‘Stock taking’ in dementia research in Malta - A review of related studies

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Dementia research in numbers

Research into dementia remains hugely underfunded compared to research into other common diseases.

There are an estimated 4,061 dementia researchers in the UK (28,062 for cancer, 6,433 for heart disease, 4,784 for stroke).

- Dementia: 10% of overall scientist numbers, 48% of overall cost to UK economy
- Stroke: 14% of overall scientist numbers, 12% of overall cost to UK economy
- Heart disease: 17% of overall scientist numbers, 18% of overall cost to UK economy
- Cancer: 61% of overall scientist numbers, 25% of overall cost to UK economy

Leading dementia research charities, UK, 2012

Leading dementia research charities, worldwide, 2012
“Make dementia a priority agenda item at the G20”

• “A share of research funding to be dedicated to finding the best ways to care for people with dementia, to assist their family carers, and to translate research into evidence-based practice”

Australia petitioning to share on dementia care research in the G20
National Strategy for Dementia in the Maltese Islands (2015-2023)

Objectives:

*Enhancing the quality of life for individuals with dementia, their caregivers and family members*

Aims:

- Increasing awareness and understanding of dementia
- Timely diagnosis and intervention
- Workforce development
- Improving dementia management and care
- Ethical approach to dementia management and care
- Research
What the strategy says about research

“Research on dementia currently receives minimal funding”

“There is limited data on how dementia is affecting the Maltese society”

“Research is essential for the planning, managing and distribution of health and social care resources”
Search strategy

• **Aim:** What is the current evidence on dementia and dementia care in Malta based on published and unpublished local studies?

• **Keywords:** Dementia and/or Alzheimer and Malta

• **Databases:**
  • For published studies: Pubmed, CINHAL and AGELINE were searched.
  • Unpublished studies: Master Dissertations retrieved from
    • UoM Dissertation Catalogue and the
    • UoM Institutional Repository (OAR@UoM).

• **Inclusion/Exclusion Criteria:**
  • Included: Empirical studies and case studies
  • Excluded: Opinion, review and discussion papers and undergraduate dissertations
Findings and analysis

• 16 studies were selected and categorised into five overarching themes –
  1. Prevalence of dementia in Malta (2 studies),
  2. Knowledge, perceptions and attitudes towards persons with dementia (3 studies),
  3. Diagnosis and pharmacotherapeutic aspects (2 studies),
  5. Hospital and institutional care care (5 studies)

• Some overlap is inevitable
1. Prevalence of dementia in Malta

Abela, Mamo, Aquilina & Scerri (2007)

Table 2: Estimated number of gender-specific dementia cases in the Maltese islands according to age groups using EURODEM data for the years ranging from 2001 to 2005. Data shown as M/F (M: males, F: females, based on end 2003 estimates of the Maltese population^1)

<table>
<thead>
<tr>
<th>Year</th>
<th>30-59</th>
<th>60-64</th>
<th>65-69</th>
<th>70-74</th>
<th>75-79</th>
<th>80-84</th>
<th>85-89</th>
<th>90+</th>
<th>Total (M/F)</th>
<th>Total (M+F)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>129/71</td>
<td>125/42</td>
<td>157/97</td>
<td>244/284</td>
<td>206/388</td>
<td>293/483</td>
<td>168/374</td>
<td>119/315</td>
<td>1441/2054</td>
<td>3495</td>
</tr>
<tr>
<td>2002</td>
<td>131/72</td>
<td>120/40</td>
<td>160/99</td>
<td>251/290</td>
<td>207/398</td>
<td>303/522</td>
<td>159/376</td>
<td>134/319</td>
<td>1465/2116</td>
<td>3581</td>
</tr>
<tr>
<td>2005</td>
<td>133/73*</td>
<td>165/53</td>
<td>175/103</td>
<td>284/319</td>
<td>217/419</td>
<td>327/586</td>
<td>243/476</td>
<td>142/357</td>
<td>1686/2386</td>
<td>4072</td>
</tr>
</tbody>
</table>
1. Prevalence of Dementia In Malta

Scerri & Scerri (2012)

<table>
<thead>
<tr>
<th>Age groups</th>
<th>2015</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>2020</td>
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<tr>
<td>60-64</td>
<td>27/124</td>
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<tr>
<td>65-69</td>
<td>240/201</td>
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<tr>
<td>70-74</td>
<td>246/344</td>
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<tr>
<td>75-79</td>
<td>419/601</td>
</tr>
<tr>
<td>80-84</td>
<td>493/945</td>
</tr>
<tr>
<td>&gt;85</td>
<td>619/1812</td>
</tr>
<tr>
<td>Total IWD</td>
<td>6071</td>
</tr>
<tr>
<td>% of the total population</td>
<td>1.47</td>
</tr>
</tbody>
</table>
2. Knowledge, perceptions and attitudes towards persons with dementia

Scerri (2010)

- Targeted population: general public
  - 38% still consider dementia as a taboo subject
  - 67% felt that awareness on dementia is lacking
  - 63% felt that not enough information is provided individuals with dementia and their caregivers regarding services that are available

- Common misconceptions among respondents included
  - the belief that symptoms of dementia are the consequence of old age
  - and that these symptoms are transient
2. Knowledge, perceptions and attitudes towards persons with dementia

Farrugia (2015)

• Knowledge on dementia care was satisfactory (63.5% correct answers in ADKS)
• The least important perceived educational need was in relation to technology; the most important was in relation to managing challenging behaviour.
• Better knowledge was associated with more positive attitudes
• Nurses were significantly more knowledgeable than nurses’ assistants and had more positive attitudes
• Nurses working on specialized dementia units were more knowledgeable and held more positive attitudes to working with persons with dementia than those on general units
2. Knowledge, perceptions and attitudes towards persons with dementia

Scerri & Scerri (2013)

- Degree Mental Health NS (8 hrs) had more training compared to Degree General NS (2hrs)
- 74% of 1st Year NS had already cared for PWD during their first clinical placement
- Training sessions in dementia for undergraduate nursing students had a positive influence on the students' knowledge on the subject
- Clinical experience and higher age are significantly associated with a more positive attitude
- There was a positive relationship between nursing students' perceived satisfaction of their experience during their clinical placement and attitude
3. Diagnosis and pharmacotherapeutic aspects

Practices in diagnosis, disclosure and pharmacotherapeutic management of dementia by general practitioners – a national survey
Cara Caruana Pulpan and Charles Scerri

• The majority of GPs indicated lack of competence in diagnosing dementia.
• Referral to a specialist was not a preferred option
• There was a significant difference in prescribing habits depending on disease progression and number of years working as GP
• 62% of the GPs do not routinely disclose the diagnosis to the patient or relatives
• Need of providing training s to GPs to increase competence and act as role players in the community
3. Diagnosis and pharmacotherapeutic aspects

Scerri, Abela & Innes (2010)

• Participants had moderate form of dementia

• The mean number of days elapsed from first visit to diagnosis was that of 41.3±19.3 (mean±SEM) days

• Most of the patients had depression and a significant number had diabetes, hypertension and hypecholesterolaemia.

• The majority of patients were prescribed four or more drugs

• 16 patients were taking anti-dementia pharmacotherapy which mainly consisted of the acetylcholinesterase inhibitor galantamine and the partial NMDA receptor antagonist memantine
4. Community Care

Innes, Abela & Scerri (2011)

• Participants developed innovative rotating care patterns

• Participants reported lack of services (e.g. respite care) or lack of awareness of available services

• Moreover, financial cost and stigma associated with using them, lead to lack of use of available services

• Community support services in Malta for caregivers and patients with dementia are lacking
4. Community Care

Vassallo (2010)

• A needs assessment in dementia
• Persons with dementia had several unmet needs of varying type and extent
• The severity of the dementia, female gender and living alone was associated with a higher number of unmet needs
• More support is needed to be given in the community especially to the most vulnerable groups.
4. Community Care

- Other persons with dementia living in the community that need special attention including:
  - **Persons with dementia and communication problems** (Gobey, 2013)
    - Influences carer relationship
    - Increase objective and subjective carer burden
    - Increase problem behaviours
  - **Persons with dementia and Diogenes Syndrome** (Ferry, 2013)
5. Hospital and institutional care

Acute hospital wards

• Patients with dementia are present in our acute hospitals but are not diagnosed.

• Some of these patients are labelled ‘social cases’ (Zammit & Ferry, 2006)
  • ‘A diagnosis of dementia was documented on the patient’s medical record in only 12%. However significant low Abbreviated Mental Test scores were found in 64’ of the patients labelled social cases’

Geriatric hospital wards

• Evidence of good care practices as reported by staff when staff build a relationship with patients and family members (Scerri, Innes & Scerri, 2013)

• However, staff perceptions of practice may not be reflect the observed patient experiences which tends to be generally task-centred (Innes, Kelly, Scerri & Abela, S.,2016)
5. Hospital and institutional care

Long term elderly care wards

- **Galea, 2015**: health care professionals perceptions of person-centred dementia (PCC) care
- **PCC was acknowledged by residential staff as the way forward** by promoting the self and normality and getting to know the person
- However, there are **organisational, environmental and cultural challenges** that limits its implementation

Psychiatric wards

- **Scerri & Cassar, 2013**: Nurses’ perceptions of placements of patients with Hungtinton disease (HD) in a psychiatric hospital
- Need to provide **alternative residential options in the community** for these persons
- Need for **specialised staff, facilities and equipment** to care for persons with HD
Conclusion

• **Recommendation of the National Dementia Strategy**
  • Promote and support research initiatives in the field of dementia management and care
  • Carry out research to assess unmet needs of community-dwelling older adults with dementia, their caregivers and family members
  • Make dementia a research priority
  • Facilitate access for individuals with dementia to participate in clinical trials

• **Current Developments to promote research in this area**
  • Master in Ageing and Dementia Studies
  • Dementia Intervention Team/s