



# **Societal, pharmacotherapeutic and policy aspects of dementia care in Malta**

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## Maltese islands

- 93 km south of Sicily, Italy
- composed of Malta, Gozo and Comino
- 316 km<sup>2</sup>
- Population: 415,000
- Independence: 1964
- EU member in 2004
- Languages: Maltese, English
- Economy: tourism
- Education and Healthcare: similar to the UK

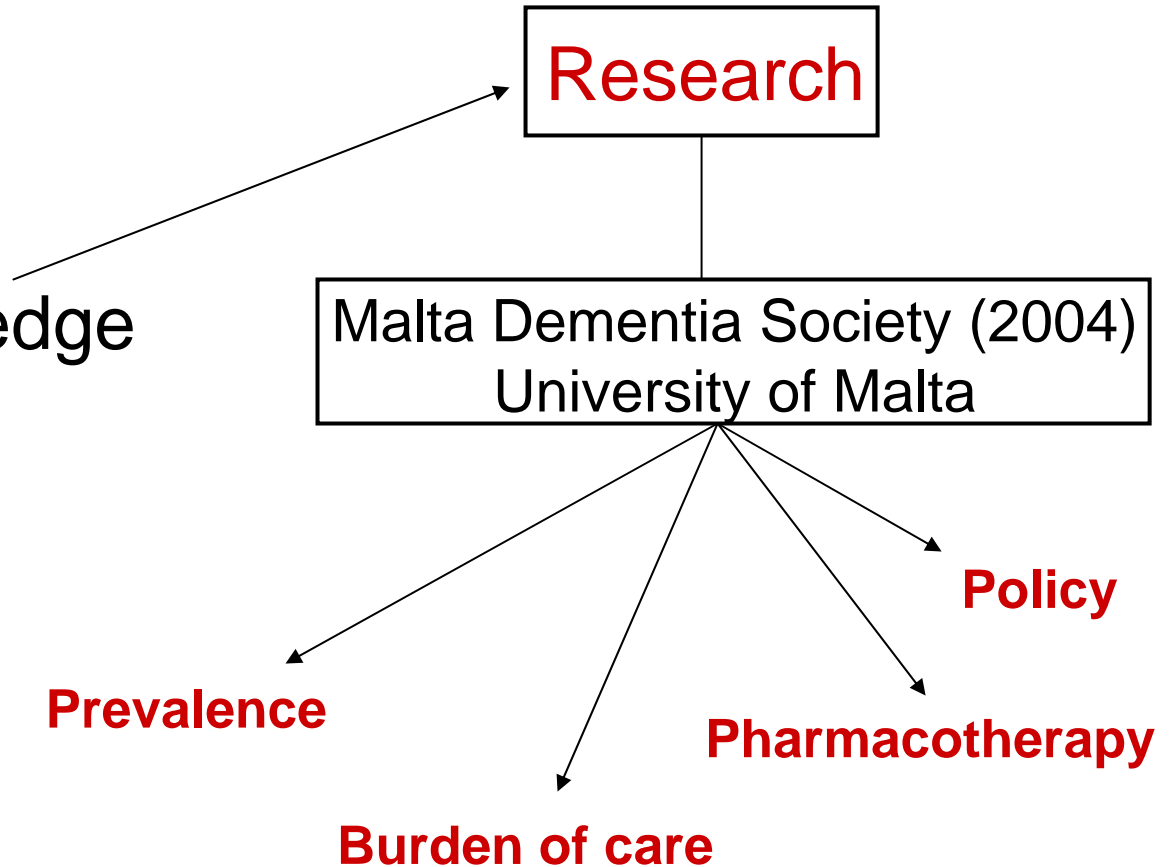
# *'Zmagat'*

- Mentally insane
  - Crazy
  - Mentally deficient
- } Social rejection

## Reasons:

- Closed society – everyone knows everybody
- Lack of knowledge – ‘so different’, ‘fear’
- Lack of facilities
- Religion – ‘act of God’
- Stigma, taboo
- Discrimination against patient and family

➤ Lack of knowledge



# Prevalence – know what you are dealing with

Original Article

## Estimated prevalence of dementia in the Maltese Islands

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### Abstract

Dementia is a serious, common, world-wide neurodegenerative disease associated with severe loss of cortical brain. It is a major predictor of morbidity and mortality in the elderly costing the health services more than cardiovascular disease and cancer put together. Recent studies have also suggested that the global prevalence of dementia would double every twenty years and should reach approximately 82 million cases by the year 2040. Using EURODEM data, we report that the estimated number of individuals with dementia in the Maltese islands is 4,072. This figure is expected to almost double by the year 2035. We discuss the implications of the forecast increase in the number of people with dementia for Malta's health services and society.

### Key words

Dementia, Malta, prevalence, EURODEM

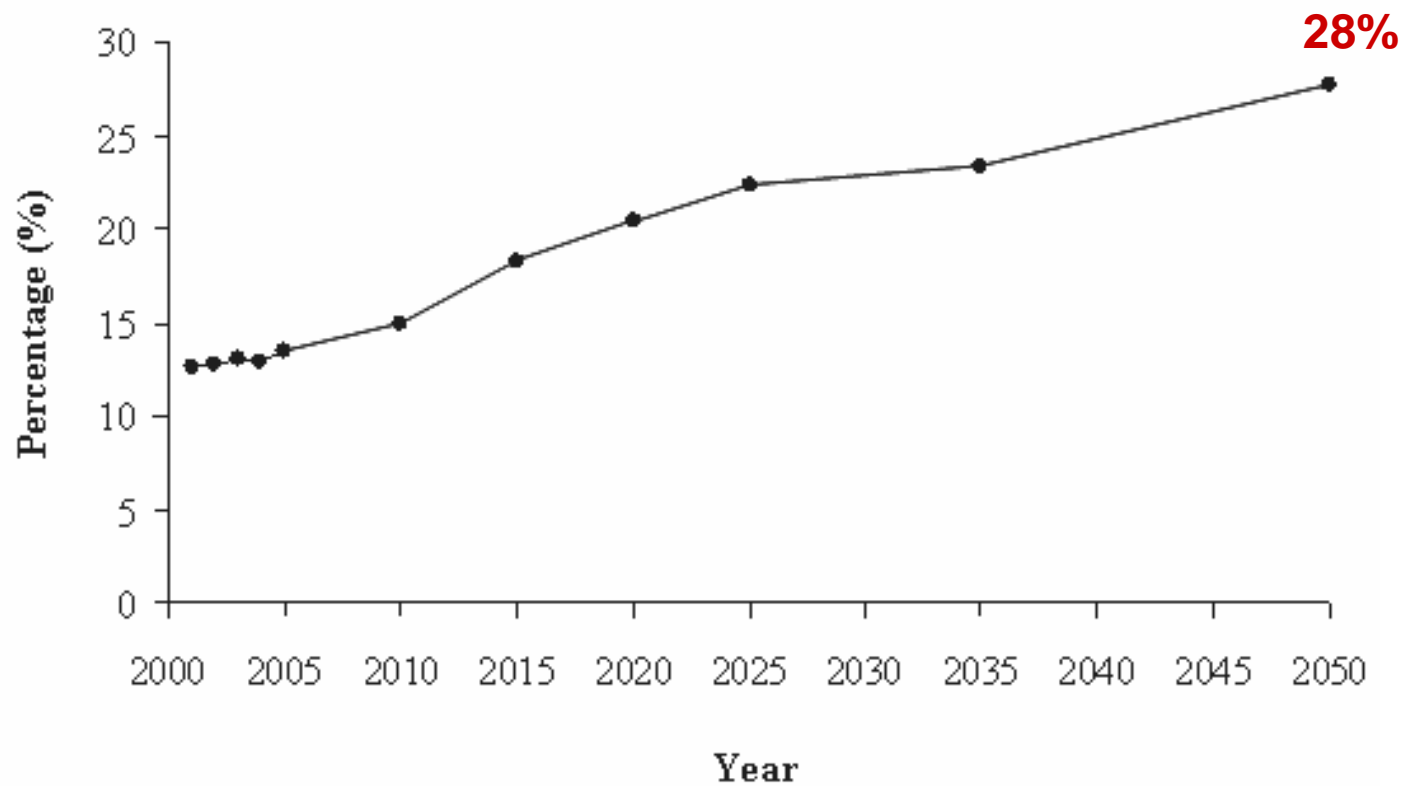
### Introduction

Dementia is a clinical term referring to a group of brain diseases that result in the progressive deterioration of cognitive functions. Dementia usually presents itself as an impairment in short- and long-term memory associated with impairment in abstract thinking, impaired judgment and other disturbances that are of such severity that they interfere with work and social activities.<sup>1</sup> As the disease progresses, the person with dementia will need increasing help and support in performing everyday tasks. Several diseases are known to cause dementia. Alzheimer's Disease accounts for 50-60% of cases, while Vascular Dementia and Lewy Body Disease account for a further 15-20% each.<sup>2</sup> Other disorders associated with this disease process include fronto-temporal dementia and Parkinson's Disease.<sup>3</sup> According to the 2003 World Health Report by the World Health Organization (WHO), dementia contributed to 11.2% of years lived with disability in people aged 60 years and over - much more than cardiovascular disease (5%) and all forms of cancer (2.4%).<sup>4</sup> This is a significant demand on family and informal carers as the majority of care for people with dementia is provided at home.

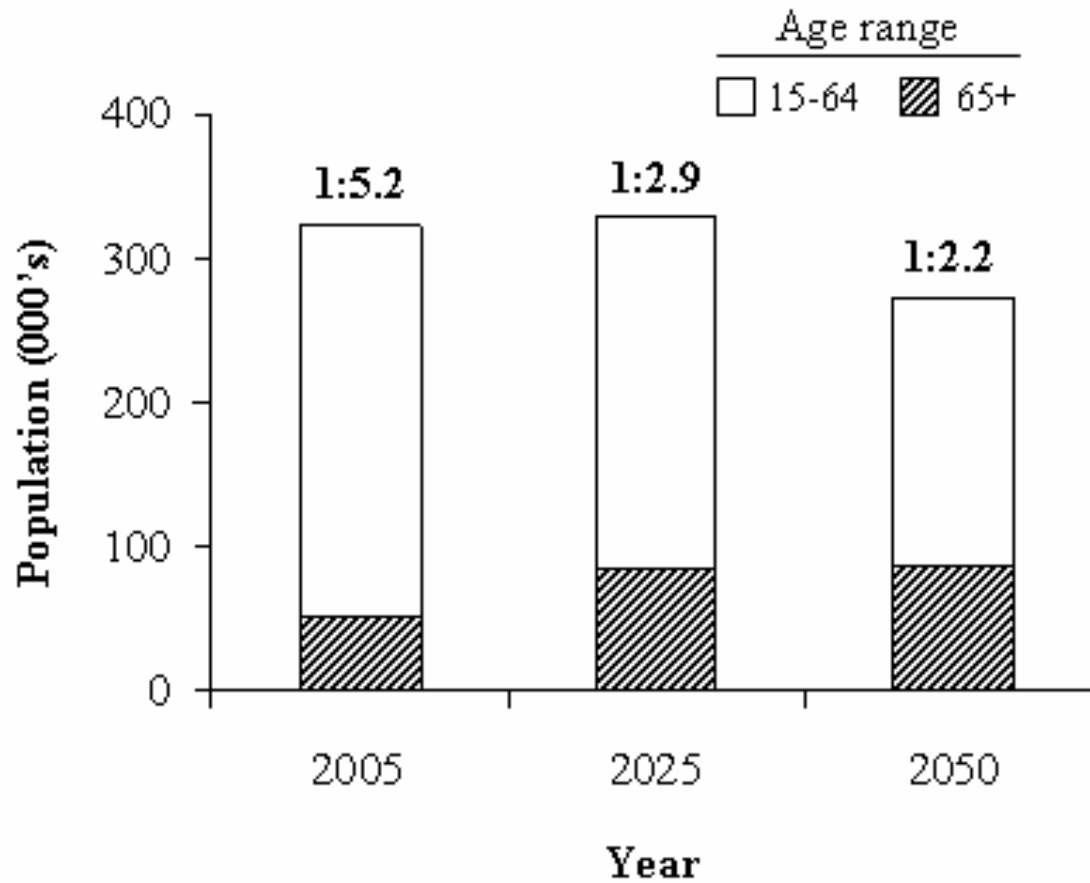
Alzheimer Disease International and Alzheimer Europe have been campaigning for years to make dementia a public health priority in view of the increasing number of people diagnosed with dementia worldwide and the financial implications of managing the consequences of this disabling condition. People

# Results:

## 1. A progressive increase in the elderly population



## 2. Decrease in old-age dependency ratio





### 3. Increase in the number of patients by 2050

Age groups

Year	30-59	60-64	65-69	70-74	75+	Total cases	% of total population
2010	203	293	316	629	2947	4388	1.12
2015	204	268	444	749	3227	4892	1.25
2020	201	285	404	1035	3660	5585	1.44
2025	201	253	422	931	4538	6345	1.66
2035	190	257	332	881	5161	6821	1.91
2050	150	268	414	970	4567	6369	2

# Burden of Care

- **Study:** *The organisation of dementia care in Malta: the experiences of family caregivers\**

## Main results:

Gender expectations

Shared filial obligation

Notions of family responsibility

\*Dementia: The International Journal of Social Research and Practice, *in print*.

# Gender expectations

## Example 1

Daughter caring for her mother with no input from her three brothers:

*D - I want that we all look after her, but it is not going to happen because my brothers don't want to... they are saying that I am obliged to do it because I am the girl, and this is the 'illness' of the family that says that the girl (cares) and the boys follow this understanding [tradition]*

# Gender expectations

## Example 2

Three daughter-in-laws expected to care for their mother by their husbands (mother-in-law spends a week in each house on rotating basis). They wish to change the care arrangements:

DL1 *'Don't you know how they are? Three professors, am I going to speak to them?'*

DL2 *'I tell him "go and watch you, see what she is saying"'*

DL3 *'We will tell them what is happening and there will be a lot of mmm and as usual we will get nowhere'*

# Shared filial obligation

**Example 1** – 3 daughters rotating care of their mother in their homes on a week by week basis

*‘and the thing is we are her family we are the ones who should be taking care of her... she brought us up... we share’*

**Example 2** – 3 daughters and son sharing the care of their mother on a day by day basis

D1 *‘and we share’*

D2 *‘we share’*

D3 *‘and we share’*

S *‘I am the driver’*

# Pharmacotherapy

- **Study:** *Pharmacotherapeutic aspects of dementia care in Malta*

## Main results:

Costs\*

Effectiveness vs fear of withdrawal\*

Co-morbidity states\*\*

Polypharmacy\*\*

\*Dementia: The International Journal of Social Research and Practice, *in print*.

\*\*Malta Medical Journal, *in print*.

# Cost

## Example 1

R – *the problem about the pills [is that they] are much too expensive... I take the lowest part of the pension you know*

## Example 2

R – *about one third of my pension goes to the chemist you know... and how? If I have a little bit of interest from the bank, because I had some money in the bank, I spend all the interest on medicine*

# Effectiveness vs fear of withdrawal

## Example

Interviewer – *so, you are saying, they don't make a difference?*

Relative – *no, it keeps, still to be getting worse. I don't know if we stop, it will get worse, and that's why we don't stop, because we don't know what will happen*





- **Study:** *GP perceptions on diagnosis, disclosure and treatment of dementia in Malta*

**Preliminary results** ( $n=132$ , 42% response rate):

GPs need more training in dementia diagnosis and management

GPs don't tend to refer to specialists

Only disclose if sure of diagnosis

A significant number adopt a 'wait-and-see' approach

Excessive use of supplements in all stages of dementia

Significant use of AChEIs in severe AD



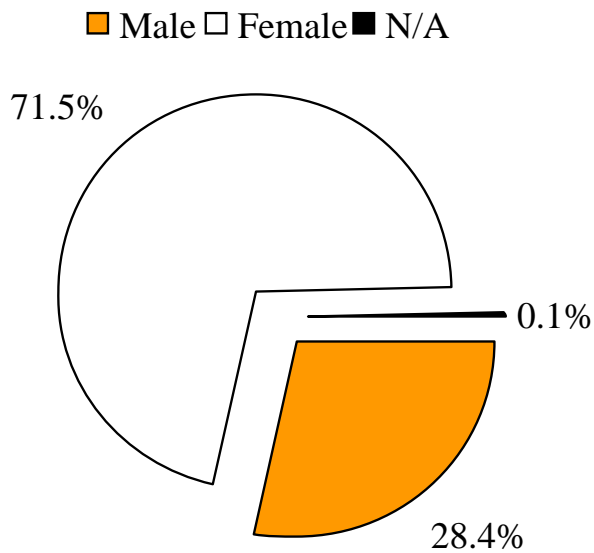
# Policy

**May 2009** – Launch of Malta Dementia Strategy Group

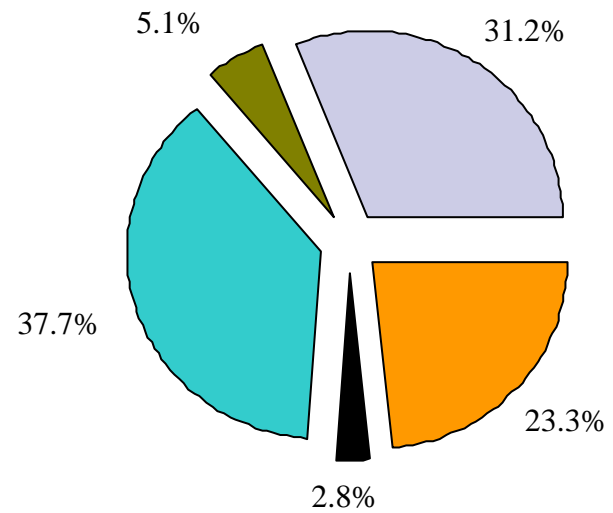
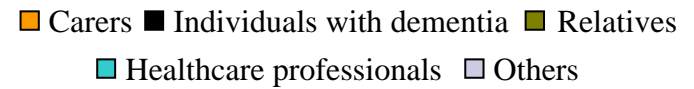
***Aims:*** To develop a series of recommendations aimed at enhancing dementia care in Malta

**Part of the consultation process involved a questionnaire – [www.dementia.gov.mt](http://www.dementia.gov.mt)**

# Results ( $n=613$ )



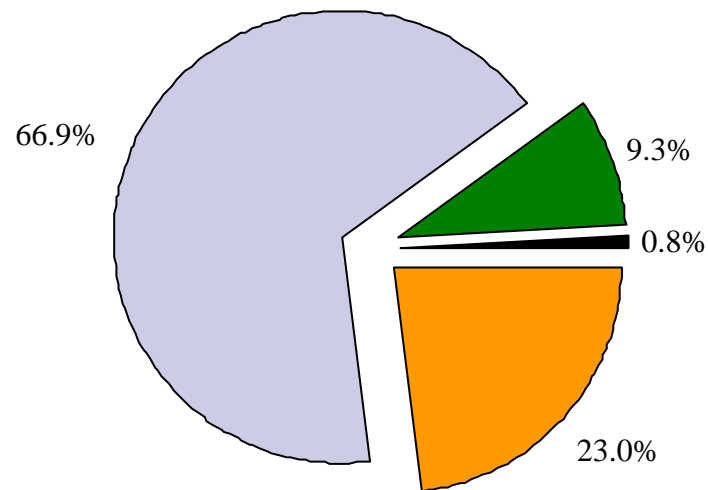
Distribution of gender



Distribution of categories

# Awareness, Education & Training

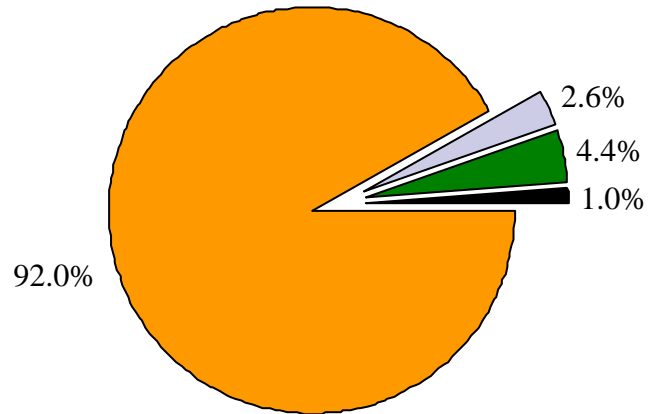
■ Yes ■ No ■ Don't know ■ N/A



**Do you think there is enough awareness on dementia?**

# Early Intervention

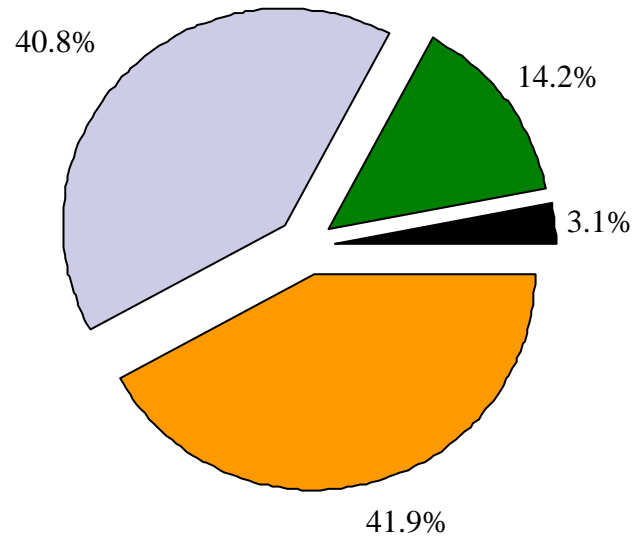
■ Yes ■ No ■ Don't know ■ N/A



**Do you think that early diagnosis  
of dementia is important?**

# Support – Governmental Structures and Services

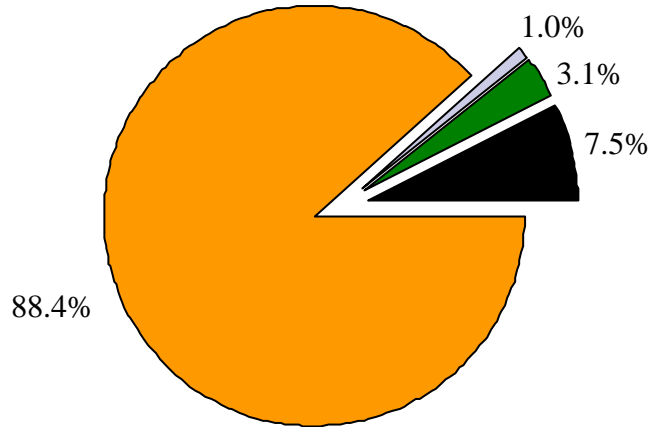
■ Yes ■ No ■ Not applicable ■ N/A



**Have you made use of the Memory Clinic?  
(feedback from individuals with dementia, carers and relatives)**

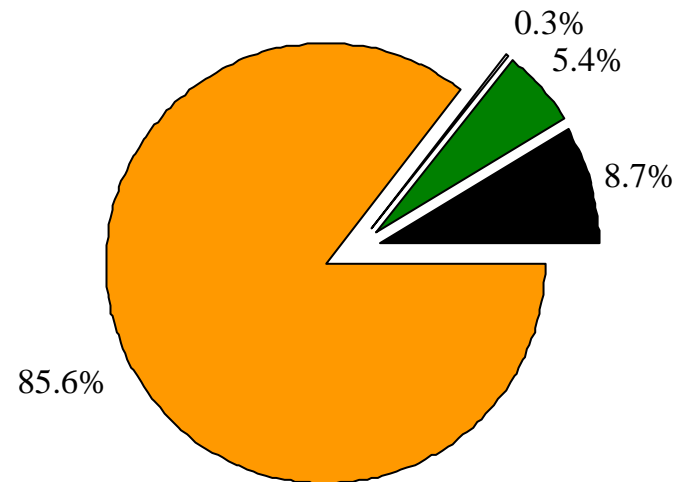
# Support – Community

■ Yes ■ No ■ Don't know ■ N/A



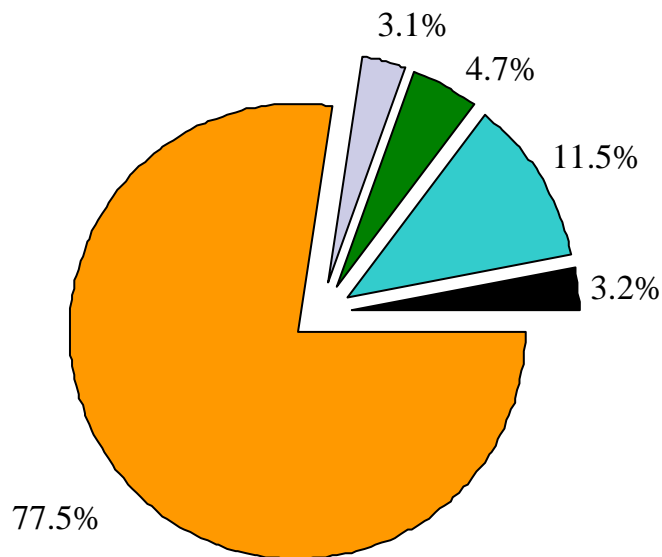
**Do you consider care in the community as important?**

■ Yes ■ No ■ Don't know ■ N/A

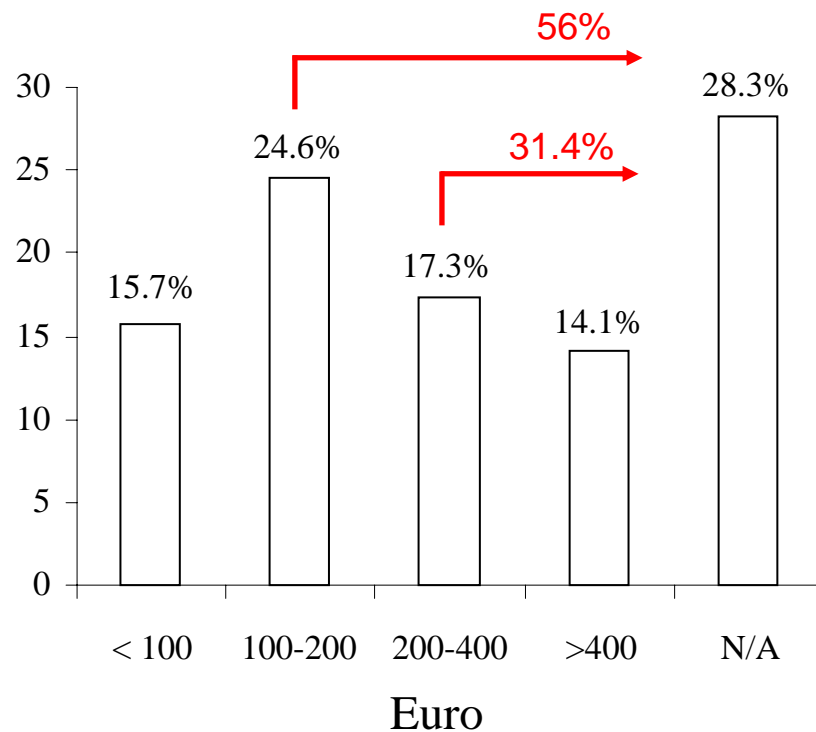


**Do you consider respite care as important?**

■ Yes 
 ■ No 
 ■ Don't know 
 ■ Not applicable 
 ■ N/A



**Does caring for a person with dementia have a significant impact on the family financial status?**

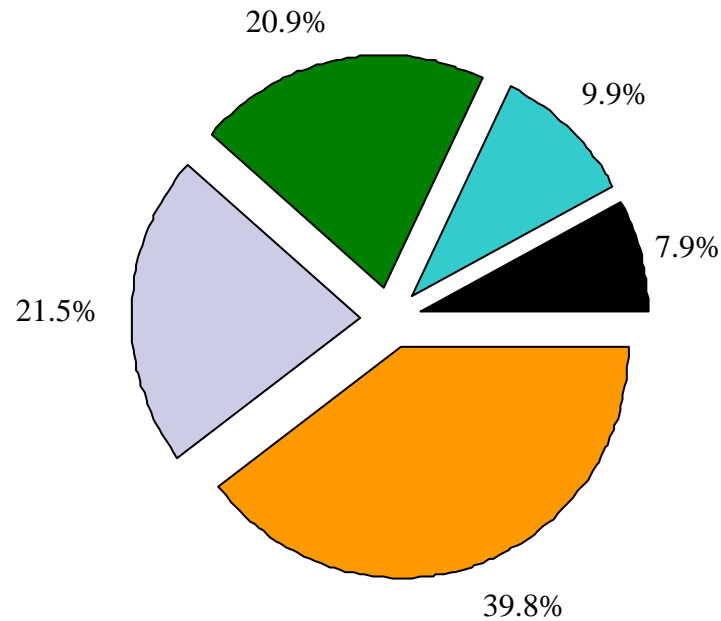


**Average amount spent on dementia care/month (feedback from individuals with dementia, carers and relatives)**  
*Minimum wage: Euro 608/month*



# Other Issues – End of Life and Palliative Care

■ Yes ■ No ■ Don't know ■ Not applicable ■ N/A



**Are you concerned with end-of-life (e.g. palliative care) issues?**

# Recommendations

***Improving awareness on dementia in the community and in relevant professional and non-professional fields***

***Improving early diagnosis and intervention***

***Providing good quality information at the point of diagnosis and beyond***

***Financial support for anti-dementia medication***

***Increase knowledge of services that are already available for individuals with dementia and their carers***

***Improve the quality of service in acute and long-term care***



***Improving support services for individuals with dementia and their carers within the community***

***Improving end-of-life support services for individuals with dementia and their cares***

***Strengthening legal and ethical issues regarding individuals with dementia, their families and caregivers***

***Implementation of the National Dementia Strategy Plan***