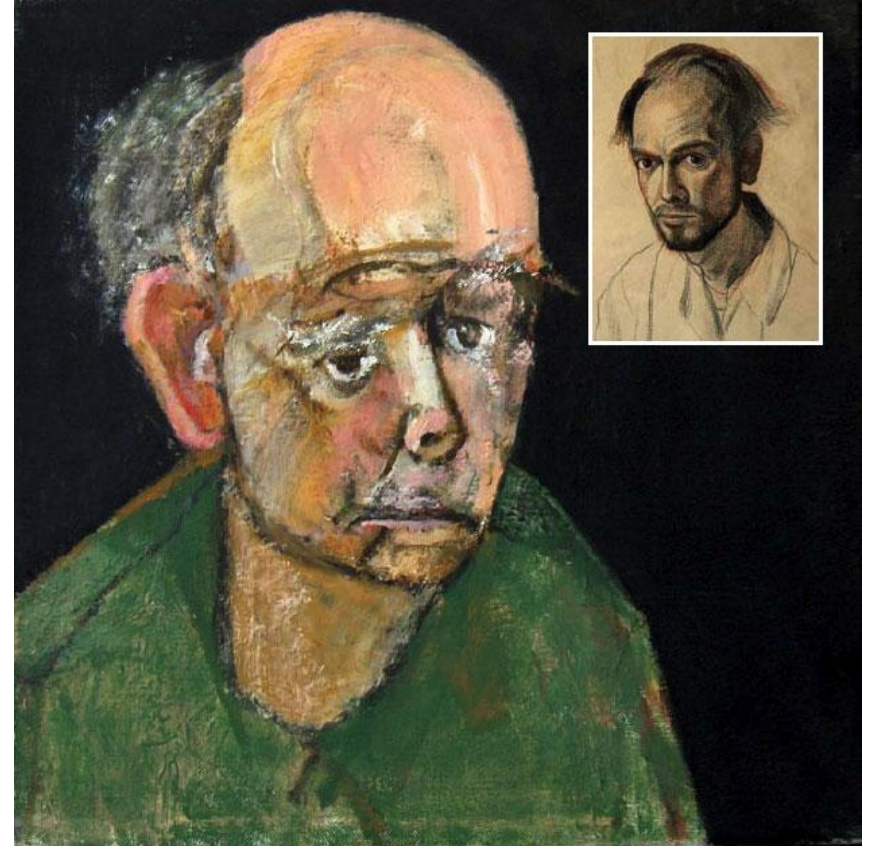


# DEMENTIA CARE

- 2003-2005
- Partners:
- University of Athens
- Cyprus institute of neurology and genetics
- Ministry of Health
- Funding:



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17/10/2012  
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CNO-CYPRUS PRESIDENCY-  
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# THE STUDY

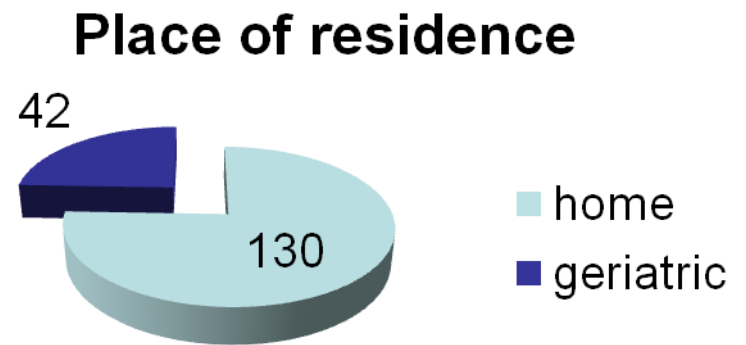
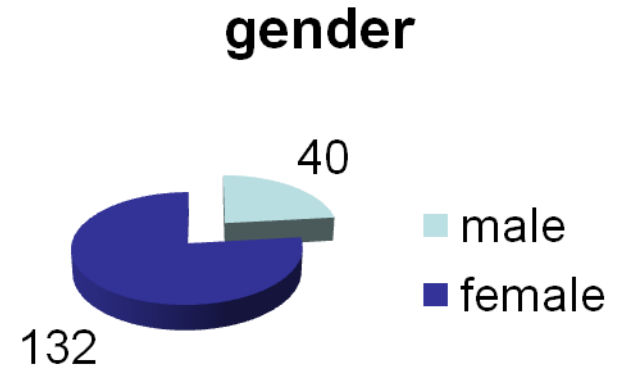
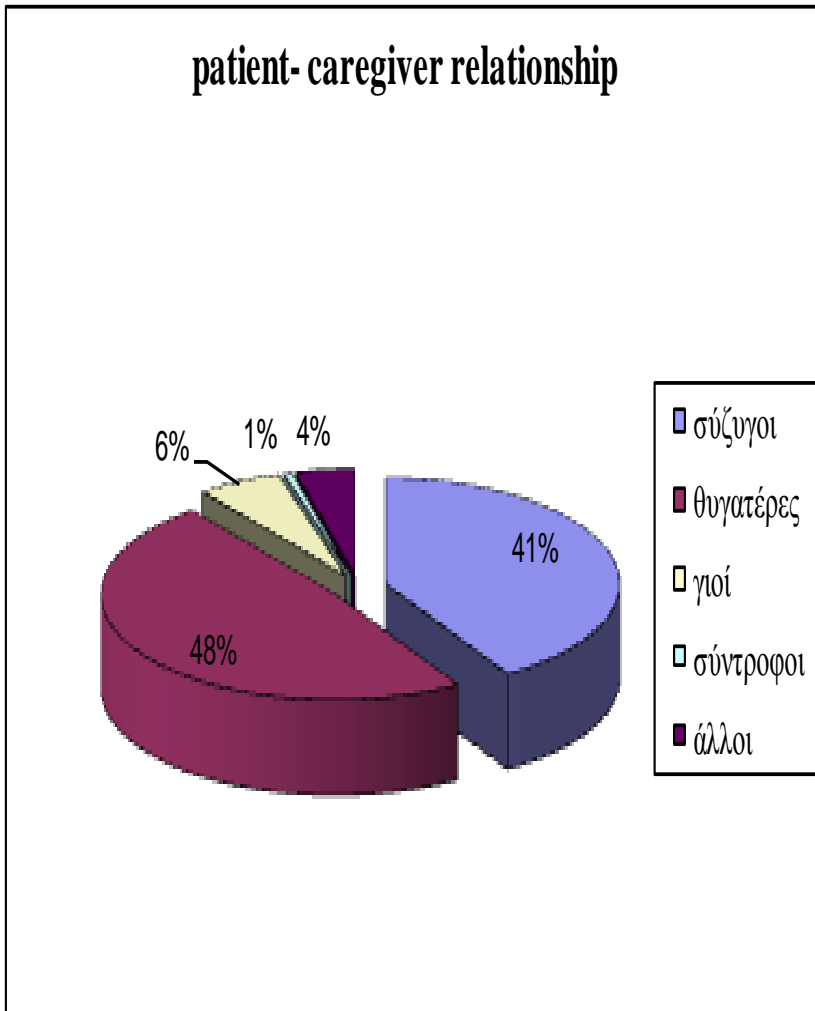
- AIMS:
  - To explore the level of caregiver burden in the care of dementia and possible causes of burden
  - To assess the psychiatric morbidity of caregivers
  - To compare the level of burden and psychiatric morbidity of caregivers of patients cared in institutions and those cared at home.
  - To investigate which coping strategies are employed by the caregivers so as to cope with the hardships of care
- PARTICIPANTS:
  - 172 patient-caregiver dyads.



# METHODS

- Patients diagnosed with dementia irrespective the cause. Primary caregivers were named by the family. Inclusion criteria: speak Greek, physically and mentally fit to undertake a caregiver role
- Instruments (translated and validated in Greek):
  - ZBI (Care giver Burden)
  - MBPC (Patient memory and behaviour problems)
  - CES-D (Depression)
  - WCQ (Ways of coping)

# THE SAMPLE



# CAREGIVER BURDEN

- 68.2% burden > 44,
  - Personal strain
  - Social deprivation
- No difference in burden and place of residence (home or geriatric care)
- Correlations
  - Patient behavioural problems ( $r=0,54$ )
  - More stressful: Aggressive behaviour ( $r=0,44$ )
  - Least stressful: Memory problems low correlation ( $r=0,22$ )

# PSYCHIATRIC MORBIDITY

- Depression
  - Mean=18,8 (cut-off point=16)
- Caregivers with burden>44, scored 20.9
- Correlations ( $r=0.57$ , level of significance= 0.01):
  - Burden (Personal strain (0,56) Relational deprivation (0,51) and role strain (0.47)
  - NO significant correlation with place of residence and kinship

# COPING WITH THE STRESSORS OF CARE

- Dimensions
  - Positive approaches
  - Seeking for help
  - Wishful thinking
  - Assertiveness
- Burden is negatively related with positive approaches ( $r=-0,20$ ).
- High burdened relatives use more wishful thinking ( $r=0,16$ ).

# SUMMARY OF THE RESULTS

- High levels of caregiver burden and depression
- Burden is related to patient behavioural problems

JAN ORIGINAL RESEARCH

## Caring for a relative with dementia: family caregiver burden

Evriddiki Papastavrou, Athena Kalokerinou, Savvas S. Papacostas, Haritini Tsangari & Panagiota Sourtzi

Accepted for publication 19 January 2007

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PAPASTAVROU E., KALOKEKINO A., PAPAOSTAS S.S., TSANGARI H. & SOUTZIS P. (2007) Caring for a relative with dementia: family caregiver burden. *Journal of Advanced Nursing* 58(5), 446–457  
doi: 10.1111/j.1365-2648.2007.04250.x

### Abstract

Title: Caring for a relative with dementia: family caregiver burden

Aim: This paper is a report of part of a study to investigate the burden experienced

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HEALTH SCIENCE JOURNAL

VOLUME 3, ISSUE 1 (2009)

### GENDER ISSUES IN CARING FOR DEMENTED RELATIVES

Evriddiki Papastavrou<sup>1</sup>, Haritini Tsangari<sup>2</sup>, Athena Kalokerinou<sup>3</sup>, Savvas S. Papacostas<sup>4</sup>, Panagiota Sourtzi<sup>5</sup>

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### Abstract

**Background:**The burden of providing care for dementia patients falls increasingly upon families and it has been identified as a chronic stressor that places family members at risk for physical and emotional problems.

**Aims:**To explore family burden in the care of patients with dementia in Cyprus and to look at gender differences in the area of caregiving and its consequences like burden, psychiatric morbidity and coping with caregiving difficulties.

**Methods:**This is a cross-sectional study, with a sample of 172 primary caregivers. The questionnaire included the Memory and Behavior Problem Checklist, the Zarit Burden Interview, the Center of Epidemiological Studies Depression scale, and the Ways of Coping Questionnaire. Several statistical methods were used for data analysis, such as independent samples t-tests, One-way ANOVA, chi-square tests of independence, reliability studies and factor analysis.

**Results:**The analysis revealed gender differences in the overall burden ( $p$ -value=0.046) and depression ( $p$ -value=0.011) where female caregivers experience higher levels compared to males. Women had a higher mean of burden in the questions included in relational deprivation (10.44 compared to 8.47 for men) and this difference is statistically significant ( $p$ =0.02). One-way ANOVA showed that, according to kinship, there exist some highly significant differences in burden ( $F$ =6.17,  $p$ =0.003) and marginal differences in depression ( $F$ =2.74,  $p$ =0.067) with the sons being less affected by the consequences of caregiving. Regarding the ways of coping, women use mostly emotional-focused strategies like denial ( $p$ =0.09).

**Conclusions:**The results of this study confirm gender differences for dementia family caregivers as regards burden and depression. The study clearly indicates the need for programs to help relieve the vulnerable caregivers especially in the area of coping so to alleviate the harmful effects of caregiving.

**Keywords:** Caregiving, burden, dementia, coping, gender

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# SUMMARY OF THE RESULTS

- Highly burdened relatives use emotion focused coping strategies
- No difference in level of burden and depression found when patients live in the community or institutions



## Aging & Mental Health

Publication details, including instructions for authors and subscription information:  
<http://www.tandfonline.com/loi/camh20>

## Caring and coping: The dementia caregivers

Evridiki Papastavrou<sup>a</sup>, Haritini Tsangari<sup>b</sup>, George Karayiannis<sup>c</sup>, Savvas Papacostas<sup>d</sup>,  
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Available online: 03 May 20

ΕΛΛΗΝΙΚΟ ΑΡΧΕΙΟ  
 ΝΟΣΗΛΕΥΤΙΚΗΣ 2014, 46(4):416-449

**Η αξιοπιστία και εγκυρότητα της κλίμακας της επιβάρυνσης (Zarit burden interview) σε Ελληνοκυπρίους φροντιστές ασθενών με άνοια**

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SPECIAL ARTICLE  
 2014, 46(4):416-449

**The validity and reliability of the Zarit burden interview in Greek Cypriot carers of patients with dementia**

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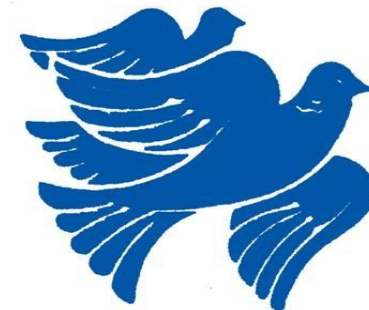
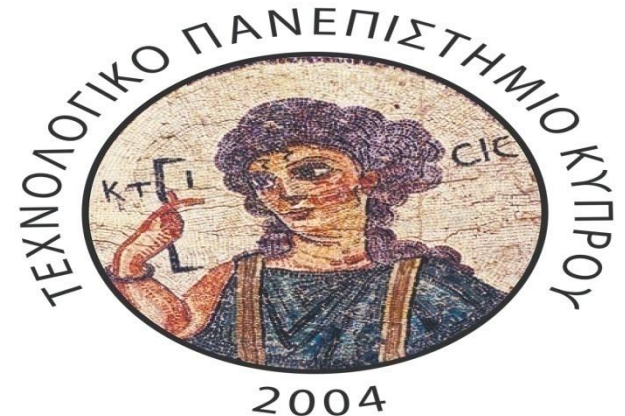
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# DEMENTIA CARING IN THE CONTEXT OF SOCIAL CAPITAL IN CYPRUS

- (2010-2012)
- Collaboration
- Cyprus University of Technology
- Ministry of Health
- Cyprus Institute of Neurology and Genetics



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# AIMS OF THE STUDY

To explore caregivers' quality of life as it is related to the level of care burden, mental health and patient dependency

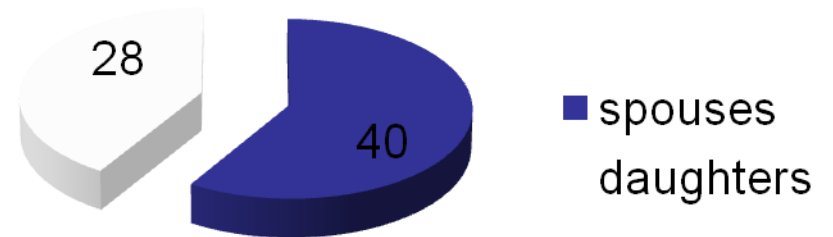
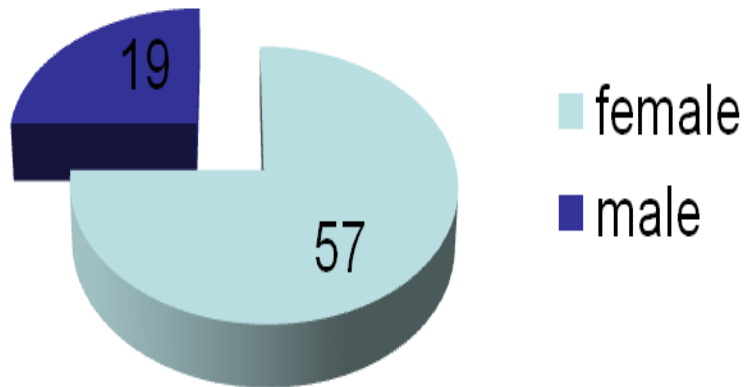


# MATERIAL AND METHODS

- Care givers (76)
  - Caring for their relative at home
  - Primary care giver as nominated by the family
  - Absence of mental or physical disability that might affect their capacity to care
  - Able to speak Greek
- Measuring instruments
  - ZBI
  - CES-D: The Center for Epidemiological Studies – Depression Scale
  - Quality of Life Quality of Life – Alzheimer’s Disease
  - The Activities of daily living

# kinship

## caregiver's gender



# QUALITY OF LIFE

- The mean value of the QoL-AD was  $M=30.89$ ,  $SD=8.21$  (range 13-52)
- The highest rating was given for the item quality of life related to **family** ( $M=2.86$ ,  $SD=0.84$ )
- The lowest for the ability to do things that are **enjoyable** to them ( $M=1.96$ ,  $SD=1.05$ ).

# BURDEN AND DEPRESSION

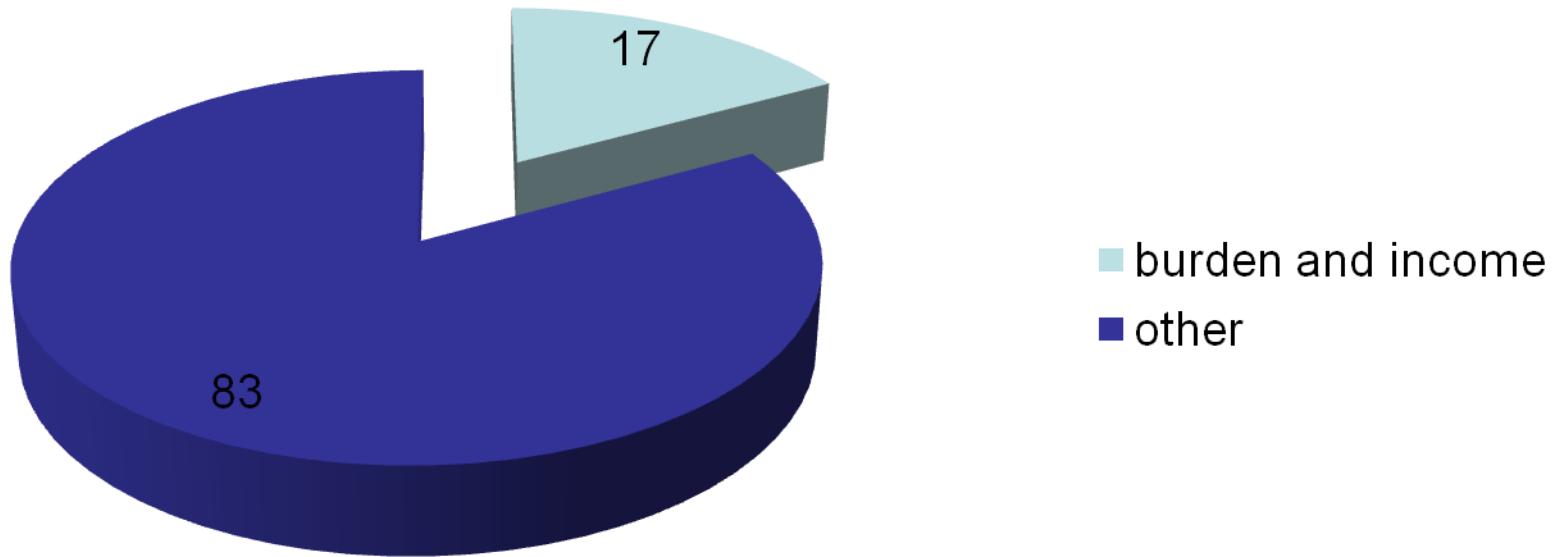
- 60% of the participants had scores over 44 (cut-off point).
  - the factor with the highest mean was “**personal strain**”  $M=19.22$  ( $SD=7.58$ )
  - The question with the highest mean was the “**do you feel your relative is dependent on you?**”  $M= 3.47$  ( $SD=0.99$ )
- 59.2% of the participants had scores of 16 or over (cut-off point) meaning symptoms of clinical depression. The mean value for the CES-D was found  $M= 19.25$ ,  $SD: 11.56$ .

# QOL CORRELATIONS

- Significant negative correlation between Quality of Life of caregivers and overall burden ( $r = -0.32$ ,  $p < 0.01$ ),
- 45 caregivers with high depression levels (scores of  $\geq 16$ ) had lower scores on Quality of Life
- There is no evidence that QoL of caregivers was correlated to the activities of daily living of patients ( $r = 0.167$ ,  $p = 0.15$ ).

# PREDICTORS OF QOL

**predictors**



# DISCUSSION

- Burden similar to the level 8 years ago
  - Need to develop community nursing and home care
  - Need for more interdisciplinary collaboration (e.g. physicia  
ns, social workers)
- Quality of life predicted by burden and income.
  - Reducing burden and increasing financial support will increase quality of life



# IMPLICATIONS

- Practice:
  - The results are expected to be a resource that will facilitate policy-makers to address the impact of dementia as an increasing threat to global health.
- Research:
  - More studies to inform practice
- Education
  - Evidence based, critical thinking and sensitive practitioners

# POLICY IMPLICATIONS

- The study aims to encourage country preparedness by strengthening or developing policy which enhance dementia care in order to improve the social well-being and quality of life of those living with dementia and their caregivers.

