

Original Article

A Profile of Paid Caregivers who Assist Older Adults with Dementia: A Descriptive Study

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Abstract

Objectives: family caregivers' burden and psychological symptoms have been widely investigated but little is known how these affect paid caregivers (PCs) of people with dementia. The primary aim of the study was to describe the PCs socio-demographic characteristics and to measure their burden as well as their knowledge about dementia.

Methods: the Greek version of the Center Epidemiological studies Depression Scale (Ces-D), the Zurit Burden Interview and the Alzheimer's disease Knowledge Scale (ADKS) were self administered. Socio- demographic characteristics (age, gender, education etc), caregiving details, income, health care insurance and relationship with care recipient family were collected for all paid caregivers.

Results: All paid caregivers (n=28) were females. Correlation between ZBI and ADKS ($r=0.48$, $p=0.013$) was found. The majority of PCs were middle to old-aged women, married and came from eastern European countries. They work and offer care as live-in caregivers, spending a 24hours care/day and their income is below average salary (351-700€/month). Our PCs suffer from mild depressive symptoms (CES-D: 12.18 ± 8.18) and low burden (ZBI: 20.37 ± 13.52). Based on the results of our study-78.6% of the PCs had some kind of training in dementia.

Conclusions: a relative low burden was observed in PCs of people with dementia. Educational programs and interventions should be developed for this working force.

Key words: paid caregivers, depression, psychological symptoms, dementia

Introduction

Dementia is a growing social and financial problem mainly affecting all family members (Ferri et al., 2005, Alzheimer's Society, Dementia 2012). Traditionally, family plays an important role in the care of elderly and there is a strong tendency to support parents with dementia to stay in their home setting rather than in a nursing home. In Greek society, up to 95% of people with dementia are cared for at home by their spouses or adult children rather than being placed in nursing homes. There are many studies

examining the burden of family caregivers, who often suffer from stress, depression, social isolation and musculoskeletal problems (Pinquart & Sorensen, 2003, Cheng, 2017). Many Greek family caregivers, although no official data is available, hire paid caregivers (PCs) to help them with daily practical issues. In our clinical experience, paid caregivers (PCs) in Greece over the last two decades are mostly women from developing countries. These women spend 24 hours per day or some hours/day with the dependent person, helping with feeding,

bathing, shopping, cleaning and medication. To our knowledge, limited studies have focused on the burden, depression and dementia knowledge of paid caregivers of people with dementia. Hence, the aim of the current study is a) to explore the characteristics, responsibilities and training in dementia of these paid caregivers b) to investigate depression, burden and knowledge among this working force and lastly, c) to identify if 24hours of care is more aggravating compared to fewer hours care. Such information is essential to design programs based on the specific needs of the PCs. Moreover, by measuring the level of dementia knowledge among PCs, might be an important step in providing evidence on the need of specific training programs. However, there is a gap in the literature regarding the profile of PCs in Greece and in other European countries.

Methods

Study design: A cross-sectional study was carried out in the four Dementia Day Care Centers of the Athens Alzheimer Association between November 2000 and February 2020. Nurses and social workers participated in the distribution and collection of the self-reported questionnaires.

Participants: Paid caregivers who had been caring a person with dementia for at least one month were recruited in the study. The paid caregivers (PCs) were enrolled in the study if they met the following criteria: a) agreed to participate and signed the informed consent form and b) could read and complete the questionnaire. Any information from the participants was treated in strictest confidence and in accordance with the latest version of Helsinki Declaration. Approval was granted by the Ethical Committee of the Greek Alzheimer Association.

Instruments: A questionnaire about general information of PCs was written in Greek and consisted of three parts. In the first part the socio-demographic characteristics of PCs were collected. These included age, gender, marital status, education, nationality, reading and writing skills and years live in Greece. The second part assessed information regarding the nature and care characteristics, included years as a paid caregiver, living arrangements, hours of daily care, days off/week, income per month and public or private social and health insurance

status. The third part of the questionnaire included questions regarding specific care tasks (bathing, cleaning etc.), previous experience as paid caregiver in elderly with dementia, training to care for people with dementia, and relationship with the family of care recipient. The depression symptoms of paid caregivers were evaluated with the Greek version (Fountoulakis et al., 2001) of the self-administered Center Epidemiological studies Depression Scale (CES-D) which includes 20 items of 4-point scale. To explore paid caregivers burden, the Zarit Burden Interview was utilised. Higher scores indicate increased caregiver burden (Zarit et al., 1980). To measure PCs' knowledge of dementia, we used the Greek version of Alzheimer's Disease Knowledge Scale (ADKS)(Prokopiadou et al., 2015). Paid caregivers were instructed to complete the ADKS independently.

Statistical analysis: The statistical analysis was performed using SPSS software, version 22. Descriptive statistics including means±sd and percentages were used to describe socio-demographic data and outcome scores. Independent Samples T test and Chi-square were used to examine the differences between paid caregivers who provide assistant 24h/day and those working some hours. A Pearson's correlation coefficient was used to explore correlations between variables. A p value of <0.05 was considered statistically significant.

Results

All paid caregivers (n=28) were females. The paid caregivers' socio-demographic characteristics are presented in Table 1. In Table 2, living arrangements and caregiving characteristics of PCs are presented. Among twenty-eight (n=28) paid caregivers, eleven (n=11) reported providing a 24 hours per day care -living with care recipient. Paid caregivers reported excellent relations (57.1%) with the primary caregiver of the care recipient. Paid caregivers were more likely to assist with specific activities of daily living such as walking for mobility reasons (89.3%), shopping (85.7%), feeding (85.7%), domestic tasks such as cleaning the house (85.7%), self-care (bathing, skin & dental care etc,85.7%), participation in the person's with dementia leisure time or companionship (67.9%) and finally medical management (85.7%).

Table 1. Socio-demographic characteristics of the paid caregivers (mean±sd, N, %)

Variables	Mean±sd	N	%
Age (yrs)			
35-40		1	3.6
41-45		1	3.6
46-50		6	21.3
51-55		5	17.9
56-60		7	25.0
61-65		7	25.0
66-70		1	3.6
Education			
Primary		3	10.7
Middle		5	17.9
High		9	32.1
College		2	7.2
University		9	32.1
<u>Reading level (Greek)</u>			
Fairly		2	7.1
Medium		12	42.9
Very good		8	28.6
Excellent			
<u>Writing level (Greek)</u>			
Fairly		6	21.4
Medium		9	32.1
Very good		10	35.7
Excellent		6	21.4
<u>Marital Status</u>			
Married		3	10.8
Single		9	32.1
Divorced		5	17.9
Widow			
<u>Nationality</u>			
Georgia		7	25.0
Greece		7	25.0
Albania			
Ukraine			

Bulgaria	9	32.1
Poland	8	28.6
Brazil	5	17.9
<u>Years in Greece (yrs) 20.5±13.4</u>	3	10.6
	1	3.6
	1	3.6
	1	3.6

Table 2. Caregiving characteristics (Mean±SD, N, %) provided by PCs in care recipients

Variables	Mean±SD	N	%
Place of residence			
Patient's home		11	39.3
Other		17	60.7
<u>Care (Hours/day)</u>	13.5±8.96		
<u>Days off/ week</u>			
1 day		17	60.7
+2 days		8	28.6
More		3	10.7
<u>Income (€)</u>			
0-300		6	21.4
301-450		4	14.3
351-600		8	28.6
601-700		8	28.6
701-800		2	7.10
<u>Health & social insurance</u>			
Yes		11	39.3
No		17	60.7
<u>Previous experience as PC</u>			
Yes		17	60.7

No	11	39.3
Training in Dementia		
Yes	6	21.4
No	22	78.6

In addition, CES-D, ZBI and ADKS scores of all paid caregivers are shown in Figure 1. We also investigated differences in depression (CES-D), burden (ZBI) and dementia knowledge (ADKS) between paid caregivers who provide assistant 24h/day (n=11) and those working some hours/day (n=17). No differences were found in CES-D (t=0.42, df25, p=0.67), ZBI (t=-0.28,

df25, p=0.77) and ADKS (t=0.35, df25, p=0.73). No differences were found between the two paid caregivers working groups in previous experience (z=-0.304, p=0.41) and training in dementia (z=-0.33, p=0.82).

Correlation between ZBI and ADKS (r=0.48, p=0.013) is shown in Figure 2. No correlation was found between ZBI, CES-D and hours of care/week

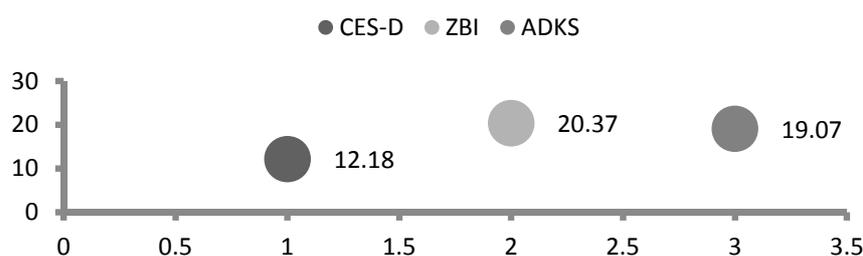


Figure 1. Mean values of depression (CES-D), burden (ZBI) and ADKS of PCs

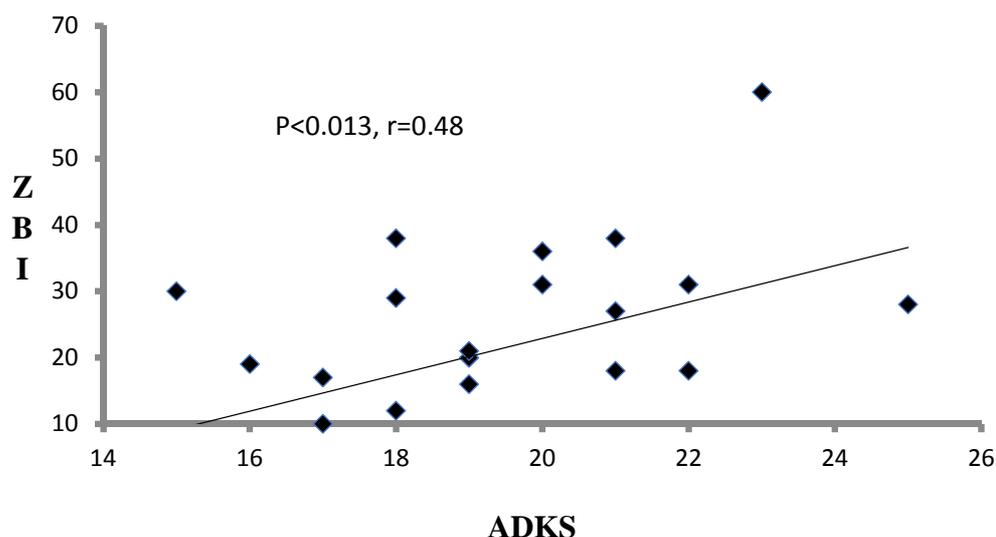


Figure 2. Correlation between the ADKS and ZBI scores

Discussion

The main aim of this study was to analyze the PCs socio-demographic characteristics. Mediterranean cultures, as in Greece, still maintain the tradition of caring in the family home. The hired PCs are called to sustain the behavioral and psychological symptoms of the person with dementia. Thus, PCs often suffer from depression and burden. However, little do we know about these two issues. In this study, the majority of the PCs were old-aged women, married and they came from eastern European countries. This finding is in line with the results of a previous study (Rosa et al., 2008) reporting that immigrant paid caregivers in Italy are mainly middle-aged married women from Ukraine, Romania, Moldavia, Poland and Russia. As a rule, Latin American and Filipino women in Europe and USA provide a 24hours care in dependent elderly people and their presence reduces the physical and emotional burden of the family (Benjumea & Roe, 2014, Rosa et al., 2004). In another study (Diaz et al., 2013) PCs were found to be middle-aged women, married and with low educational level. But no additional data was available in this article regarding the nationality or other socio-demographic characteristics. Brenner et al., (2006) conducted a pilot study in paid caregivers of dementia patients in USA enrolling 28 middle-aged (51.3±11.3) African Americans (3 Hispanic, 3 Caucasian, 3 other ethnic backgrounds) but this study does not provide other data about their socio-demographic characteristics. Interestingly, the PCs of our study reported high educational level, with medium knowledge of reading and writing of the Greek language, and they have been living in Greece for 20.5±13.4yrs. These women might have been professionals in their countries and due to economic reasons left their own families and regular life behind. These women are called to financially support their families working abroad. They work and offer care as live-in caregivers, spending a 24hours care/day and their income is below average salary (351-700€/month). Most of them (60%) do not have social and health insurance. These PCs women are treated as family members but often are requested to go beyond their contractual duties and take on the full care of the care recipient. Thus, Greek families are not usually concerned about their (PCs) previous experience or training in dementia caregiving and are more concerned for their kindness and integrity. Based

on the results of our study the 78.6% of the PCs had any kind of training in dementia despite the fact that a high percentage (60.7%) had a previous experience as paid caregiver for a person with dementia. In our knowledge, there are no published studies evaluating the ADKS scores of PCs. Compared to ADKS scores of nursing students (Scerri & Scerri, 2013) our participants had no differences with them (19-22 score) but both could be improved. A recent study (Eshbaugh& Stratton, 2016) examined the level of knowledge of 142 family members using ADKS and found a mean total score of 22.81(±2.79). This difference is not very high compared to our PCs, and we should take into account the educational level of PCs and the age as both affecting the better access to information (Brown et al., 2013). Moreover, ADKS is focused on knowledge of Alzheimer's disease specifically and therefore does not evaluate knowledge of other dementias that probably our study sample looks after. In addition, the current study confirmed positive correlations between ADKS and burden (ZBI score). Probably this finding shows that better understanding of dementia reduces caregiving burden. A better knowledge of the specific disease leads to more efficient management of the dementia symptoms. In contrast to our study results, knowledge of dementia was not correlated with caregiver burden but was strongly correlated with mood status probably because of unfamiliarity with language and culture (Lin et al., 2012). Although caregivers burden and depression has been extensively in family caregivers (Park et al., 2015, Win et al., 2017) and professional staff (Seidel &Thyrian, 2019), few studies explore paid caregivers burden and depression. Indeed, in one study (Brenner et al. 2006) found lower ZBI score (14.6±8.4) compared to our study sample (20.37±13.54). Our PCs suffer from mild depressive symptoms (12.18±8.18) and this is in line with the results of another previous study (Rosa et al., 2008). We detected similar results regarding ZBI and CES-D with those by Lin et al., (2012) and by Liang et al., (2018).

To the best of our knowledge this is the first study which aims at describing paid caregivers socio-demographic characteristics, burden and dementia knowledge. Several limitations are worth highlighting. First, the sample size was small and it may be difficult to generalize the findings. Second, it would be useful to gather more information about the dementia clinical

stage and BPSD (Behavioral and Psychological symptoms in dementia) of care recipients.

Paid caregivers always had to do everything by themselves, to observe the needs and routine of the care recipient and work almost without days off as they have to financially support their families. Therefore, educational programs and interventions should be developed for this working force. PCs ought to be supported and respected within our communities and their special needs assessed. Policies to improve access to paid caregiving could support quality of life for both PCs and families of people with dementia.

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

References

- Alzheimer's Society. Dementia 2012: A national challenge. United Kingdom: Alzheimer's Society 2012.
- Benjumea C. de la cuesta & Roe B. (2014). The experience of family care-givers and migrant paid care-givers' relief of burden: a contrasted qualitative analysis. *Ageing & Society*, 34:1219-1242.
- Brenner R., Madhusoodanan S., Brodsky E., Soberano W., Shack M., Nelson-Sasson A., Czobor P. (2006). Psychological symptoms in paid caregivers of dementia patients: a pilot study. *Psychiatry*, 46-49.
- Brown A.F., Vassr S.D., Connor K.I., Vickrey B.G. (2013). Collaborative care management reduces disparities in dementia care quality for caregivers with less education. *Journal of American Geriatric Society*, 61:243-251.
- Cheng Sheung-Tak. (2017). Dementia caregiver burden: a research update and critical analysis. *Current Psychiatry Reports*, 19:64.
- Diaz T.M.E., Martinez M.V., Jorda M.J.M., Blasco B.I. (2013). Characteristics of informal caregivers of patients with dementia in Alicante province. *Neurologia*, 28(2):95-102.
- Eshbaugh E. & Stratton L. (2016). Knowledge of Alzheimer's Disease Among family caregivers. *Journal of Community & Public Health Nursing*, 2 (4):2-6.
- Ferri C.P., Prince M., Brayne C., Brodaty H., Fratiglioni L., Ganguli M., Hall K., Hasegawa K., Hendrie H., Huang Y., Jorm A., Mathers C., Menezes P.R., Rimmer E., Sczufca M. (2005). Global prevalence of dementia: a Delphi consensus study. *Lancet* 366, 2112-2117.
- Fountoulakis K., Iacovides A., Kleanthous S., Samolis S., Kaprinis G.S., Sitzoglou K., Kaprinis G. St, Per Bech. (2001) Reliability, Validity and Psychometric Properties of the Greek Translation of the Center for Epidemiological Studies-Depression (CES-D) Scale. *BMC Psychiatry*, 1:3.
- Park M., Sung M., Kim K.S., Kim S. (2015). Multidimensional determinants of family caregiver burden in Alzheimer's disease. *International Psychogeriatrics*, 27(8):1355-1364.
- Pinquart M., Sorensen S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology Aging*, 18(2):250-67.
- Prokopiadou, D., Papadakaki, M., Roumeliotaki, T., Komninos, I. D., Bastas, C., Iatraki, E., Saridaki, A., Tatsioni, A., Manyon, A., & Lionis, C. (2015). Alzheimer's Disease Knowledge Scale—Greek Version. *APA PsycTests*.
- Rosa E., Ambrogio M., Binetti G., Zanetti O. (2004). Immigrant paid caregivers' and primary caregivers' burden. *International Journal of Geriatric Psychiatry*, 19:1103-1104.
- Rosa E., Lussignoli G., Sabbatini F., Chiappa A., Di Cesare S., Lamanna L., Surrente B., Zanetti O. (2008). The immigrant paid caregivers' role in the care of patients with severe dementia. *International Journal of Geriatric Psychiatry*, 23:331-333.
- Scerri A. & Scerri C. (2013) Nursing students' knowledge and attitudes towards dementia- A questionnaire survey. *Nurse Education Today*, 33:962-968.
- Seidel D. & Thyrian J.R. (2019). Burden of caring for people with dementia- comparing family and professional caregivers. A descriptive study. *Journal of Multidisciplinary Health*, 12: 655-663.
- Win K.K., Chong M.S., Ali N., Chan M., Lim W.S. (2017). Burden among family caregivers of dementia in the oldest-old: an exploratory study. *Frontiers in Medicine*, 5:205.
- Zarit S., Reever K., and Bach-Peterson J. (1980). Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *The Gerontologist* 20 (6): 649-655.