

Malta's strategic vision for a National Dementia Policy

Charles Scerri¹

Abstract. Malta is experiencing a demographic transition characterised by an increase in the old age population. While this may indicate social success, it creates important challenges such as the inevitable rise in age-related neurodegenerative disorders, including the most common forms of dementia. This will pose significant societal demands as most dementia care is provided informally by family members living in the community. Furthermore, local research studies have shown that there is considerable lack of awareness and professional training that is seriously undermining timely diagnosis and management. As a result, Malta opted to take a holistic approach towards dementia care by embarking on a long-term strategy focusing on increasing awareness, providing the best services leading to high quality dementia care, and fostering dementia training to healthcare professionals in order to be better equipped to support individuals with dementia. It is a vision that promotes excellence, and effectively reflects the current and future needs of these individuals, their relatives and caregivers.

Keywords: Alzheimer's disease, dementia care, dementia national strategy, Malta.

Introduction

Dementia is a group of brain disorders characterized by progressive deterioration of cognitive function. It is the most common neurological disorder in old age and a major predictor of morbidity and mortality in the elderly. The most common form of dementia is Alzheimer's disease (AD) with other types including vascular dementia, dementia with Lewy bodies, fronto-temporal dementia and dementia secondary to disease (Jellinger, 2006). Symptoms include impairment of short-term memory, difficulty in verbal communication and decision making, difficulty in carrying out complex activities of daily living (ADL) and changes in mood and behaviour. With disease progression, individuals become more forgetful, have increased difficulty in communication, are unable to perform basic ADL and live independently and may display inappropriate behaviour such as wandering, hallucinations and disinhibition (Reisberg, 2006). The amount of informal caring for an

¹ Department of Pathology, Faculty of Medicine & Surgery, University of Malta. (charles.scerri@um.edu.mt)

individual with dementia is also related to progression with half of the caregivers spending more than ten hours a day in caring for an individual with late-stage dementia compared to 20 per cent for early-stage dementia (Georges et al., 2008). For the most common form of dementias, no cure exists that stops or reverses the observed brain cell death.

According to Alzheimer's Disease International, the total number of people with dementia worldwide is projected to almost double every twenty years reaching 75.6 million in 2030 and 135.5 million in 2050 (Alzheimer's Disease International, 2013). Much of this increase is attributed to low- and middle-income countries, and driven by population growth and demographic ageing (World Health Organization, 2012). The global societal costs of dementia are enormous as the total estimated worldwide expenditure for the year 2015 was calculated to reach US\$818 billion (Alzheimer's Disease International, 2015).

In the recent years, there has been a significant shift in advancing the dementia agenda on the global stage. In the European Union (EU), research on neurodegenerative disorders has been strengthened as part of the Health Theme within FP7 (2007-2013) with special reference to brain research and particular emphasis placed on translational research and the development of new drugs. In 2011, the European Parliament adopted a resolution calling for dementia to be made an EU health priority and urging member states to develop dedicated national plans and strategies with the aim of addressing the social and health consequences, as well as services and support for affected individuals and their family members. Taking action against dementia through various intervention streams such as strengthening capacity, leadership, governance, risk reduction, public awareness and facilitating technological and social innovations was one of the main recommendations put forward by the World Health Organization (WHO) in its first Ministerial Conference on Global Action Against Dementia organized at the beginning of 2015. The Organization for Economic Co-operation and Development (OECD) also identified dementia as an increasing threat to global health and recommended member countries to strengthen health and social care systems in order to improve care and services for people with dementia.

As a consequence of the need to address the challenge of dementia, and following the example of other European countries including the United Kingdom and France, Malta embarked on a nationwide consultation process, starting in 2009, with the aim of developing a holistic approach towards dementia management and care through policy development that focuses on issues including awareness, the provision of high quality dementia care, development of an able work force and increase in funding. Following numerous discussions with stakeholders, a policy document was published and officially launched in April 2015 making Malta the 21st country to have a national dementia plan worldwide.

Dementia in Malta

The first study to determine the prevalence rates of dementia in the Maltese Islands was published in 2007 (Abela et al., 2007). Using the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) data methodology, it reported that in 2050, the number of individuals with dementia would reach 6,369, accounting to 2

per cent of the Maltese population. This data was revised in another study published in 2012 (Scerri & Scerri, 2012) using the latest prevalence rates as reviewed by the EuroCoDe project (Table 1). The results showed that the estimated number of individuals with dementia in Malta in 2010 was 5,198; a significant increase from the previous predicted data. Likewise, the number of dementia individuals over the age 60 in 2030 is projected to be close to 10,000 or 2.3 per cent of the total population. Thus the 2 per cent estimate will be reached in 2025, twenty-five years prior to what was previously reported. This discrepancy between the two prevalence set of data originates mostly from the oldest-old age groups, the latter being underreported in previous estimation studies. The significant increase reaching 3.6 per cent of the Maltese population over the next 50 years will invariably put greater demands on the already stretched national health care services resulting in considerable socioeconomic consequences.

Although state-run services for individuals with dementia and their caregivers have received a boost recently, they remain limited and currently not meeting the demands of the ever increasing number of diagnosed dementia cases. Two dementia activity centres are currently available, one located within the premises of the largest long-term residential care facility in Malta with the other located in the sister island of Gozo. This service provides an opportunity of social interaction for residents and non-residents with dementia. Rehabilitation services, a Memory Clinic, respite care and a round-the-clock Dementia Helpline are also offered and managed by staff comprising interdisciplinary healthcare professionals. With few exceptions, none of the privately owned residential homes are dedicated to solely cater for the needs of individuals with dementia. In 2015, the Dementia Intervention Team was launched with the objective of having a number of multidisciplinary professionals providing support to community-dwelling individuals with dementia and their caregivers. In late 2012, in conjunction with the introduction of donepezil in the government formulary list, there was the setting up of dementia clinics in the community intended to offer support to the already existing Memory Clinic and the Cognitive Behavioural Disorders Clinic within the Neurology Department at Mater Dei Hospital, the latter being the main and largest acute hospital in the Maltese Islands. Although free drug entitlement is only authorized by consultant geriatricians, neurologists and psychiatrists in patients with a Mini Mental State Examination score ranging from 13-26, all treatment options are available as an out-of-pocket expense from community pharmacies following prescription by any medical practitioner. To date, no protocol exists on the use of medication to control the behavioural and psychological symptoms of dementia (BPSD) experienced by the majority of individuals with dementia. Interestingly, these drugs are rarely used in Malta among in-patients with dementia (Scerri, Abela & Innes, 2010).

Table 1. Estimated number of gender-specific cases of individuals with dementia (IWD) in the Maltese Islands according to age groups using EuroCoDe data for the years ranging from 2010 to 2060. Data shown as M/F (M: males; F: females) (adapted from Scerri & Scerri, 2012).

Age groups	Year						
	2010	2015	2020	2030	2040	2050	2060
60-64	30/139	27/124	27/127	21/100	27/123	29/127	25/105
65-69	179/154	240/201	223/186	217/177	198/164	234/193	246/185
70-74	242/346	246/344	381/513	376/493	292/391	382/488	419/507
75-79	367/577	419/601	446/616	671/871	677/847	639/800	777/959
80-84	448/834	493/945	620/1038	1100/1672	1154/1681	946/1380	1306/1784
>85	483/1399	619/1812	750/2248	1164/3021	2012/4806	2337/5400	2356/5368
Total IWD	5198	6071	7175	9881	12372	12957	14037
% of the population	1.24	1.47	1.73	2.37	3.04	3.26	3.62

Dementia awareness and support in the community mostly comes from the Malta Dementia Society. This non-governmental, non-profit organization was launched in 2004 with the aim of increasing awareness on dementia care and management in the Maltese Islands through the organization of talks and seminars for individuals with dementia, their caregivers and healthcare professionals. Another important aim of the society is that of collaborating with the central health and social care authorities to improve and design new services that enhance the quality of life of individuals with dementia. As previously highlighted, most of the dementia care is provided by family members in the community. A study on the organization of dementia care in the Maltese Islands found significant difficulties in providing care for a relative with dementia (Innes, Abela & Scerri, 2011). Furthermore, caregivers views of formal services were dismissive as to their lack of suitability for their or relatives' needs.

Dementia in Malta: policy development

Given the huge burden of dementia, the challenges facing governments worldwide in terms of social, medical and economic aspects are considerable. In these last few years, there has been an increase in recognizing the extent of this problem and the need to take action. Apart from Malta, only a few countries have dementia plans and policies in action that address the key aspects that dementia pose on the society in general (World Health Organization, 2012). In the beginning of 2009, the Malta Department of Health, through its then Parliamentary

Secretariat for the Elderly and Community Care, launched the National Dementia Strategy Group with the aim of identifying a number of recommendations that would provide a strategic framework in order to deliver quality improvements in local dementia services and address any local shortfalls in dementia care (Scerri, 2012). The work undertaken at the time included a detailed analysis of services that were available to individuals with dementia and their caregivers, a consultation process with stakeholders working in the field of dementia management and care including professional bodies, and a questionnaire designed for the public in order to obtain feedback regarding the various aspects of informal dementia care. The general findings, as highlighted in a report presented to the health authorities in January of 2010, included:

- a. Considerable lack of support at all levels of dementia care together with a dearth of healthcare staff professionally trained in dementia patient-centred care.
- b. Services available were not tailored for the needs of these individuals, their family members and caregivers.
- c. Professional training at undergraduate and postgraduate level mostly focused on the medical model with very limited emphasis on social models of care.
- d. Basic awareness among the general population was found to be lacking with most individuals adopting a wait-and-see approach towards seeking professional advice.

A number of recommendations were also included, aimed at:

- a. Improving awareness of dementia in the community
- b. Facilitating early diagnosis and intervention
- c. Providing information at the point of diagnosis and beyond
- d. Increasing knowledge of services that are already available
- e. Enhancing the quality of care in acute and long-term settings
- f. Strengthen community support services
- g. Providing end-of-life support services
- h. Adopting an ethical approach to dementia management and care

Following the publication of this report, a number of government-led initiatives were launched. These included the addition of one anti-dementia medication (donepezil) on the national drug formulary, the collection of data on the number of dementia cases, the publication of a number of information booklets to increase awareness among the general public and the delivery of training sessions on dementia care to healthcare professionals and support staff working in long-term residential/nursing homes. With a change in government in 2013, a National Focal Point on Dementia was appointed with the aim of advising the local authorities on measurements that need to be adopted in order to improve the quality of lives of individuals with dementia, their caregivers and family members. This included the revision of the 2010 recommendations and the drafting of a dementia strategy for the Maltese Islands.

Concurrently, research interest in the field of dementia increased significantly at the University of Malta, the latter being the only tertiary-level academic institution in the Maltese Islands. As a result, a number of research initiatives related to dementia policy development were conducted in recent years. These included investigating the organisation of dementia care by families in Malta (Innes, Abela & Scerri, 2011), knowledge and attitudes of nursing students towards dementia (Scerri & Scerri, 2013), the role of general practitioners in diagnosing, disclosing and pharmacotherapeutic management of dementia (Caruana-Pulpan & Scerri, 2014), hospital staff perceptions of dementia care (Innes *et al*, 2016), implementation of person-centred dementia care programmes in hospital wards (Scerri, Innes & Scerri, 2016), knowledge and pharmacological management of Alzheimer's disease by managing community pharmacists (Zerafa & Scerri, 2016), training of older adults about Alzheimer's disease (Scerri & Scerri, 2016) and knowledge of Alzheimer's disease and training needs in final year medical and pharmacy students (Scerri, 2016). Complimentary to this, the University of Malta launched, in February of 2016, a Master in Arts degree programme in ageing and dementia studies with the objective of empowering professionals working in the gerontological and geriatric setting to be leaders in future dementia care.

The road towards empowering change

In April of 2015, Malta officially launched its national dementia strategy titled 'Empowering change: a national strategy for dementia in the Maltese Islands (2015-2023)'. It highlights various measures that need to be implemented in order to enhance the quality of life of individuals with dementia, their caregivers and family members. The vision of this strategy is for people in various sectors of society to come together and create a system whereby individuals with dementia have access to the support and care they require. Dementia also has a profound effect on relatives and caregivers and thus the policy document is also aimed to address their needs as part of the holistic approach to dementia care.

The strategy outlines a number of recommendations spread out over 6 interventions streams that include; an increase in awareness and understanding of dementia, the provision of timely diagnosis, the availability of a trained workforce, improving dementia management and care, promoting an ethical approach to dementia care and strengthening research in this field (Table 2). Its implementation will run till the year 2023. Due to the challenging nature of dementia, this exercise will entail substantial investment in human, financial, technical and infrastructural resources. However, the gradual delivery of the objectives is projected to have a considerable positive impact on the quality of life of individuals with dementia, their family members and caregivers. The latter are carrying an enormous burden and thus require more solidarity from the government and society in general.

Since its launch, a number of recommendations have already been implemented. In the intervention stream of workforce development, all nursing staff working in the area of long-term care has attended an extensive training course in dementia care and skills development. This 14-hour programme was jointly financed by the Maltese government and the European Social Fund. Initiatives in other intervention streams included the extension in operation of the Dementia Helpline, the opening of a new dementia activity centre in Gozo,

the opening of new hospital wards for individuals with dementia, the launch of new information booklets intended for the general public and community caregivers, the organisation of dementia training programmes in all day centres for the elderly and the launch of the Dementia Intervention Team, the latter composed of multidisciplinary professionals that offer support to community-dwelling individuals with dementia. A pilot project on dementia-friendly communities has also started in the village of San Lawrenz in Gozo.

Table 2. Streams of interventions, objectives and main recommendations of the National Strategy for Dementia in the Maltese Islands (2015-2023)

Interventions	Objectives	Main recommendations
Increase awareness and understanding of dementia	Changing the perception of dementia Encourage help seeking Provide guidance	Continuing information campaigns Appointing Dementia Activists Online guide on dementia caregiving Promote the work of civil society organizations Strengthening of the Dementia Helpline
Timely diagnosis and intervention	Improve diagnosis at an early stage Provide information on available services upon diagnosis Timely access to care	Promote the value of early diagnosis in primary care Enhance training in dementia diagnosis, disclosure and management to primary care physicians Setting up of Dementia Intervention Teams Development and distribution of information at the point of diagnosis and beyond
Workforce development	Ensure health and social care professionals working with individuals with dementia receive specialized training	Provision of dementia patient-centred care training to the workforce Supporting information technology platforms that facilitate online training Continuous professional development programmes
Improving dementia management and care	Availability of all dementia medications on the drug formulary Improve care delivery Provide community support Implementation of dementia-friendly measures	Full access to medication and regular review Establishing training opportunities in non-pharmacological methods Ensure individuals with dementia have a care plan Involvement of all stakeholders in decision taking Increase respite facilities Implementation of dementia-friendly design Availability of palliative care support Ensuring the necessary quality standards in residential/nursing settings

Interventions	Objectives	Main recommendations
Ethical approach to care	Promote an ethical approach to dementia management and care	Provision of training in ethical decision taking, respect for personhood and wellbeing Promoting the use of advanced directives Provision of psychological support services Adoption of the 'partners in care' approach Monitoring of abuse
Research	Promote and foster research in the field of dementia	Ensure that dementia becomes a national research priority Facilitate access to clinical trials Enhanced participation in European and pan-European research projects on dementia

During the implementation process, a number of gaps may become apparent. Interim evaluations will be carried out to gather new information and assess the usefulness of different projects being proposed in the various areas of dementia care. This will aid in further detailed planning of long-term objectives. Moreover, the implementation exercise is expected to reveal other important needs that will require assessment and further plans to adequately address them. Individuals with dementia, their family members, caregivers and policy makers all expect to see progress in a cost-effective way. It is therefore important that the results achieved are regularly communicated to the general public in an efficient and comprehensible manner.

Conclusion

There is little doubt that dementia will pose one of the greatest societal and health challenges that must be addressed nationally as well as at personal and family level. The huge costs involved in its care and management will challenge health systems worldwide with the predicted increase in the prevalence rates in line with an ageing population. Dementia is also overwhelming for family carers who often feel that they are left to fend on their own due to the lack of adequate support that promotes independence and wellbeing. Community support is needed to enable informal carers to continue in their caring role for as long as possible and should involve respite services and financial support. Moreover, training for healthcare professionals should be expanded and include multidisciplinary educational programmes focusing on patient-centred dementia management and care. The organization of effective campaigns that enhance public understanding of dementia will not only reduce misconceptions, stigma and discrimination but will invariably aid in timely diagnosis and support seeking. The full implementation of the national dementia strategy, aimed at holistically addressing the dementia challenge, will undoubtedly have a positive impact on the quality of life of individuals with dementia in the Maltese Islands.

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