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Research paper

UTILISATION OF SERVICES BY INFORMAL CAREGIVERS OF COMMUNITY-DWELLING PERSONS LIVING WITH DEMENTIA MAKING USE OF THE DEMENTIA ACTIVITY CENTRES IN THE MALTESE ISLANDS

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Abstract. Dementia is one of the most important socio-medical conditions and public health challenges facing the Maltese informal and formal caregivers. In recent years, a number of services, including dementia-specific services, have been launched locally in order to assist persons living with dementia and their informal caregivers residing in the community. Although a number of these services have proved to be popular with informal caregivers, research on their utilisation and level of satisfaction is lacking. As a result, this study aimed to investigate service use and levels of service satisfaction of local informal caregivers of persons living with dementia. Data from 38 informal caregivers of community-dwelling persons living with dementia making use of the available Dementia Activity Centres was collected using a specifically designed questionnaire to determine which services were being utilised and the level of satisfaction on service use by informal caregivers. Persons living with dementia had a mean age of 76.7+/-6.1 years and were mostly living with their relatives. Informal caregivers had a mean age of 60.3+/-11.5 years, in the majority were daughters to the person living with dementia and had been in their caregiving role for more than five years. Results showed that caregivers mostly required assistance with bathing, handling of medication and transportation. Among the dementia-specific services available to persons living with dementia, caregivers mostly utilised the Dementia Activity Centres, the Dementia Wards at St. Vincent de Paul and the Dementia Helpline. Informal caregivers' knowledge on dementia-specific services that were introduced following the launch of the National Dementia

Strategy for the Maltese Islands were found to be lacking. In general, informal caregivers indicated a high degree of satisfaction with most of the services they utilised but unmet needs still subsisted. The findings demonstrated that although a number of services aimed at persons living with dementia and their caregivers are available, there is still lack of awareness of their existence. Such data can be useful to inform education and dementia practice and policy regarding the components required for the delivery of community-based dementia services aimed at bettering the quality of dementia care in the Maltese Islands.

Keywords: dementia, caregiving, community, services, knowledge

1 Introduction

Dementia is a clinical syndrome characterised by progressive deterioration of cognitive function beyond what might be expected from normal ageing (World Health Organisation, 2017). It mostly affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Alzheimer's Disease International (2013) described dementia as the biggest global health challenge facing the current generation with projected worldwide figures of 75.6 million persons living with dementia by 2030. In 2015, it was estimated that there were 6,071 persons living with dementia in the Maltese Islands with this number expected to rise to 12,955 by the year 2050 (Scerri & Scerri, 2012).

Dementia is characterised by progressive deterioration of cognitive abilities. As a result, affected individuals become increasingly dependent on the care of others (Innes et al., 2011). As the severity of symptoms increases, so does the difficulty in performing activities of daily living and participation in social activities often leading to situations where care would be constantly required (Zwaanswijk et al., 2013). As the number of older persons continues to increase,

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there will be even more demand for informal caregivers. Alzheimer's Disease International (2012) rated dementia among the top ten most burdensome conditions among older persons worldwide. In contrast with other conditions, its impact comes mainly from years lived with disability, rather than years of life lost from premature mortality (Alzheimer's Disease International, 2012).

In the majority of cases, care for persons living with dementia is provided by informal caregivers, typically a family member. Wimo et al. (2010) reported that the longer the person is provided with informal care, the less the costs to society. Supporting caregivers play an important part in preventing institutionalisation of persons living with dementia (Ervin & Reid, 2015) even though significant underutilisation of services for reasons such as lack of knowledge of the service, limited hours of service provision and cost or lack of availability has been reported (Xiao et al., 2013). In order to support caregivers in appropriate and supportive use of services, programme planners and health and social care service providers need a good understanding of the factors influencing use and non-use of services (Phillipson et al., 2014).

Within the local context, a wide range of services, including those specifically developed for persons living with dementia, are available (Scerri, 2015). These include the Memory Clinics, Dementia Rehabilitation Programme at Rehabilitation Hospital Karin Grech (RHKG), Dementia Intervention Team, Rehabilitation Wards (RHKG), Memory Classes (RHKG), Respite Care at St. Vincent de Paul (SVP), Dementia Activity Centres (SVP in Malta and Dar Padova in Ghajnsielem, Gozo), Dementia Helpline and services offered by the Malta Dementia Society, the latter being the sole national non-governmental organisation representing the voice of persons living with dementia (Scerri & Abela, 2006). Though not specific to dementia, persons living with dementia and their informal caregivers can also benefit from other services including the Community Geriatrician Services, Commcare (including Domiciliary Nursing, Occupational Therapy Service, Physiotherapy Service and Podiatry Service), Social Work, Home Help, Meals on Wheels, Telecare Plus, Continence Service, Night Shelters, Handyman Service, KartAnzjan and Telephone Rent Rebate. A full list of services is available online (Parliamentary Secretariat for Persons with Disability and Active Ageing, 2019).

Although utilisation of services by informal dementia caregivers in the community is essential in promoting their wellbeing and preventing early institutionalisation of the person living with dementia, to date, no study has been conducted locally on the utilisation of such services. Therefore, the main aim of this study was to investigate which services informal caregivers of community-dwelling persons living with dementia utilise. Furthermore, the level of satisfaction with the use of such services was also explored.

2 Methods

Fieldwork for this study was conducted in the Maltese Islands in October of 2017. Participants were all informal caregivers of community-dwelling persons living with dementia making use of the two available state-run

Dementia Activity Centres located at SVP in Luqa, Malta (n=35) and at Dar Padova in Ghajnsielem, Gozo (n=15) at the time of the study. These Centres provide a safe, secure and dementia-friendly environment for persons living with dementia and who still reside in their communities. On agreeing to their participation and following an explanation of the objectives of the study, informal caregivers were handed a study information sheet, consent form and the study questionnaire. All documentation was available in both English and Maltese language and was distributed and collected by gatekeepers to secure anonymity. Translation of the questionnaire to the Maltese version was carried out by a graduate in translation studies. Piloting of the questionnaire was conducted with six caregivers who previously used the Dementia Activity Centres (three in both language versions). All agreed that the questionnaire was easy to understand and free from complex technical terminology that participants would find difficult to understand. The results of the pilot study were not included in the main study.

The questionnaire was adapted from Ervin & Reid (2015) and was divided into two sections. This adaptation included the addition of a number of services, a list of which is accessible online (Parliamentary Secretariat for Persons with Disability and Active Ageing, 2019), that were available to Maltese dementia informal caregivers but unavailable to the list of services in the population sample tested by Ervin & Reid (2015). The first section included sociodemographic data comprising gender, age, civil status, level of education, relationship with the person living with dementia, duration of caregiving in years, number of hours per day spent in caregiving, whether the caregiver was living with the person living with dementia, if the caregiver received information on services available for dementia caregivers upon diagnosis and whether they were aware that there was a National Strategy for Dementia in the Maltese Islands. Caregivers were also asked to select from a list of activities they help the person living with dementia with. These included bathing, taking medication, eating meals, walking, household tasks, food preparation, transport, shopping and administration of finances. Participants were also asked to provide sociodemographic data of the person living with dementia including gender, age, civil status, level of education and whether the person with dementia lives alone.

The second part of the questionnaire investigated the utilisation and level of satisfaction on services that were available for informal caregivers of persons living with dementia in the Maltese Islands. Response alternatives to a list of community services were (i) I use or have used this service; (ii) This service has been offered but I have not used it; (iii) I did not know about this service. A 5-point Likert-type scale rating from very unsatisfied (1) to very satisfied (5) was used to measure level of satisfaction of any utilised service.

The study was approved by the Faculty for Social Wellbeing Research Ethics Committee and by the University of Malta Research Ethics Committee following the approval from the Chief Executive Officer and Medical Superintendent of St. Vincent de Paul in Malta (for the Dementia Activity Centre in Luqa, Malta) and the Director of Active Ageing

and Community Care Directorate and the Dementia Activity Centre Coordinator (for the Dementia Activity Centre in Ghajnsielem, Gozo). Participants were guaranteed confidentiality and anonymity and were free to withdraw at any stage without giving a reason. Written consent was obtained by all participants.

Analysis of data was conducted using the IBM® Statistical Package for Social Sciences (SPSS®) version 24.00. Descriptive statistics including mean data, standard deviations and percentages were used to describe sociodemographic data, service utilisation and level of satisfaction scores. Following data analysis for normality of distribution by the Shapiro-Wilk test, the data was found not to be normally distributed. As a result, sociodemographic and service use data were compared using the chi-square test. Service use level of satisfaction by informal caregivers was analysed with Kruskal-Wallis test followed by pairwise comparison. Cronbach alpha was utilised to determine the internal consistency of the research instrument. Mean data was expressed as a mean +/-SD (standard deviation). The significance level was set at 0.05.

3 Results

3.1 Characteristics of persons living with dementia and informal caregivers

Out of a total of 50 service users, 38 informal caregivers returned the questionnaire (response rate: 76%). Descriptive statistics of community-dwelling persons living with dementia and their informal caregivers are presented in Table 1. The majority of persons living with dementia were females, had a mean age of 76.7 +/- 6.1 years (range: 67-90 years), were either married or in a domestic relationship, had primary level of education and were living with their relatives.

Informal caregivers were mostly females, had a mean age of 60.3 +/- 11.5 years (range: 37-79 years), hailed from the Northern Harbour and Southern Harbour regions (for Maltese caregivers), were married or living in domestic partnership, had secondary level of education, were daughters of the person living with dementia, were caring for their relative with dementia for more than five years, spent more than 20 hours per day in caregiving, were living with the person living with dementia in the same household and indicated that they received information on available services upon diagnosis. Only 63.2% of informal caregivers were aware that a National Dementia Strategy was available in the Maltese Islands.

Table 1. Sociodemographic characteristics of community-dwelling persons living with dementia and their informal caregivers (iCG, informal caregiver; PLWD, person living with dementia)

Variables	PLWD (N=38)		iCG (N=38)	
	n (%)	Mean +/-SD	n (%)	Mean +/-SD
Gender				
Male	15 (39.5)		11 (28.9)	
Female	23 (60.5)		27 (71.1)	
Age (years)		76.7 +/- 6.1		60.3 +/- 11.5
Status				
Single	2 (5.3)		8 (21.1)	
Married/Domestic partnership	22 (57.9)		27 (71.1)	
Widowed	14 (36.8)		0 (0.0)	
Separated	0 (0.0)		3 (7.9)	
Education				
Primary	24 (63.2)		11 (29.0)	
Secondary	13 (34.2)		16 (42.1)	
Post-secondary	1 (2.6)		11 (29.0)	
Relationship with PLWD				
Spouse			16 (42.1)	
Son			4 (10.5)	

Variables	PLWD (N=38)		iCG (N=38)	
	n (%)	Mean +/-SD	n (%)	Mean +/-SD
Caregiving	Daughter		17 (44.7)	
	Sibling		1 (2.6)	
	Others		0 (0.0)	
	≤1 year		0 (0.0)	
	>1-2 years		3 (7.9)	
	>2-3 years		3 (7.9)	
	>3-4 years		8 (21.1)	
	>4-5 years		8 (21.1)	
	>5 years		16 (42.1)	
Number of caring hours/day	<5hours		3 (7.9)	
	5-8 hours		5 (13.2)	
	9-12 hours		0 (0.0)	
	13-16 hours		2 (5.2)	
	17-20 hours		3 (7.9)	
	21-24 hours		24 (63.2)	
	No answer		1 (2.6)	
	Living with PLWD	Yes		31 (81.6)
No			7 (18.4)	

3.2 Activities that informal caregivers need help with

Bathing (94.7%), handling of medication (94.7%) and transportation (92.1%) were the three top activities that informal caregivers of persons living with dementia indicated that they needed help with. Activities such as helping their relative with dementia with feeding and to walk/stand up were indicated as the least in terms of need (60.5%; 65.8% respectively). As expected, and on considering the psychological burden associated with caring for person living with dementia, help with emotional support was also considered to be in high in terms of need (89.5%).

3.3 Utilisation and service satisfaction by informal caregivers

The use of available services together with the level of satisfaction about their utilisation by informal caregivers are shown in Table 2 and Table 3 respectively. Services that informal caregivers utilised the most included the Active Ageing Centres that are located across the Maltese Islands,

St. Vincent de Paul and the Dementia Activity Centres. These were followed by KartAnzjan, the Pharmacy of Your Choice, the Dementia Wards located at St. Vincent de Paul, the Continence Service and the Telecare Plus. Services which caregivers used the least included the Geriatrician Services, Commcare and Social Work. Interestingly, informal caregivers were not using a number of dementia-specific services that were available and aimed at supporting them in their caregiving roles. These included the organisation of Memory Classes for individuals who have recently received a diagnosis of dementia and their informal caregivers, the Memory Clinics (Paola and Floriana Health Centres) and in the Rehabilitation Hospital Karin Grech, and the availability of the Dementia Intervention Team. However, most informal caregivers had knowledge about the availability of the Dementia Helpline.

Table 2. Utilisation of services by informal caregivers (N=38; ID: Identity Card, OT: Occupational therapy, POYC: Pharmacy of Your Choice, PT: Physiotherapy, RHKG: Rehabilitation Hospital Karin Grech, SVP: St. Vincent de Paul). Cronbach alpha=0.884

Service	Percentage (n)		
	I use or have used this service	This service has been offered but I have not used it	I did not know about this service
Active Ageing Centres, Malta/Gozo	100.0 (38)	0.0 (0)	0.0 (0)
St. Vincent de Paul	71.1 (27)	28.9 (11)	0.0 (0)
Homes for the Elderly	10.5 (4)	78.9 (30)	10.5 (4)
Carer at Home Scheme	15.8 (6)	50 (19)	34.2 (13)
Commcare including Domiciliary Nursing, OT, PT and Podiatry services	7.9 (3)	28.9 (11)	63.2 (24)
Respite	18.4 (7)	60.5 (23)	21.1 (8)
Night Shelters	10.5 (4)	44.7 (17)	44.7 (17)
Home Help	15.8 (6)	63.2 (24)	21.1 (8)
KartAnzjan	92.1 (35)	5.3 (2)	2.6 (1)
Special ID	55.3 (21)	23.7 (9)	21.1 (8)
Social Work	7.9 (3)	36.8 (14)	55.3 (21)
Continence Service	47.4 (18)	47.4 (18)	5.3 (2)
Telephone Rent Rebate	21.1 (8)	52.6 (20)	26.3 (10)
Meals on Wheels	21.1 (8)	71.1 (27)	7.9 (3)
Telecare Plus	52.6 (20)	42.1 (16)	5.3 (2)
Handyman Service	10.5 (4)	73.7 (28)	15.8 (6)
POYC – Pharmacy of Your Choice	97.4 (37)	0.0 (0)	2.6 (1)
Dementia Helpline - 1771	29.0 (11)	57.9 (22)	13.2 (5)
Dementia Activity Center, SVP	71.1 (27)	28.9 (11)	0.0 (0)
Dementia Activity Centre, Gozo	28.9 (11)	65.8 (25)	5.3 (2)
Dementia Intervention Team	13.2 (5)	42.1 (16)	44.7 (17)
Dementia Wards, SVP	21.1 (8)	76.3 (29)	2.6 (1)
Memory Clinic, RHKG	15.8 (6)	36.8 (14)	47.4 (18)
Memory Clinic, Floriana Health Centre	7.9 (3)	28.9 (11)	63.2 (24)
Memory Clinic, Paola Health Centre	7.9 (3)	26.3 (10)	65.8 (25)
Memory Classes, RHKG	5.3 (2)	23.7 (9)	71.1 (27)
Geriatrician Services	7.9 (3)	23.7 (9)	68.4 (26)
Dementia Rehabilitation Programme, RHKG	10.5 (4)	28.9 (11)	60.5 (23)
Dementia Information Booklet	36.8 (14)	39.5 (15)	23.7 (9)
Guardianship Board	7.9 (3)	31.6 (12)	60.5 (23)

Among the services that were utilised by informal caregivers during their caring role, the respondents were mostly satisfied with Telecare Plus, the Active Ageing Centres, St. Vincent de Paul and the Special ID card. Among the dementia-specific

services that informal caregivers used, all participants were satisfied with the Dementia Activity Centres.

Table 3. Level of satisfaction on service use by informal caregivers (ID: Identity Card, OT: Occupational therapy, POYC: Pharmacy of Your Choice, PT: Physiotherapy, RHKG: Rehabilitation Hospital Karin Grech, SVP: St. Vincent de Paul)

Service	n	Percentage (%)		
		Unsatisfied	Neutral	Satisfied
Active Ageing Centres, Malta/Gozo	38	0.0	12.6	97.4
St. Vincent de Paul (SVP)	27	0.0	3.7	96.3
Homes for the Elderly	4	25.0	25.0	50.0
Carer at Home Scheme	6	0.0	33.3	66.7
Commcare including Domiciliary Nursing, OT, PT and Podiatry services	3	0.0	33.3	66.7
Respite	7	14.3	28.6	57.2
Night Shelters	4	25.0	25.0	50.0
Home Help	6	0.0	16.7	83.3
KartAnzjan	35	2.8	2.8	94.4
Special ID	21	4.7	0.0	95.3
Social Work	3	0.0	66.7	33.3
Continence Service	18	0.0	5.6	94.4
Telephone Rent Rebate	8	0.0	25.0	75.0
Meals on Wheels	8	0.0	25.0	75.0
Telecare Plus	20	0.0	0.0	100.0
Handyman Service	4	0.0	25.0	75.0
POYC – Pharmacy of Your Choice	37	0.0	0.0	100.0
Dementia Helpline – 1771	11	0.0	9.0	91.0
Dementia Activity Center, SVP	27	0.0	0.0	100.0
Dementia Activity Centre, Gozo	11	0.0	7.7	92.3
Dementia Intervention Team	5	0.0	20.0	80.0
Dementia Wards, SVP	8	0.0	25.0	75.0
Memory Clinic, RHKG	6	0.0	16.7	83.3
Memory Clinic, Floriana Health Centre	3	0.0	66.7	33.3
Memory Clinic, Paola Health Centre	3	0.0	33.3	66.6
Memory Classes, RHKG	2	0.0	50.0	50.0
Geriatrician Services	3	0.0	33.3	66.6
Dementia Rehabilitation Programme, RHKG	4	0.0	25.0	75.0
Dementia Information Booklet	14	0.0	7.0	93.0
Guardianship Board	3	33.3	33.3	33.3

Statistical analysis on the relationship between service utilisation and informal caregivers' and persons living with dementia demographic data indicated that the district demographic variable showed a strong significant effect on services including St. Vincent de Paul ($\chi^2(4)=38.000$, $p<0.001$), the Dementia Activity Centre in Luqa, Malta ($\chi^2(4)=27.495$, $p<0.001$), Commcare ($\chi^2(8)=22.862$, $p=0.004$), Telecare Plus ($\chi^2(8)=20.267$, $p=0.009$), the Dementia Wards at St. Vincent de Paul ($\chi^2(8)=23.886$, $p=0.002$), the Memory Clinic at Rehabilitation Hospital Karin Grech ($\chi^2(8)=23.256$, $p=0.003$) and the Memory Clinic at the Floriana Health Centre ($\chi^2(8)=21.839$, $p=0.005$).

Other important sociodemographic data that showed a significant effect on service utilisation included the caregivers' civil status and the age of the person living with dementia. With respect to informal caregiver status, strong significant differences were found in Night Shelters ($\chi^2(4)=27.776$, $p<0.001$), with informal caregivers who had a separated status making use of the shelters more often than those who indicated that they were single ($p=0.001$) or in a married/domestic relationship ($p<0.001$). The Dementia Wards at St. Vincent de Paul was also found to show significant differences with informal caregiver status ($\chi^2(4)=15.202$, $p=0.004$).

The age of the informal caregiver had a significant impact on the Carer at Home Scheme ($\chi^2(4)=10.115$, $p=0.039$), Night Shelters ($\chi^2(4)=11.586$, $p=0.021$), Memory Classes at the Rehabilitation Hospital Karin Grech ($\chi^2(4)=9.604$, $p=0.048$), the Dementia Rehabilitation Programme at the Rehabilitation Hospital Karin Grech ($\chi^2(4)=11.025$, $p=0.026$) and the Dementia Information Booklet ($\chi^2(4)=9.621$, $p=0.047$). Interestingly, a significant difference was reported between the informal caregivers' relationship with the person living with dementia and the use of the Dementia Helpline ($\chi^2(6)=20.279$, $p=0.002$). Further analysis revealed that daughters ($p=0.007$) and sons ($p=0.009$) of persons living with dementia use or have used this service more often compared to partners/spouses.

Significant differences between satisfaction levels of services utilised by informal caregivers of persons living with dementia were observed ($\chi^2(29)=65.766$, $p<0.001$) denoting that informal caregivers participating in the study were more satisfied with a number of services compared to others. Pairwise comparison analysis showed that the service that informal caregivers indicated that they were very satisfied with was the Active Ageing Centres located across the Islands, followed by St. Vincent de Paul, the Special ID and the Dementia Activity Centres. Satisfaction levels for the Active Ageing Centres was significantly higher than the Homes for the Elderly ($p<0.01$), Carer at Home Scheme ($p<0.01$), Respite ($p<0.05$), Home Help ($p<0.05$), Social Work ($p<0.01$), Continence Service ($p<0.01$), Meals on Wheels ($p<0.01$), Dementia Wards at St. Vincent de Paul ($p<0.05$), Memory Clinic at the Rehabilitation Hospital Karin Grech ($p<0.05$), Memory Clinic at the Floriana Health Centre ($p<0.05$), the Dementia Rehabilitation Programme at the Rehabilitation Hospital Karin Grech ($p<0.05$) and the Guardianship Board ($p<0.01$).

Among the dementia-specific services available, informal caregivers were satisfied with the Dementia Activity Centres. Satisfaction levels for the Dementia Activity Centres of informal caregivers was significantly higher compared to the Homes for the Elderly ($p<0.05$), Carer at Home Scheme ($p<0.01$), Respite ($p<0.05$), Social Work ($p<0.01$), Continence Service ($p<0.05$) and Meals on Wheels ($p<0.05$).

4 Discussion

The main objective of this study was to investigate service utilisation and level of service satisfaction among informal caregivers of community-dwelling persons living with dementia making use of the available Dementia Activity Centres in the Maltese Islands. Although participants were overall satisfied with the services they use, the results also indicated that a number of services were not being utilised.

The age of persons living with dementia was found to play a significant role in a number of services including the Carer at Home Scheme, Night Shelters, Memory Classes, the Dementia Rehabilitation Programme and the Dementia Information Booklet. As the age of the individual with dementia increased, so did the use of the Carer at Home Scheme. This was expected as age is positively related to dependency in dementia and this can have a negative impact on the caregiver (Van Bruggen et al., 2016). The majority of participants in the >80-year cohort did not know about the availability of Memory Classes organised at the Rehabilitation Hospital Karin Grech. These classes are useful in communicating information about quality management and care at home to persons living with dementia and their caregivers following dementia diagnosis. It may be that the availability of such a service was not effectively being suggested to these individuals upon diagnosis and beyond and therefore greater public education is needed in accessing information regarding multi-modality management and care (Peterson et al., 2016). Interestingly, the oldest age cohort had good knowledge of the Dementia Information Booklet. This suggested that, in this particular cohort, printed information was the preferred method of obtaining information.

The majority of informal caregivers participating in this study were females. Although many countries are experiencing a shift in the incidence of male caregivers in dementia (Mc Donnell & Ryan, 2011), informal caregiving in the Maltese Islands is mostly regarded as an activity cared for by the female gender (Innes et al., 2011). Gender was found to have a significant effect on the Telephone Rent Rebate and the Telecare Plus services. Males were found to be less likely to use these services compared to females. Gender differences in caregiving among informal caregivers of persons living with dementia are well documented in literature (Pöysti et al., 2012). Whereas men consider caregiving more as a task, women may take it more comprehensively (Baker & Robertson, 2008). Furthermore, male caregivers are less likely to suffer as much as female caregivers with respect to burden denoting that the male gender seems to be protective when caring for a person with dementia (Pöysti et al., 2012).

Informal caregivers of persons living with dementia mainly came from two age cohorts; the 50-59 years and the 70-79 years. The latter age cohort appears to comprise most informal caregivers of community-dwelling persons living with dementia in the Maltese Islands having been reported in two previous local studies (Gobey, 2013; Muscat, 2015). Interestingly, none of the informal caregivers in this age cohort indicated that they used or have used the Dementia Helpline. This was surprising on considering that telephone-based information and referral helplines are useful in disseminating knowledge about resources, especially to older caregivers of community-dwelling persons with cognitive impairment (Coyne, 1991). Furthermore, extended telephone contact increase the use of community services and decrease caregiver burden (Coyne et al., 1995).

Most of the informal caregivers were daughters, closely followed by spouses/domestic partners. These findings were in accordance with Muscat (2015) who also reported that the percentage of daughters caring for a parent with dementia in the community is high in the Maltese Islands. Studies suggest that daughters, acting as primary caregivers, have higher burden and are more likely to experience guilt (Romero-Moreno et al., 2014) and may have to relinquish or reduce employment to take up a primary caring role (Innes et al., 2011).

The data presented in this study showed that Maltese informal caregivers of persons living with dementia who attended the Dementia Activity Centre in Luqa, Malta mostly resided in the Southern and Northern Harbour districts, the latter being areas of close geographical proximity to this service. Interestingly, no caregiver of persons living with dementia who attended this Centre hails from the Northern district. A possible explanation to this may be that the distance to the Dementia Activity Centre in Malta and significant delays in traffic encountered when using this service acted as limiting factors for Maltese caregivers. Although transport to and from the Dementia Activity Centre in Gozo was provided by the service provider at the time of study, such service was not available in Malta. While the transport of persons living with dementia may work where the distance is short, it can become a traumatic experience where larger distances are involved. The need of increasing the number of Dementia Activity Centres across the Maltese Islands, thereby reducing the distance taken by travel by service users, is one of the recommendations included in the National Dementia Strategy launched in April of 2015 (Scerri, 2015).

Participating informal caregivers indicated that they mostly needed help with activities that included bathing, handling of medication and transportation. This was consistent with impairment of activities in daily living associated with mild to moderate dementia with the latter being the most common stage of dementia in individuals attending the Dementia Activity Centres in the Maltese Islands (Muscat, 2015). Assistance with activities associated with severe dementia such as feeding (Cohen-Mansfield et al., 1995) were the least indicated in need of support. Dementia is a progressive disorder which is accompanied by the need of a gradual increase in support in the conduct of activities

of daily living. This progressive loss of independence in such activities is also associated with poorer quality of life (Andersen et al., 2004).

This research work had a number of limitations. Caregivers were selected amongst those using the Dementia Activity Centres and this may have affected the generalisability of the data. Caregivers who do not use the Dementia Activity Centres are difficult to identify for surveys and are therefore not represented in the present study. As a result, participants to this study do not necessarily represent the perspectives of informal caregivers who are yet to actively seek support or that use other services. Although all caregivers making use of the Dementia Activity Centres were approached to participate in this study, leading to a high response rate, the sample size remained small and this may have affected statistical power. Moreover, caregivers that participated in this study was not a representation of the total population of informal caregivers of community-dwelling persons living with dementia in the Maltese Islands.

5 Conclusion

Dementia presents a significant challenge not only to those individuals who are affected but also to their informal caregivers, who in the majority of cases are relatives of the individual living with dementia. This study investigated the level of knowledge and degree of satisfaction of informal caregivers of persons living with dementia residing in the community on services intended to support them in their caregiving role. The results have indicated that although informal caregivers used and were satisfied with the provision of various services that were available, a number of dementia-specific services were still underutilised. This data can be useful to inform dementia practice and policy development regarding the essential components required for the delivery of community-based dementia services aimed at enhancing the quality of dementia care in the Maltese Islands.

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8 Conflicts of interests

The authors report no conflicts of interest

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