

Dementia Report

2013



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Telephone	00356 25599000

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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.

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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

Improvements in health care over the past century have contributed to a situation where people are living longer and leading healthier lives. This has also led to an increase in the number of people suffering from chronic non-communicable diseases such as dementia. Dementia is a chronic progressive disease of the brain which causes a lot of morbidity to its sufferers as well as impacting the lives of those involved in their care. Improving the quality in dementia care is therefore a major public health concern.

This first report is based on data collected in the Dementia Register between the beginning of January 2013 till the end of December 2013 during which time a total of 694 cases were entered in the register. Predominance in female numbers was noted with 69.3% of total cases being female and 30.7% being male. Although the number of cases with dementia peaks in the 75-84 year olds for both genders, age specific prevalence rates increase with increasing age reaching a peak in 85-89 year olds. The mean age at diagnosis of dementia was 79 years in males and 80 years in females.

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.

Alzheimer's disease was the most common type of dementia (70.9%) followed by Mixed dementia (8.2%) and Vascular dementia (4%).

The severity of dementia at diagnosis was assessed using the Mini Mental State Examination. A mean MMSE score of 19.2 was obtained for the total cases diagnosed in 2013 for whom MMSE score was stated. The majority of cases had moderate dementia (58.2%) with a mean Mini Mental State Examination score of 16.6. The level of dependency (need for care) was measured using the Barthel Activities of Daily Living Index. Dementia patients living in the community were more likely to have a low dependency level compared to those living in an institution.

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 partially explained by the fact that as people grow older, informal support decreases because the spouse dies. In fact, only 22.9% of people with dementia living in the community were widowed, in contrast to 40.7% of people with dementia living in an institution being widowed.

At a certain point in the disease process, the majority of people with dementia require some form of care. This need tends to escalate over time as the dementia becomes more severe. The leading contributors to care-giving were immediate relatives with 40.2% being spouses, 28.4% daughters and 12.3% being sons. Caregivers were predominantly of the female gender at 58.4% compared to 37.4% being male.

What is Dementia?

Dementia is a term used to describe a collection of symptoms that can be caused by a number of diseases which affect the brain. Symptoms include a progressive decline in memory, reasoning and communication skills and a gradual loss of functional skills needed to carry out daily activities [1].

Alzheimer's disease is the most common form of dementia accounting for 60-80% of all people with the disease. Other dementias include dementia with Lewy bodies, Frontotemporal dementia and Vascular dementia which occurs due to brain damage secondary to repeated disruption of the brain's blood circulation by strokes or other blood vessel pathology. Mixed dementia is more common than previously thought and is characterized by brain abnormalities seen in Alzheimer's disease and another type of dementia, most commonly Vascular dementia [2].

Dementia is most common in older people with prevalence roughly doubling every 5 years over the age of 65. Onset before this age is known as early onset dementia which is relatively uncommon and in the case of Alzheimer's disease, often suggests a genetic cause. Dementia affects every person differently depending on the type of dementia and on factors such as the individual's personality, lifestyle and physical health prior to the onset of the disease. Significant relationships that a person has also play a role [3].

Early dementia symptoms are often dismissed as a normal part of aging. During the initial stages of the disease, individuals may have difficulty with communication and memory loss especially for things that just happened. They may lose track of time of day or day of the week and may become lost in familiar places. Mood and behaviour change may become manifest as anxiety or depression, unusual angry or aggressive reactions, reduced activity and motivation and loss of interest in hobbies [4]. As the disease progresses symptoms worsen and the individuals become increasingly more dependent and inactive.

Early diagnosis of dementia is the first step towards planning for the future. It is important so that the person suffering from dementia and carers are educated about how to cope with this disease and be prepared about what to expect. Optimising physical health, detecting and treating behavioural and psychological symptoms and providing long-term support to carers are among the main goals in dementia care [5].

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 Directorate for Pharmaceutical Affairs and Pharmacy of Your Choice.

This report is based on data which was received and entered in the Dementia Register between the beginning of January 2013 and end-December 2013. During this period, information on 694 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.

Throughout the report, unless otherwise specified, age refers to the patient's age at the end of December 2013. However, the report includes a section that describes the number of persons with dementia according to their age at diagnosis.

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. However, there were cases whose MMSE score was scored out of a denominator of less than 30. Reasons for this may include factors such as illiteracy or blindness. These scores were prorated from denominators of less than 30 to denominators of 30 for the purpose of data analysis [6].

In the section regarding dependency, scores were compiled using the 20-point Barthel Index. Scores that were compiled using the modified version of the Barthel Index with a possible score of 100 were prorated to a denominator of 20.

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.

1. Demographic Characteristics

1.1 Overview

Between the beginning of January 2013 and the end of December 2013, a total of 694 cases were entered in the Dementia Register. Of these, 213 (30.7%) were male and 481 (69.3%) were female. Of these, 33 persons died during this period. Therefore the number of prevalent cases registered in the dementia register over this time period was of 661.

The mean age of this cohort alive at the end of 2013 was 80 years and the mean age by gender was 79 and 80 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 2013		Age-specific rates per 1000 population*	
	Females	Males	Females	Males
55-59	2	5	0.1	0.3
60-64	10	2	0.7	0.1
65-69	19	17	1.3	1.2
70-74	57	20	6.8	2.8
75-79	127	51	15.9	8.5
80-84	128	54	22.4	15.9
85-89	95	39	29.9	22.6
90-94	24	8	20.3	15.7
95+	2	1	7.3	11.4
Total	464	197	2.2	0.9

*mid-year population 2013 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 2013, by gender and age group

Alzheimer Europe estimated that the number of people with dementia in Malta in 2012 was 5,301. This represents 1.26 % of the total population [7]. The number of people with dementia as a percentage of the total population is somewhat lower than the EU average of 1.55% [7]. The total prevalent cases within the dementia register at the end of 2013 represent 0.16% of the total population which is much lower than 1.26% estimated by Alzheimer Europe. 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.

Although the number of cases with dementia peak in the 75-84 year age groups for both genders as seen in the table 1 above, age-specific rates increase with increasing age in both genders reaching a peak in 85-89 year olds.

1.2 People with dementia by age at diagnosis and gender

Date of diagnosis was stated for 500 cases out of the 694 persons on the dementia register at the end of 2013 (72%). The mean age at diagnosis of dementia was 79.0 years. As shown in Figure 1, 55.2% of the cases were diagnosed in the 75-84 year age groups.

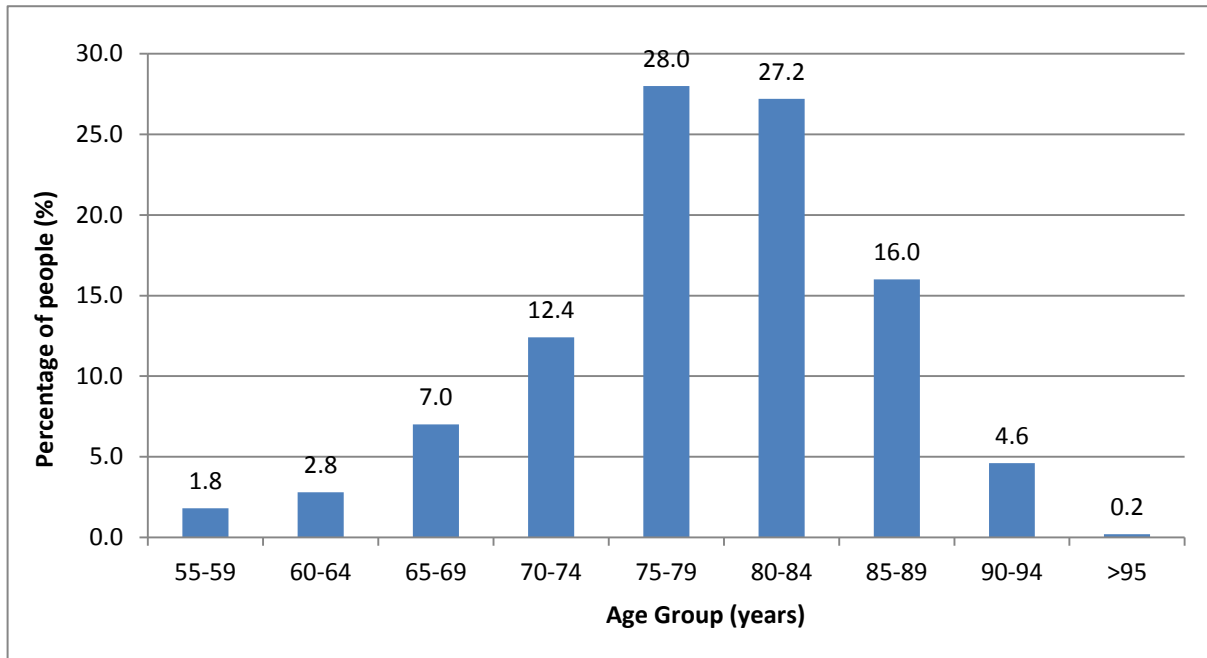


Figure 1 – Percentage of people with dementia by age at diagnosis (n=500)

Dementia can be classified into early onset dementia¹ and late onset dementia². The vast majority (95.4%) were late onset dementia cases, whereas early onset dementia constituted 4.6% of all cases (Figure 1). Of the 23 cases (4.6%) of early onset dementia, 9 cases were male and 14 cases were female.

The mean age at diagnosis amongst females was 79 while that for males was 78 years. The female to male gender ratio of people diagnosed with early onset dementia was 1.6, while the female to male ratio for those diagnosed with late onset dementia was 2.3, approximately 2 women for every man affected.

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 [1].

¹ Dementia onset before the age of 65 years

² Dementia onset after the age of 65 years

1.3 Educational level

The educational level completed was stated for 637 dementia cases from a total of 694 cases in the Dementia Register. The majority of patients (427 cases, 61.5%) had only completed up to a primary level of education. There were 157 cases (22.6%) that had completed up to secondary level of education, with the numbers decreasing down to 32 cases (4.6%) for those achieving a post-secondary educational level and 21 cases (3.0%) for those completing tertiary education.

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 68.0% (327 cases) as compared to 46.9% (100 cases) in males. Inversely, the proportion of males having completed higher educational levels (secondary, post-secondary and tertiary) was 43.2% (92 cases) as compared to 24.5% (118 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.

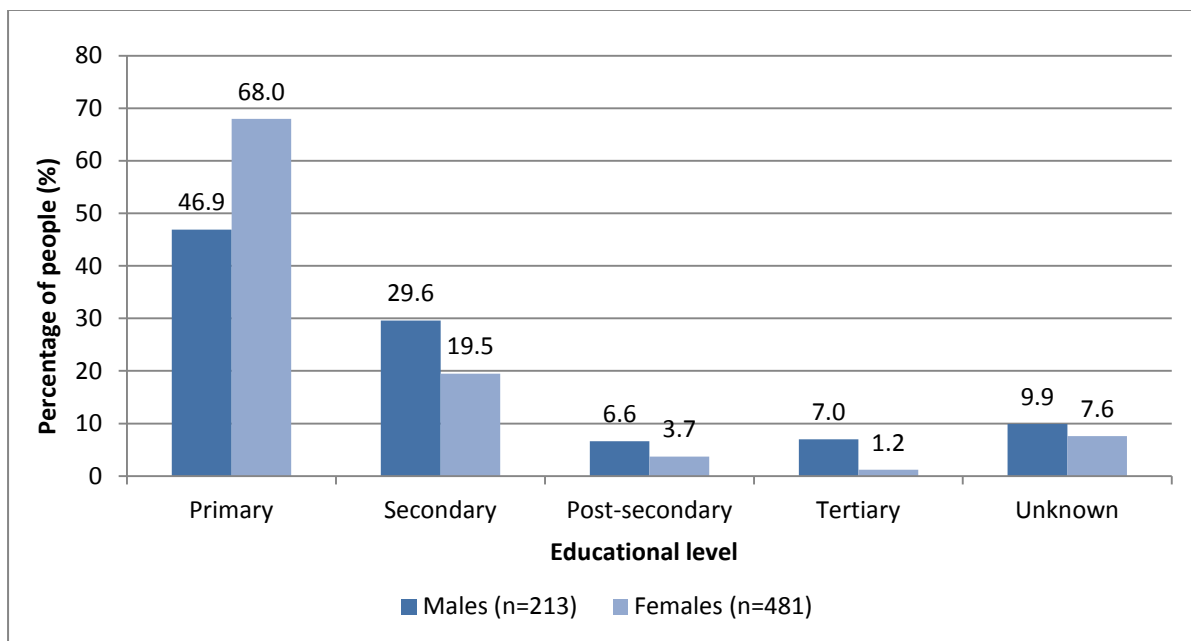


Figure 2 – Comparison of males and females with dementia by educational level completed

1.4 Geographical Distribution

Crude rates by region of residence were calculated for the live cohort of 661 persons entered in the Dementia Register till the end of 2013. 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.

Region	Males		Females	
	Crude rate	95% CI	Crude rate	95% CI
Gozo	38.56	(15.68, 88.49)	88.53	(50.39, 152.51)
Northern Harbour	114.6	(89.68, 146.19)	258.53	(220.52, 302.92)
Northern	69.30	(44.52, 106.81)	190.51	(146.98, 246.37)
South Eastern	104.39	(73.44, 147.62)	170.31	(129.20, 223.92)
Southern Harbour	103.60	(75.31, 141.96)	268.42	(221.06, 325.60)
Western	90.16	(60.13, 134.13)	238.99	(187.71, 303.71)

Table 2 – Crude rates for live cohort (n=661) by gender and region of residence per 100,000 population

1.5 Marital status

The marital status was stated for 526 cases out of 694 cases in the Dementia Register entered till the end of 2013. Just over 40% were married while those in the single, separated, or widowed categories represented 34.4% (Figure 3).

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 4).

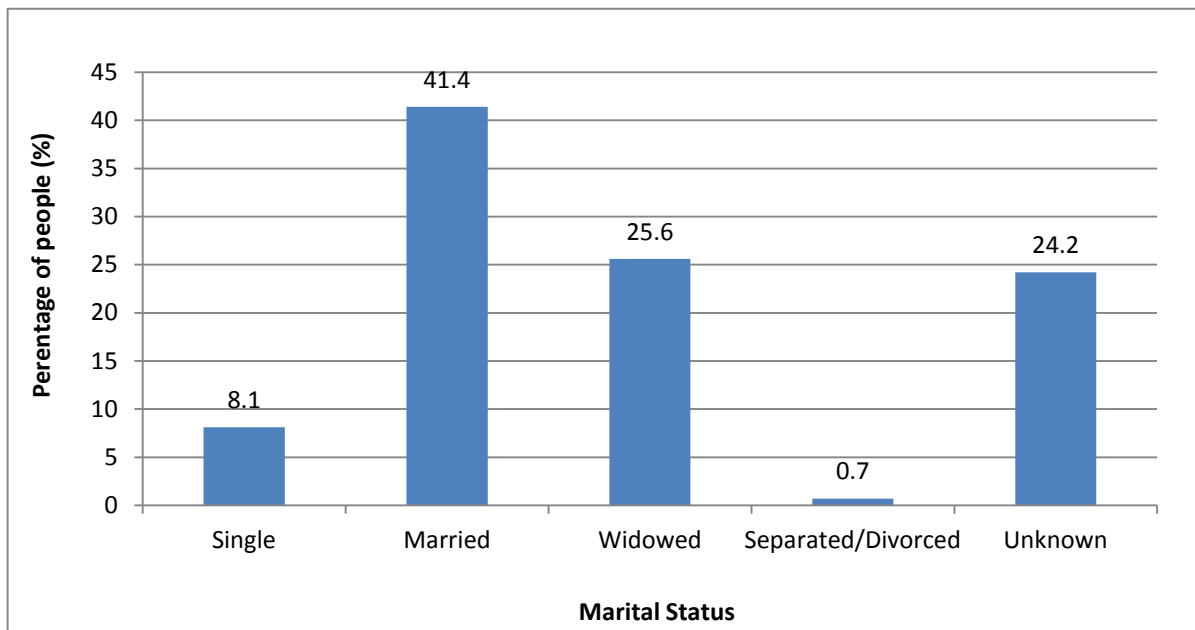


Figure 3 – Percentage of people with dementia by marital status (n=694)

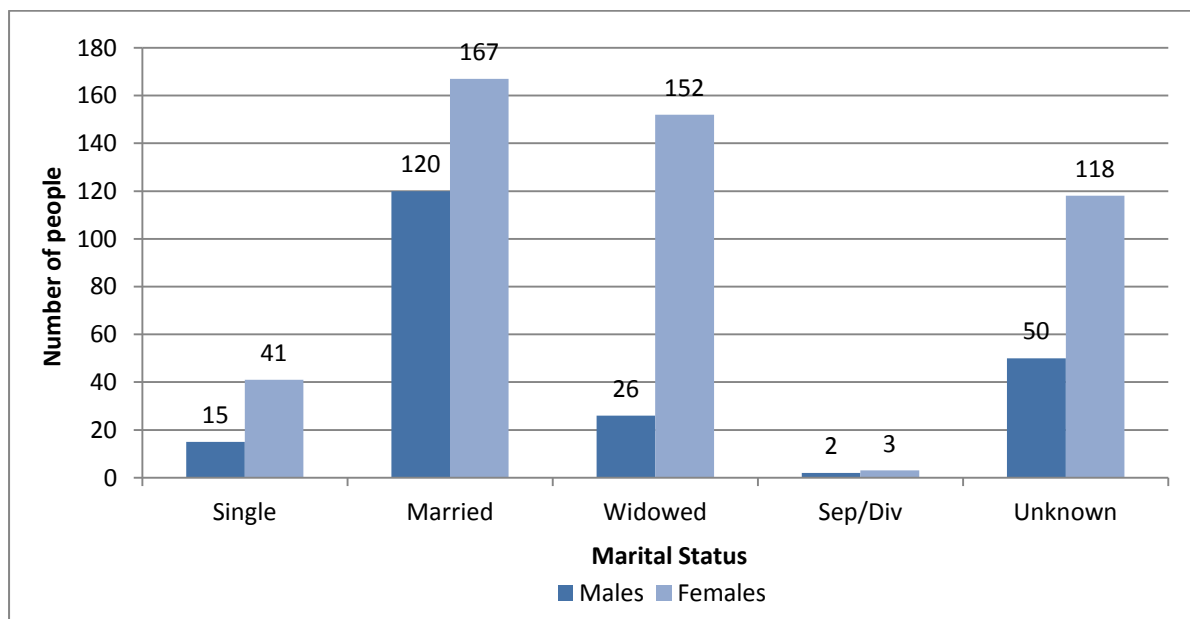


Figure 4 – Number of people with dementia by gender and marital status

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 587 cases out of 694 cases entered in the Dementia Register till the end of 2013. Of these, 492 cases (70.9%) were reported to have Alzheimer's disease (Figure 5) which was in fact the most dominant subtype across all age groups and, particularly so, in women. The next most common subtypes were Mixed dementia with 57 cases (8.2%) and Vascular dementia accounting for 28 cases (4.0%) of the total cases. There were very few cases with the other types of dementia which together were grouped as 'Other subtypes'. For a considerable proportion of cases, the dementia subtype was not stated (107 cases, 15.4%).

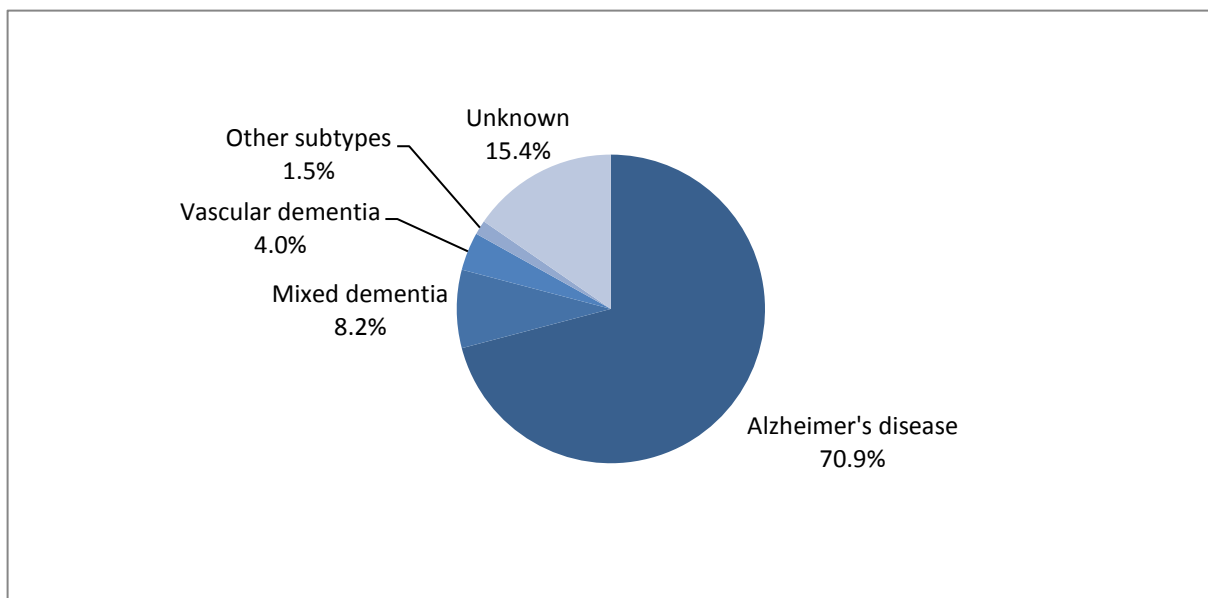


Figure 5 – Percentage of dementia cases by dementia subtype (n=694)

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.

The literature also indicates that diagnosis of the different subtypes needs to be interpreted with caution given that diagnoses are made clinically, based on typical patterns of disease presentation and course. Some clinico-pathological studies, which assessed the agreement between the diagnosis made clinically and the pathology evident in the brain post-mortem suggested that mixed pathologies are much more common than 'pure' ones [8].

The distribution of subtypes differed between males and females (Figure 6). In the female group, 352 cases (73.2%) had Alzheimer's disease, 31 (6.4%) had Mixed dementia and 14 cases (2.9%) had Vascular dementia. Among the male patients, a smaller proportion suffered from Alzheimer's disease (140 cases, 65.7%), while a larger proportion compared to females had Mixed dementia (26 cases, 12.2%) and Vascular dementia (14 cases, 6.6%). Dementia subtype was not stated for 79 females (16.4%) and 28 males (13.1%).

This data exhibits a similar pattern to that provided in the Dementia UK Report in that Alzheimer's disease was more common in females (67% in women compared with 55% in men in the UK) and Vascular dementia was more common in males (20% in men compared to 15% in women in the UK) [1].

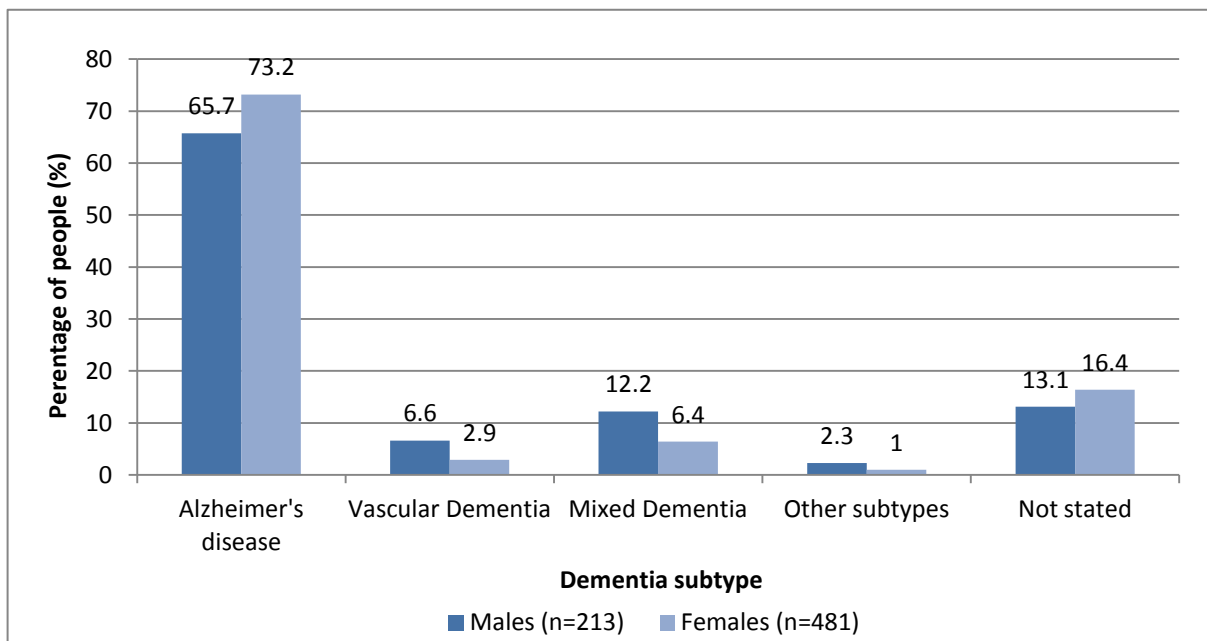


Figure 6 – Percentage of males and females by dementia subtype

Table 3 shows the distribution of people with dementia according to dementia subtype and age at diagnosis (which were both known in 426 cases). It can be noted that the vast majority of cases in all age groups were clinically diagnosed with Alzheimer's disease. Those affected by early onset dementia were almost exclusively diagnosed with Alzheimer's disease. The other subtypes of dementia, notably Vascular and Mixed dementia featured mostly in those aged over 75 years.

Dementia Subtype	Age Groups							
	55-64 (n=18)		65-74 (n=79)		75-84 (n=233)		85 & over (n=96)	
	n	%	n	%	n	%	n	%
Alzheimer's	15	83.3	69	87.3	197	84.5	73	76.0
Mixed	1	5.6	6	7.6	24	10.3	8	8.3
Vascular	1	5.6	3	3.8	10	4.3	14	14.6
Other subtypes	1	5.6	1	1.3	2	0.9	1	1.0

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 [9]. 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 [10].

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 [11].

Of the 694 cases entered in the dementia register during 2013, 282 cases were diagnosed in 2013, 217 cases were diagnosed in previous years, and in 195 cases date of diagnosis was not stated. Analysis of MMSE scores was done for cases diagnosed in 2013 in order to get a picture of the severity of dementia in these patients at the time of diagnosis. A mean MMSE score of 19.2 was obtained for the total cases diagnosed in 2013 in whom MMSE score was stated. Mean MMSE score for males was 18.9 and in females was 19.3.

Of 282 cases diagnosed with dementia in 2013, a total of 108 cases (38.3%) had mild cognitive impairment with an average score of 23.2, and 164 (58.2%) had moderate cognitive impairment with a mean score of 16.6 and 2 cases (0.7%) had severe cognitive decline with an average score of 3.5 (Figure 7). 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.

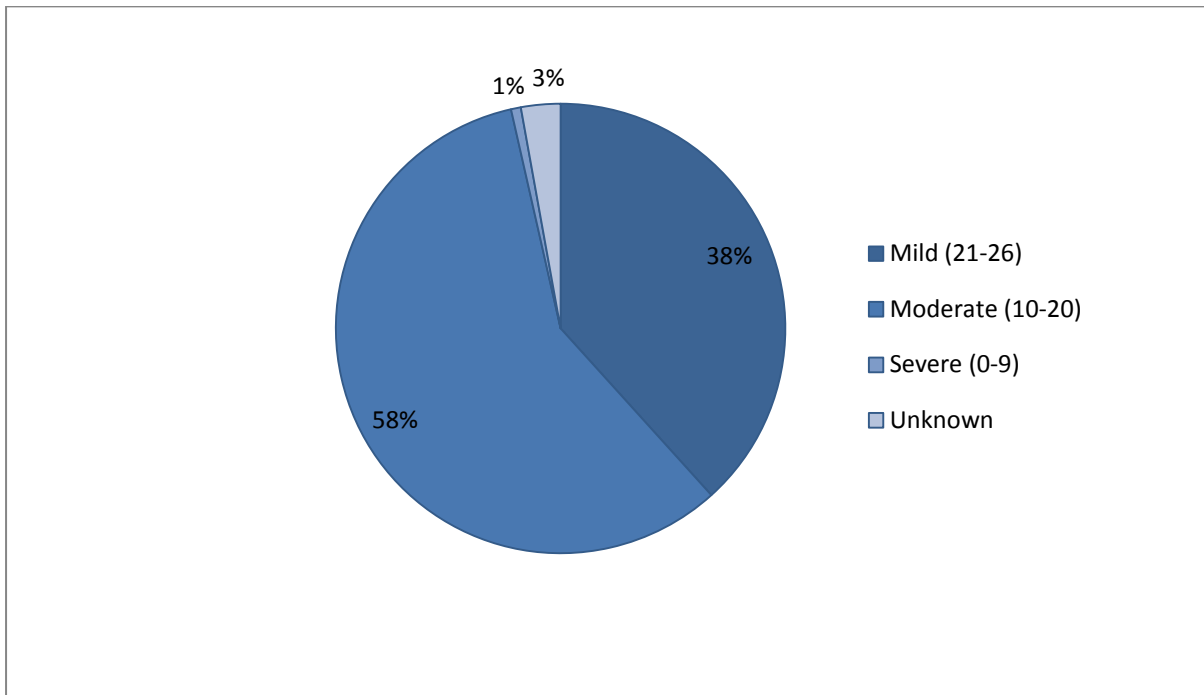


Figure 7 – Stratification of people with dementia diagnosed in 2013 by severity of cognitive impairment (MMSE score) (n=282)

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 was seen to decline with increasing age (Figure 8).

Age Group	Severity of cognitive impairment (MMSE score)							
	Mild		Moderate		Severe		Unknown	
	n	%	n	%	n	%	n	%
55-64	7	6.5	3	1.8	0	0	0	0
65-74	25	23.1	17	10.4	0	0	1	12.5
75-84	60	55.6	88	53.7	1	50	5	62.5
85-94	12	11.1	40	24.4	1	50	2	25
95 & over	4	3.7	16	9.8	0	0	0	0

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

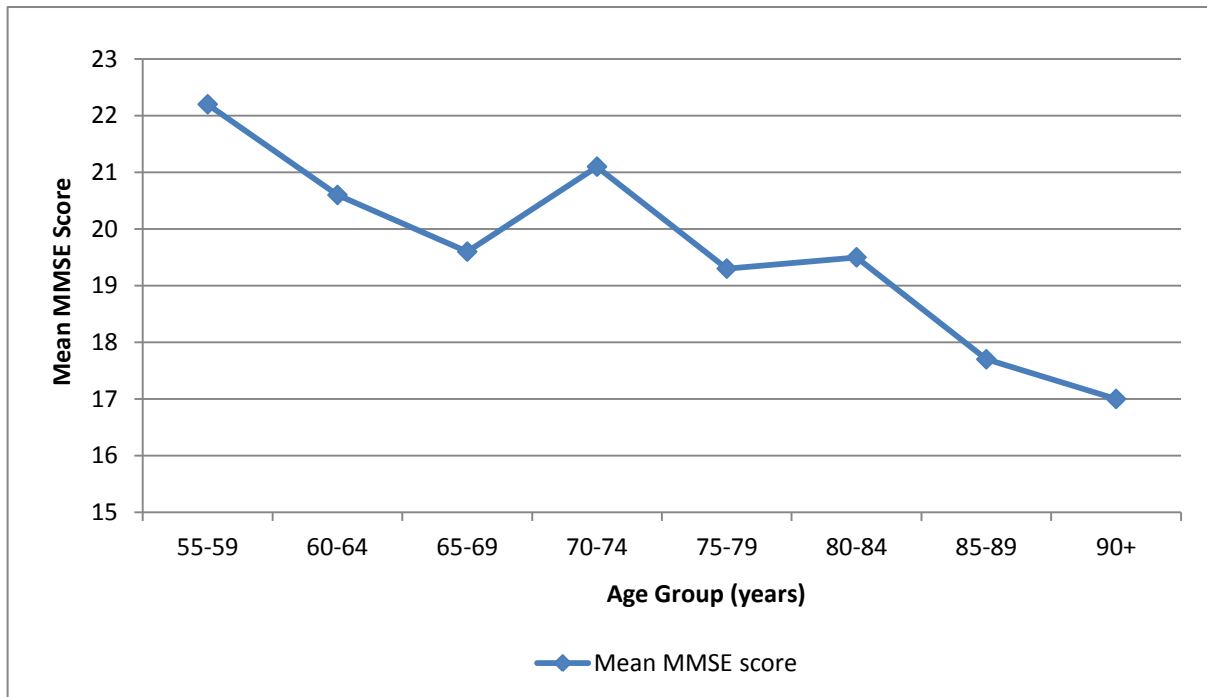


Figure 8 – Change in mean MMSE score of people diagnosed with dementia in 2013 with increasing age

3.1 Cognitive decline and educational level

A higher educational level is associated with a decreased risk of Alzheimer’s disease and other dementias [2]. 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 [12]. 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 [13].

Figure 9 looks at the level of education attained by people with dementia grouped according to their level of cognitive impairment. This information was available for 274 cases out of the total cases. 58.3% of those with mild cognitive decline (MMSE score 21-26) had attained up to a primary level of education. This percentage rose to 73.8% in those with a moderate level of cognitive impairment (MMSE score 10-20). Inversely, there was a higher proportion (29.6%) of people with a secondary educational level among those with mild cognitive impairment compared to those with a moderate level of cognitive impairment (17.1%). There was a clear inverse relationship of cognitive impairment by level of education and this gradient remained the same after adjusting for age.

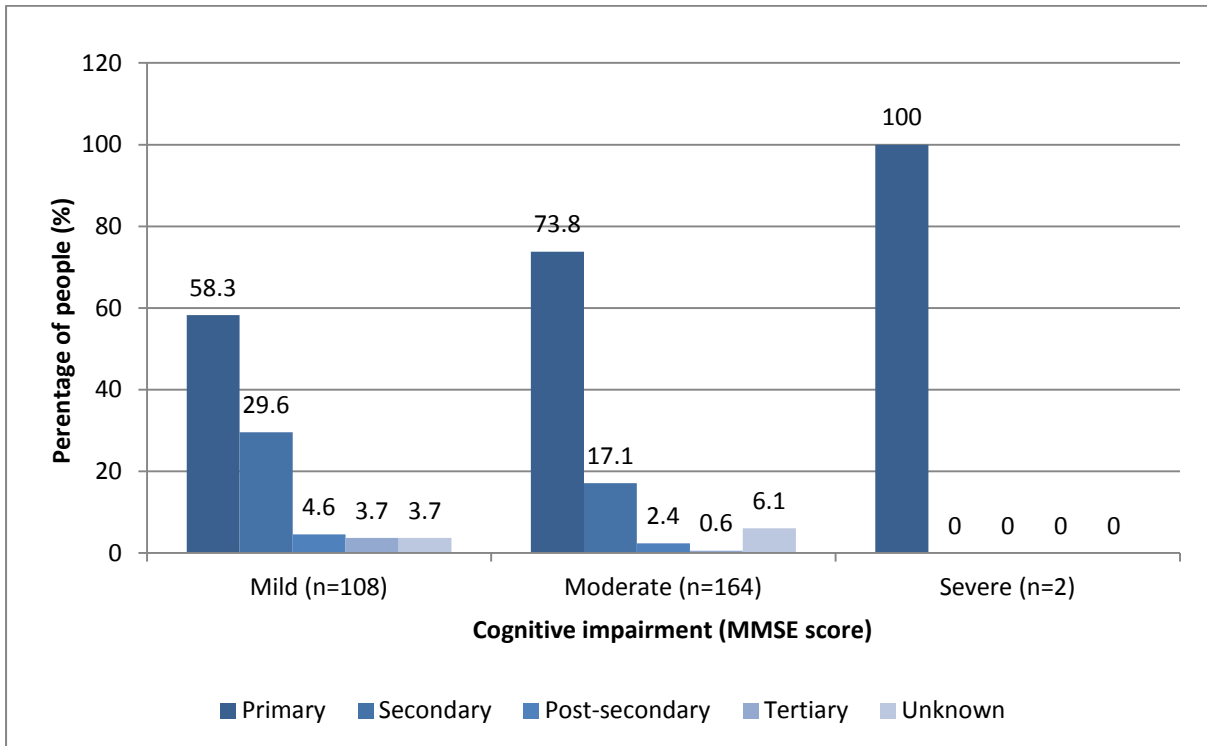


Figure 9 – Percentage of people with dementia by MMSE score and educational level

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 [14].

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 [15].

The Barthel score was stated for 495 cases out of a total of 694 cases. The majority of cases (60.8%) had low dependency (Figure 10). For the whole cohort, the mean Barthel score was 17.3. The mean score for males was 17.0 and that for females was almost identical at 17.4.

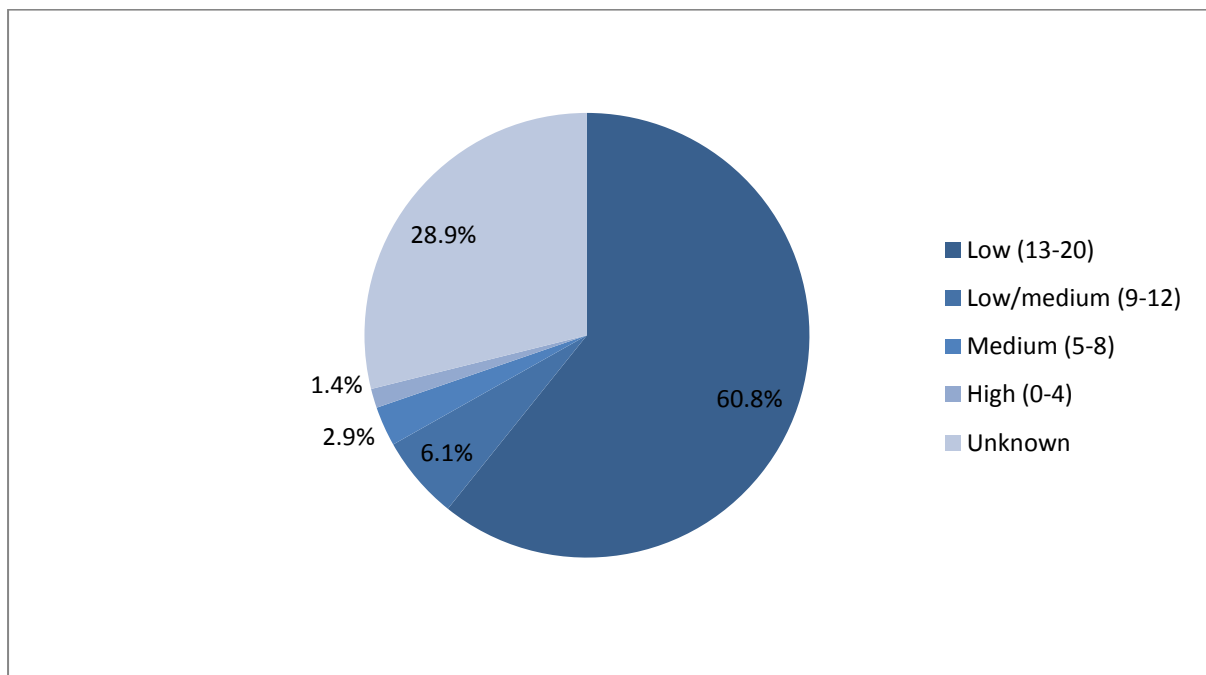


Figure 10 – Percentage of people with dementia by level of dependency (Barthel score) (n=694)

Dependency was more prevalent in the older age groups. In fact, the mean Barthel score for those aged 55-59 years was 19.7 and this decreased to 18 in those between 70-79 years, and 14.4 in those aged 90 years and over (Figure 11).

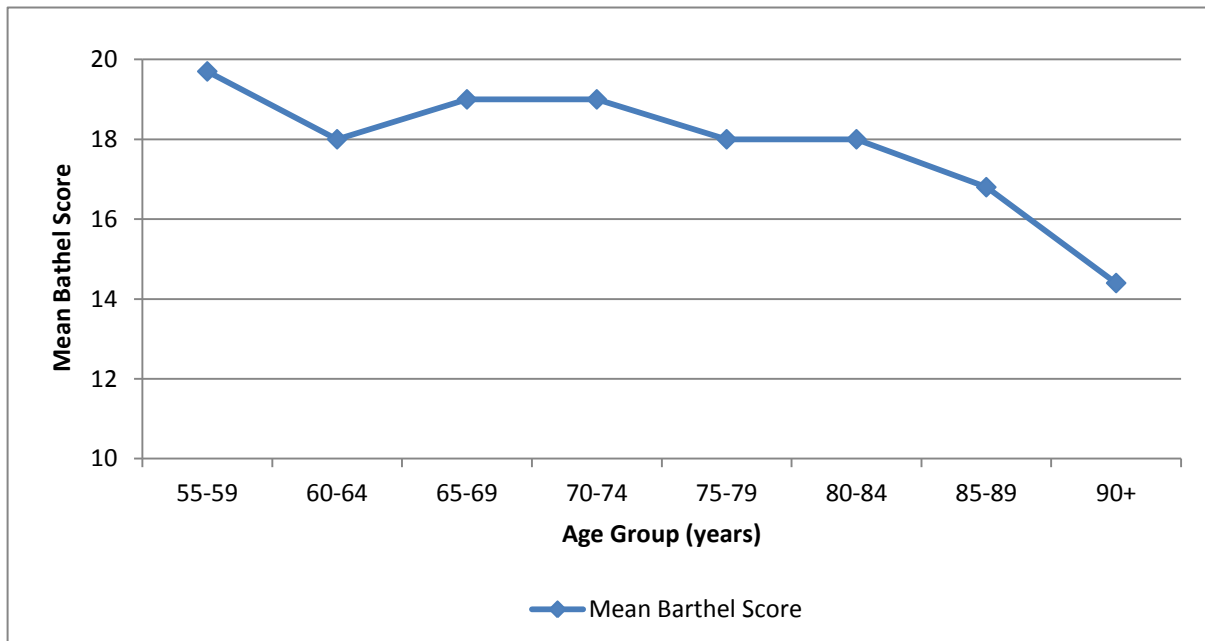


Figure 11– Change in mean Barthel score with increasing age

Figure 12 depicts the mean Barthel and MMSE scores for each age group in persons diagnosed with dementia in 2013. The mean MMSE and Barthel score follow a similar overall decreasing pattern with increasing age.

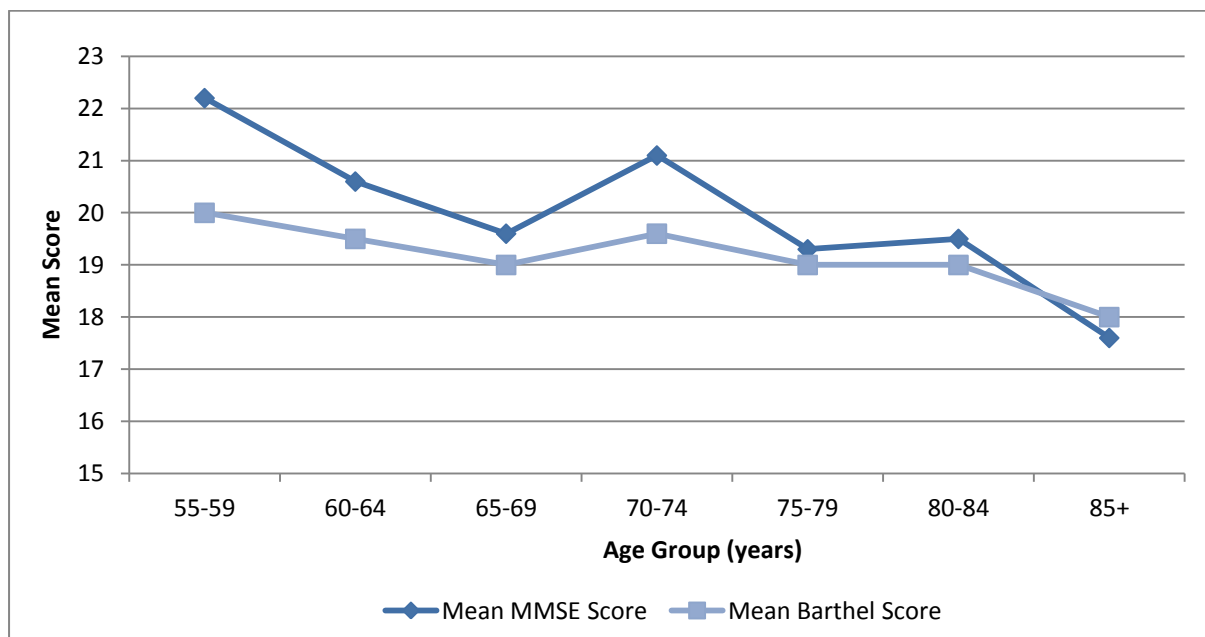


Figure 12 – Mean MMSE and Barthel scores for people diagnosed with dementia in 2013 by age at diagnosis

5. Residential status

The residential status was stated for 663 cases out of 694 cases entered in the Dementia Register in 2013. Of these, 545 (78.5%) lived in private households (the community) and 118 (17.0%) 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 5 cases in the under 75 years age groups, to 50 cases in those aged 75-84, and 63 cases in the 85 plus age group (Figure 13).

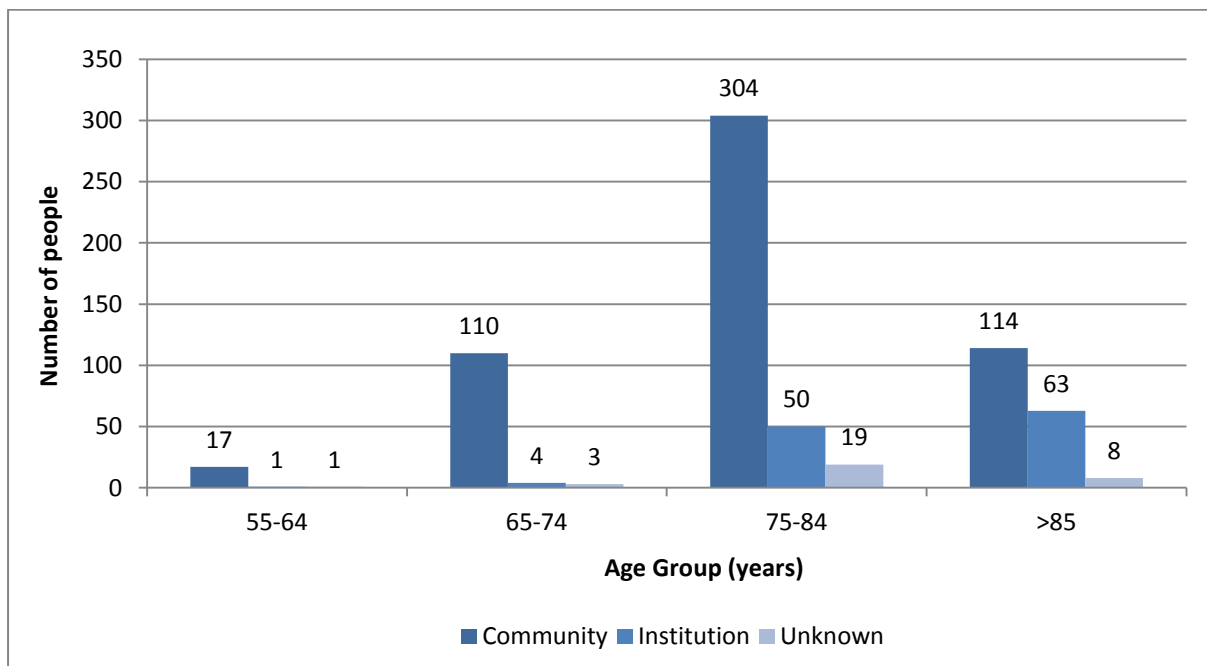


Figure 13 – Number of people with dementia by age and place of residence

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 22.9% of people with dementia living in the community were widowed, in contrast to 40.7% of people with dementia living in an institution being widowed (Figure 14). 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 [16]. 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.

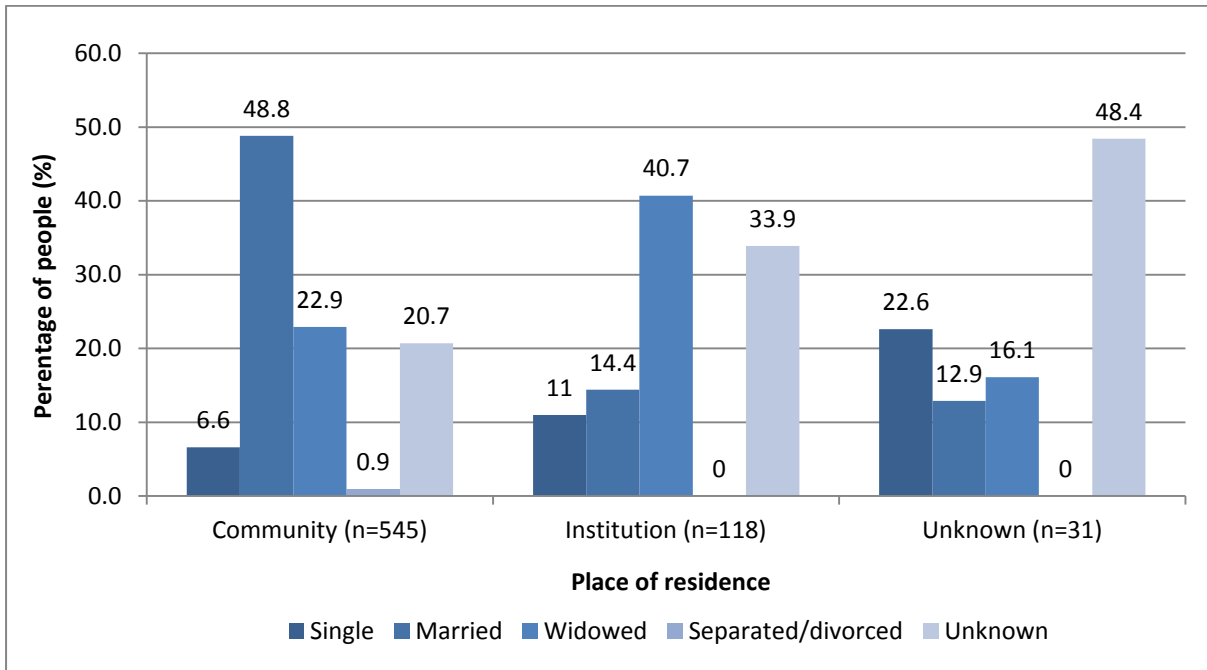


Figure 14 – Comparison of people living in the community with those living in an institution by marital status

In accordance with the above is the fact that when looking at the cohort of people with dementia living in the community, more than half (287 cases, 52.7%) lived with their spouse, 13.9% (76 cases) lived with their children while 22.2% (121 cases) lived on their own (Figure 15). Out of 121 cases that lived alone, 39% had normal or mild cognitive function (MMSE 21 or above), and 57% had moderate cognitive impairment (MMSE 10-20).

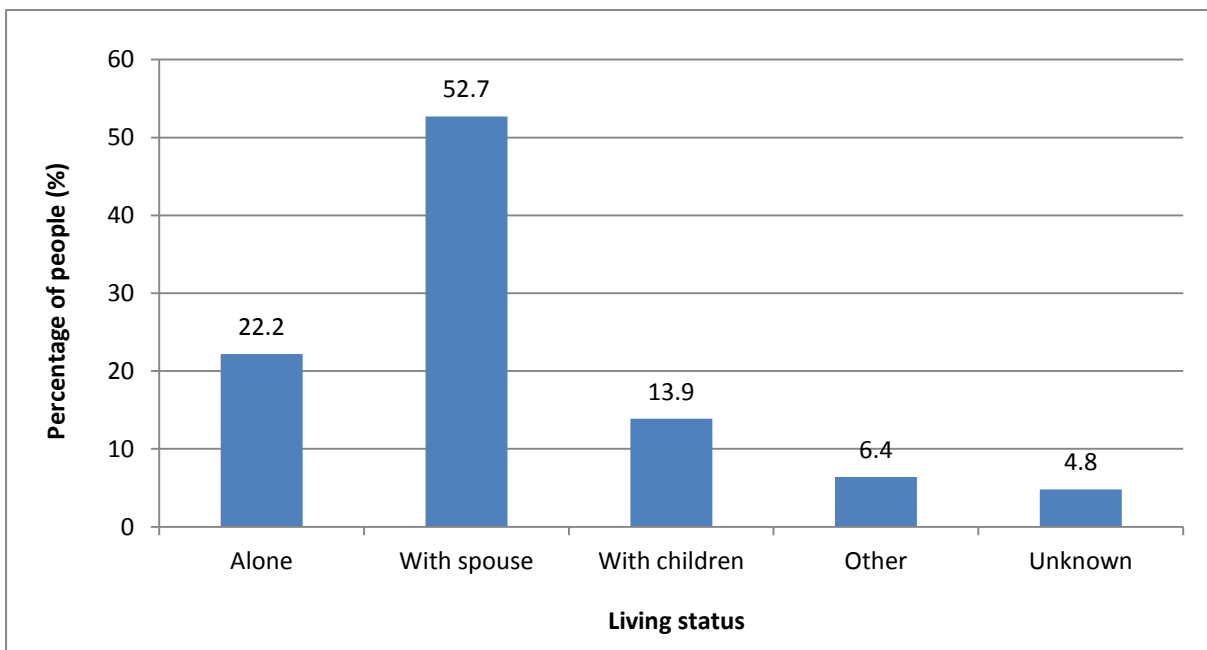


Figure 15 – Percentage of people with dementia living in the community by living status (n=545)

People with dementia living in an institution were more likely to be suffering from moderate dementia (78.0%) than mild dementia (13.6%). However quite a high percentage of persons with moderate dementia (54.9%) lived in the community (Figure 16). Most persons with dementia living in the community had a low dependency level (66.8%) with only small percentages having higher levels of dependency and living in the community (Figure 17). 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 [17].

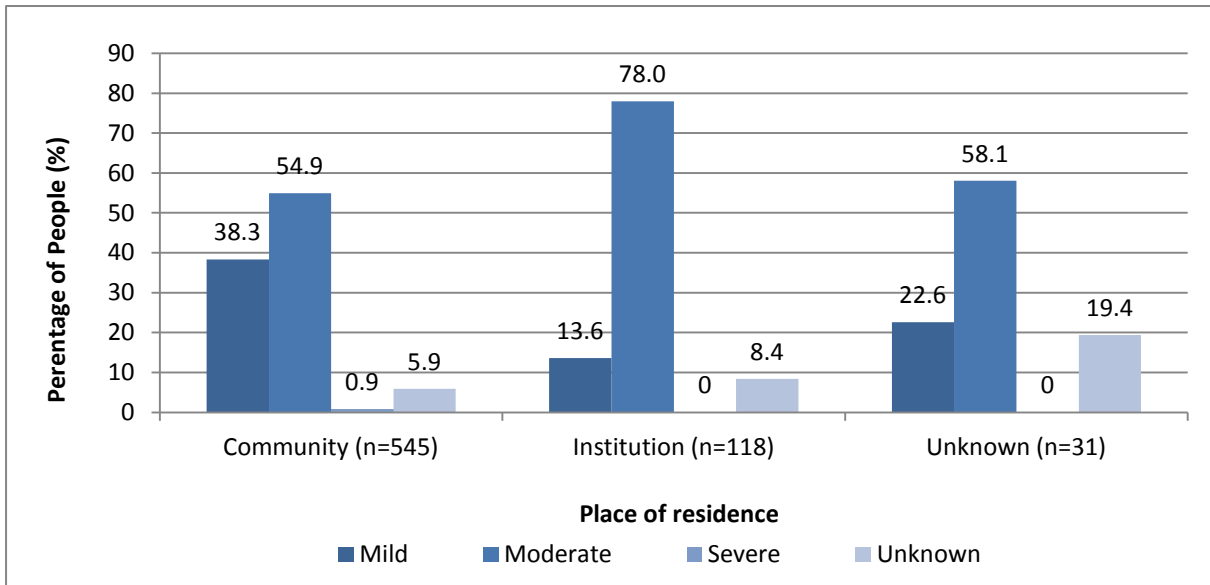


Figure 16 – Comparison of people with dementia living in the community with those living in an institution by cognitive impairment (MMSE score)

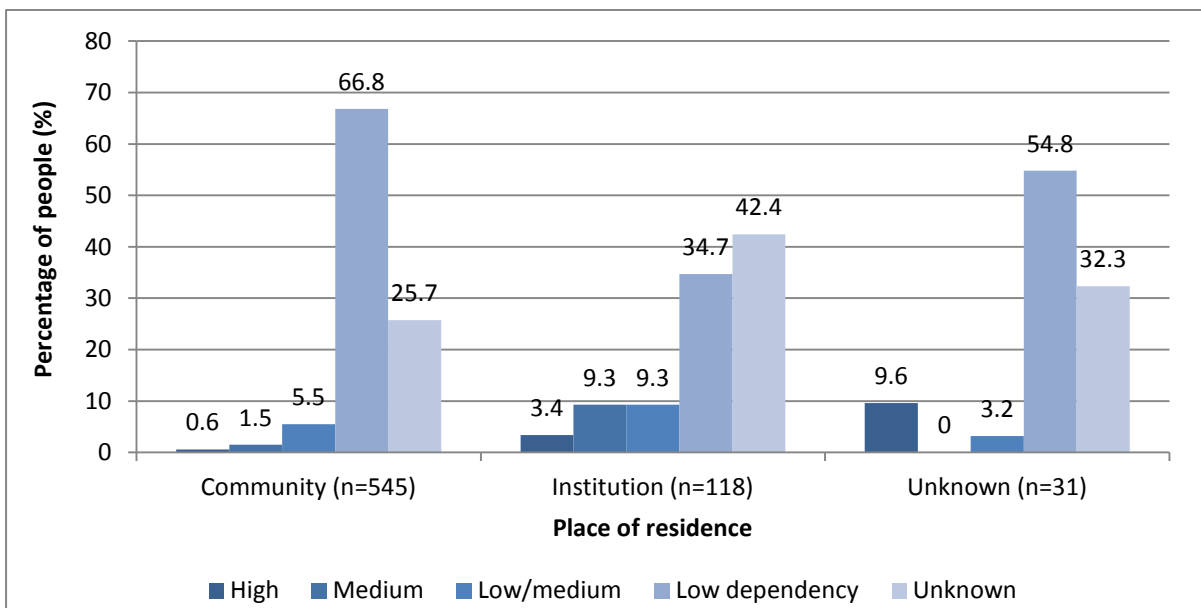


Figure 17 – Comparison of people with dementia living in the community with those living in an institution by dependency level (Barthel score)

6. The Family and other informal carers

Dementia is the largest contributor to disability and dependency (needs for care) among older people [3]. At a certain point in the disease process, the majority of people with dementia require some form of care. This need tends to escalate over time as the dementia becomes more severe. In all parts of the world, care is generally provided by informal (family) carers [3].

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 [18], carers are very likely to experience strain. They may suffer from high levels of psychological morbidity [19] and are at risk of increased physical ill health [20]. 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.

The main carer for persons with dementia living in the community was the spouse (husband 21.2%, wife 19%) followed by the daughter (28.4%). Only a minority of non-relatives were carers (1.1%). As seen, the leading contributors to care-giving were immediate relatives (Figure 18). The greater number of husbands as caregivers may be explained by the fact that there were more female dementia patients when compared to males. Caregivers were predominantly of the female gender (58.4%) compared to 37.4% who were male (for 4.2%, gender was not stated). Such a situation was also indicated 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 [21].

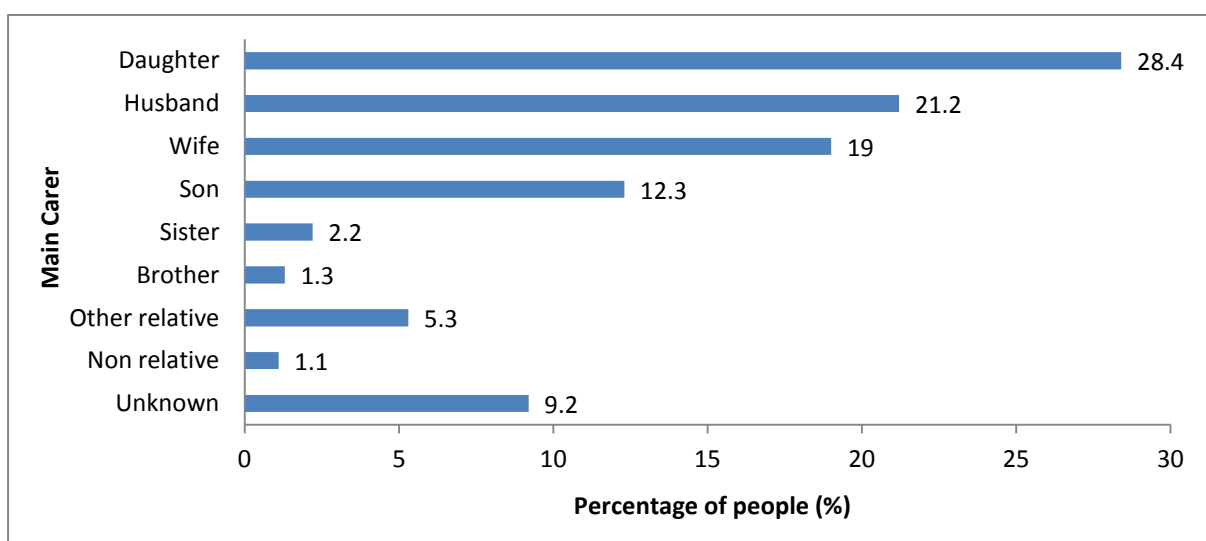


Figure 18 – Percentage of people with dementia living in the community according to their main carer (n=546)

7. Referral by type of Medical Speciality

Only Consultants in psychiatry, geriatrics and neurology can prescribe anti-dementia medications according to protocol. During 2013, of the 694 cases entered in the Dementia Register, 548 cases (79%) were seen by geriatricians, 30 cases (4.3%) were seen by neurologists and 85 cases (12.2%) were seen by psychiatrists. In 31 cases (4.5%) the consultant was not specified. Persons with early onset dementia were referred for anti-dementia medications mainly by neurologists or geriatricians as seen in figure 19.

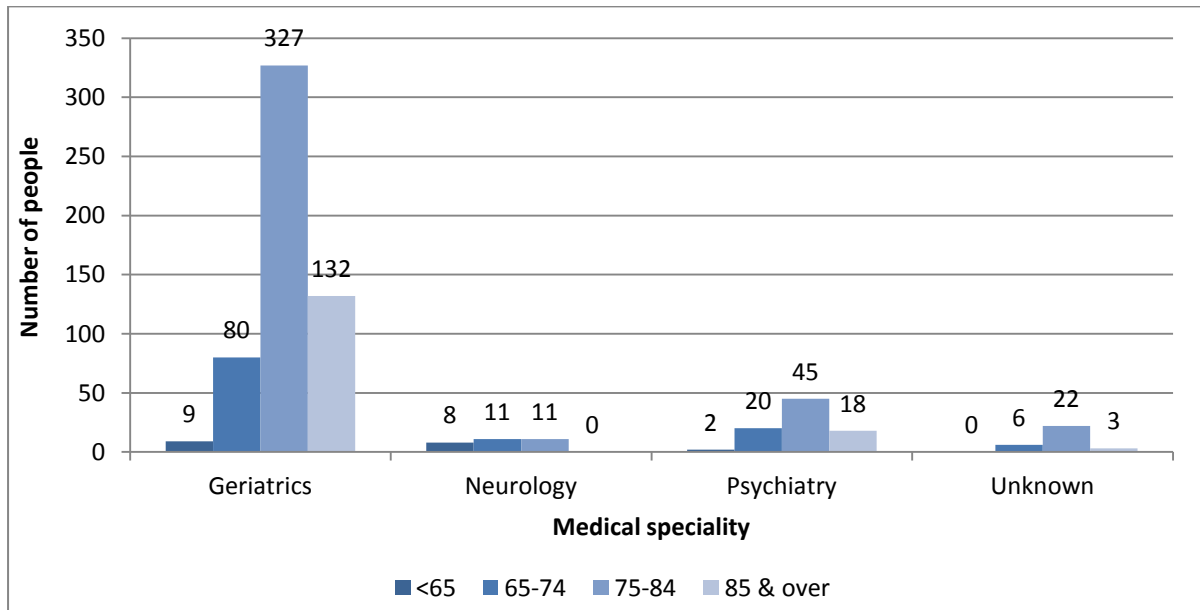


Figure 19 – Number of people with dementia according to age group and speciality referral

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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 <input type="checkbox"/> secondary <input type="checkbox"/> post-secondary <input type="checkbox"/> non-tertiary <input type="checkbox"/> tertiary <input type="checkbox"/>	Social Status:	S M W Sep Div
Resident at:	Own Home <input type="checkbox"/>	Nursing Home <input type="checkbox"/> Specify:	Other <input type="checkbox"/> Specify:
Living status:	Alone <input type="checkbox"/>	With Spouse <input type="checkbox"/> Other <input type="checkbox"/>	With Children <input type="checkbox"/>
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 <input type="checkbox"/> Fronto-temporal Dementia <input type="checkbox"/> Other <input type="checkbox"/> Specify:	Vascular Dementia <input type="checkbox"/> Alcohol Related Dementia <input type="checkbox"/>	Mixed Dementia <input type="checkbox"/> Lewy-Body Disease <input type="checkbox"/>
Clinic:	RHKG <input type="checkbox"/> Community <input type="checkbox"/>	MDH <input type="checkbox"/> Other <input type="checkbox"/> Specify:	MCH <input type="checkbox"/>
Radiology:	CT	Date:	
	MRI	Date:	
	SPECT	Date:	
Behavioural and Psychological Sypt:	Wandering <input type="checkbox"/> Depression <input type="checkbox"/>	Aggression <input type="checkbox"/> Shouting <input type="checkbox"/>	Agitation <input type="checkbox"/>
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:		Barthel score:	
MMSE score:		side-effects of dementia treatment:	
Dementia Treatment:		side-effects of Psychiatric treatment:	
Psychiatric Treatment:			
Current housing Location:	Own Home <input type="checkbox"/>	Nursing Home <input type="checkbox"/> Specify:	Other <input type="checkbox"/> 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 <input type="checkbox"/> secondary <input type="checkbox"/> post-secondary <input type="checkbox"/> non-tertiary <input type="checkbox"/> tertiary <input type="checkbox"/>	Social Status:	S M W Sep Div
Resident at:	Own Home <input type="checkbox"/>	Nursing Home <input type="checkbox"/>	Other <input type="checkbox"/>
		Specify:	Specify:
Living status:	Alone <input type="checkbox"/>	With Spouse <input type="checkbox"/>	With Children <input type="checkbox"/>
		Other <input type="checkbox"/>	
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 <input type="checkbox"/> Fronto-temporal Dementia <input type="checkbox"/> Other <input type="checkbox"/> Specify:	Vascular Dementia <input type="checkbox"/> Alcohol Related Dementia <input type="checkbox"/>	Mixed Dementia <input type="checkbox"/> Lewy-Body Disease <input type="checkbox"/>
Clinic:	RHKG <input type="checkbox"/> Community <input type="checkbox"/>	MDH <input type="checkbox"/> Other <input type="checkbox"/> Specify:	MCH <input type="checkbox"/>
Radiology:	CT	Date:	
	MRI	Date:	
	SPECT	Date:	
Behavioural and Psychological Sypt:	Wandering <input type="checkbox"/> Depression <input type="checkbox"/>	Aggression <input type="checkbox"/> Shouting <input type="checkbox"/>	Agitation <input type="checkbox"/>
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 <input type="checkbox"/>	Nursing Home <input type="checkbox"/>	Other <input type="checkbox"/>
		Specify:	Specify:
Part 4: To be completed always:			
Consultant:		Signature:	
Reg No:			