Use of health and social care services in a cohort of Italian dementia patients

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Summary

The aim of this study, conducted in the Region of Lazio, Italy, in 2008-2010, was to describe the use, over a one-year period, of health and social care services in a cohort of 712 patients with a diagnosis of dementia. These patients had never previously used such services.
We evaluated the association between the patients' sociodemographic and clinical characteristics and their use of services. Sociodemographic and clinical data were collected at baseline using validated instruments, while the use of services was investigated at the end of the one-year follow-up through a structured (questionnaire-based) interview with the caregiver.
We found that 11.9% of patients used health or social care services. The most frequent diagnoses were: Alzheimer's disease (72.1%), mixed dementia (20.5%), and vascular dementia (9.7%). A higher probability of use of services was observed in patients with: more than five years of schooling (OR=1.79; 95%CI:1.08-2.96); one or more comorbidity (OR=4.87; 95%CI:2.05-11.57); severe (OR=4.78; 95%CI:1.75-13.06) or moderate dementia (OR=2.08; 95%CI:0.98-4.40). The low health and social care service use among dementia patients in this study could be explained by a lack of availability of services. Public health authorities should plan adequate networks of services, considering both patients and caregivers' needs.

KEY WORDS: cohort study, dementia, health and social care services, healthcare system, memory clinics

Introduction

Dementia is a syndrome characterized by cognitive, behavioral and functional impairments that interfere with the affected person's basic and instrumental daily life activities and social relationships and has a strong impact on the quality of life of both patients and their families (Agüero-Torres et al., 2002). Dementia causes progressive disability, and it is one of the main causes of disability and death in persons over 65 years of age in industrialized countries.
The global estimated prevalence of dementia at age ≥60 years has been found to range between 5% and 7%, with a prevalence of 6.9% reported in Western Europe (Prince et al., 2013); the EURODEM study (Lobo et al., 2000) found a prevalence of 6.4% for all dementias and 4.4% for Alzheimer's disease (AD) at age 65+. In Italy, the prevalence of any form of dementia among persons aged 65-84 years has been estimated to be around 6%, whereas the estimated prevalence of AD is around 2.5% (The Italian Longitudinal Study on Aging Working Group, 1997). Extending the analysis to persons over 84 years of age, the estimated prevalence ranges from 5.9% to 6.4% for any type of dementia and from 3% to 3.3% for AD (Ravaglia et al., 2002; Rocca et al., 1990). The estimated annual incidence rate per 1,000 person-years is 7.5 (Ferri et al., 2005), while the Italian Longitudinal Study on Aging (ILSA) estimated that the average incidence rate per 1,000 person-years is 12.5 (Di Carlo et al., 2002). The life expectancy of people with dementia is estimated to be around 10 years from diagnosis (Zanetti et al., 2009).
The care of persons with dementia requires a complex network of health and social care services, planned according to the different stages of the disease. Evidence from randomized controlled trials showed that case management improves function and appropriate use of medications, increases use of community services, and reduces nursing home admissions. Evidence, mostly from non-randomized trials, shows that integrated care increases service use (Low et al.,

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2011). A recent review underlined the positive effects, with regard to clinical conditions, direct and indirect costs of care, institutionalization and caregiver burden, of integrated/multidisciplinary management of dementia compared with standard treatment (Rivoiro et al., 2011).

Even though community services are necessary to support the intensive levels of care provided by family caregivers of dementia sufferers, literature data consistently indicate low rates of service utilization by these caregivers (Lim et al., 2012; Bookwala et al., 2004). The most common reasons for such non-use include: perceived lack of need, reluctance to use, distance and costs of services, lack of awareness about the availability of services, lack of time, and the presence of domestic help (Lim et al., 2012; Brodaty et al., 2005).

The framework most widely used to explain the use of services is the Andersen and Newman model (Andersen and Newman, 1973), which takes into consideration numerous individual and environmental factors: predisposing factors (demographics, beliefs), enabling factors (family, community, available services), and need factors (stage of dementia, caregiver's perceived burden and health, perceived needs). Enabling variables are at least as important as need variables in predicting the use of services by family caregivers of persons with dementia (Toseland et al., 2002).

The use of health and social care services is always mediated by caregivers, as they play a key role in choosing the care pathway (Livingston et al., 2010).

Given the potentially negative economic and social consequences of failure to support family caregivers, greater understanding of the factors associated with the use of health and social care services would be useful to policy makers and healthcare providers (Lim et al., 2012).

Our study focuses on a peculiar and specific group of patients, namely ones who have received a diagnosis of dementia (mean time since diagnosis: 27±22 months) and been assigned a drug treatment in a specialized center/memory clinic, but have never made use of health and social care services. Our hypothesis was that memory clinics, being a source of specialist information with the capacity to raise awareness of the disease, constitute a setting likely to facilitate the use of these services.

The aim of our study was to describe the frequency of health and social care service use over a 12-month period in a population of patients with dementia who had never previously used such services, and the individual, clinical and social characteristics associated with this use.

Materials and methods

Study population, setting and design

Between June 1st 2008 and April 30th 2009, 712 patients with dementia, diagnosed at five Alzheimer's evaluation units located in the Region of Lazio (Italy),

who had never previously used any health or social care services, were enrolled in our cohort study, which envisaged a 12-month follow-up for each subject (study end: May 2010).

In Italy, an Alzheimer's Disease Assessment Unit, or "Unità Valutativa Alzheimer" (UVA), is a specialized public outpatient center set up by the Italian Health System to diagnose and administer pharmacological treatments for AD and other forms of dementia (Italian Ministry of Health, Decree of July 20th, 2000). In Italy, UVA physicians are authorized to prescribe anti-dementia [acetylcholinesterase inhibitors (AChEIs) or memantine] and antipsychotic drugs, according to a plan of drug treatment that is periodically confirmed or changed after clinical evaluation at the UVA. The UVA's treatment plan must be ratified by the patient's general practitioner and the prescribed drugs are refunded by the Regional Health Authority.

Five of the 35 UVAs located in the Region of Lazio were chosen to take part in this study: three of the 23 located in the city of Rome (the Lazio region's main city), one of the six located in the Rome suburbs, and one of the six located in the region's rural areas. These five centers thus represented the sociodemographic areas characterizing this region.

The health and social care services available in Lazio to patients with dementia are home-based or residential ones.

The home-based services comprise: support services such as home help (around six hours a week), day care programs for patients with dementia (around six hours a day for five days a week), services provided by voluntary associations (assistance with home care and counseling for caregivers), home visits by general practitioners and domiciliary assistance provided by other healthcare professionals (specialists, physiotherapists, nurses).

The residential services comprise: AD care facilities, public and private care facilities for the elderly, rehabilitation facilities, long-term care facilities, and respite care. AD and public care facilities combine health and social care, while rehabilitation and long-term care facilities are reserved for patients just discharged from acute hospitals whose disease has not yet stabilized and who therefore have specific healthcare needs. The fees of public care, rehabilitation and long-term care facilities are in part refunded by the Regional Health Authority, according to the family's income, while private care facilities are completely paid for by patients and their families.

This study was designed by researchers from the Lazio Region Agency for Public Health, who also analyzed the data collected by the clinicians employed at the five UVAs. The study was part of an Italian Ministry of Health-funded project aimed at improving the planning of integrated health and social care programmes for people with dementia, according to the different stages of the disease.

The study was performed in compliance with the Declaration of Helsinki and was approved by the ethics committee of the "Policlinico Umberto I -

Sapienza University" of Rome in May 2008. All participants (both patients and caregivers) signed an informed consent form.

The patients were selected according to the following criteria: they had to be a patient at a UVA, with a diagnosis of a form of dementia, who had never previously used any kind of health or social care services.

Assessment of clinical and sociodemographic information

The UVA clinicians collected clinical and sociodemographic data at baseline. Clinical data were collected using validated clinical instruments. Information about the use of health and social care services over the one-year follow-up was obtained through a multiple-choice questionnaire, which listed all the available services in the Lazio region, administered to the primary caregiver 12 months after the enrollment.

We defined the primary caregiver as the person who provides the majority of the daily care and coordinates the different social and health interventions for the patient, and bears most of the economic and psychological burden. Thirteen patients (1.8%) had no primary caregiver and in these cases the questionnaire was compiled by another suitably informed person, who had accompanied the patient to the UVA (secondary caregiver).

All data were collected in a central data management system and were submitted to the standard procedure for data quality assurance.

The diagnosis of any form of dementia was made according to the DSM-IV criteria (The American Psychiatric Association, 1994), while AD was diagnosed according to NINCDS-ADRDA criteria (McKhann et al., 1984), vascular dementia according to the NINDS-AIREN criteria (Román et al., 1993), and frontotemporal dementia according to the Lund and Manchester criteria (The Lund and Manchester Groups, 1994). Mixed dementia was defined as the presence of both AD and vascular dementia. Mild cognitive impairment was diagnosed according to the criteria of Petersen et al. and Ritchie and Touchon (Petersen et al., 1999; Ritchie and Touchon, 2000; Petersen et al., 2001a,b). The stage of dementia was assessed using the Clinical Dementia Rating Scale (CDR) (Hughes et al., 1982). Cognitive impairment was assessed using the Mini-Mental State Examination (MMSE) (Folstein et al., 1975; Magni et al., 1996). Functional status was evaluated using the Basic Activities of Daily Living (BADL) (Katz et al., 1963) and the Instrumental Activities of Daily Living (IADL) (Lawton and Brody, 1969) scales. The presence of behavioral and psychological symptoms in dementia (BPSD) was investigated with the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994). The presence and severity of comorbidities were assessed using the Cumulative Illnesses Rating Scale (CIRS) (Parmelee et al., 1995).

The UVA clinicians also collected information about caregiver type and gender and about use of anti-dementia (AChEIs or memantine) and psychotropic (antidepressants, anxiolytics, antipsychotics, hypnotics) drugs.

Statistical analysis

We calculated crude odds ratios with 95% confidence intervals through logistic regression models to evaluate the association between the many relevant demographic, clinical and social variables collected in the study and the use of any health or social care service. We also performed a multiple logistic regression model to investigate the factors associated with the use of any health or social care service. Several variables (level of education, type of caregiver, clinical dementia rating scale scores, number of comorbidities) were analyzed as potential confounding factors using automatic forward stepwise selection, fixing a probability to enter value of <0.20. Variables considered relevant for the analysis (age, gender, BADL score, IADL score, MMSE score, time since dementia diagnosis) were also included in the model.

Statistically significant differences between the service users and the non-users in the distribution of some variables (age, MMSE, BADL, IADL, length of disease) were evaluated through the non-parametric Kruskal-Wallis test, a generalization of the two-sample rank-sum test.

We performed a Spearman rank-based correlation analysis to evaluate consistency in the distribution of cognitive and functional scales and duration of disease. For this analysis, dementia, according to the CDR scale scores, was classified as uncertain/very mild/mild (0.5-1), moderate (2), and severe/late dementia (3-4-5). Observing that the patients had a very low mean number of comorbidities – the average score on the CIRS, which is the index of severity of comorbidities, was 1.35 (SD 0.25) –, we decided to categorize comorbidities as "absent" versus "present (one or more)". The presence of a comorbidity was taken as a proxy of a heavier health burden.

Data were analyzed using Stata/SE 11.0 for Windows.

Results

Table I (over) shows the main sociodemographic and clinical characteristics of the patients, both those who used health and/or social care services in the 12 months following their enrollment, and those who did not make use of such services in the same period of time: 11.9% used at least one service (any kind), while 88.1% made no use of any kind of service. No statistically significant difference (p=0.20) in mean age was found between the patients who used (79.5±7.2 years) and those who did not use (80.4±7.4 years) any service. The duration of dementia (months since diagnosis) was longer (p=0.09) in the service users (30.7±23.0) than in the non-users (26.3±22.2). The MMSE, BADL and IADL scores were higher among the non-users.

Table I – Patients' baseline characteristics by use of services.

		No service used		At least one (any) service used			Total	
		n.	mean (SD)	n.	mean (SD)	p	n.	mean (SD)
Age	(years)	627	79.5 (7.2)	85	80.4 (7.4)	0.20	712	79.6 (7.2)
MMSE	(score)	627	15.2 (6.8)	85	12.7 (8.0)	0.02	712	14.9 (7.0)
BADL	(score)	627	4.4 (1.7)	85	3.7 (1.9)	0.001	712	4.3 (1.7)
IADL	(score)	627	2.9 (2.1)	85	1.9 (1.8)	0.001	712	2.8 (2.1)
Dementia duration	(months since diag.)	627	26.3 (22.2)	85	30.7 (23.0)	0.09	712	26.8 (22.4)
		n.	%	n.	%	p	n.	%
Gender	• Men	190	30.3	28	32.9	0.62	218	30.6
	• Women	437	69.7	57	67.1		494	69.4
Level of education	• Low (≤5 years)	421	67.1	46	54.1	0.02	467	65.6
	• High (>5 years)	206	32.9	39	45.9		245	34.4
Type of caregiver	• Paid home carer	64	10.2	8	9.4		72	10.1
	• Spouse	252	40.2	31	36.5		283	39.8
	• Adult child	257	41.0	37	43.5	0.42	294	41.3
	• Other relative	41	6.5	9	10.6		50	7.0
	• None	13	2.1	0	0.0		13	1.8
Form of dementia	• Alzheimer disease	384	61.2	129	66.5		433	60.8
	• Vascular dementia	61	9.7	8	9.4		69	9.7
	• Mixed dementia	127	20.3	19	22.3		146	20.5
	• Frontotemporal d.	21	3.3	3	3.5	0.35	24	3.4
	• Lewy body dementia	5	0.8	3	1.5		8	1.1
	• Parkinson's dementia	10	1.6	0	0.0		10	1.4
	• Other forms	19	3.0	3	3.5		22	3.1
CDR	• Uncertain/mild (0.5-1)	230	36.7	14	16.4		244	34.2
	• Moderate (2)	284	45.3	37	43.5	<0.001	321	45.1
	• Severe/late (3,4,5)	113	18.0	34	40.0		147	20.6
MMSE	• Mild (24-30)	90	14.4	11	12.9		101	14.2
	• Moderate (18-23)	245	39.1	23	27.1	0.04	268	37.6
	• Mod. severe (11-17)	203	32.4	30	35.3		233	32.7
	• Severe (0-10)	89	14.2	21	24.7		110	15.5
Comorbidities	• Absent	179	28.5	6	7.1	<0.001	185	26.0
	• Present (1 or more)	448	71.5	79	92.9		527	74.0
AChEIs & memantine	• No	133	21.2	25	29.4	0.09	158	22.2
	• Yes	494	78.8	60	70.6		554	77.8
Anti-BPSD drugs	• No	316	50.4	38	44.7	0.33	354	49.7
	• Yes	311	49.6	47	55.3		358	50.3
NPI (presence of symptoms)	• Delusions	35	5.6	10	11.8	0.03	45	6.3
	• Hallucinations	35	5.6	10	11.8	0.03	45	6.3
	• Agitation/aggression	174	27.8	24	28.2	0.93	198	27.8
	• Depression	193	30.8	23	27.1	0.48	216	30.3
	• Anxiety	168	26.8	21	24.7	0.68	189	26.5
	• Elation/euphoria	5	0.8	2	2.3	0.17	7	0.9
	• Apathy	167	26.6	21	24.7	0.71	188	26.4
	• Disinhibition	20	3.2	6	7.1	0.07	26	3.7
	• Irritability/lability	142	22.6	25	29.4	0.17	167	23.5
	• Motor disturbances	42	6.7	9	10.6	0.19	51	7.2
	• Sleep disorders	116	18.5	18	21.2	0.55	134	18.8
	• Appetite and eating	40	6.4	5	5.9	0.86	45	6.3

Abbreviations: MMSE=Mini-Mental State Examination; BADL=Basic Activities of Daily Living; IADL=Instrumental Activities of Daily Living; CDR=Clinical Dementia Rating Scale; AChEIs=acetylcholinesterase inhibitors; BPSD=behavioral and psychological symptoms of dementia; NPI: Neuropsychiatric Inventory.

The most common symptoms, as shown by administration of the NPI, were depression (30.3%), agitation or aggression (27.8%), anxiety (26.5%), apathy (26.4%), and irritability or lability (23.5%). Drug treatment for BPSD was present in 50.3% of patients, with no statistically significant differences emerging between the two groups. Among these treated patients, 30.1% received antidepressant agents, 16.0% atypical antipsychotics, 9.3% anxiolytic agents, 5.6% other antipsychotic agents, and 3.7% hypnotics.

Table II shows the health and/or social care service use profiles of the 85 service users in the 12 months following their enrollment. A single patient could have used more than one service. The vast majority (85.9%) used only one type of health and/or social care service, while 14.1% used a combination of two service types. "Domiciliary assistance provided by healthcare professionals" was the service type most frequently used in association with another service; the most frequent combination was "Domiciliary assistance provided by healthcare professionals" & "Home visits by general practitioners" (3.5%). Each of the patients who attended day care programs received an average of 569 days' care while those who entered long-term care facilities remained at these facilities for an average of 795 days.

Table III shows the results of a multiple logistic regression model performed to investigate the demographic, clinical and social factors associated with the use of health and/or social care services. Taking into account

Table II – Profiles of service use.

Type(s) of service used	n.	%
Day care programs for patients with dementia	34	40.0
Domiciliary assistance provided by healthcare professionals	14	16.5
Rehabilitation facilities	7	8.2
Home help services	6	7.1
Home visits by general practitioners	5	5.9
Domiciliary assistance provided by healthcare professionals & Home visits by general practitioners	3	3.5
Alzheimer's disease care facilities	3	3.5
Long-term care facilities	2	2.3
Day care programs for patients with dementia & Home help services	2	2.3
Day care programs for patients with dementia & Domiciliary assistance provided by healthcare professionals	2	2.3
Services provided by voluntary associations & Domiciliary assistance provided by healthcare professionals	1	1.2
Public care facilities	1	1.2
Private care facilities	1	1.2
Domiciliary assistance provided by healthcare professionals & Home help services	1	1.2
Domiciliary assistance provided by healthcare professionals & Private care facilities	1	1.2
Day care programs for patients with dementia & Rehabilitation facilities	1	1.2
Day care programs for patients with dementia & Home visits by general practitioners	1	1.2
TOTAL	85	100

Table III – Logistic regression model for factors associated with the use of any service.

		Crude OR (95%CI)	p	Adjusted OR (95%CI)	p
Age	each 1 additional year	1.02 (0.98-1.05)	0.31	0.99 (0.95-1.02)	0.53
Gender	Men	1.00	-	1.00	-
	Women	0.89 (0.55-1.44)	0.62	0.81 (0.44-1.51)	0.51
Level of education	≤ 5 years	1.00	-	1.00	-
	>5 years	1.73 (1.10-2.74)	0.02	1.79 (1.08-2.96)	0.02
Type of caregiver	Paid home care worker	1.00	-	1.00	-
	Spouse	0.98 (0.43-2.24)	0.97	1.11 (0.43-2.87)	0.83
	Adult child	1.15 (0.51-2.59)	0.73	1.75 (0.74-4.14)	0.20
	Other relative	1.76 (0.63-4.92)	0.28	2.66 (0.89-7.80)	0.08
	None	-	-	-	-
Comorbidities	Absent	1.00	-	1.00	-
	Present (one or more)	5.26 (2.25-12.28)	<0.001	4.87 (2.05-11.57)	<0.001
CDR (severity of dementia)	Uncertain/mild (0.5-1)	1.00	-	1.00	-
	Moderate (2)	2.14 (1.13-4.06)	0.02	2.08 (0.98-4.40)	0.06
	Severe/late (3,4,5)	4.94 (2.55-9.58)	<0.001	4.78 (1.75-13.06)	0.001
BADL (functional impairment)	each 1 additional ability	0.80 (0.70-0.90)	0.003	0.96 (0.78-1.17)	0.66
IADL (functional impairment)	each 1 additional ability	0.76 (0.68-0.88)	0.002	0.91 (0.74-1.11)	0.34
MMSE (cognitive impairment)	each 1 additional point	0.95 (0.92-0.98)	0.003	1.03 (0.98-1.08)	0.29
Duration of dementia	each 1 additional month	1.01 (1.00-1.02)	0.09	1.00 (0.99-1.01)	0.58

Abbreviations: CDR=Clinical Dementia Rating Scale; BADL=Basic Activities of Daily Living; IADL=Instrumental Activities of Daily Living; MMSE=Mini-Mental State Examination; OR=odds ratio; CI=confidence interval

all the variables shown in the model, the following categories were found to have a higher probability of using any service: patients with more than five years of schooling (OR=1.79; 95%CI:1.08-2.96), patients with one or more comorbidities (OR=4.87; 95%CI: 2.05-11.57), and patients with severe/late (OR=4.78; 95%CI:1.75-13.06) or moderate dementia (OR=2.08; 95%CI:0.98-4.40) compared with uncertain/mild dementia. The probability of using any service was higher when the primary caregiver was a relative (other than a spouse or child) as opposed to a paid home care worker (OR=2.66; 95%CI:0.89-7.80).

A Spearman rank correlation analysis (data not shown in tables) was used to compare cognitive scales, functional scales and disease duration: MMSE with BADL, MMSE with IADL, BADL with IADL, days since diagnosis with MMSE, days since diagnosis with BADL, and days since diagnosis with IADL. We observed a statistically significant correlation between all the variables evaluated (Spearman's rho, p<0.001).

Discussion

The most remarkable finding of the present study was that only 11.9% of 712 patients with dementia made use of at least one health or social care service during the 12 months of follow-up. The rate of service utilization by elderly people with dementia found in this study was lower than that reported by other studies (Lim et al., 2012; Brodaty et al., 2005; Galvin et al., 2010). Lim et al. (2012) found a utilization rate of 40%, while Brodaty et al. (2005) found that about 65% of caregivers of individuals diagnosed with dementia accessed at least one community service. Furthermore, in a large American population survey conducted on patients with Lewy body dementia, Galvin et al. found that only 29% hired in-home assistance, while less than 40% used respite or adult day care, geriatric case management, or attended a support group (Galvin et al., 2010).

However, those were cross-sectional studies, whereas we evaluated the use of services over a period of one year, through a cohort study design. In addition, we evaluated the incidence of service use, while the above studies evaluated the prevalence. Moreover, those studies are comparable with our study in terms of age and gender distribution, whereas they differ greatly from ours in terms of disease severity, setting and source of data acquisition (internet or community surveys versus memory clinic patients) (Lim et al., 2012; Brodaty et al., 2005; Galvin et al., 2010).

The poor utilization of health and social care services in the 12 months of our observation is remarkable because the patients in our study population had never previously made any use of such services, even though they had already received clinical evaluations and drug prescriptions at UVAs. It would seem that attendance of UVAs, which are potentially a source of information about available health and social care services, was not enough to prompt caregivers to

seek the support of these services for the cognitively and functionally impaired individuals in their care.

Recently, a randomized clinical trial showed no evidence that memory clinics, similar to the Italian UVAs, are more effective than general practitioners with regard to post-diagnosis treatment and coordinating care for patients with dementia. The authors suggest that the resources (knowledge and experience) of memory clinics and general practitioners should be combined in order to provide truly integrated dementia treatment (Meeuwsen et al., 2012).

The paradoxical situation encountered in our sample, i.e. that of patients who have been diagnosed and receiving drug treatment for around two years, but show a low rate of use (11.9%) of health and social care services, might be explained by the fact that the patients in our study were in an early stage of the disease – they had been diagnosed relatively recently (27±22 months earlier) – and 80% of them showed mild/moderate dementia. According to a recent report by the World Health Organization and Alzheimer's Disease International (2012), life expectancy following the onset of dementia is estimated at 7.1 years for patients with AD, 5.4 years for those with mixed dementia, and 3.9 years for those with vascular dementia.

Patients are not usually institutionalized until they reach an advanced stage of dementia. Accordingly, as only 20% of the patients in our study had severe dementia, use of long-term care facilities was found to be less frequent than that of home help services and day care programs, the latter generally used by patients with mild/moderate dementia.

Furthermore, in Lazio, health and social care services are not readily accessible to the majority of patients. This poor availability together with the presence of a still only informal family support network could also explain the reluctance of caregivers to use the services. The availability of day care programs in Lazio is four places per 1000 expected patients with dementia, calculated according to the estimated rate of dementia for Western Europe (Prince et al., 2013).

It is possible that the choice of care pathway is influenced not only by the severity of the impairment, but also by the presence and type of services available in the area where the patient lives, and by the effectiveness of the multidisciplinary network approach. The most commonly used services could simply be the most accessible ones: each of the patients in our study who attended day care programs received an average of 569 days' care. The number of skilled nursing facilities in the area where a patient resides has been demonstrated to be a predictor of the use of home-based services (Beeber et al., 2008).

We found that use of services is more likely in patients with one or more comorbidities, and with more severe dementia. Patients with other chronic diseases are probably more likely to be closely looked after by healthcare professionals in health and social care settings.

We also observed, on the univariate analysis, an association between functional and cognitive status and the use of health and social care services. In most studies,

the global stage of dementia (Robinson et al., 2005) and associated domains such as functional (Beeber et al., 2008; Wattmo et al., 2011; Skarupski et al., 2008) and cognitive impairment (Gaugler et al., 2009) are the factors found to be associated with the use of services. Another striking finding of our study was the association that emerged between a higher level of education and a greater probability of using health or social care services. In many healthcare settings, educational level is associated with the use of health and social care services. As education is generally considered a predictor of the use of healthcare services, a low educational level contributes to the cumulative disadvantage of existing health disparities. Furthermore, cuts to health programs for the elderly or increases in the costs to consumers may exacerbate such inequities (Villa et al., 2012).

We did not find any association between use of services and type of caregiver that could represent a proxy of family support. Previous studies indicate that the use of health and social services is always mediated by caregivers, as they play a key role in choosing the care pathway (Livingston et al., 2010). In Italy, the most frequent solution when a family member is not able to care for a person diagnosed with dementia is to engage a paid home care worker. This could be explained by the fact that in Italy there is a shortage of public home help services (offered for about six hours a week) and of public residential facilities, both of which are still inadequate for the number of individuals affected.

The low use of health services for patients with AD may also be explained by the fact that the caregivers of individuals diagnosed with dementia do not often request support services, mainly due to a lack of perceived need and awareness (Brodaty et al., 2005) and to the poor availability and inadequacy of existing services (Bond et al., 2005; Dello Buono et al., 1999). Our study showed that patients cared for by a relative other than a spouse or child were slightly more likely than those cared for by a paid home carer (p=0.08) to use available services. Moreover, other studies also revealed a higher risk of institutionalization in patients who live alone, with relatives other than their spouse, or whose caregivers shoulder greater burdens (Soto et al., 2006). We did not find differences in service use between patients cared for by a paid home care worker and those cared for by a close relative, probably because, in both cases, the patient receives home care. Robinson and colleagues found that spouse caregivers were significantly less likely to have recourse to services, in comparison with caregivers who are other family members, while the caregiver's age, level of education, gender and living arrangements did not influence the use of services (Robinson et al., 2005). We also compared (data not shown in the tables) four possible situations, considering the patient's educational level (more or less than five years) and the presence of a spouse/child or other person (other relative/paid home care worker) as primary caregiver: patients with a low educational level cared for by a family member; patients with a low educational level cared for by another person; patients with a high educational level cared for by a family member; patients with a high educational level cared for by other persons. We did not observe any differences in health or social care service use between these four groups. The strengths of our study are that it is, to our knowledge, the first in Italy to explore the use of care services in a large diagnosed and drug-treated population, using accurate and standardized criteria for the diagnosis of dementia, and a complete standardized and validated clinical assessment battery. Our decision to focus only on patients who had never previously used services any kind allowed us to estimate, in this "services-free" cohort, the incidence of the new users, an evaluation not possible with the cross-sectional design used in other studies (Lim et al., 2012; Brodaty et al., 2005; Galvin et al., 2010).

The main limitation of our study was the short follow-up period. This may have been a factor helping to determine the low percentage of health and social care service users (greater use of these services presumably being more related to a worsening of cognitive and functional status, during the disease process). In fact, caregivers frequently begin to use services later in the disease process and indeed could decide to use formal services when the intensity of their need surpasses the potential of the services to support them (Markle-Reid and Browne, 2001). As our study was conducted among patients with mild/moderate dementia, the sample may not be representative of the whole population of individuals with dementia in our region.

Another limitation was our decision (dictated by the low number of users for each type of service) to use, as the outcome variable, the broad definition "use of services", which includes both "home help services" and "long-term care facilities".

In conclusion, our findings show that care pathways for people with dementia are still not adequate, suggesting that more information is needed to raise caregiver awareness and to reduce the stigma associated with the disease, also among health professionals.

Considering that dementia is the main reason for the admission of elderly people to residential facilities, specialized home care services, able to reduce the burden on family caregivers, could limit the need for long-term residential care for advanced cases of dementia that require more intensive assistance, thereby also reducing the costs for the health system (Macdonald and Cooper, 2007; Berr et al., 2005).

In a region where the availability of health and social services for patients with dementia is still not adequate, public health authorities should plan and promote a network of health and social care services, based on a multidisciplinary approach, to treat and care for patients in the different stages of the disease, considering both the patient and the caregiver's needs.

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