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 km²
- 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

Malta Dementia Society (2004)
University of Malta

- Prevalence
- Policy
- Pharmacotherapy
- Burden of care
Prevalence – know what you are dealing with

Estimated prevalence of dementia in the Maltese Islands

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Abstract

Dementia is a serious, common, worldwide 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.

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. 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. Other disorders associated with this disease process include fronto-temporal dementia and Parkinson's Disease. 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 (9%) and all forms of cancer (2.4%). This is a significant demand on family and informal care 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.

Key words

Dementia, Malta, prevalence, EURODEM
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

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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:** Pharmacotherapeutico aspects of dementia care in Malta

Main results:

Costs*
Effectiveness vs fear of withdrawal*
Co-morbidity states**
Polypharmacy**


**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
Results \( (n=613) \)

Distribution of gender:
- Male: 71.5%
- Female: 28.4%
- N/A: 0.1%

Distribution of categories:
- Carers: 23.3%
- Individuals with dementia: 5.1%
- Relatives: 31.2%
- Healthcare professionals: 37.7%
- Others: 2.8%
Awareness, Education & Training

Do you think there is enough awareness on dementia?
Early Intervention

Do you think that early diagnosis of dementia is important?

- Yes: 92.0%
- No: 2.6%
- Don't know: 4.4%
- N/A: 1.0%
Support – Governmental Structures and Services

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

Do you consider care in the community as important?

- Yes: 88.4%
- No: 1.0%
- Don't know: 3.1%
- N/A: 7.5%

Do you consider respite care as important?

- Yes: 85.6%
- No: 0.3%
- Don't know: 5.4%
- N/A: 8.7%
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

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

- Yes: 39.8%
- No: 21.5%
- Don't know: 20.9%
- Not applicable: 9.9%
- N/A: 7.9%
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