Dementia Report

2014/2015

DHIR
DIRECTORATE FOR HEALTH INFORMATION AND RESEARCH

Document Information

Document reference	DHIR/MDR/2014,2015
Current version	1.0
Release date	May 2016
Document owner	Directorate for Health Information & Research
Website	http://health.gov.mt/en/dhir/Pages/Registries/dementia.aspx
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Version Control

Version	Date	Action	Name
1.0	May 2016	Compilation	Dr Jason Attard Dr Kathleen England

Comments

The accuracy of information contained in this document may be limited by factors beyond the author's control. Some data in this document may be subject to interpretation. Users should always acknowledge the source in all works based on information supplied in this document.

We encourage doctors to fill in the dementia forms according to all information that is available as the absence of important variables e.g. date of incidence, MMSE and Barthel score limits the analysis of data that can be performed.

Acknowledgements

This report would have not been possible without the collaboration of geriatricians, neurologists and psychiatrists who duly filled in the Dementia Register Forms as well as the the Pharmacy of Your Choice in Malta and Gozo who also collaborated in the collection of data. The compilers of this report would also like to acknowledge the support of colleagues and the Director, Dr Neville Calleja, at the Directorate for Health Information and Research. Special thanks go to the significant work of the Dementia Registry staff namely Mr Anthony Spiteri who constantly updates the Dementia Registry.

Acknowledgments are also due to Dr Stephen Abela who was instrumental in the formulation of the dementia registry forms and Dr Analise Buttigieg who was instrumental in the development of the structure of the First Dementia Report.

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Abbreviations and Acronyms

CdB – Common database

DHIR – Directorate for Health Information and Research

GC – Gozo and Comino

MMSE – Mini Mental State Examination

NH – Northern Harbour district

NICE – National Institute for Health and Clinical Excellence

NO – Northern district

PAS – Patient Administration System

SE – South Eastern district

SH – Southern Harbour district

WE – Western district

WHO – World Health Organisation

Executive summary

- This second report is based on data collected in the Dementia Register from the inception of the register in 2013 till the end of December 2015 with an emphasis on the newly collected data in 2014 and 2015.
- The number of prevalent cases registered in the dementia register from the start of the register in 2013 to the end of December 2015 was 1145, with a male to female ratio of 1:2.5. The mean age of this cohort alive at the end of 2015 was 80 years and age-specific prevalence rates increased with age.
- The mean age at diagnosis of persons diagnosed with dementia in 2013, 2014 and 2015 were 79.2, 79.1 and 79.2 years respectively. More cases were diagnosed in the younger age groups in 2014 and 2015 compared to 2013. However one most note that 2013 was the first year of data collection with a back-log of cases awaiting anti-dementia medication.
- In males, crude prevalence rates were highest in the Northern Harbour region, while in females rates were highest in the Southern Harbour region. Standardised rates showed highest rates in the South Eastern harbour in males and similarly in females. Rates were lowest for Gozo, however since data collection started recently there, this cannot be compared with other regions at this point.
- Alzheimer's disease was the most common type of dementia reported in 2014 and 2015 (63.6%) followed by Mixed dementia (12.0%) and Vascular dementia (10.2%).
- Mean MMSE score for males was 20.8 and 21.8 for cases diagnosed in 2014 and 2015 respectively. Mean MMSE score for females was 20.2 and 20.0 for 2014 and 2015 respectively.
- Out of the 657 cases reported in 2014 and 2015, 523 (79.6%) lived in private households (the community) and 96 (14.6%) lived in an institution.
- People with dementia living in an institution were more likely to be suffering from moderate dementia (66.7%) than mild dementia (30.2%) for cases reported in 2014/2015. However quite a high percentage of persons who lived in the community had moderate dementia (45.3%).
- Also persons with dementia living in the community were more likely to have a low dependency level compared to those living in an institution.
- The main carer for persons with dementia living in the community was the spouse (wife 18.9% husband 17.4%) followed by the daughter (24.7%).

The Burden of Dementia

Dementia is a term which refers to a group of diseases which affect the brain. The characteristic symptoms include a progressive decline in short and long term memory loss, impairment in reasoning, judgement and communication, personality change and difficulty with day-to-day tasks.

Alzheimer's Disease International (ADI) estimated that 46.8 million people were living with dementia worldwide in 2015. This is expected to increase to 74.7 million in 2030 and reach 131.5 million by 2050 [1]. Locally, it was estimated that approximately 6,071 people were living with dementia in 2015. It is expected to affect 9,883 individuals in 2030 and 13,000 individuals in 2050 [2]. The rising prevalence is mainly due to population ageing. This phenomenon occurs when the median age of a country or region increases due to an increase in the life expectancy coupled with a decrease in the fertility rate. However, according to Wu et al., the number of people with dementia in some western European countries is stabilising. This is possibly related to improvements in education, social determinants of health and health behaviours [3].

The economic impact of dementia is enormous. ADI estimated that the global cost of the disease increased from US$ 604 billion in 2010 to US$ 818 billion in 2015 [1]. In the European Union, the total cost of illness of dementia was estimated to amount to approximately €160 billion in 2008 [4]. In Malta, the cost of dementia was estimated between €63.1 - €96.2 million (Wimo et al., 2010) in 2009 [5]. These figures include both direct costs of medical and social care, and indirect costs of informal care. Medical care accounts for approximately 20% of the total costs. The costs of social care and informal care each account for approximately 40% [1].

The burden of dementia must be recognised as a public health priority. So far only 13 out of 193 WHO countries have national dementia plans in place [6]. At a local level, the National Strategy for Dementia in the Maltese Islands (2015-2023) was officially launched by the Parliamentary Secretary for the Rights of Persons with Disability and Active Ageing on the 2nd of April 2015 [7].

Methods

In 2013, the Directorate for Health Information and Research (DHIR) started the collection of data to set up a Dementia Register. Various stakeholders were consulted in order to verify which variables should be captured and which sources of information should be utilised.

This registry collects information on all patients in the Maltese Islands who were diagnosed with dementia and who were deemed eligible for dementia treatment as per Government Formulary List. Geriatricians, neurologists and psychiatrists complete the Dementia Register form entitled '*For persons on anti-dementia medication D1'* (Appendix 1) along with the Schedule V form when applying for anti-dementia medication. Information on patients who do not fulfil the criteria for eligibility for dementia treatment on the Government Formulary List but attend outpatient clinics seeing persons with dementia, is entered in a different Dementia Register form '*For persons not applying for anti-dementia medication D2*' (Appendix 2). These forms are subsequently sent to the DHIR to be inputted in the Dementia Registry. Data is collected in collaboration with the Pharmacy of Your Choice in Malta and Gozo.

This report is based mainly on data which was received and entered in the Dementia Register between the beginning of January 2014 and end-December 2015, however data for all cases entered from the inception of the register in 2013 is also included in certain areas of this report. During this period, information on new patients was collected, checked, validated (demographic data was confirmed and verified with the Patient Administration System (PAS) and Common Database (CdB) and entered in the register.

The Mini Mental State Examination (MMSE) was used to assess the cognitive status of patients. This is usually scored out of a possible maximum score of 30 points. In the section regarding dependency, scores were compiled using the 20-point Barthel Index.

It is important to note that the figures in this report are likely not to reflect incidence or prevalence of persons with dementia in Malta and Gozo, which are estimated to be much higher. There are a number of reasons for this including the fact that the first anti-dementia drug to be added to the Government Formulary List was late in 2012 and that the dementia register is currently still in its infancy. Furthermore, although doctors are encouraged to complete either the D1 or the D2 form according to the case, the vast majority of forms received were D1 i.e. for those applying for the anti-dementia medication and therefore having an MMSE score according to certain entitlement criteria. Furthermore, persons with dementia may not access clinics run by geriatricians, neurologists or psychiatrists.

The dementia register has also recently started to include (from 2014) cases applying for anti-dementia medication in Gozo thus enriching the register and giving it a more national representation.

1. Demographic Characteristics

1.1 Overview

Between the beginning of January 2013 and the end of December 2015, a total of 1350 cases were entered in the Dementia Register. Of these, 410 (30.4%) were male and 940 (69.6%) were female. Of these, 205 persons died during this period. Therefore the number of prevalent cases registered in the dementia register by the end of December 2015 was 1145.

The mean age of this cohort alive at the end of 2015 was 80 years and by gender were 80 and 81 years for males and females respectively. Predominance in female numbers and age-specific prevalence rates were noted in almost all age groups of people suffering from dementia (Table 1).

Age Group (years)	Live cohort of persons with dementia at end 2015		Age-specific rates per 1000 population*	
	Females	Males	Females	Males
55-59	4	4	0.3	0.3
60-64	17	8	1.2	0.6
65-69	42	24	2.8	1.7
70-74	83	37	9.1	4.7
75-79	172	67	21.1	10.6
80-84	248	98	41.6	27.2
85-89	172	65	53.2	36.4
90-94	64	23	50.5	42.3
95+	14	3	44.2	29.1
Total	**816**	**329**	**3.8**	**1.5**

***mid-year population 2014 was used to calculate age-specific rates**

Table 1 - Number and age-specific prevalence rates of people registered in the dementia register and alive at end 2015, by gender and age group

Scerri and Scerri estimated that the number of people with dementia in Malta in 2015 was 6,071. This represents 1.47 % of the total population [2]. The number of people with dementia as a percentage of the total population is somewhat lower than the 2012 EU average of 1.55% [8]. The total prevalent cases within the dementia register at the end of 2015 represent 0.27% of the total population which is much lower than 1.47% estimated by Scerri and Scerri. This is due to a number of reasons including the fact that the dementia register is still in its infancy, it mainly captures individuals who are taking anti-dementia

drugs on the Government Formulary List as per entitlement criteria and also because it is well known that a number of dementia cases remain undiagnosed and therefore untreated.

1.2 People with dementia by age at diagnosis and gender

Date of diagnosis was stated for 389 cases out of the 657 persons on the dementia register from the beginning of 2014 to the end of 2015 (59%). The rate of reporting date of diagnosis fell from a 72% in 2013.

The mean age at diagnosis of persons diagnosed with dementia in 2013, 2014 and 2015 were 79.2, 79.1 and 79.2 years respectively.

As shown in Figure 1, most cases were diagnosed in the 75-84 age group. More cases were diagnosed in the younger age groups in 2014 and 2015 when compared to 2013 while the opposite is true for the 85+ age group. However one must note that 2013 was the first year of data collection with a back-log of cases awaiting anti-dementia medication.

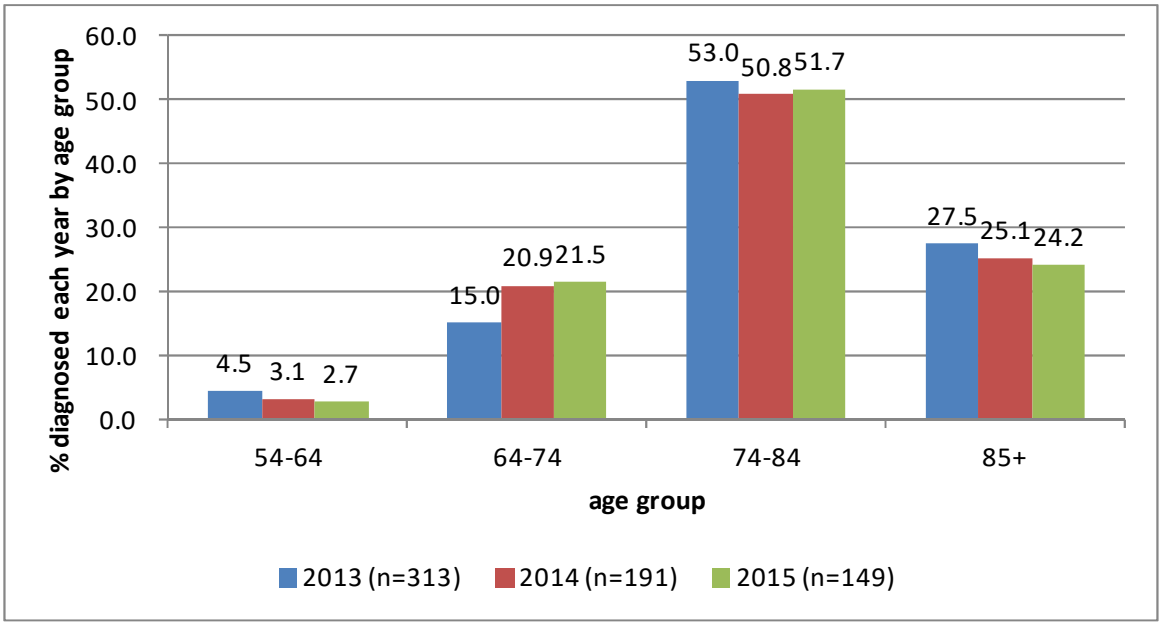

Figure 1 – Percentage of people with dementia by age at diagnosis and year diagnosed (n = 313 in 2013; n=191 in 2014; and 149 in 2015)

Dementia can be classified into early onset dementia[1] and late onset dementia[2]. The vast majority were late onset dementia cases, whereas early onset dementia constituted 4.5%, 3.1% and 2.7% of all cases diagnosed in 2013, 2014 and 2015 respectively (Figure 1).

The mean age at diagnosis amongst females was 80.0, 79.2 and 79.4 years for 2013, 2014 and 2015 respectively. The mean age at diagnosis amongst males was 77.4 and 79.0 and

[1] Dementia onset before the age of 65 years
[2] Dementia onset after the age of 65 years

78.7 years for 2013, 2014 and 2015 respectively. The female to male gender ratio of people diagnosed with late onset dementia was 2.3.

The above findings compare favourably with a report on dementia in the UK in that females with late onset dementia predominate over males with approximately 2 women for every man affected [9].

1.3 Educational level

The educational level completed was stated for 611 dementia cases from a total of 657 cases diagnosed in 2014 and 2015. The majority of patients (421 cases, 64.1%) had only completed up to a primary level of education. There were 148 cases (22.5%) that had completed up to secondary level of education, with the numbers decreasing down to 28 cases (4.3%) for those achieving a post-secondary educational level and 14 cases (2.1%) for those completing tertiary education. There were 46 cases in which the educational level was unknown.

As seen in Figure 2, males tended to have a higher level of education completed when compared to females. The proportion of females having completed up to primary level of education was 67.5% (310 cases) as compared to 56.1% (111 cases) in males. Inversely, the proportion of males having completed higher educational levels (secondary, post-secondary and tertiary) was 37.9% (75 cases) as compared to 25.1% (115 cases) in females.

Despite these gender differences, primary education was the predominant educational level reached in both males and females, with only a minority reaching the tertiary level of education. These gender discrepancies in educational level are probably related to cultural differences in the exposure to education among males and females in the 1930s.

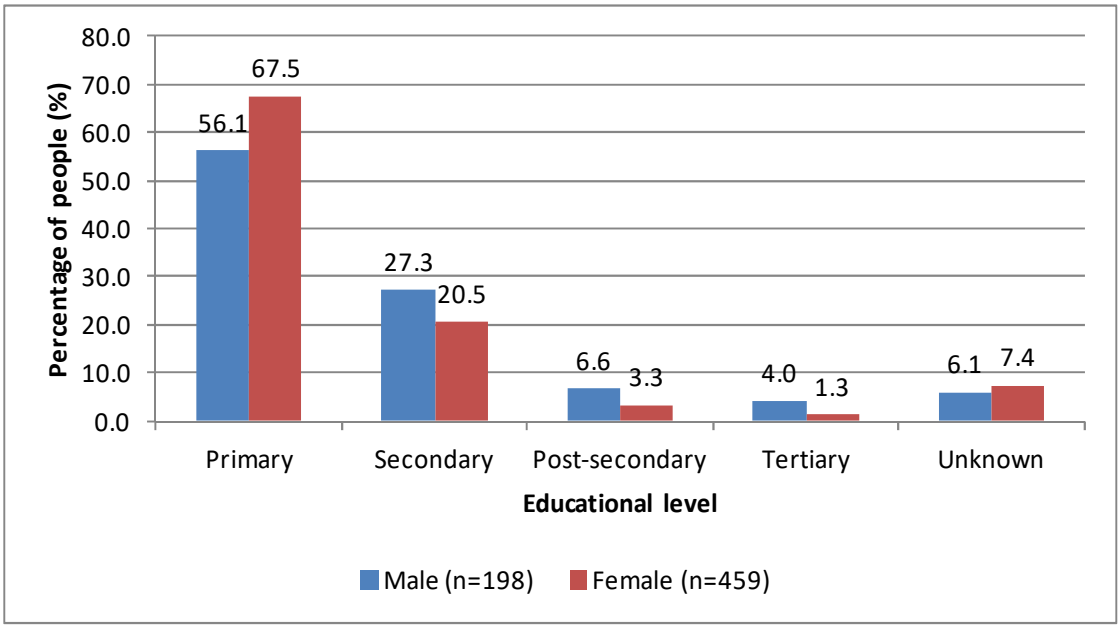

Figure 2 – Comparison of males and females with dementia by educational level completed

1.4 Geographical Distribution

Crude rates by region of residence were calculated for the live cohort of 1145 persons entered in the Dementia Register till the end of 2015. As seen in table 2 below, crude rates for females by region were higher than for males in all regions. In males, crude rates were highest in the Northern Harbour region and lowest in Gozo while in females, rates were highest in the Southern Harbour region and again lowest in Gozo. These rates do not necessarily reflect the geographical distribution of all persons with dementia in Malta and Gozo since as already mentioned, the register is still in its infancy and only captures a selection of persons with dementia. Also collection of cases for Gozo started later (since 2014 rather than 2013) and would need a longer period of time to compare equally with other regions in Malta.

Region	Males		Females	
	Crude rate	95% CI	Crude rate	95% CI
Gozo	89.97	(51.21, 154.99)	164.41	(109.99, 244.55)
Northern Harbour	183.70	(151.56, 222.45)	448.34	(397.63, 505.38)
Northern	148.45	(110.01, 198.60)	346.66	(286.55, 418.97)
South Eastern	175.00	(133.78, 228.38)	328.01	(269.38, 398.98)
Southern Harbour	156.66	(121.53, 202.18)	469.11	(405.47, 542.47)
Western	138.70	(100.41, 190.80)	389.21	(322.57, 469.18)

Table 2a – Crude rates for live cohort (n=1145) by gender and region of residence per 100,000 population using the census population of 2011

Region	Males		Females	
	Age standardized rate	95% CI	Age standardized rate	95% CI
Gozo	154.73	(146.58, 162.88)	295.35	(283.98, 306.72)
Northern Harbour	342.13	(335.71, 348.56)	885.22	(874.73, 895.71)
Northern	377.10	(366.29, 387.92)	931.97	(913.83, 948.51)
South Eastern	500.96	(487.88, 514.04)	935.03	(916.82, 953.23)
Southern Harbour	282.79	(275.75, 289.84)	821.41	(809.63, 833.19)
Western	309.80	(300.16, 319.43)	812.73	(797.75, 827.71)

Table 2b – Standardised rates for live cohort (n=1145) by gender and region of residence per 100,000 population using the census population of 2011

Standardised rates which allow for differences in age structures of the different regions show highest rates in the South Eastern harbour in males and similarly in females. Due to reasons mentioned above comparing rates with Gozo needs a longer time frame.

1.5 Marital status

The marital status was stated for 491 cases out of 657 cases in the Dementia Register in 2014 and 2015 (74.7%). 36.4% were married while those in the single, separated or widowed categories represented 38.4%.

There were many more females who were widowed than males and this is most likely related to a better life expectancy in females in general (Figure 3).

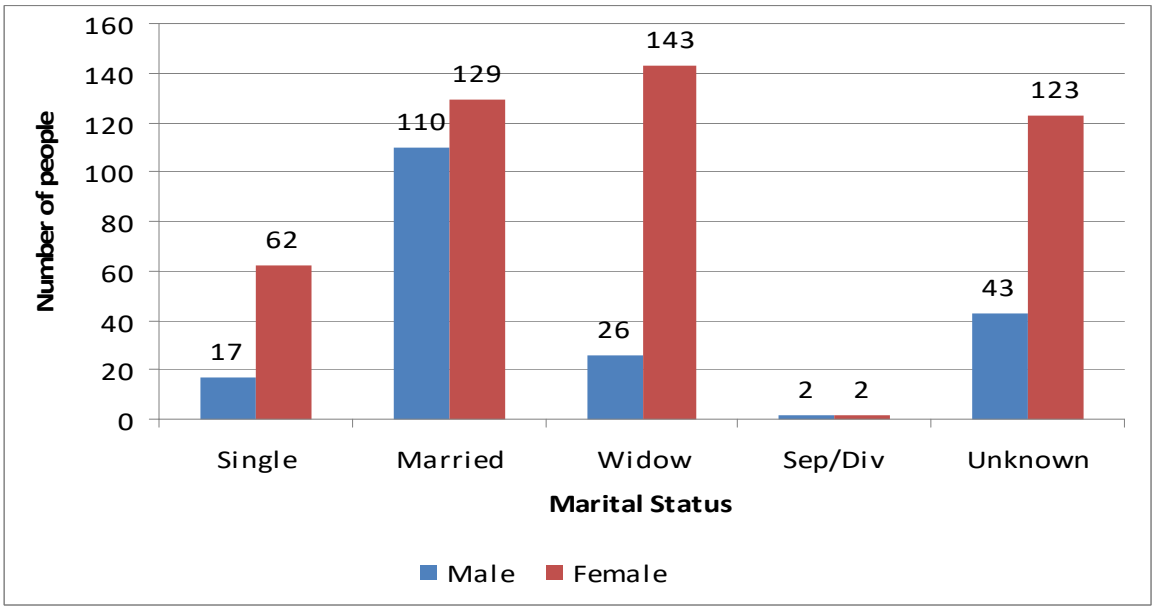

Figure 3 – Number of people with dementia by gender and marital status

2. Dementia Subtypes

The different types of dementia present in the dataset included Alzheimer's disease, Mixed dementia, Vascular dementia, Frontotemporal dementia, Alcohol-related dementia, dementia with Lewy bodies and dementia in Parkinson's disease.

The dementia subtype was stated for 576 cases out of 657 cases entered in the Dementia Register in 2014 and 2015. Of these, 418 cases (63.6%) were reported to have Alzheimer's disease (Figure 4) which was in fact the most dominant subtype. The proportions of the other subtypes are as per Figure 4.

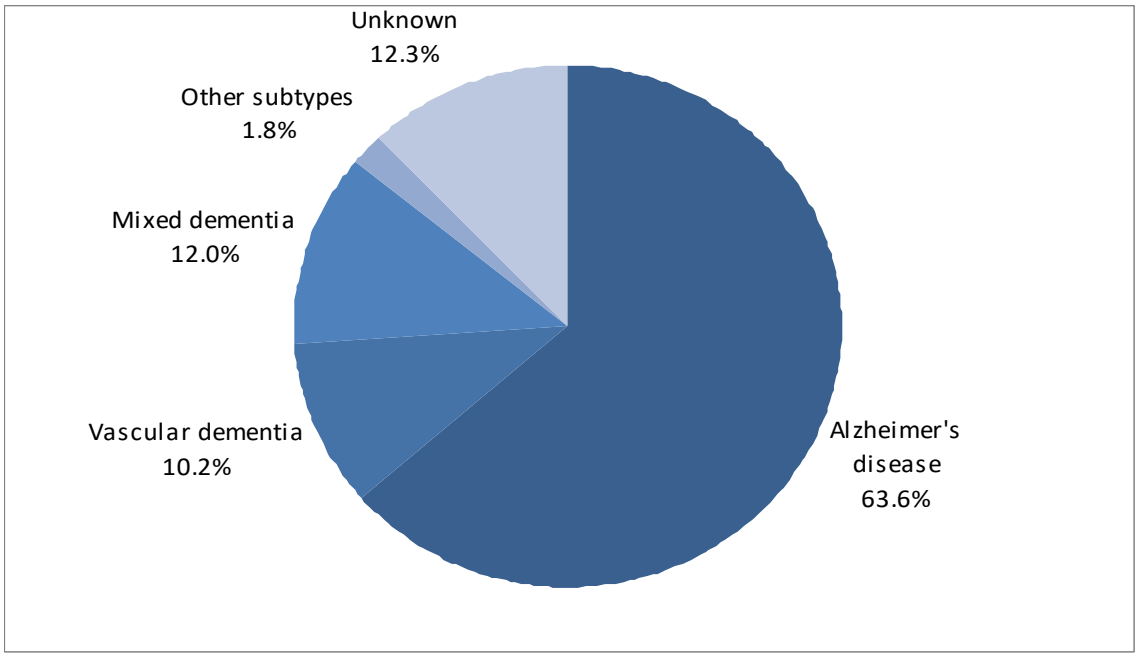

Figure 4 – Percentage of dementia cases by dementia subtype (n=657)

A high proportion of Alzheimer's disease cases may be due to a predominance of D1 forms submitted by doctors when applying for anti-dementia drugs on the Government Formulary List. The set criteria for application for such medication is a diagnosis of mild to moderate Alzheimer's disease. Doctors are encouraged to also complete the dementia register form for persons not applying for the anti-dementia medication (D2), but are being followed up within the out-patients clinics. This would ensure the development of a comprehensive dementia register.

Alzheimer's disease and vascular dementia are the most common causes of cognitive decline in the elderly. However, according to the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS), more than 50% of brains at post mortem showed evidence of abnormalities characteristic of more than one type dementia occurring simultaneously [10].

Figure 5 illustrates the distribution of subtypes between males and females of cases entered in 2014 and 2015. Alzheimer's disease was more common in females and vascular dementia was more common in males.

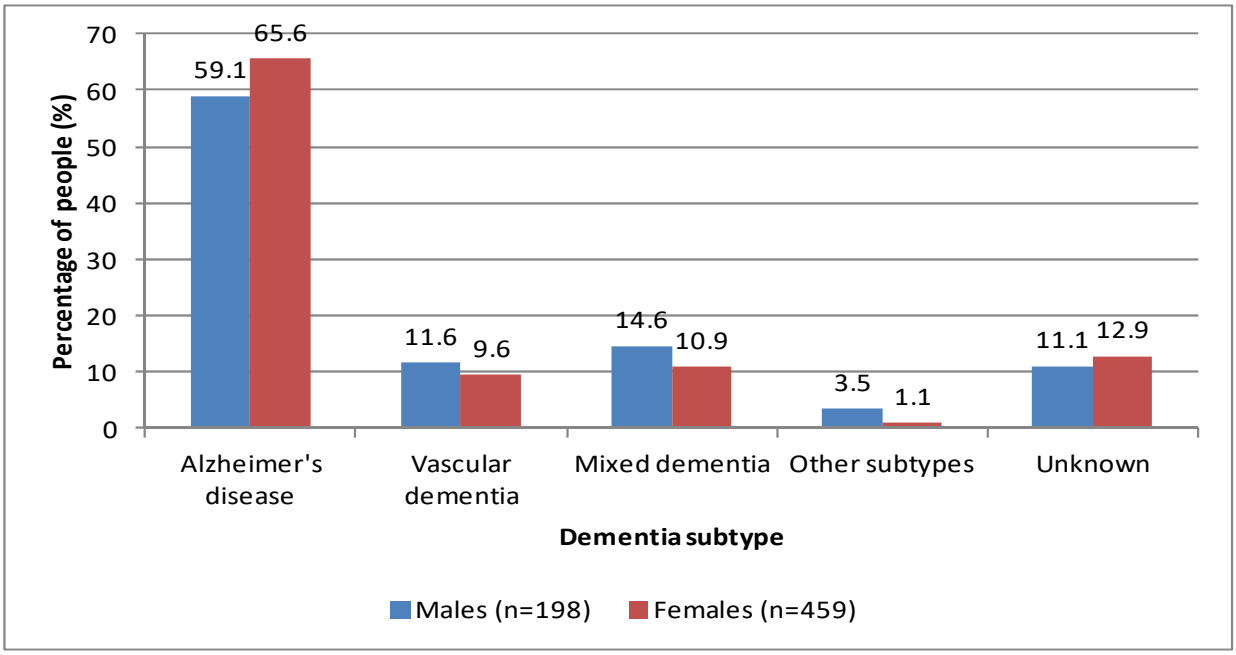

Figure 5 – Percentage of males and females by dementia subtype

Table 3 shows the distribution of people with dementia according to dementia subtype and age at diagnosis for all cases entered in the dementia register from 2013 to date (which were both known in 762 cases). It can be noted that the vast majority of cases in all age groups were clinically diagnosed with Alzheimer's disease.

Dementia Subtype	Age Groups							
	=<64 (n=40)		65-74 (n=164)		75-84 (n=379)		85 & over (n=179)	
	n	%	n	%	n	%	n	%
Alzheimer's	29	72.5	131	79.9	295	77.8	139	77.7
Mixed	7	17.5	21	12.8	59	15.6	22	12.3
Vascular	2	5.0	8	4.9	21	5.5	16	8.9
Other	2	5.0	4	2.4	4	1.1	2	1.1

Table 3 – Distribution of people with dementia by age at diagnosis and dementia subtype

3. Cognitive Decline

The cognitive status refers to a patient's level of alertness, orientation, attention, memory, language functions and executive functions. In dementia patients, the cognitive status deteriorates with disease progression.

The Mini Mental State Examination (MMSE) is a validated tool used to assess the cognitive status of patients. It makes part of a comprehensive assessment of the patient in the diagnosis of dementia [11]. In patients who have already been diagnosed with dementia, the MMSE may help to give an indication of how severe a person's symptoms are, how quickly their dementia is progressing and may act as a guide to the choice of drug treatment [12].

The MMSE consists of a series of questions and tests, each of which scores points if answered correctly. A maximum score of 30 points is possible. The test examines the patients' orientation to time and place, registration (repeating three objects), calculation or attention, recall ability, naming two items shown, repetition of a phrase, following a verbal and a written command; writing a sentence and construction (copying a diagram).

When using the MMSE test one should take into account factors such as the educational level, any physical, sensory (such as blindness) or learning disabilities, or communication difficulties that could affect the results and make appropriate adjustments accordingly.

The patients were classified into normal, mild, moderate and severe categories of cognitive decline depending on their MMSE score. According to the National Institute for Health and Clinical Excellence (NICE) guidelines, a score of 21-26 is indicative of mild Alzheimer's disease, 10-20 moderate Alzheimer's disease and a score less than 10 is consistent with severe dementia [13].

Of the 657 cases entered in the dementia register during 2014-2015, 191 cases were diagnosed in 2014 and 149 cases were diagnosed in 2015. 317 cases were either diagnosed in previous years or date of diagnosis was not stated. Analysis of MMSE scores was done for cases diagnosed in 2014-2015 in order to get a picture of the severity of dementia in these patients at the time of diagnosis. A mean MMSE score of 20.4 and 20.5 was obtained for 2014 (n=187) and 2015 (n=145) respectively, in cases in which the MMSE score was stated. Mean MMSE score for males was 20.8 and 21.8 for 2014 and 2015 respectively. Mean MMSE score for females was 20.2 and 20.0 for 2014 and 2015 respectively.

The proportion of people diagnosed in 2013-2015 are summarised in Figure 6. Of 191 cases diagnosed with dementia in 2014, a total of 100 cases (52.4%) had mild cognitive impairment with an average score of 23.5, and 87 (45.5%) had moderate cognitive impairment with a mean score of 16.9. Of 149 cases diagnosed with dementia in 2015, a total of 84 cases (56.4%) had mild cognitive impairment with an average score of 23.3, and

61 (40.9%) had moderate cognitive impairment with a mean score of 16.7. There were no cases with severe cognitive impairment at diagnosis for 2014 and 2015.

These MMSE scores may not be truly representative of the MMSE scores of the population of people suffering from dementia. This may be due to the fact that although doctors are encouraged to fill in both Dementia Register forms (i.e. D1 form for persons applying for anti-dementia medication and D2 form for persons not applying for anti-dementia medication), the vast majority of submitted forms were D1 forms which require a patient to have a MMSE score between 13-26 in order to qualify for anti-dementia drugs on the Government Formulary List. Patients with severe cognitive impairment (MMSE score between 0-9) are not eligible for free anti-dementia medication at the point of use, and thus are not picked up by the Dementia Register.

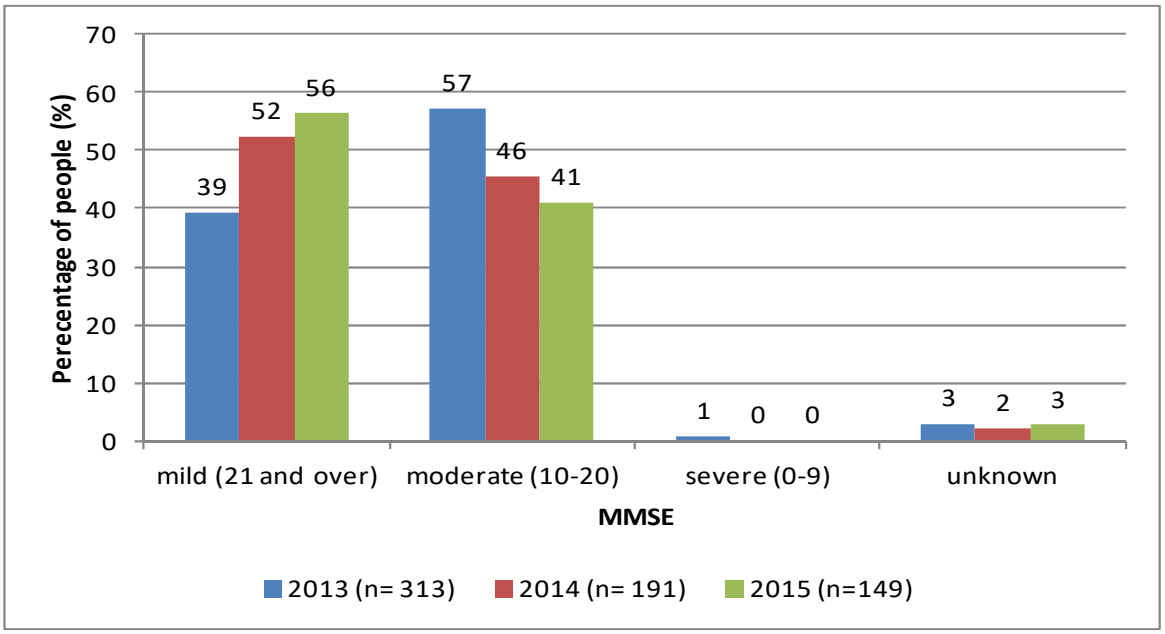

Figure 6 – Stratification of people with dementia diagnosed in 2013-2015 by severity of cognitive impairment (MMSE score)

As shown in Table 4, the younger persons tended to be diagnosed at an earlier stage of dementia, while older persons tended to be diagnosed at a later stage. The mean MMSE score of persons with dementia who were diagnosed in 2013, 2014 and 2015 was seen to decline with increasing age (Figure 7) however they improved over the time period from 2013 to 2015.

Age Group	Severity of cognitive impairment (MMSE score)							
	Mild (n=307)		Moderate (n=327)		Severe (n=2)		Unknown (n=17)	
	n	%	n	%	n	%	n	%
55-64	18	5.9	13	4.0	0	0	0	0
65-74	85	27.7	47	14.4	0	0	3	17.6
75-84	151	49.2	157	48.0	1	50.0	8	47.1
85+	53	17.3	110	33.6	1	50.0	6	35.3

Table 4 – Number of people diagnosed with dementia in 2013, 2014 and 2015 together by age and severity of cognitive impairment (MMSE score)

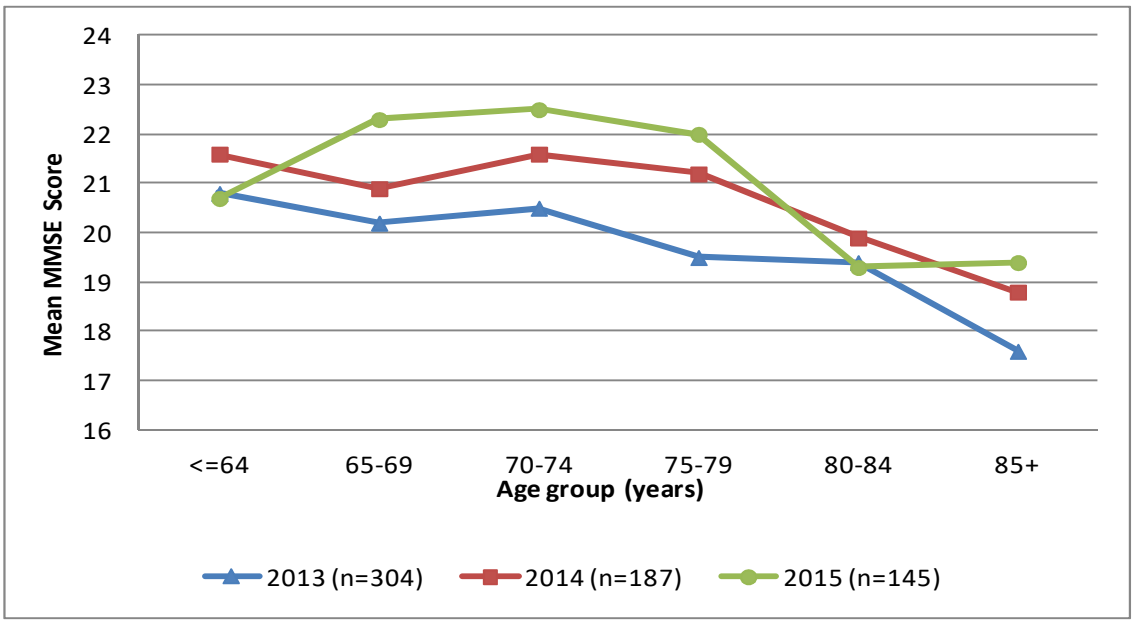

Figure 7 – Mean MMSE score per age group of people diagnosed with dementia in 2013, 2014 and 2015

3.1 Cognitive decline and educational level

A higher educational level is associated with a decreased risk of Alzheimer's disease and other dementias [14]. Research has shown that having more years of education builds a "cognitive reserve" that enables individuals to cope better with changes in the brain without observable clinical deficits in cognition. At a particular level of Alzheimer's disease pathology, highly educated individuals are therefore less likely to manifest clinical symptoms of dementia compared to less-educated individuals [15]. Cognitive tests are likely to have an education bias making it more likely for a highly educated person to obtain a false-negative result on the screening test [16].

Figure 8 looks at the level of education attained by people with dementia grouped according to their level of cognitive impairment. This information was available for 322 cases out of 340 cases diagnosed in 2014 and 2015. 62.4% of those with mild cognitive decline (MMSE score 21 and over) had attained up to a primary level of education. This percentage rose to 78.7% in those with a moderate level of cognitive impairment (MMSE score 10-20). Inversely, there was a higher proportion (27.1%) of people with a secondary educational level among those with mild cognitive impairment compared to those with a moderate level of cognitive impairment (19.1%). There was a clear inverse relationship of cognitive impairment by level of education and this gradient remained the same after adjusting for age.

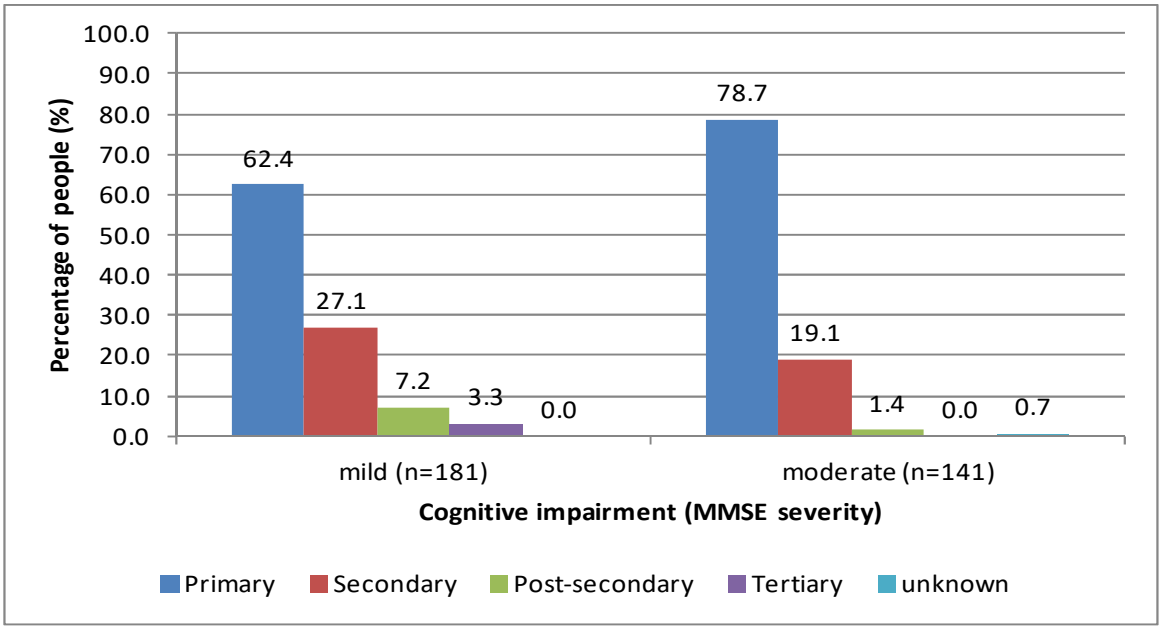

Figure 8 – Percentage of people diagnosed with dementia in 2014 and 2015 by MMSE score and educational level

4. Dependency

Dementia causes a decline in memory, reasoning and communication skills as well as a gradual loss of skills required to carry out daily activities. This leads to the loss of independence and the degree of dependence increases as the disease progresses.

The cases in the dementia register were classified into low, low/medium, medium and high dependency categories according to the Barthel Activities of Daily Living Index [17].

The aim of the Barthel index is to establish the degree of independence from any help, be it physical or verbal in performing activities of daily living. Activities assessed include; bowel and bladder continence, personal grooming, toilet use, feeding, transfer (for example moving from bed to commode), dressing, stair climbing, bathing and mobility. Information is obtained from the patients themselves, from carers and sometimes also by direct observation. Total possible scores range from 0-20, with lower scores indicating increased disability. A score of 13-20 is indicative of low dependency, a score of 9-12 indicates low/medium level of dependency, 5-8 is consistent with a medium level of dependency while a score of 0-4 indicates severe dependency [18].

The Barthel score was stated for 387 cases out of a total of 657 cases received during 2014/2015. The percentage of people where the Barthel score is not indicated has risen from 28.9% in 2013 to 41.1% for cases received in 2014 and 2015. The majority of cases for which the Barthel score was stated had low dependency (Figure 9). For all cases received during 2014/2015, the mean Barthel score was 17.8. The mean score for males was 18.3 and that for females was 17.7.

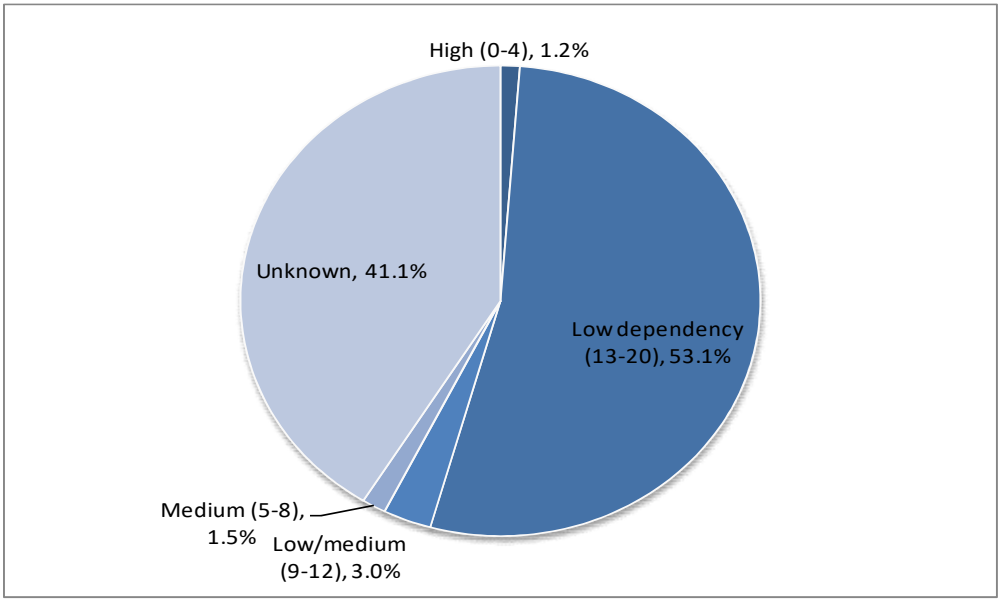

Figure 9 – Percentage of people with dementia by level of dependency (Barthel score)

Figures 10 and 11 depict the mean Barthel and MMSE scores for each age group in persons diagnosed with dementia in 2014 and 2015 respectively. The mean MMSE and Barthel score follows an overall similar pattern, however there was quite a high percentage of missing Barthel scores.

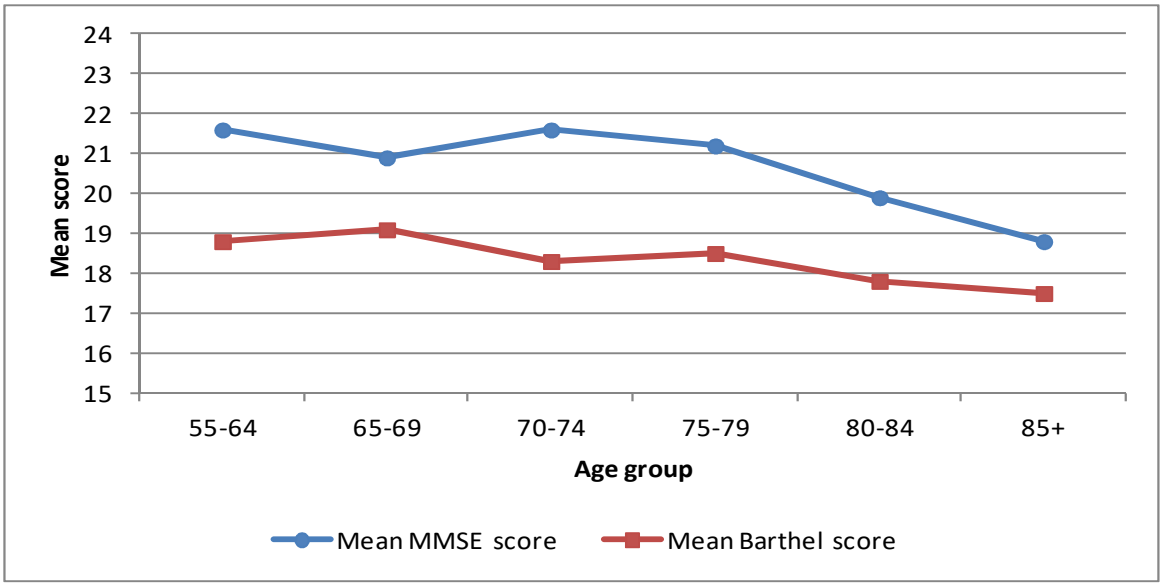

Figure 10 – Mean MMSE and Barthel scores for people diagnosed with dementia in 2014 by age at diagnosis

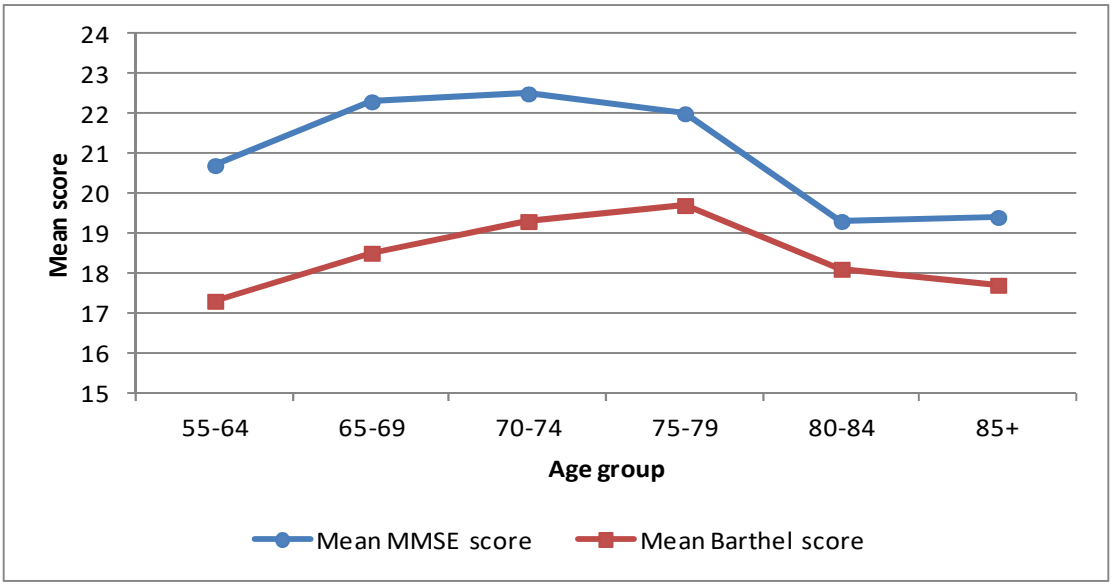

Figure 11 – Mean MMSE and Barthel scores for people diagnosed with dementia in 2015 by age at diagnosis

5. Residential status

The residential status was stated for 619 cases out of 657 cases entered in the Dementia Register in 2014 and 2015. Of these, 523 (79.6%) lived in private households (the community) and 96 (14.6%) lived in an institution. Institutions consisted of Government-owned and private residential care homes found all over Malta.

The proportion of people with dementia living in an institution increased steadily with age, with just 7 cases in the under 75 years age groups, to 36 cases in those aged 75-84, and 53 cases in the 85 plus age group (Figure 12).

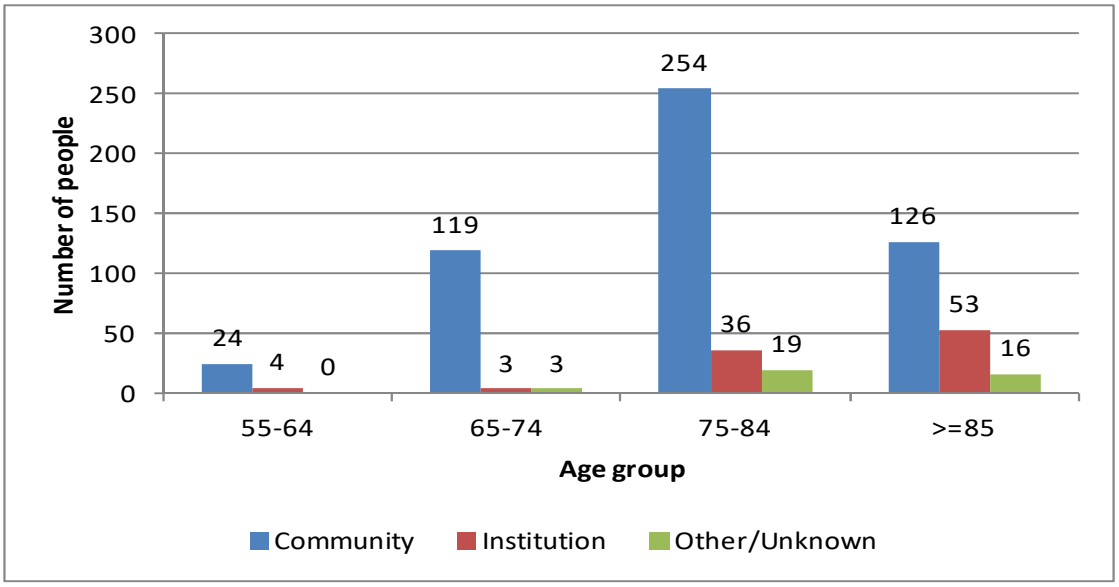

Figure 12 – Number of people with dementia by age and place of residence

The likelihood of people with dementia to be living in an institution rather than in the community was seen to increase with increasing age. This may be explained partially by the fact that as people grow older, informal support decreases because the spouse dies. In fact, only 24.3% of people with dementia living in the community were widowed, in contrast to 32.3% of people with dementia living in an institution being widowed (Figure 13).

A small longitudinal study in the UK found a 20-fold increased risk of institutionalisation among people with dementia without a co-resident caregiver living in the same household as the person with dementia [19]. In addition, with increasing age and with progression of the disease, people with dementia are more likely to suffer disability and become more dependent. This may make informal care insufficient and call for institutionalised care.

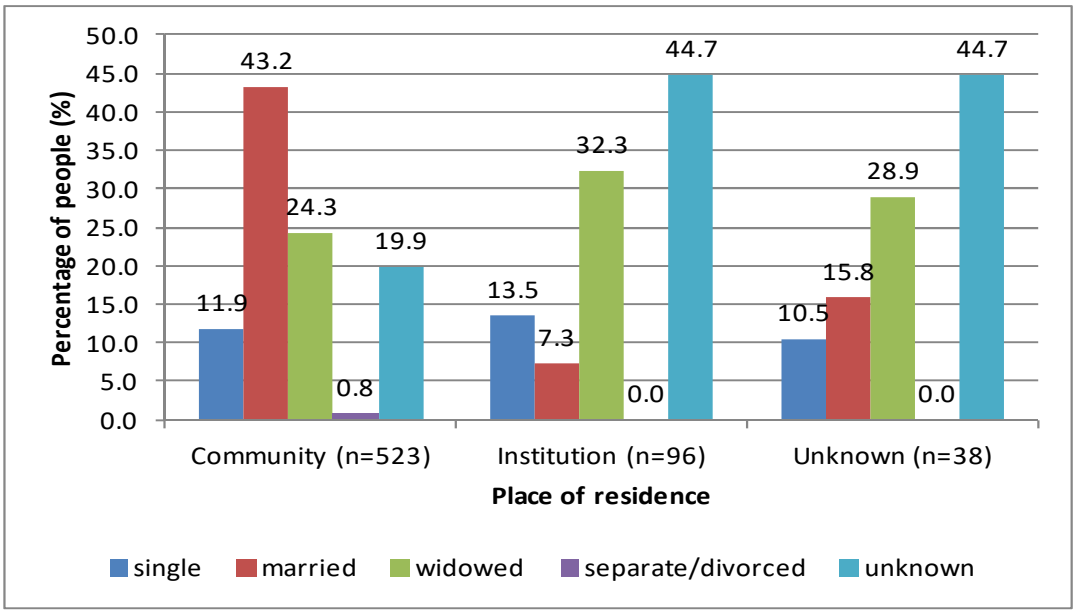

Figure 13 – Comparison of people living in the community with those living in an institution by marital status

In accordance with the above is the fact that when looking at the cohort of people with dementia living in the community, just less than half (250 cases, 47.8%) lived with their spouse, 10.1% (53 cases) lived with their children while 29.3% (153 cases) lived on their own (Figure 14). Out of 73 cases that lived alone, 49.7% had normal or mild cognitive function (MMSE 21 or above), and 46.9% had moderate cognitive impairment (MMSE 10-20).

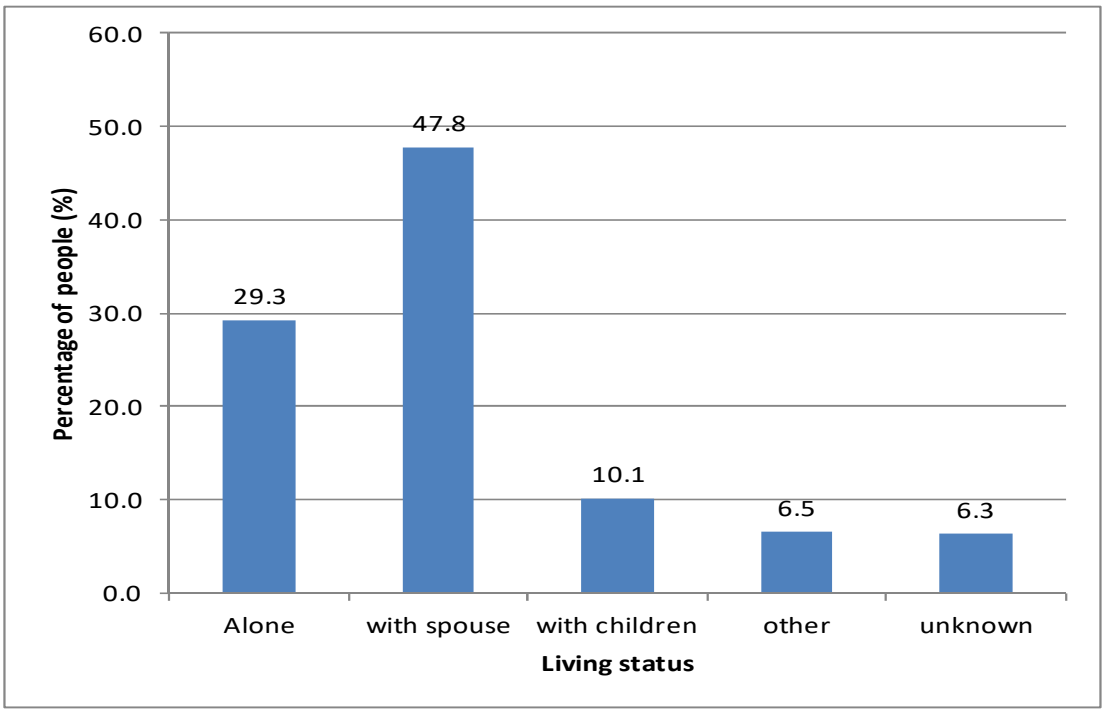

Figure 14 – Percentage of people with dementia living in the community by living status (n=523)

People with dementia living in an institution were more likely to be suffering from moderate dementia (66.7%) than mild dementia (30.2%). However quite a high percentage of persons with moderate dementia (45.3%) lived in the community (Figure 15).

Most persons with dementia living in the community had a low dependency level (59.3%). The dependency level for persons in institutions or where the place of residence was not stated could not be commented upon as the dependency level was left unstated in 57.3 and 60.5% respectively (Figure 16). Dementia and cognitive impairment, contribute to dependency and they are the main causes behind transitions from independent or supported living in the community, into care homes [20].

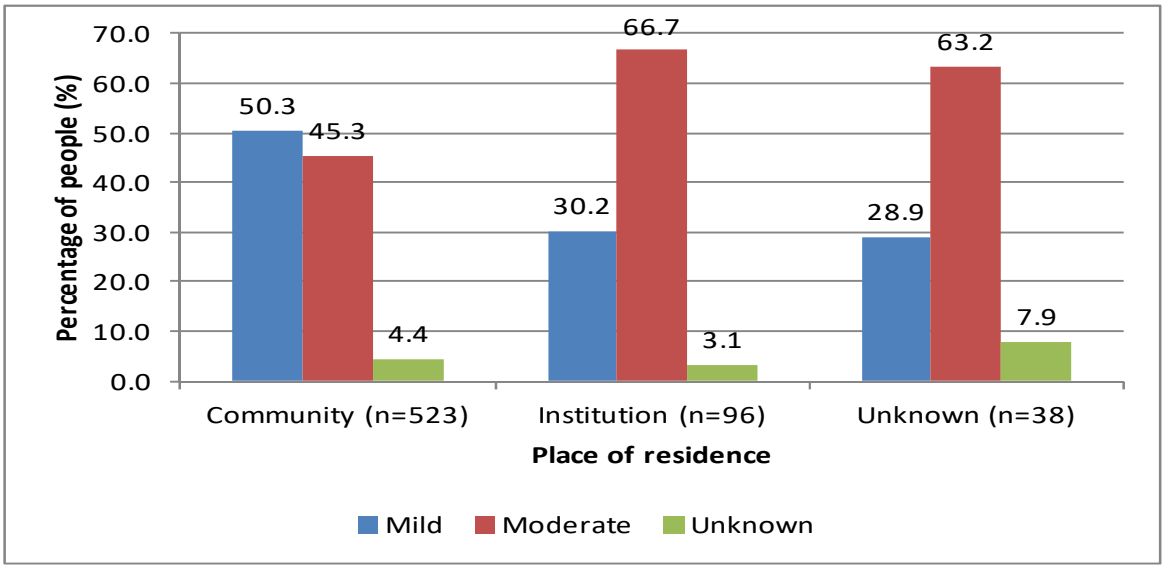

Figure 15 – Comparison of people with dementia living in the community with those living in an institution by cognitive impairment (MMSE score)

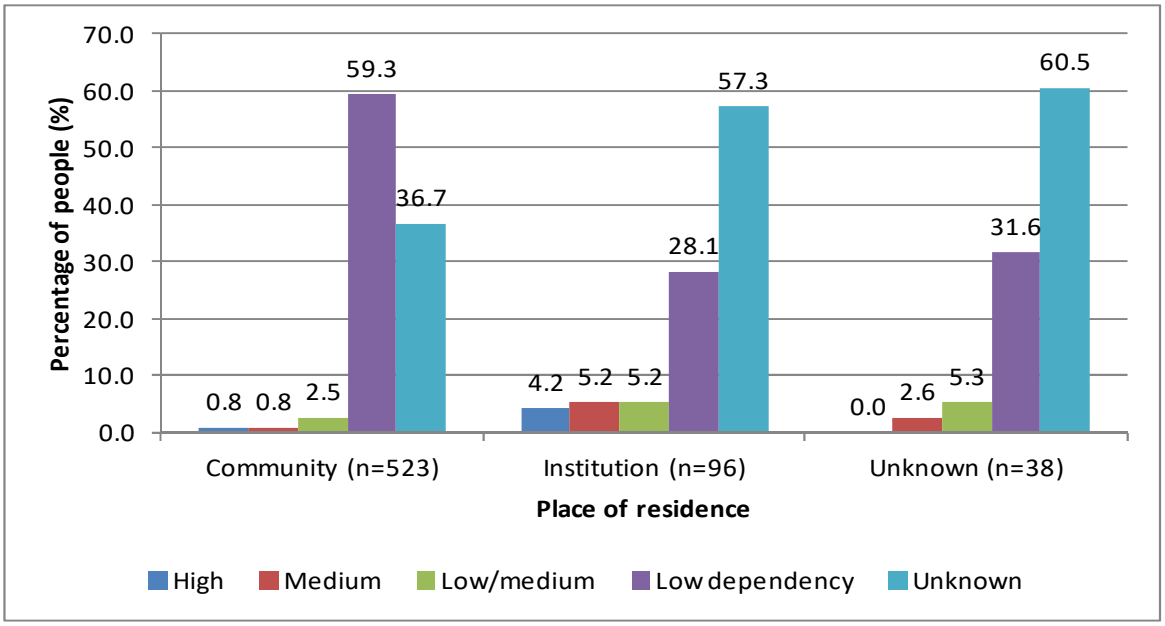

Figure 16 – Comparison of people with dementia living in the community with those living in an institution by dependency level (Barthel score)

6. The Family and other informal carers

Dementia is the largest contributor to disability and dependency (needs for care) among older people [21]. The need for care increases as the disease becomes more severe. Globally, care is generally provided by informal (family) carers [21].

Care includes support with personal activities of daily living such as washing, dressing, toileting and eating, as well as help with instrumental activities of daily living like cooking, shopping and managing household finances. Some patients require constant supervision. While there are many positive aspects of caring, such as companionship and fulfilment [22], carers are very likely to experience strain. They may suffer from high levels of psychological morbidity [23] and are at risk of increased physical ill health [24]. An economic disadvantage and strain may also be imparted on the family as a whole when caregivers have to give up work in order to support people with dementia. This is especially true as informal care giving time strongly increases with the severity of dementia [25].

The main carer for persons with dementia living in the community was the spouse (wife 18.9% husband 17.4%) followed by the daughter (24.7%). Only a minority of non-relatives were carers (1.5%). Figure 17 illustrates that the vast majority of informal care in the community was provided by the immediate family. Where stated, caregivers were predominantly of the female gender 64.0%, compared to 36.0% who were male. Such a situation was also observed for other European countries in the World Alzheimer's report 2010; the proportion of female caregivers was 66% and 74% for the WHO regions of Western Europe and Central Europe respectively [26].

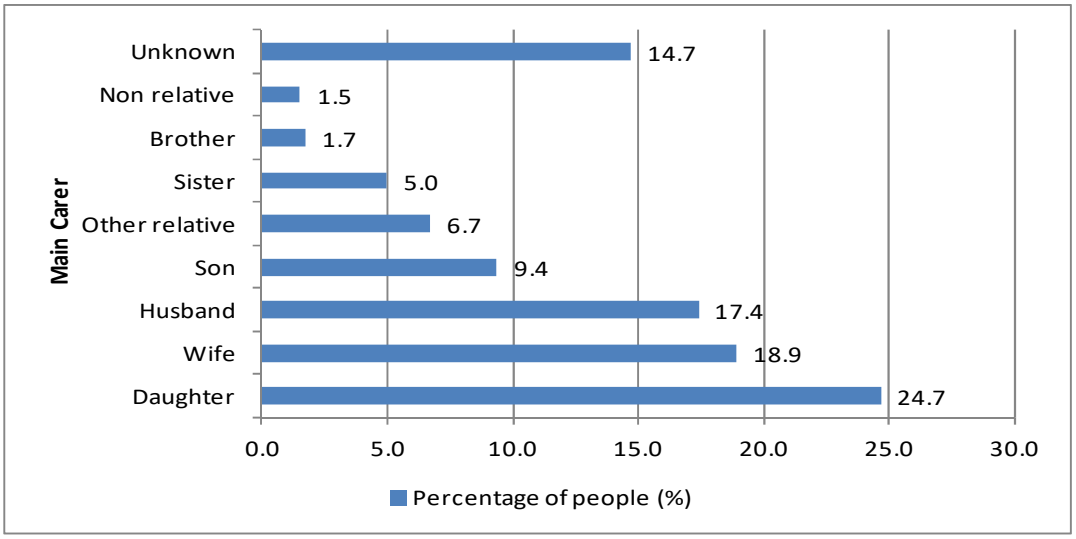

Figure 17 – Percentage of people with dementia living in the community according to their main carer (n=523)

7. Referral by type of Medical Speciality

Only Consultants in psychiatry, geriatrics and neurology can prescribe anti-dementia medications according to protocol. During 2014-2015, of the 657 cases entered in the Dementia Register, 530 cases (80.7%) were seen by geriatricians, 9 cases (1.4%) were seen by neurologists and 97 cases (14.8%) were seen by psychiatrists. In 21 cases (3.2%) the consultant was not specified. The number of people with dementia according to age group and speciality referral is illustrated in Figure 18.

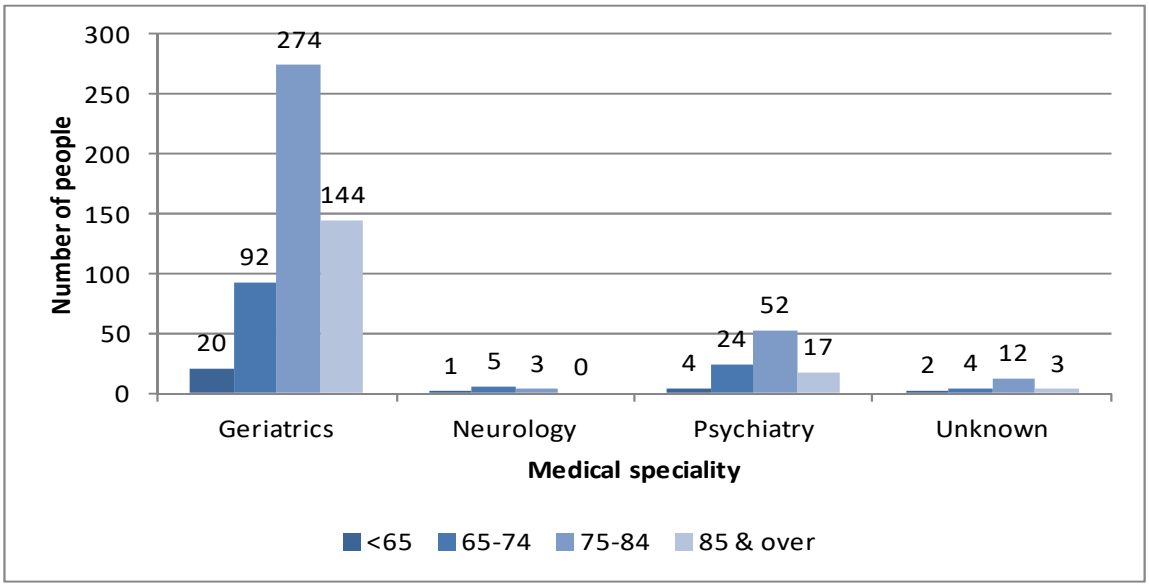

Figure 18 – Number of people with dementia according to age group and speciality referral

References

1. Prince M, Wimo A, Guerchet M, Ali G, Wu Y, Prina M. World Alzheimer Report 2015. London: Alzheimer's Disease International (ADI); 2015.
2. Scerri A, Scerri C. Dementia in Malta: new prevalence estimates and projected trends. Malta Medical Journal. 2012;24(3):21-24.
3. Wu Y, Fratiglioni L, Matthews F, Lobo A, Breteler M, Skoog I et al. Dementia in western Europe: epidemiological evidence and implications for policy making. The Lancet Neurology. 2016;15(1):116-124.
4. Alzheimer-europe.org. Alzheimer Europe - Research - European Collaboration on Dementia - Cost of dementia - Cost of illness and burden of dementia [Internet]. 2009 [cited 29 January 2016]. Available from: http://www.alzheimer-europe.org/Research/European-Collaboration-on-Dementia/Cost-of-dementia/Cost-of-illness-and-burden-of-dementia
5. Wimo A, Winblad B, Jönsson L. The worldwide societal costs of dementia: Estimates for 2009. Alzheimer's & Dementia. 2010;6(2):98-103.
6. Prince M, Guerchet M, Prina M. The global impact of dementia 2013-2050. London: Alzheimer's Disease International; 2013.
7. Activeageing.gov.mt. National Dementia Strategy [Internet]. 2016 [cited 29 January 2016]. Available from: http://www.activeageing.gov.mt/en/Pages/National-Dementia-Strategy.aspx
8. Alzheimer Europe Website: http://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/The-prevalence-of-dementia-in-Europe/Malta (accessed on 8th March 2016).
9. Knapp, M., Prince, M., et al. Dementia UK: The Full Report. London, Alzheimer's Society, 2007.
10. Neuropathology Group of the Medical Research Council Cognitive Function and Aging Study. Pathological correlates of late-onset dementia in a multicentre, community-based population in England and Wales. Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). Lancet, 2001. 357 (9251): p. 169–175.
11. NICE. Dementia: Supporting people with dementia and their carers in health and social care (CG42). London, National Institute for Health and Clinical Excellence, 2006. Available at: *guidance.nice.org.uk/cg42*
12. Alzheimer's Society. The Mini Mental State Examination (MMSE) Factsheet 436. 2013. Available at: *www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=121*

13. NICE. Alzheimer's disease - donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (TA217). London, National Institute for Health and Clinical Excellence, 2011. Available at: *www.nice.org.uk/guidance/TA217*
14. Alzheimer's Association. 2013 Alzheimer's disease facts and figures. Chicago, Alzheimer's Association, 2013.
15. Roe, C.M., et al. Education and Alzheimer disease without dementia: support for the cognitive reserve hypothesis. Neurology, 2007. 68(3): p. 223-8.
16. Kukull, W.A., et al. Dementia and Alzheimer disease incidence: a prospective cohort study. Archives of neurology, 2002. 59(11): p. 1737-46.
17. Mahoney, F.I., and Barthel, D.W. Functional Evaluation: The Barthel Index. Maryland State Medical Journal, 1965. 14: p. 61-5.
18. Mozley, C., et al. Towards Quality Care: Outcomes for older people in care homes. Aldershot, Ashgate Publishing Limited, 2004.
19. Banerjee, S., et al. Predictors of institutionalisation in people with dementia. Journal of neurology, neurosurgery, and psychiatry, 2003. 74(9): p. 1315-6.
20. Alzheimer's Disease International. World Alzheimer Report 2013: Journey of Caring, an analysis of long-term care for dementia. London, Alzheimer's Disease International, 2013.
21. Alzheimer's Disease International. World Alzheimer's Report 2009. London, Alzheimer's Disease International, 2009.
22. Cohen, C.A., Colantonio, A. and Vernich, L. Positive aspects of caregiving: rounding out the caregiver experience. International journal of geriatric psychiatry, 2002. 17(2): p. 184-8.
23. Schneider, J., et al. EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: Factors associated with carer burden. International journal of geriatric psychiatry, 1999. 14(8): p. 651-61.
24. Schulz, R. and Martire, L.M. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry, 2004. 12(3): p. 240-9.
25. Hajek, A., Brettschneider, C., Ernst, A., Posselt, T., Wiese, B., & Prokein, J. et al. (2015). Longitudinal predictors of informal and formal caregiving time in community-dwelling dementia patients. *Social Psychiatry And Psychiatric Epidemiology*, *51*(4), 607-616. http://dx.doi.org/10.1007/s00127-015-1138-7
26. Alzheimer's Disease International. World Alzheimer's Report 2010: the global economic impact of dementia. London, Alzheimer's Disease International, 2010.

Appendix 1 – Dementia Register Form for persons on anti-dementia medication (D1)

Dementia Register Form for persons on anti-dementia medication D1	Registration no: (for office use only)

Part 1: To be completed always

Name:		**ID No:**	
Surname:		**DOB:**	
Address:			
Locality:		**Post code:**	

Part 2: To be completed when applying for dementia drugs for the first time:

Educational Level completed:	primary ☐ secondary ☐ post-secondary ☐ non-tertiary ☐ tertiary ☐	**Social Status:**	S M W Sep Div
Resident at:	Own Home ☐	Nursing Home ☐ Specify:	Other ☐ Specify:
Living status:	Alone ☐	With Spouse ☐ Other ☐	With Children ☐
Main Carer (Name):		**Main Carer (Relation):**	
Main Carer (Tel No):		**Own telephone no:**	
Referred by (GP):		**Date of referral :**	
Reason for referral:		**Date of 1st attendance to specialist clinics:**	
Diagnosis Status:		**Date of Diagnosis:**	
MMSE score:		**Barthel Score:**	
Dementia Sub-Type:	Alzheimer's Disease ☐ Fronto-temporal Dementia ☐ Other ☐ Specify:	Vascular Dementia ☐ Alcohol Related Dementia ☐	Mixed Dementia ☐ Lewy-Body Disease ☐
Clinic:	RHKG ☐ Community ☐	MDH ☐ Other ☐ Specify:	MCH ☐
Radiology:	CT	**Date:**	
	MRI	**Date:**	
	SPECT	**Date:**	
Behavioural and Psychological Sypt:	Wandering ☐ Depression ☐	Aggression ☐ Shouting ☐	Agitation ☐
Dementia Treatment:		**Side-effects of Dementia treatment:**	
Psychiatric Treatment:		**Side-effects of psychiatric medication:**	

Part 3: To be completed during all subsequent visits:

Date of visit:			
MMSE score:		**Barthel score:**	
Dementia Treatment:		**side-effects of dementia treatment:**	
Psychiatric Treatment:		**side-effects of Psychiatric treatment:**	
Current housing Location:	Own Home ☐	Nursing Home ☐ Specify:	Other ☐ Specify:

Part 4: To be completed always:

Consultant:		**Signature:**	
Reg No:			

Appendix 2 – Dementia Register Form for persons not applying for anti-dementia medication (D2)

Dementia Register Form for persons not applying for anti-dementia medication D2	Registration no: (for office use only)

Part 1: To be completed always:

Name:		**ID No:**	
Surname:		**DOB:**	
Address:			
Locality:		**Post code:**	

Part 2: To be completed when first diagnosed with dementia:

Educational Level completed:	primary ☐ secondary ☐ post-secondary ☐ non-tertiary ☐ tertiary ☐	**Social Status:**	S M W Sep Div
Resident at:	Own Home ☐	Nursing Home ☐ Specify:	Other ☐ Specify:
Living status:	Alone ☐	With Spouse ☐ Other ☐	With Children ☐
Main Carer (name):		**Main Carer (relation):**	
Main Carer (Tel No):		**Own telephone no:**	
Referred by (GP):		**Date of referral:**	
Reason for referral:		**Date of 1st attendance to specialist clinics:**	
Diagnosis Status:		**Date of Diagnosis:**	
MMSE score:		**Barthel Score:**	
Dementia Sub-Type:	Alzheimer's Disease ☐ Fronto-temporal Dementia ☐ Other ☐ Specify:	Vascular Dementia ☐ Alcohol Related Dementia ☐	Mixed Dementia ☐ Lewy-Body Disease ☐
Clinic:	RHKG ☐ Community ☐	MDH ☐ Other ☐ Specify:	MCH ☐
Radiology:	CT	**Date:**	
	MRI	**Date:**	
	SPECT	**Date:**	
Behavioural and Psychological Sypt:	Wandering ☐ Depression ☐	Aggression ☐ Shouting ☐	Agitation ☐
Anti-dementia Medication:		**Side-effects from Anti-dementia medication:**	
Psychiatric Treatment :		**Side-effects of psychiatric medication:**	

Part 3: To be completed during all subsequent visits:

Date of visit:			
MMSE score:		**Barthel score:**	
Anti-dementia Medication:		**Side-effects from Anti-dementia medication:**	
Psychiatric Treatment:		**side-effects of Psychiatric treatment:**	
Current housing Location:	Own Home ☐	Nursing Home ☐ Specify:	Other ☐ Specify:

Part 4: To be completed always:

Consultant:		**Signature:**	
Reg No:			