

Original Article

Evaluating the Needs of Dementia Patients' Caregivers in Greece: A Questionnaire Survey

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The work was carried out in Athens Alzheimer Association's Day Care Center 89, Markou Mousourou and 33 Stilponos street, Mets 11636, Athens, Greece

Abstract

Aim: The aim of this study was to explore the needs of dementia patients' caregivers throughout Greece in order to use the acquired data for designing a comprehensive national dementia strategy.

Methods: The work was carried out in Athens Alzheimer Association's Day Care. A questionnaire containing 14 close question and 2 open ended was completed by 248 caregivers looking after people with dementia living at home and participating in the activities of the Day Care Centers of the Alzheimer's Association.

Results: The majority of caregivers were females (78.2%), mainly daughters or spouses. A 41.1% had 12-18 years of formal education. Most of them lived with the person with dementia (69.4%). A 57.8% reported neither difficulties nor complaints regarding the existing medical and social services they took advantage of. However, financial problems and lack of allowances were crucial issues for most of them. Moreover, caregivers needed more support in caring and especially in every day practical and legal issues.

Conclusion: The findings of this survey highlight the importance of assessing the needs of family caregivers when designing health and social care policies.

Key words: Alzheimer disease, family caregivers, services

Introduction

"Dementia, including Alzheimer's disease, remains one of the biggest global public health challenges facing our generation. The number of people living with dementia worldwide today is estimated at 44 million, set to almost double by 2030 and more than triple by 2050. The global cost of dementia was

estimated in 2010 at US \$604billion, and this is only set to rise" (ADI, 2014).

The main symptoms of dementia include loss of cognitive abilities, difficulties in activities of daily living and changes in personality and behavior. It is important for families to detect symptoms of dementia and seek professional help early.

Many family caregivers choose to take care of their affected loved ones at home as long as they can. In Italy, 80% of people with dementia live at home and receive support and care mainly from their spouses or daughters (Rosa et al., 2010). In the United States, more than 15 million Americans provide unpaid care for people with Alzheimer's Disease and other dementias. They usually are close family members, relatives or friends, are recognized as informal caregivers and are not financially compensated for their services. In general «caregiving is based on a reverence for life and the belief that human beings have the innate right to function to their highest level of mental and physical capacity.

The major mission of caregiving is to promote independence by maintaining the person's most functional state- physically, intellectually, emotionally, and spiritually» (Bridges, 1995). Since caring for dementia patients continues for many years, the progress of the disease sometimes leads to a 24 hour care per day (Andrieu et al., 2005). According to the latest reports, 43% of the caregivers of people with dementia provide care for 1 to 4 years and 32% provide care over 5 years (Alzheimer's Association, 2014).

Care giving tasks are sometimes shared by family members, however the most typical scenario is that the largest amount of care is provided by the principal caregiver (Schulz & Martire, 2004). Caregiver burden threatens physical, psychological, emotional health and functionality (Zarit et al., 1980). Informal care, especially if it is provided frequently or for a prolonged period of time, has far-reaching consequences such as depression, anxiety, mood disorders and also leads to poor physical health (Tremont, 2011).

A study by Raivio et al., (2007) found that caregivers consider official services poorly respond to patients' needs. They reported unmet needs for spouse physiotherapy (56%), financial support (50%), house cleaning (41%) and better home-based respite care (40%).

Another study by Brodaty et al., (2005) found that one in three caregivers was not receiving any service and one in four was using only one service. The main reason for this was the lack of knowledge of existing services.

Given the rising prevalence of dementia, countries must be prepared to lessen its impact on individuals, society and health insurance organizations. In the last 10 years, there have been some developments in

Greece concerning services provided for demented people. In large cities, there are some memory clinics, day care centers and private residential homes. It is recognized that understanding and meeting the needs of caregivers is important for further improvement of dementia care. Up to now, there is no extensive research work or other available information about the needs of family caregivers of dementia patients in Greek society. The aim of this study is to explore caregivers' needs and to examine utilization of available services by them.

Specifically, the research question is, if there are unmet needs and problems in the fields of medical and social care for patients and families. A more precise understanding of basic unmet needs can serve as a platform on which to build a national dementia strategy.

Methods

The survey was organized by Athens Alzheimer Association within the framework of the development of a National Dementia Strategy supported by the Greek Ministry of Health. The survey sample consisted of family caregivers (n=248) looking after a person with dementia living at home, recruited from users of the Greek Alzheimer Association Day Care Centers in urban regions of Greece. The questionnaire used was distributed amongst informal caregivers by the social workers of the Day Care Centers of Greece Alzheimer Associations. The caregivers were asked to complete the questionnaire, after the social worker had provided information about the aim of the study. The distribution period lasted 2 months.

The study was carried out in accordance with the latest version of Helsinki Declaration. Approval was granted by the Ethical Committee of the Greek Alzheimer Association. All participants signed an informed consent.

Questionnaire

In the first phase, two researchers identified the carers needs in health care service provision through the literature review between 2009-2014: (domains: social demographic, caregiving details, medical or social services difficulties, extra services required) and developed a set of items based on these specific domains. In the second phase, two focus groups consisted of 10 informal carers and 10 health care professionals were organised by the research team. The focus groups aimed to add and confirm the selected dimensions derived from the literature

review and also to generate new items. The researchers integrated the focus group findings with the items derived from the literature review and then circulated the questionnaire to the research team in order to receive feedback, rewording and suggestions of any other additional item. In the third phase, the questionnaire was administered to a small group of 6 informal carers and detailed discussion on the included items (phrasing, rewording, syntax etc) followed.

The necessary revisions were made before the general administration of the survey. The questionnaire required about 20 minutes to complete and was composed of four parts, including closed (yes or no response) and open ended questions. In the first part information on socio-demographic parameters was asked (4 items). In the second part caregiving details (5 items) were collected. In the third part, caregivers were invited to specify in which domains of care they encounter difficulties (5 items). In the fourth part, caregivers were asked to report which extra services, they required (5 items). Lastly, two open ended questions were included for caregivers to freely express their views and wishes (2 items).

Statistical Analysis

Statistical analyses were made using IBM SPSS 19 software package. The characteristics of caregivers were analyzed with descriptive statistics (percentages). Cronbach's alpha was used to calculate questionnaire's reliability. The construct validity of the questionnaire was tested with factor analysis.

Reliability and Validity of the Questionnaire

Cronbach's coefficient was computed for the two subscales and was 0.78 and 0.79, respectively, considered reliable (Field, 2009).

With a factor analysis, the construct validity of a questionnaire can be tested (Rattray & Jones, 2007). KMO coefficient for the first subscale of questions was 0.68 and Bartlett analysis used with a satisfactory result ($\chi^2=201.96$, $p<0.001$). Using factor analysis 1 factor emerged. One component had eigenvalues over Kaiser's criterion of 1 and explained 55.92% of the variance. The items that cluster on the same components suggest that component 1

represents the problems caregivers facing with services of State. KMO coefficient for the second subscale of questions was 0.68 and Bartlett analysis used with a satisfactory result ($\chi^2=282.44$, $p<0.001$). Using factor analysis 1 factor emerged. One component had eigenvalues over Kaiser's criterion of 1 and explained 54.24% of the variance. The items that cluster on the same components suggest that component 2 represents needs that caregivers would desire from official services.

Results

The mean age of the caregivers ($n=248$) was 63.16 ± 14.54 years. The majority of caregivers were female ($n=194$) with a mean age 60.28 ± 13.96 yrs (min: 19- max: 90 yrs). The mean age of male caregivers ($n=54$) was 66.04 ± 15.12 yrs. Table 1 describes the demographic characteristics of the 248 informal caregivers, as well as the relationship to the care recipient.

In Table 2, the living arrangements of the caregivers are presented. Caregivers reported spending an average of 13.65 ± 9.0 hours per day providing care to the dementia patient. 38.7% ($n=96$) of caregivers reported providing a 24 hours per day care.

The average amount of years spent in caring was 5.29 ± 2.92 for male and 4.23 ± 2.4 for female caregivers. 34.3% ($n=85$) of the families used a paid professional caregiver.

An additional finding was that during the last 3 years most of caregivers ($n=217$, (88%)) had experienced an income decline because of the general economic crisis.

In Greece, patients with dementia, according to caregivers answers were mostly treated by specialized doctors (Figure 1). Caregivers needs regarding medical, social, financial and legal issues are presented in Figure 2. In absolute numbers, 106 caregivers out of 248 mentioned problems with medical services, 107 with social services, 164 reported difficulties in getting financial support from the State and a vast majority ($n=199$) reported facing problems with legal issues (proxy appointment and living will). According to views expressed in the open ended questions the main areas in which caregivers seek counselling and help are listed in Table 3.

Table 1. Demographic characteristics of caregivers (n, %)

Parameters	n, (%)
Gender	
Males	
Sons	28 (51.9)
Spouse	26 (48.1)
Females	
Daughters	92 (47.4)
Spouse	76 (39.1)
Grandmother-father	4 (2.1)
Brother-sister	4 (2.1)
Other	18 (9.3)
Education (yrs)	
1-6	42(16.9)
7-12	88(35.5)
13-16	102(41.1)
+ 17	16 (6.5)

Table 2. Living Arrangements (n, %)

Living Arrangements	n, (%)
Males	
Lives with care recipient	42 (77.8)
Lives alone	12 (22.2)
Females	
Lives with care recipient	130 (67)
Lives alone	64 (33)

Table 3. Caregivers' views and wishes (n, %)

Caregivers' views & wishes	n, %
Financial support/ allowances	(223) 90
More Day Care Centers providing non pharmacological interventions	(198) 80
Education how to deal with the disease	(186) 75
Residential homes	(161) 65
Training for paid caregivers	(124) 50
Home care services	(124) 50
Every day practical support	(124) 50
Peer support groups for caregivers	(112) 45

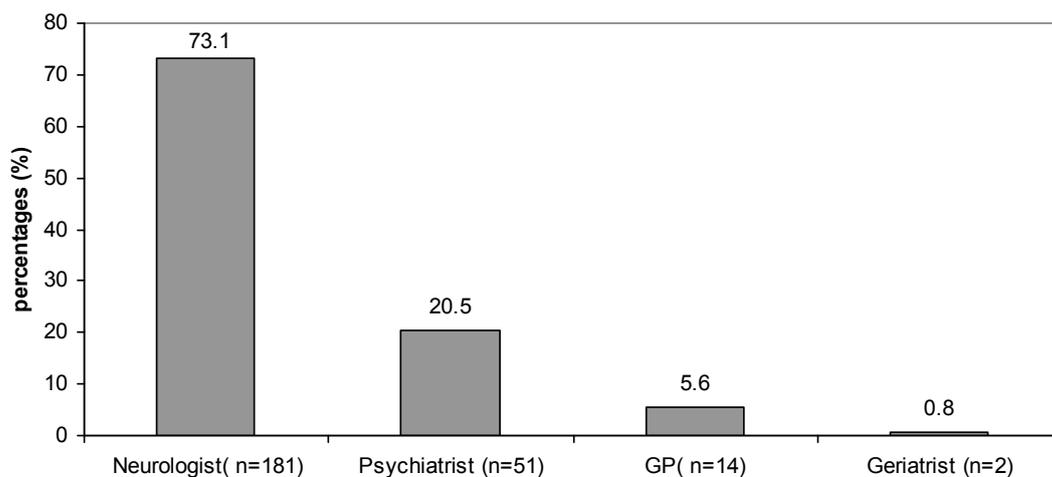


Figure 1. Percentage of patients treated by specialists

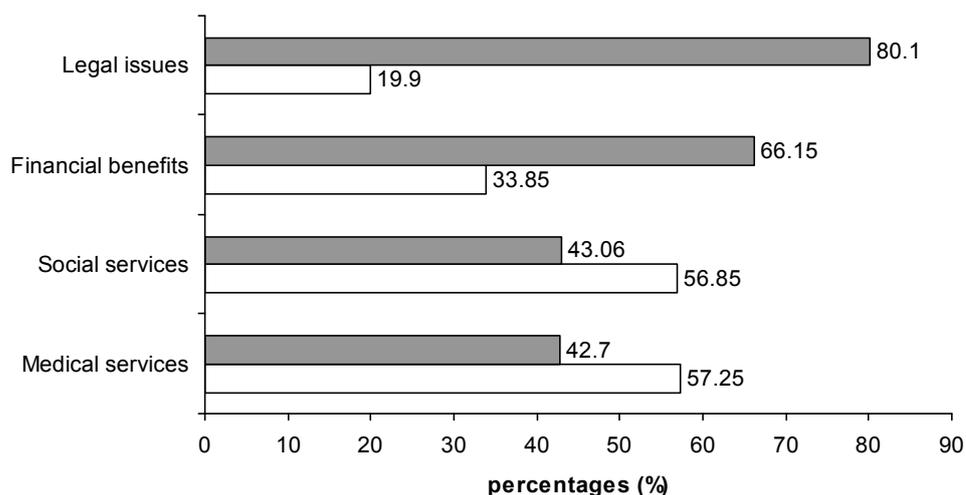


Figure 2. Type of needs expressed (%) by caregivers of patients with dementia

Discussion

The aim of this study was to explore the needs of family caregivers in Greece in order to define what additional resources and services could be employed to address their needs. Demographic characteristics of the study sample were similar to that described by other studies (Lai & Chung, 2007, Zwaanswijk et al., 2013, Rosa et al., 2010). Sons, daughters or spouses, formed the largest group of caregivers and this finding is in line with previous studies (Lai & Chung, 2007, Wolff & Kasper, 2006). Women formed the largest group of caregivers in our study thus confirming the societal trend that mainly women are to be responsible for caring for dependent people. This finding regarding women caregivers is in

agreement with results of recent studies by Hodgson et al. (2014), Toribio-Diaz et al. (2013), Godinho et al., (2008) and Andren & Elmstahl (2007). The majority of the patients in the study were treated by specialists due to the structure of the National Health System in Greece.

Caregivers were generally satisfied with available medical and social services. This is understandable since the majority of the study sample had access to the few Day Care Centers for people with dementia in big cities of Greece. On the contrary, a high percentage of caregivers expressed unmet needs, regarding financial support, psycho-education, help at home, assistance in legal matters and absence of special units for hospitalisation or prolonged stay of

patients. The critical concern of the carers in this study was the financial strain they experienced. The economic crisis is connected with deteriorating health status and less utilisation of medical services (Zavras et al., 2012). A study by Andren & Elmstahl (2007) found that caregivers with low income experienced a higher degree of depression and practical burden. In addition, low income caregivers also experience significantly more distress than caregivers with higher income (Williams et al., 2003).

Lack of education about dementia was an important request of caregivers participating in this survey as well as in previous ones (Scott et al., 2005). A high percentage of caregivers (75%) asked for training how to cope with behavioural challenges of the patients. Another major concern of family caregivers was finding appropriate professional and paid help at home. This finding is in accordance with studies reporting that caregivers substantially need every day help by trained professionals (Peeters et al., 2010), especially at the early stage of dementia (Zwaanswijk et al., 2013). According to the Eurofamcare- National Background Report for Greece (Triantafillou et al., 2006) no extensive research work or information is available on the dimensions of family care or the needs of caregivers of older people in Greece. Based on the findings of Mestheneos & Triantafillou (1993) two thirds of caregivers of older people are over 60 years and principal caregiver is the spouse (46.5%) or the co-residential child (38.6%). There are no data available services or unmet needs of caregivers of people with dementia in Greece too.

Strengths and limitations

A limitation of our study is, that sample consisted of caregivers who were members of the Alzheimers' organizations and might have received some type of support services. The way of recruitment implies that all caregivers had been already acquainted with some kind of support or information on available services.

Nonetheless, this survey was a pioneer one, given that we managed to gather information and views expressed by caregivers of people with dementia for the first time in our country. Additionally, the sample of this study involved different types of caregivers e.g spouses, daughters, sons or other relatives and the questionnaire used addressed practically all aspects of the major issue of dementia.

Conclusions

The results of our study showed that the Greek caregivers' profile follows the facts and figures

included in the latest 2014 Alzheimer's disease Facts and Figures worldwide report. Till now limited research has been done to explore the needs of caregivers in Greece and the data collected could be serving as guidelines in the development of national dementia strategy.

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