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# Research on caregivers in Greece by the Greek Association of Alzheimer's Disease and Related Disorders

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ΑΡΙΣΤΟΤΕΛΕΙΟ  
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AGING  
RESEARCH



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İZMİR EKONOMİ  
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# Who are we?



- non-for-profit organization
- founded in 1995
- 2 Day Care Centres & 1 Palliative Care Centre in Thessaloniki
- funded from Ministry of Health and European Union
- 60 psychologists, doctors, social workers, nurses, physical therapists, etc.



'St. John'  
Day Centre



'St. Helen'  
Day Centre



Palliative  
Care Centre



# In numbers



ΕΛΛΗΝΙΚΗ ΕΤΑΙΡΕΙΑ ΝΟΣΩΝ ΑΛΖΧΕΙΜΕΡ ΚΑΙ ΣΥΓΓΕΝΩΝ ΔΙΑΤΑΞΕΩΝ

- More than 6.000 members
- Serves an average of about **1.400 patients** per month which perform approximately **8.000 visits** per month!
- During the last 10 years we recorded **410.000 visits** of elderly people with cognitive problems
- We count **3.500** people who took part in interventions for carers from 2008 until now
- Home care team has visited **3.000 patients** from 2008






**Diagnosis-  
Medical  
care**



**Care at home**




**Non-  
pharmacolog  
ical  
therapies**




**Lectures  
Conferences**




**DAY CENTERS  
IN GREECE**



**Information  
(24hour  
help-line)**



**Education  
Training**



**Events -  
awareness**



**Research**



1. **AD- GAMING** - DEVELOPMENT OF A TRAINING PROGRAM FOR THE IMPROVEMENT OF QUALITY OF LIFE OF PERSONS WITH ALZHEIMER THROUGH "SERIOUS GAMES" <http://adgaming.ibv.org/>



2. **iCONNECT** - Intergenerational CONTACT between students and people with dementia through Creative education <http://iconnectdementia.eu/>



3. **S.IN.CA.L.A** - Supporting Informal Carers: A Whole Family & Lifecourse Approach <http://www.sincala.eu>

*Intergenerational CONTACT between students and people with dementia through Creative education*

4. **BRIDGE** - narrow the gap between generations by creating games during social events called "Bridge Game Jams" <https://projectbridge.eu/>



5. **Story 2 remember** - Using drama and storytelling in dementia care <https://story2remember.eu/>



6. **E.L.So.M.C.I.** - English Lessons with the Use of Songs for People with Mild Cognitive Impairment

7. **DEMENTIA RIGHT** - Developing a rights-based approach to dementia



8. **PIA** - Peer Support Workers as an Innovative force in Advocacy in dementia care



9. **Game4CoSkills** - Mobile game for cognitive skills development and concept teaching for adults with intellectual disabilities

10. **INFOCARE** - Supporting Informal Caregivers of People with Dementia

11. **GECONEU** - Genetic counseling in European universities: The case of neurodegenerative diseases



GECONEU

12. **De-sign** - Raising Awareness for Dementia in Deaf Older Adults in Europe



INFOCARE

# The Five Domains of Holistic Care



**Spiritual  
Care**

**Cultural  
Care**



**Circle  
of palliative  
care**

**Emotional  
Care**

**Physical  
Care**



**Social  
Care**



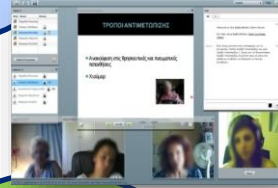
**Psycho-educational Group**



**Online Psycho-Educational Group**



**Support Group**



**Family psychological support**



**Radio broadcast "All about Dementia"**



**Carers**

**Dyadic Intervention "Writing our couples" life book**



**Who am I, grandpa?" A workshop for children and adolescents**



**Support Group for grief**



**Theatre performance "Caregiver's voice"**



**Support Group Intervention "Listen to my story..."**



**Relaxation intervention**





## Special Article – Family Caregivers

# Interventions for Caregivers of People with Dementia in Greece

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## Abstract

Recent researches have shown that intervention programs are essential in order to facilitate the caregivers' role and improve their emotional state and quality of life. This study presents the therapeutic interventions that are provided in the Day Center for Caregivers of Greek Association of Alzheimer Disease and Related Disorders (Alzheimer Hellas). Day Center for Caregivers is established in order to give psycho-educational and psychological support to dementia caregivers. Participating in therapeutic interventions caregivers learn to take care of the people with dementia and themselves physically and emotionally.

**Keywords:** Caregivers; Dementia; Interventions; Day center

## Introduction

Dementia is considered to be one of the major public health

interventions on caregiver mood or burden [15,16]. Self-efficacy, coping, mastery, depressive symptoms, emotional distress, burden



#### OPEN ACCESS

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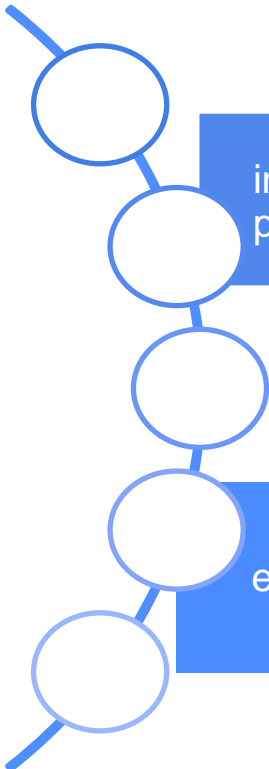
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# Attitudes toward pre-symptomatic screening for Alzheimer's dementia in five European countries: a comparison of family members of people with Alzheimer's dementia *versus* non-family members

Ioanna A. Angelidou<sup>1</sup>, Marina Makri<sup>2,3,4</sup>, Konrad Beyreuther<sup>1</sup>, Mercè Boada Rovira<sup>5</sup>, Akyllina Despoti<sup>6</sup>, Sebastiaan Engelborghs<sup>7</sup>, Andrea Miguel<sup>5</sup>, Isabel Rodríguez<sup>5</sup>, Hannah Stocker<sup>1</sup>, Joke Temmerman<sup>7</sup>, Magda Tsolaki<sup>2</sup>, Görsev Yener<sup>8</sup>, Deniz Yerlikaya<sup>8</sup> and Birgit Teichmann<sup>1\*</sup>

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# Objectives



investigate the **attitudes** of family members and non-family members of people with AD toward **pre-symptomatic screening**

explore possible differences in attitudes across **5 European countries**



Co-funded by  
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GECONEU



# Methods

- N = 650 from Belgium, Germany, Greece, Spain, Turkey
  - “Perceptions regarding pRE-symptomatic Alzheimer’s Disease Screening” questionnaire (PRE-ADS)
  - Subscale “Acceptability of Screening” to explore willingness to undergo screening
  - Group comparisons were performed to investigate differences regarding family history and country of origin
- female (76.5%)
  - highly educated (71.5%)
  - aged between 20 - 60 years old (73.2%)
  - 50% had a family member with AD



# Results

- Overall, 56.9% of the total sample expressed a positive intention toward pre-symptomatic AD screening.
- Personal experience with an affected family member emerged as a significant factor motivating a more positive attitude.
- An international comparison revealed differences in the “Acceptability of Screening” mean score across the countries.
- The Greek and Spanish subgroups ➡ higher acceptance
  - family-oriented cultures
  - strong tradition of family caregiving
  - receptive to early diagnosis
  - hoping to have more time to prepare
  - aware of the harms associated with care, including costs, family burden, and lack of a well-structured plan for AD patients



# Results

- The **Turkish** subgroup had the lowest interest in pre-symptomatic AD screening.
- A variety of **religious**, **socio-cultural**, and **healthcare**-related factors could explain these differences to an extent.
- The samples from the Central European countries **Belgium** and **Germany** fall in the lower middle of cross-cultural comparisons and show no significant differences from each other, indicating similar cultural or healthcare-related influences.
- When it comes to dementia, both have well-established healthcare-systems and offer a substantial number of healthcare facilities, caregiver training, and support group.



# Conclusion

- The PRE-ADS and its subscale are reliable tools for assessing pre-symptomatic AD screening attitudes.
- Variations in screening perceptions seem to be linked to
  1. family history
  2. cultural influences
  3. religious differences
  4. differences in healthcare
- To gain deeper insights into these relationships, future research should delve into the connections between family history, knowledge about dementia, attitudes toward pre-symptomatic AD screening, and comprehension of the benefits and limitations of such screenings.





# **The importance of palliative care in late-stage dementia: Looking through caregivers' eyes**





- **To examine the attitudes of carers for the offered palliative care and measure the relief of their burden after 1 year.**
- **20 carers**
- **Measures:**
  - Beck Depression Inventory (BDI)
  - Zarrit Burden Inventory (ZBI)
  - Beck Anxiety Inventory (BAI)
  - Marwit-Meuser Caregiver Grief Inventory (MMCGI)
  - Semi-structured interview (10 participants)



# Results



**Use of Paired Samples t-test to calculate repeated measures**

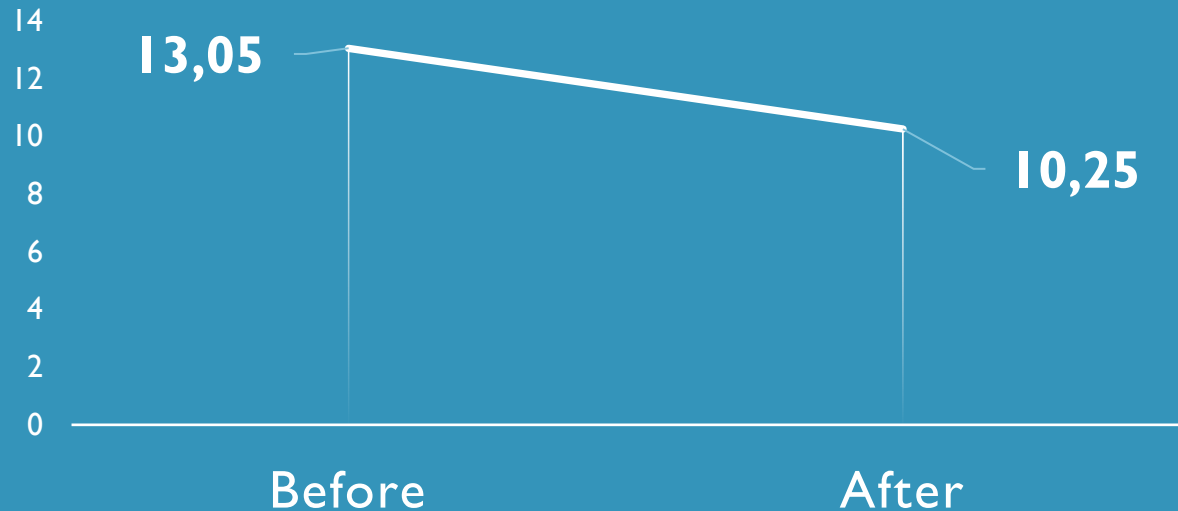


**Statistically significant results in ZBI, BDI and MMCGI**

# CAREGIVERS' DEPRESSION

## CHANGES IN BDI OVER TIME

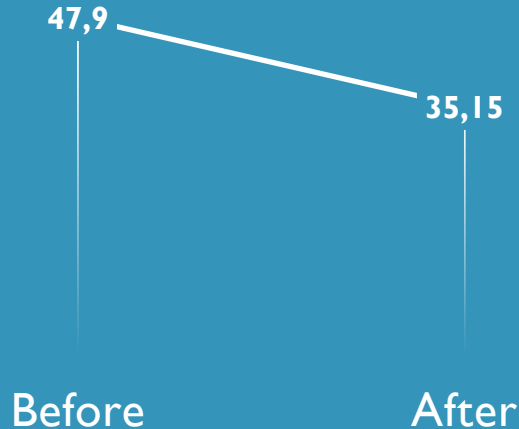
$t = -2,760, p =$



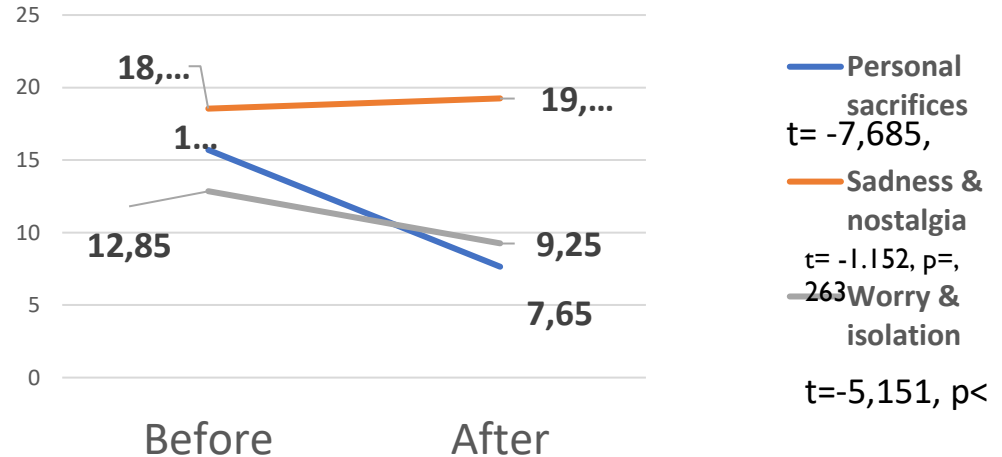
# CAREGIVERS' GRIEF

## CHANGES IN MMCGI OVER TIME

$t = -9,138, p < ,001$

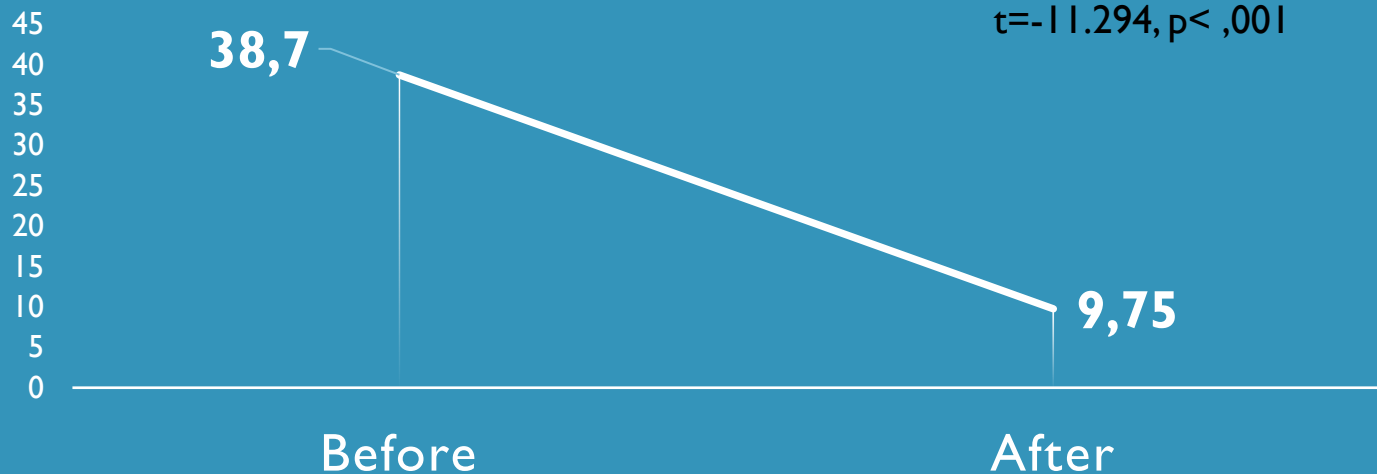


## CHANGES IN MMCGI SUBSCALES OVER TIME



# CAREGIVERS' BURDEN

## CHANGES IN ZBI OVER TIME



# Quality analysis

## Thematic analysis:

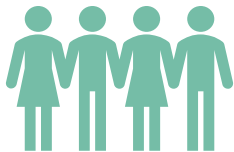
### Before the entrance in the unit:

- ✓ Full dedication to the care of the PwD
- ✓ Economic problems
- ✓ Different negative feelings (depression, anxiety)

### Changes

- ✓ Difficulty in acceptance of the absence of their person
- ✓ Changes in daily life and routine (more time for their selves)

# Quality analysis



## Strategies

Participation in psychological support group

Focus on present

Support from relatives and friends

Seek of spiritual support



## Positive feelings

More freedom

More peaceful and relaxing daily routine

Trust to the work of the unit

Feeling as family

# Discussion

## Limitations:

- Sample size
- Lack of measures

## Conclusions:

- ❑ Secondary benefits of palliative care
- Important help to the caregivers (decrease of the burden)
- ❑ Need for more similar structures





# Hybrid Conference



Participation Speakers/Programme Venue Sponsor Certific. of Attendance Proceedings



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