

# Unmet Needs for Family Caregivers of Elderly People With Dementia Living in Italy: What Do We Know So Far and What Should We Do Next?

INQUIRY: The Journal of Health Care Organization, Provision, and Financing  
Volume 54: 1–8  
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sagepub.com/journalsPermissions.nav  
DOI: 10.1177/0046958017713708  
journals.sagepub.com/home/inq



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## Abstract

Care of the elderly with dementia represents one of the major challenges for the modern society worldwide. The burden of dementia care often falls on the family members, entailing heavy psychosocial and economic consequences. The aim of this study was to evaluate the caregiver's perspective concerning the support for disease management on behalf of the physicians and the local Sicilian administrations (Italy), and the burden of care and effects on their lifestyle, to propose new prevention strategies and service for managing dementia and caregiver's burden. Fifty-nine caregivers of Italian elderly people with dementia (mean age, 73; age range: 63–83) were interviewed, and 55 of them completed an ad hoc self-report questionnaire composed of 54 multiple-choice questions. Our findings suggest that caregivers need more information on the disease's management, as well as on how to deal with the stress due to the disease burden. Moreover, a negative perception about the services offered from the local administration emerged. Assistive technology (AT) could be useful in promoting interaction between general practitioners and specialized centers for diagnosis, pharmacological and psychosocial treatments, and in saving costs. Moreover, case manager could follow patients and support family members within the care pathway, besides collecting and sharing information among the different health professionals involved. Further studies should be aimed at investigating whether AT and/or the use of specific educational strategies could be the right approach for meeting the needs of families living with dementia.

## Keywords

dementia, care needs, caregivers, health care perception, elderly

## Introduction

Dementia includes a wide range of brain diseases characterized by memory loss and cognitive impairment. It has been estimated that about 47 million people worldwide suffer from dementia, and this number is expected to reach 75 million by 2030.<sup>1</sup> In Italy, dementia affects approximately 1 million elderly people, including 7.23% of the population aged 65 years or above, and the number of carers is about 3 million.<sup>2</sup> Given the continuous growth of incidence of this illness, especially in elderly often affected by other chronic diseases, dementia represents one of the major plagues for the modern society. As the disease progresses, a host of symptoms can emerge, such as disorientation, mood swings, confusion, more serious memory loss, behavioral changes, difficulties in speaking and swallowing, and problems with walking. Thus, dementia interferes with daily, social and professional functioning of patients, also affecting the daily life of their families.<sup>3</sup>

From an epidemiological point of view, in Europe only 50% of the elderly receive a diagnosis of dementia by a specialized center and this often occurs when the patient is already in a moderate stage of the disease.<sup>4</sup>

But, a timely diagnosis can facilitate care and support patients and their families to take control of their situation.<sup>4,5</sup> Moreover, interventions focused on modifiable risk factors, if provided earlier in life, might be promising preventive actions,<sup>6,7</sup> reducing between 1.1 and 3 million cases of Alzheimer disease (AD).<sup>8</sup>

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Received 30 January 2017; revised May 11 2017;  
revised manuscript accepted 11 May 2017

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The worldwide economic costs of dementia were estimated to be more than \$600 billion in 2010,<sup>9</sup> and \$818 billion in 2015,<sup>1</sup> a substantial economic impact for a single group of disorders. Globally, 87% of the direct costs occur in high-income countries, mainly in strategies, to compensate lost function rather than treatment for prevention.<sup>3</sup> Indirect costs, due to informal care, include the estimation of the amount of lost work productivity and the costs to pay a professional caregiver to reduce the time spent on caregiving tasks.<sup>10</sup> In addition to direct and indirect costs, there are the intangible costs of reduced quality of life of both patient and familiars. Indeed, informal care is the most important form of care in many countries, especially when dedicated health care services (home care, nursing homes, and daycare) are almost inexistent.<sup>11</sup> In Italy, as across all European countries, it is the relatives who predominantly manage AD patients, and the main out-of-pocket expenditure borne by the Italian relatives concerns the cost of private care workers (€13 590/y). In 2015, the societal burden of AD, composed of public, patient, and informal care costs, was about €20 000/y; out of this, the cost borne by the public sector was €4534/y, mainly for the national cash-for-care allowance (€2324/y) and drug prescriptions (€1402/y).<sup>12</sup>

Care for a familiar affects the working life of the caregiver, who may be compelled to opt for part-time or leave the job<sup>13</sup>; for this reason, the informal caregivers are mainly women, usually spouses, but also daughters or daughters-in-law. However, the increasing employment rates for women is clashing with their availability in providing informal care for familiars with dementia.<sup>14</sup>

Within this context, assistive technology (AT) may lead to possible cost savings in care delivery. Indeed, ad hoc technologies could be used for monitoring people with dementia (PWD), facilitating access to health care services, and promoting interaction with general practitioners.

The aim of this study was to evaluate the perception of southern Italy families dealing with dementia about services received by the local Sicilian administration, general practitioners, and neurologists of our specialized center. We also investigated on the psychosocial problems perceived by carers of elderly PWD, to propose new prevention strategies and service for managing dementia and caregiver's burden.

## Materials and Methods

### Study Population

All the eligible caregivers of the patients referred for dementia to IRCCS Centro Neurolesi "Bonino-Pulejo" of Messina were asked to complete a questionnaire during a period of 4 weeks in May 2015. Fifty-nine participants (32 females and 27 males) completed the questionnaire after having signed a written informed consent. Four questionnaires were excluded because missing data did not allow further analysis. Thus, the study population consisted of 55 caregivers aged 21 to 85

years (mean age:  $53.04 \pm 14.21$  years), who cared for patients having a mean age of  $72.94 \pm 9.59$  years. Table 1 shows in detail the demographic characteristics of both patients and caregivers. The study was approved by our IRCCS Local Ethical Committee (Ref. No. 13/2016). To secure privacy and anonymity of participants, we used study codes on data documents (ie, completed questionnaire) instead of recording participants' identifying information, which were conversely kept in a separate document where codes and identifying information were matched/linked. This document was locked in a separate location, and the access to it was restricted to the principal investigator of the study.

### Data Collection

Caregiver perspective was assessed by a self-report Italian questionnaire composed of 54 multiple-choice questions (see the appendix), created ad hoc by the authors, that evaluates the personal perception about three main issues: (1) support for disease management from physicians and local administrations, (2) effects of the disease on the caregiver lifestyle, and (3) caregiver burden. As the main purpose of this study was to know whether patients and caregivers felt abandoned in disease management, especially by the local administration and the health system, as well as to observe the caregivers' lifestyle to conceive potential strategies suitable for the situation, we did not use any standardized scale or test. However, we included, within the questionnaire, a set of questions aimed at evaluating the caregiver burden. These included emotions, behaviors, and problems perceived by the caregiver. The questionnaire included another 10 items aimed to collect demographical information on both the patient and caregiver.

### Statistical Analysis

Statistical analysis was performed by using the 3.2.3 version of the open-source software R.<sup>15</sup> A *P* value <.05 was considered as statistically significant.

Results for continuous variables were expressed in mean  $\pm$  standard deviation, whereas categorical variables were expressed in frequencies and percentages. Initially, a bivariate statistical analysis was performed to investigate on caregivers' lifestyle and disease management, aside from support provided by physicians and local administrations. Thus, correlations between quantitative variables were computed by Pearson coefficient, or by point-biserial correlation coefficient when one variable was dichotomous. The chi-square test or the Fisher exact test were used for proportion comparison, and the Student *t* test was used to compare the mean age by gender, as well as the frequency of medical examination by the general practitioner and the neurologist. Next, we also conducted a multiple correspondence analysis (MCA) on the last 24 questions of the questionnaire concerning caregiver burden and help in disease management. The analysis

**Table 1.** Sociodemographic and Health Description of Patients and Caregivers.

	Patients			Caregivers		
	Males	Females	All	Males	Females	All
Participants	21 (38.18%)	34 (61.82%)	55 (100%)	25 (45.46%)	30 (54.54%)	55 (100%)
Age, y	72.62 ± 8.46	72.91 ± 9.99	72.94 ± 9.59	56.68 ± 15.25	50 ± 12.74*	53.04 ± 14.21
Education						
None	4 (19.05%)	5 (14.70%)	9 (16.36%)	—	—	—
Primary school	12 (57.14%)	12 (35.29%)	24 (43.64%)	2 (8.0%)	3 (10.0%)	5 (9.09%)
Middle school	3 (14.29%)	12 (35.29%)	15 (27.27%)	5 (20.0%)	9 (30.0%)	14 (25.45%)
High school	2 (9.52%)	3 (8.82%)	5 (9.09%)	13 (52.0%)	13 (43.34%)	26 (47.27%)
Vocational school	—	1 (2.95%)	1 (1.82%)	1 (4.0%)	1 (3.33%)	2 (3.64%)
University	—	1 (2.95%)	1 (1.82%)	4 (16.0%)	4 (13.33%)	8 (14.55%)
Marital status						
Not stated	—	—	—	—	1 (3.33%)	1 (1.82%)
Single	1 (4.76%)	1 (2.95%)	2 (3.64%)	5 (20.0%)	6 (20.0%)	11 (20.0%)
Married	16 (76.19%)	20 (58.82%)	36 (65.45%)	18 (72.0%)	20 (66.67%)	38 (69.09%)
Divorced	1 (4.76%)	—	1 (1.82%)	—	3 (10.0%)	3 (5.45%)
Living with partner	—	2 (5.88%)	2 (3.64%)	—	—	—
Widowed	3 (14.29%)	11 (32.35%)	14 (25.45%)	2 (8.0%)	—	2 (3.64%)
Chronic disease (at least one)	19 (90.48%)	31 (91.18%)	50 (90.0%)	6 (24.0%)	9 (30.0%)	15 (60.0%)
Job						
Not stated	—	—	—	—	1 (3.33%)	1 (1.82%)
Pensioner	—	—	—	10 (40.0%)	3 (10.0%)	13 (23.64%)
Unemployed	—	—	—	2 (8.0%)	7 (23.33%)	9 (16.36%)
Housewife	—	—	—	—	11 (36.67%)	11 (20.0%)
Student	—	—	—	—	—	—
Construction worker	—	—	—	2 (8.0%)	—	2 (3.64%)
Office worker	—	—	—	7 (28.0%)	3 (10.0%)	10 (18.18%)
Teacher	—	—	—	—	1 (3.33%)	1 (1.82%)
Freelance professional	—	—	—	2 (8.0%)	1 (3.33%)	3 (5.45%)
Entrepreneur	—	—	—	2 (8.0%)	2 (6.67%)	4 (7.27%)
Artisan/trader	—	—	—	—	—	—
Other	—	—	—	—	1 (3.33%)	1 (1.82%)
Degree of kinship						
Not stated	—	—	—	2 (8.0%)	—	2 (3.64%)
Spouse/partner	—	—	—	6 (24.0%)	9 (30.0%)	15 (27.27%)
Mather/father	—	—	—	10 (40.0%)	20 (66.67%)	30 (54.54%)
Daughter/son	—	—	—	1 (4.0%)	—	1 (1.82%)
Other relative	—	—	—	6 (24.0%)	1 (3.33%)	7 (12.73%)

Note. Quantitative variables are in mean ± standard deviation; qualitative variables are in frequencies (n) and percentage.

\* $P < .005$ .

of the MCA was carried out with regard to the correlations between the variables and the factorial axes.

## Results

### *Sociodemographic Aspects and Health of the Sample*

As shown in Table 1, the caregivers were mainly graduated (47.27%), as compared with patients, who were poorly educated. About 65% of the patients were married and 25.45% widowed, whereas caregivers were principally

married (69.09%). More than half of caregivers cared for their parents (54.54%), who were mainly pensioners or housewives. We found that female caregivers were slightly younger than males ( $t = -1.74$ ,  $df = 47$ ,  $P < .05$ ). No other significant differences by gender emerged. However, we found a significant association between gender and job ( $P < .01$ ): Women were mainly housewives (36.67%) or unemployed (23.33%), whereas men were mainly pensioned (40%) or office makers (28%). On the contrary, 32.73% declared having to interrupt their working activity (12.72% definitively) to take care of their own loved-one (Table 2, Q13).

**Table 2.** Support for Disease Management From Physicians and Local Administrations, Economic Burden and Aspects of the Caregiver Lifestyle.

Questions (yes/no)		n (%)
Information for disease management	Q2	25 (45.45%)
	Q3	36 (65.45%)
	Q5	51 (92.73%)
	Q6	22 (40.0%)
	Q7	33 (60.0%)
	Q8	11 (20.0%)
Economic support	Q9	34 (61.82%)
	Q10	12 (21.82%)
	Q11	8 (14.55%)
Economic burden	Q12	47 (85.85%)
	Q13	18 (32.73%)
Caregivers lifestyle	Q28	43 (78.18%)
	Q18	44 (80.0%)
	Q19	4 (7.27%)
	Q20	20 (36.37%)
	Q21	29 (53.73%)
	Q22	28 (50.91%)
	Q23	37 (67.27%)
	Q24	15 (27.27%)
	Q25	27 (49.09%)
	Q26	8 (14.55%)
	Q27	28 (50.91%)

Note. Questions concerned information for disease management (Q2-Q9), economic burden (Q13, Q28), economic support (Q10-Q12), and caregiver's lifestyle (Q18-Q27) are described in the appendix.

A substantial percentage of caregivers (80%) lived with the patients (Table 2, Q18): 32.73% declared of having to move in with their loved-one after the diagnosis of dementia, whereas 47.27% already lived with him or her.

Fifty out of 55 patients (90.9%) suffered from at least one chronic disease, and in particular, 35 out of 55 patients had at least three chronic diseases (Q29). Hypertension (49.2%), arthrosis (47.4%), and anxiety and depression (45.6%) were the most common. Moreover, 27.27% of the caregivers were married to the patients, and 52.78% of them, in turn, suffered from at least one chronic disease (Q30).

### Support to the Patients' Management

Patients went to their general practitioner (Q1) more often than to the neurologist (Q4;  $t = 3.9$ ,  $df = 31$ ,  $P < .001$ ), and in 92.73% of the cases, neurologists provided clear information about the disease, versus 65.45% of the general practitioner (Table 2, Q5 and Q3, respectively). However, 40% of caregivers declared of not having received suggestions on how to manage the familiar's disease (Table 2, Q6) and 80% of them of not having received suggestions on how to deal with the burden (Table 2, Q8). Around 46% of the patients had only one caregiver (Q14), apparently because he or she was the most appropriate (40%), or because others had no time (28%; Q16).

Only 14.55% of caregivers declared of having received an economical or material (eg, health aid) support from local administration, and 21.82% an attendance allowance (Table 2, Q11 and Q10, respectively). However, 78.18% of the caregivers declared that the disease had affected the family's economical balance (Table 2, Q28). Indeed, 85.85% found the national and local administration support inadequate (Table 2, Q12).

### Caregiver Lifestyle and Burden

Concerning lifestyle, although 50.91% of caregivers were motorized (Table 2, Q27), they spent their free time mainly watching TV and listening to the radio (67.27%; Table 2, Q23), as well as reading books and newspapers (50.91%; Table 2, Q22). Around 53% of the caregivers did not attend meeting places (Table 2, Q21), and 36.37% did not see friends (Table 2, Q20). However, 49.09% attempt to regularly cultivate a hobby (Table 2, Q25). On the other hand, we think the caregivers' free time was inversely correlated with their difficulty to manage anger ( $r = -0.25$ ), and with the caregivers' perception that their loved-ones were perceived as a "weight" ( $r = -0.31$ ). Similarly, the number of caregivers was moderately correlated to their guilty for leaving the familiar alone ( $r = 0.32$ ). However, only 7.27% of caregivers declared to use psychiatric drugs (Table 2, Q19).

### Multiple Correspondence Analysis

The results of the MCA conducted on the last 24 questions supported our idea about the caregivers' burden and stress (Table 3). Indeed, the first factorial axis, which accounts for 23.61% of total inertia, can be considered as the axis of the caregiver's burden, because it correlated highly with many questions concerning the emotional management of the caregivers. They felt stressed (Q50;  $r = 0.79$ ), not able to deal with their problems (Q49;  $r = 0.74$ ), angry (Q51;  $r = 0.69$ ) especially with himself (Q47;  $r = 0.78$ ), and sometimes they felt the wish to escape from the situation (Q45;  $r = 0.79$ ).

On the other hand, the second factorial axis (10.42% of total inertia) could be considered as the axis of need for help in disease management. Indeed, this axis correlated highly with the caregivers' desire in receiving additional information about the disease (Q33;  $r = 0.69$ ), their necessity to have advice on how to assist their loved-one (Q36;  $r = 0.69$ ), and their quarrels for care management with other family members (Q37;  $r = 0.59$ ).

Overall, caregivers wish to have more time for themselves (Q35;  $r = 0.56$  and  $r = 0.40$ , respectively).

### Discussion

According to literature, the care and support provided for PWD often cover several areas of their lives.<sup>3</sup> Typical health care delivery structures usually do not pay much attention to this support, with an enormous impact on the



**Table 3.** Correlations Between the Last 24 Variables of the Questionnaire and the First Two Factorial Axes of the Multiple Correspondence Analysis.

Questions		Factorial axis 1	Factorial axis 2
Help in disease management	Q31	0.216	0.012
	Q32	0.286	0.475
	Q33	0.108	<b>0.688</b>
	Q34	0.379	0.032
	Q35	<b>0.555</b>	0.401
	Q36	0.081	<b>0.688</b>
	Q37	0.033	<b>0.589</b>
	Q38	0.381	0.160
	Q39	0.312	0.049
Emotional aspect	Q40	<b>0.563</b>	0.060
	Q41	0.307	0.208
	Q42	0.416	0.277
	Q43	<b>0.666</b>	0.085
	Q44	0.316	0.157
	Q45	<b>0.792</b>	0.053
	Q46	0.437	0.156
	Q47	<b>0.777</b>	0.008
	Q48	<b>0.575</b>	0.255
	Q49	<b>0.744</b>	0.092
	Q50	<b>0.792</b>	0.115
Disease perception	Q51	<b>0.692</b>	0.373
	Q52	0.046	0.090
	Q53	0.295	0.120
	Q54	0.433	0.467

Note. The 24 questions concerned help in disease management (Q31-Q39), emotional burden (Q40-Q51), and disease perception of the caregivers (Q52-Q54) are described in the appendix. Correlations higher than 0.5 are in bold.

whole family, ranging from the caring burden to the psychosocial and economic aspects.

Familiars are physically, emotionally, and financially involved by the disease, and the burden has a significant impact on their physical and mental health, personal and social life, and overall well-being.<sup>16</sup> In our sample, around 60% of the caregivers declared the necessity of having more information on the disease's management (Table 2, Q7), and 61.82% on how to deal with the disease caring-related stress (Table 2, Q9). According to previous works, caregivers sustain an ever-increasing burden of care in the management of patients associated with progression of dementia. They spend many hours in supporting the patient in direct care activities (personal hygiene, preparation and serving of meals, dispensing of drugs and medications, care and support) and surveillance, which imply a gradual reorganization of their lives. Indeed, spaces and roles required assisting the patient expose the entire family to stress and pressures that threaten to destabilize, even dramatically, their "equilibrium."<sup>17</sup> Thus, conflicts secondary to fatigue and economic or psychological problems may frequently emerge. The variability of the patient's behavior

increases caregiver's disorientation and sense of fragility and helplessness. Furthermore, an increasing risk of coronary heart disease and mortality for caregivers have been found in previous studies.<sup>18,19</sup>

In this study, we found that caregivers experienced a stress condition related to dementia. MCA results showed that caregivers were not capable of emotional management, with regard to anxiety, anger, and frustration; furthermore, bivariate analysis highlighted relationship problems and social isolation. In particular, difficulty in anger management was associated with a decrease in the time spent on their own needs ( $r = -0.25$ ). Moreover, 47.27% of caregivers declared a sense of guilt. Notably, the most important aspect that we want to underline is the caregivers' perception of the inadequate service offered from the local government: Only 14.55% of families received an economical or material (eg, health aid) support, whereas 78.18% of the caregivers declared that the disease management affected the family budget. These participants declared they needed more support from local and national governments to manage all the aspects involved in dementia. However, the notable contribution provided by familiars is a benefit for the health care system, in terms of cost-effectiveness advantages.<sup>20</sup>

In this scenario, strategies to bridge the gap between patient demands and their families and the public health care system are crucial for the quality of care.<sup>21</sup> Thus, political strategies should be integrated with voluntary and private organizations to create an environment able to meet patients' needs, in terms not only of care (eg, eating, dressing, and hygiene) but also supporting psychosocial and existential needs. Similarly, programs for case management, counseling, daycare, and education by different care providers, as well as interventions for helping familiars to manage the personal burden of caring, need to be developed. Indeed, many studies showed that support for family members and other caregivers can represent a valuable cost-effective use of resources,<sup>22,23</sup> reducing or postponing nursing-home admissions,<sup>24,25</sup> and improving psychological caregivers' conditions.<sup>26,27</sup> Moreover, by providing better training for dementia care, healthcare services will improve the global quality of care, also reducing the growing necessity of future costs.

AT can improve the quality of life and cut down on health care costs. Alarms, GPSs, watches, smartphones, and so forth could be used for monitoring PWD, facilitating access to health care services, and promoting interaction with general practitioners. After all, PWD have demonstrated a positive response to AT use, but if and when this can facilitate autonomy and independence nobody knows.<sup>28,29</sup> Moreover, it has been shown that telemedicine can be considered as an important tool for improving health, cognitive function, and quality of life in the elderly living in nursing homes.<sup>30,31</sup> AT for carers could also be useful in "caregivers' empowerments,"<sup>32</sup> as

well as in reducing their burden.<sup>33,34</sup> Telehealth systems could play a pivotal role for both the families living with dementia and health care administrations in a cost-effective approach, avoiding the unnecessary hospital admissions,<sup>35</sup> which have been estimated to be about 40% higher in PWD and/or cognitive impairment than in the elderly without deficit.<sup>36</sup> Thus, general practitioners could use AT to promote interventions targeting multiple modifiable factors and to bridge the gap between families and specialist centers to provide a timely diagnosis of dementia. In fact, general practitioners often perceive a failure in traditional care, declaring the need for routine provision of medication dose decision aids.<sup>37</sup> Similarly, case management may offer potential benefit to patients, their caregivers, and community-based professionals through continuity of care with a trusted and qualified individual, who can address the needs of the families living with dementia.<sup>38</sup> Although it is not possible to rate whether case management could delay institutionalization in care homes or can be successfully incorporated into routine general practice,<sup>39,40</sup> it could have a place within initiatives for health and social services integration. Indeed, the case manager could follow the patients within a specialist local care network, supporting the familiars in the disease management, and collecting and sharing information among the different health professionals.

The dependence on the participants' subjective assessments/self-report, and the absence of objective measures incorporated to support the participants' subjective responses may be considered the main limitations of this work. Nonetheless, no standardized scales or tests exist to estimate how patients and caregivers perceive the local administration and the health system services in dementia support care.

## Conclusions

Territorial health care systems do not pay much attention to the care of PWD. Consequently, the burden of dementia often is supported by the family members. To meet the needs of PWD and their carers is a challenge that has to be addressed as an important part of clinical decision making. Thus, there is a growing need to have local and national policy strategies in a multidisciplinary care program management, with the organization of a network linking specialist centers for diagnosis and pharmacological and psychosocial treatments, general practitioners, sheltered housing facilities, integrated home care, and nursing homes. Implementation of a guideline and new national and local policy strategies for dementia care are therefore necessary to fulfill such a necessity. Thus, further studies should be fostered to investigate whether AT and/or the use of specific educational interventions could be the right approach to better meet the needs of families living with dementia.

## Appendix

### Description of the Self-Report Italian Questionnaire Composed of 54 Multiple-Choice Questions.

Questions	Description
Q1	Patient annual number of visits by the practitioner
Q2	Action of the practitioner concerning the disease
Q3	Considerations about the information provided by the practitioner
Q4	Patient annual number of visits by the neurologist
Q5	Considerations about the information provided by the neurologist
Q6	Physicians' advices for disease management
Q7	Need of more information for disease management
Q8	Physicians' advices for deal with the stress
Q9	Need of more information for deal with the stress
Q10	Attendance allowance from local administration
Q11	Economical or material (eg, health aid) help from local administration
Q12	Need for more support from local administration
Q13	Working interruption to care the person with dementia
Q14	Number of caregivers
Q15	Other caregivers
Q16	Caregiver motivations
Q17	Caregiver's relation with the person with dementia
Q18	Caregiver's cohabitation with the person with dementia
Q19	Use of psychiatric drugs
Q20	Free time: meet friends
Q21	Free time: attend meeting places
Q22	Free time: read books and newspapers
Q23	Free time: listen to the radio
Q24	Free time: walk and bike
Q25	Free time: cultivation of hobbies
Q26	Free time: go to the cinema or theater
Q27	Car equipped
Q28	Effect of the disease on the family's economical balance
Q29	Chronic disease comorbidity of the patient
Q30	Chronic disease comorbidity of the caregiver
Q31	Need of more help by familiars and friends
Q32	Help in daily activities
Q33	Need of more information about the disease
Q34	Need of help to manage fatigue
Q35	Need of more time for himself
Q36	Need of more advices for caring the person with dementia
Q37	Quarrels for care management with other family members
Q38	Cooperation in care management with other family members
Q39	Worsening in work performance
Q40	Shame for the patient's behavior
Q41	Resentment feeling for the person with dementia
Q42	Uncomfortable feeling in presence of other people
Q43	Emotionally emptiness feeling
Q44	Resentment feeling for the other family members
Q45	Desire to escape from the situation
Q46	Irritation for the patient's request
Q47	Caregiver anger
Q48	Guilty feeling for leaving alone the patient
Q49	Being able to deal with all the problems
Q50	Stress feeling
Q51	Difficulty to restrain anger
Q52	Perception that the patient feels a "weight"
Q53	Being able to speak about the disease
Q54	Helplessness feeling about the disease

Note. Q1-Q9: Information for disease management by physicians. Q10-Q12: Economic support from local administration. Q13: Economic burden of illness. Q14-Q16: Availability of other caregivers. Q17: Relation with the person with dementia. Q18-Q27: Caregiver's lifestyle. Q28: Economic burden of illness. Q29: Chronic disease comorbidity of the patient. Q30: Chronic disease comorbidity of the caregiver. Q31-Q39: Help in disease management. Q40-Q51: Emotional burden. Q52-Q54: Disease perception.

## Acknowledgments

The authors wish to thank Mrs Antonina Donato for English editing.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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