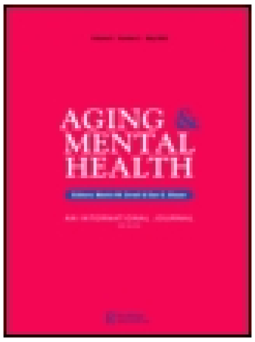

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Factors associated with the perception of services by dementia informal caregivers in Greece: the role of familism

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ABSTRACT

Aim: To investigate perceptions of informal caregivers of community-dwelling persons with dementia (PwD) regarding health and social care services and their correlates using the Behavioral Model of Healthcare Utilization as the theoretical framework.

Methods: This was a cross-sectional study using a purposive sampling technique to identify, through community-based health and social care services, caregivers of PwD. Face-to-face interviews were conducted with 118 informal caregivers (78.8% female, mean age = 58.9 years) *via* a structured questionnaire.

Results: Three 'Perceptions of Services' subscales were identified: 'Availability and Adequacy of Services' (AAS), 'Physicians' Competence' (COMP), and 'Professionals' Behavior' (PB). Predisposing factors (gender, employment, familism) and enabling/impeding factors (caregiving impedes work, quality of life aspects – environment and social relationships, information about dementia) were significant correlates of the AAS and COMP subscales. Familism was negatively associated with the AAS subscale. PwD's perceived declined physical and behavioral functioning was related to worse perceptions regarding professionals' behavior (PB) toward the PwD.

Conclusion: Understanding the factors associated with caregivers' perceptions of health and social care community services may guide the development of interventions that facilitate the appropriate use of those services, provide increased support to PwD and their caregivers, and delay potential institutionalization.

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Dementia; familism; informal caregivers; service perception; caregiving; Andersen model; Greece

Introduction

Dementia is a progressive neurodegenerative disease increasing exponentially with age and posing a tremendous burden for the person with the disease, the caregivers, and the health care system (ADI, 2018). According to European Commission data (2018) the prevalence of dementia will escalate rapidly in the coming years. In Greece, where 21.3% of the inhabitants are over 65 years old (Eurostat, 2016), dementia affects approximately 200,000 people (Alzheimer Europe, 2013). Results from a Cretan Aging Cohort of community-dwelling adults aged 60–100 years estimated the prevalence of dementia and mild cognitive impairment at 10.8% and 32.4%, respectively (Zaganas et al., 2019).

The effects of caregiving

It is well documented that people with dementia are mainly supported by informal carers (Wimo, Gauthier, & Prince, 2018). Caregiving tasks vary as the disease progresses from the provision of assistance with activities of daily living to the supervision of medical treatments, or of the quality of paid care (Dassel & Carr, 2016; Gallagher-Thompson et al., 2020). Despite some benefits, such as meaning in life or sense of greater closeness toward the persons with dementia (PwD) (Cheng et al., 2014), the effects of caregiving are generally negative. Numerous studies have shown that high levels of caregiving burden are associated with physical and psychological morbidity (Laks, Goren, Dueñas, Novick, & Kahle-Wrobleski, 2016; National Academies of Sciences, Engineering, and Medicine, 2016), problems in self-care activities (Wang, Liu, Robinson, Shawler, & Zhou, 2019), social isolation and loneliness (Carers UK, 2015; Vasileiou et al., 2017), or financial hardship and poor quality of life (Abdollahpour, Nedjat, Salimi, Noroozian, & Majdzadeh, 2015; Bastida, Esteve, Font, & Eickhoff, 2016).

Perceptions and use of services by dementia caregivers

Besides managing many aspects of the PwD daily life, family caregivers' perceptions of the services might be critical for their decisions to use them and, ultimately, for the quality of care their relatives receive. For example, it was found that dementia caregivers' positive perceptions and

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attitudes concerning service use are among the main factors associated with getting help from various professional caregivers, such as GPs, nurses, and home care workers (Lloyd, Patterson, & Muers, 2016; Roelands, van Oost, Depoorter, 2008).

Empirical findings suggest that caregivers' use of support services is low (Brodaty, Thomson, Thompson, & Fine, 2005; Phillipson, Jones, & Magee, 2014; Vecchio, Fitzgerald, Radford, & Fisher, 2016), many of them hesitate to use professional support (Greenwood & Smith, 2015), or use more frequently medical services than community services (Weber, Pirraglia, & Kunik, 2011). Restricted use of formal services is attributed to both individual and contextual factors (Bieber, Nguyen, Meyer, & Stephan, 2019), including caregivers' belief that services are not necessary, lack or inadequate knowledge about the services, the reluctance of the PwD to use them (Brodaty et al., 2005; Wolfs, de Vugt, Verkaaik, Verkade, & Verhey, 2010), or stigmatic beliefs about the disease (Werner, Goldstein, Karpas, Chan, & Lai, 2014).

Thus, the overarching goal of this study was to identify factors associated with the Greek dementia informal caregivers' perceptions about the availability of services for the PwD and for themselves.

The 'behavioral model of healthcare utilization'

One of the most extensively used conceptual frameworks for analyzing factors related to service use is the 'Behavioral Model of Healthcare Utilization' (Andersen & Davidson, 2007). According to this model, the use of healthcare services is associated with predisposing, enabling/impeding, and need factors, either contextual and/or individual. Predisposing characteristics reflect a propensity to use services and include (e.g. gender, age, education, occupation, family status) and health beliefs (i.e. attitudes, values, and knowledge). Enabling or impeding factors reflect an individual's ability to find and access services (e.g. community and family resources, including social and economic factors). Need factors include either perceived needs for health care (e.g. self-rated health) or evaluated needs (e.g. more measurable/objective needs, such as the evaluation of them by healthcare professionals). Although the initial model was criticized for not including cultural factors, the authors suggested that cultural traits might be conceptualized as a predisposing factor (Andersen & Davidson, 2007).

Familism, the caregiving experience and perception of services

Indeed, cultural norms and values have been identified as major correlates of the caregiving experience (for a review see McCleary & Blain, 2013). Familism, one of the most studied aspects of culture (Nápoles, Chadiha, Eversley, & Moreno-John, 2010), might be an important correlate of caregivers' perceptions of his/her role and of healthcare services. Conceptually defined as the valuing of interconnectedness and solidarity among family members (Magaña, 1999), high familism is expressed by a sense of obligation to family members, preferring them as the primary source of social support from formal services. Recent studies related to caregiving and familism or related concepts, such as filial piety or family cohesion, have been conducted in various ethnic groups of older adults with dementia and their caregivers (Gonçalves-Pereira et al., 2020; Kim, Kehoe, Gibbs, & Lee, 2019; Rote, Angel, & Hinton, 2019; Zhang, Clarke, & Rhynas, 2019).

Although familism is a fundamental value of the Greek culture (Koukouli, Pattakou-Parasyri, & Kalaitzaki, 2014), to the best of our knowledge, there are no studies examining how it relates to the caregivers of PwD's perceptions regarding the availability and quality of healthcare services provided. Therefore the main objectives of this study were:

1. To identify predisposing, enabling/impeding and need factors associated with caregivers' perceptions of services for PwD;
2. To explore the possible association of familism to these perceptions.

Methods

Participants and procedure

This was a cross-sectional study. A total of 145 potential participants were contacted. Among them, 22 refused to participate citing various reasons (e.g. lack of time, mistrust of the interviewers, or did not believe this would be helpful, etc.) and five could not be reached at home despite continuous efforts. The final sample consisted of 118 caregivers (response rate = 81.4%).

Potential participants were recruited through a purposive sampling technique from community-based health or social care services in the prefecture of Heraklion (Crete). Inclusion criteria were: (a) being identified as the person primarily responsible for the care of a family relative who had been diagnosed with ADRD (Alzheimer's Disease and Related Dementias) based on a neuropsychiatric evaluation; (b) living in the community; and (c) being able to understand and complete the study questionnaire. Exclusion criterion was cognitive deterioration.

Networks such as Alzheimer's societies, primary and secondary health care practitioners (i.e. physicians and social workers), and employees in daily care centres for the elderly provided relevant information to potential participants, who were contacted by phone and were asked to give their preliminary consent to participate. Following this, meetings were scheduled, and trained interviewers conducted face-to-face interviews *via* home visits. Some caregivers were interviewed in a university hospital during the hospitalization of the PwD. Before enrolment, all participants signed an informed consent form, in which their rights were fully explained (i.e. voluntary participation, anonymity, and confidentiality). The research protocol was approved by the Ethics Committee of the Institution to which the senior author is affiliated.

Measures

Dependent variable

Perceptions regarding services. Caregivers' perceptions of services were assessed using the *'Perceptions of Services Scale' (PSS),* a 13-item questionnaire, developed by Abo

Jabel & Werner (2018), and translated back and forth into Greek (example item: 'to what extent you think there are adequate community services for PwD'). The scores ranged from 1 to 5, with higher scores indicating more positive perceptions.

Independent variables

Predisposing variables. Caregiver's characteristics. These included gender, age, marital status, educational level, employment status, and relationship to the PwD.

Cultural values: familism. Familism was assessed using the Greek translation of 'the Familism Scale' (Sabogal, Marín, Otero-Sabogal, Marín, & Perez-Stable, 1987), consisting of 14 items ranging from 1 ('strongly disagree') to 5 ('strongly agree'). Its three subscales were also used: (a) 'familial obligations' (FO) included six items (e.g. 'Aging parents should live with their relatives'); (b) 'family's support' (FS) included three items (e.g. 'When one has problems, one can count on help from his/her relatives'); and (c) 'family as referents' (FR) included five items (e.g. 'Children should live in their parents' house until they get married'). Overall indices were calculated for each subscale by summing the items, with higher scores reflecting higher perceptions of familism. (Cronbach's alpha = .657, .616, and .600 for FO, FS, and FR, respectively).

Enabling/impeding factors.

- *Caregiving context* variables referred to: caregiving as an obstacle to work ability, assistance in caregiving, cohabitation of the caregiver with the PwD, caregiver's adequate information about the disease and their perceived need for extra training.
- *Caregiver's* social relationships, and environment they were living in was assessed by the two related domains of the *'WHOQOL-BREF'* (The WHOQOL Group, 1998) with higher scores in each domain denoting better quality of life (Cronbach's alphas = .731 and .623, for social relationships and environment, respectively).

Need factors.

- *Caregivers' need variables*, that is, existence of chronic disease, self-perceived health status and self-perceived burden assessed with the 22-item 'Zarit Burden Interview' (Zarit, Reever, & Bach-Peterson, 1980). Responses range from 0 ('never') to 4 ('nearly always'). An overall index was calculated by summing the items (Cronbach's alpha = .909).
- *Caregiver's physical and psychological health* assessed with the two related domains of the *'WHOQOL-BREF'* with higher scores in each domain indicating better health (Cronbach's alpha = .618 and .651 for physical and psychological health, respectively).
- *Care recipient's need variables: The 'Katz Activities of Daily Living Scale'* (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), an ordinal index using dichotomous ratings (dependent = 0/independent = 1) to assess PwD ability to perform six activities of daily living (ADLs) (bathing, dressing, toileting, transferring, continence, and feeding). Scores range from 0 (high dependence) to 6 (high independence) (Cronbach's alpha = .886). *'The Lawton Instrumental Activities of Daily Living Scale'* (Lawton & Brody, 1969) was used to assess the PwD's ability to perform instrumental activities of daily living (IADLs). Scores range from 0 (dependence) to 8 (independence) (Cronbach's alpha = .785). *'The Problematic Behavior Scale'* (Pearlin, Mullan, Semple, & Skaff, 1990), a 14-item measure evaluating the PwD's problematic behaviors (e.g. restlessness, suspiciousness, irritability, or night wandering). Frequency responses range from 0 (no day) to 7 (7 days). An overall index was created by summing the items (Cronbach's alpha = .848). *Cognitive functioning:* the Mini-Mental State Examination (MMSE) was used (Fountoulakis, Tsolaki, Chantzi, & Kazis, 2000), consisting of 11 items assessing a variety of cognitive abilities. Scores range from 0 to 30, with scores equal to or less than 23/24 indicating cognitive impairment.

Statistical analyses

Descriptive statistics (means, standard deviations, percentages) were used to describe the sample and the main variables. An Exploratory Factor Analysis (EFA) using varimax rotation was conducted to identify the underlying factor structure of the PSS. The number of extracted factors were determined by the magnitude of eigenvalues (>1.0). To test the bivariate relationships between the PSS subscales and other variables, Pearson product–moment correlations and analysis of variance were used. Multiple regression analysis (method 'stepwise') was used to reveal the best correlates of the three PSS subscales. Socio-demographic and health status characteristics of the caregiver and the care receiver and characteristics of caregiving were the independent variables with dependent variables the PSS subscales. Categorical independent variables were transformed into binary (dummy) variables. Parametric assumptions (residual normality, linearity, independence, heteroscedasticity) were examined. Heteroscedasticity and linearity were checked by plotting the residuals vs. the fitted values. The normal probability plot of the residuals was also examined and the variance inflation factor (VIF) for each independent variable was used to check multicollinearity in each one of the three regression models. Statistical significance for all analyses was defined as $p \leq .05$. The analyses were performed using SPSS Version 21 (Armonk, NY).

Results

Sample characteristics

The participants' mean age was 59, and the majority were female, had completed 9 years of education or less, married with adult children, were not employed, and reported having a moderate to bad financial situation. Two-fifths reported having a chronic disease. The majority of the PwD were female, widowed, with primary education or less, had low cognitive functioning and high dependence levels on both daily and instrumental activities of living (Table 1).

The caregiving context

Most participants lived in the same house with the PwD and provided care for an average of 7 years. Nearly 30%

received no assistance in caregiving, whereas for the rest another family member (41.9%) or a paid caregiver (28.2%) provided help. Also the majority reported that caregiving had an impact on their ability to work, considered themselves adequately informed about the disease, although emphasized the need for (extra) training (Table 1).

Factor analysis of the PSS

An EFA was conducted in order to identify the underlying factor structure of the PSS. Three factors were extracted explaining 85.1% of the variance (Table 2): 'AAS' contained eight items denoting the adequacy and availability of community services; 'COMP' comprised two items referring to the availability of competent physicians in diagnosing and treating the disease; 'PB' consisted of three items referring to the professionals' stigmatic behavior toward PwD. Overall indices were created for each factor by averaging the items. The internal reliability of the indices was excellent (Cronbach's alphas = .949, .934, and .858 for the AAS, COMP, PB factors, respectively). The mean score for AAS was moderate and higher for both COMP and PB.

Table 1. Sample's characteristics – caregiver and person with dementia (PwD) – (*N* and %).

	Caregiver	PwD
Age (mean ± SD)	58.9 ± 11.5	82.7 ± 7.4
Gender		
Female	93 (78.8%)	73 (61.9%)
Marital status		
Single	7 (5.9%)	–
Married	101 (85.6%)	49 (41.5%)
Widowed	2 (1.7%)	61 (51.7%)
Other	8 (6.8%)	8 (6.8%)
Educational level		
Illiterate (no school)	–	12 (10.6%)
Primary education (not completed)	11 (11.3%)	45 (39.8%)
Primary education (completed)	32 (27.1%)	33 (29.2%)
Secondary education (level 1)	35 (29.7%)	11 (9.7%)
Secondary education (level 2)	17 (14.4%)	8 (7.1%)
Post-secondary	7 (5.9%)	2 (1.8%)
Higher education	16 (13.6%)	2 (1.8%)
Employed (yes)	45 (38.1%)	4 (3.4%)
Caregiving impedes work (yes)	73 (61.9%)	–
Financial situation		
Bad	36 (30.5%)	–
Moderate	65 (55.1%)	–
Good/Very good	17 (14.4%)	–
Chronic disease (yes)	48 (40.7%)	–
Relationship with PwD		
Partner	30 (25.4%)	
Daughter/Son	74 (62.7%)	
Other	14 (11.9%)	
Years after diagnosis (Mean ± SD)	–	6.73 ± 4.80
Hospitalisations last 6 month (≥1)	–	52 (44.1%)
Cohabitation (yes)	61 (52.1%)	–
Assistance in caregiving (yes)	82 (70.1%)	–
Adequate information (yes)	70 (60.3%)	–
Need for training (yes)	102 (87.9%)	–

Bivariate associations between PSS subscales and the study variables

Positive and statistically significant associations were found between the first two PSS factors (AASxCOMP, $r = .65$, $p < .01$) and moderate negative associations of PB with AAS and COMP (AAS and PB, $r = -.28$, $p < .01$ and COM and PB, $r = -.20$, $p < .05$). Hence as participants' perceptions about the availability of services and the competency of physicians increased, their perceptions about the health professional's behavior decreased (e.g. they believed they were more stigmatic in their relationship with the PwD) (Table 3).

Among the predisposing variables the socio-economic status of the caregiver (education and financial situation) was statistically and positively associated with perceptions of the availability and adequacy of community services (AAS). Also, the male carers and those who were employed evaluated more positively professionals' competence (COMP) compared to women and the non-employed. Familism was negatively correlated to both AAS and COMP. None of the predisposing variables was significantly related to the third PSS factor (PB), except the familism-support subscale. From the set of enabling variables being restricted in the working roles due to caregiving was associated with worse evaluation of the availability and adequacy of community services and of the physicians' competence levels. Moreover quality of life related to social relationships and environmental conditions was associated positively to AAS and COMP, being adequately informed about the disease was associated with better evaluation of physicians' competence and living with the PwD was correlated to worse evaluation of healthcare professionals' behavior. Finally, significant associations were found between the majority of caregivers' needs variables and

Table 2. Factors extracted from the principal component analysis (Varimax rotation)[a] for the 'Perceptions of Services Scale' (PSS) items, means, and SDs.

Items	AAS[b]	COMP[c]	PB[d]
Available community services for caregivers of PwD	0.912		
Available sources of knowledge for caregivers of PwD	0.902		
Adequate community services for caregivers of PwD	0.897		
Available sources of knowledge for PwD	0.751	0.413	
Available community services for PwD	0.743	0.428	
Adequate community services for PwD	0.735		
Professionals (physicians, nurses, social workers) who can manage the treatment of a PwD	0.673	0.503	
Professionals who help caregivers of PwD	0.667	0.532	
Competent physicians for the treatment of dementia/AD		0.901	
Competent physicians for the diagnosis of dementia/AD		0.863	
Professionals (physicians, nurses, social workers) who ignore the PDA			0.917
Professionals (physicians, nurses, social workers) who force treatment on the PDA			0.883
Professionals (physicians, nurses, social workers) who mock the PDA			0.829
Mean (SD)	2.31 (1.06)	2.81 (1.30)	4.25 (0.96)

[a] Only factor loadings greater than 0.40 are shown.

[b] Factor 1 – AAS: 'Adequacy and availability of services'.

[c] Factor 2 – COMP: 'Competent physicians'.

[d] Factor 3 – PB: 'Professionals' behavior'.

Table 3. Bivariate associations between PSS subscales and study variables.[a]

	AAS	COMP	PB
Predisposing variables			
Gender			
Males	NS	3.26 (1.31)*	NS
Females		2.69 (1.28)	
Education levels			
Low ($\leq$9 years)	2.06 (1.03)**	NS	NS
Moderate (9–12 years)	2.24 (1.05)		
High ($>$12 years)	2.93 (0.90)		
Employed			NS
Yes	NS	3.12 (1.24)**	
No		2.62 (1.31)	
Financial situation		NS	NS
Bad	1.91 (0.95)**		
Moderate	2.36 (0.98)		
Good	2.91 (1.24)		
Familism			
Fam_total	−0.28**	−0.23*	NS
1. Fam_obligations	−0.23*	NS	NS
2. Fam_support	NS	NS	−0.23*
3. Fam_referent	−0.31**	−0.28**	NS
Enabling/impeding variables			
Caregiving impedes work			
Yes	1.97 (0.99)**	2.57 (1.33)**	NS
No	2.85 (0.94)	3.20 (1.17)	
Cohabitation	NS	NS	
Yes			4.09 (0.84)*
No			4.44 (1.04)
Adequate information	NS		
Yes		3.14 (1.28)**	NS
No		2.29 (1.17)	
Quality of life			
Domain 3. Social relationships	0.25**	0.25**	NS
Domain 4. Environment	0.29**	0.27**	NS
Need variables			
A. Caregiver's needs			
Quality of life			
Domain 1. Physical health	0.19*	−0.24**	NS
Domain 2. Psychological health	NS	0.20*	NS
Zarit_total	−0.18**	−0.21*	NS
B. Needs of the PwD			
Katz (PwD)	NS	NS	0.20*
Lawton-Brody (PwD)	0.22*	NS	NS
Problematic Behavior Scale (PBS)	NS	0.27**	−0.22*
MMSE	NS	NS	0.24*

NS, non significant.

[a] *p* Values are derived from two-way analysis of variance for categorical variables and Pearson's r for continuous variables. For each subscale are presented: means (SDs) for categorical variables and Pearson's r for continuous variables. Only statistically significant associations are included in the table.

*$p < 0.05$; **$p < 0.01$.

AAS or COMP, while better physical, mental, and behavioral functioning of the PwD increased the likelihood of positive perception of health professionals' behavior.

Multiple regression analyses

The results of the examination of the parametric assumptions were satisfactory. No problem of heteroscedasticity neither linearity was found, as the degree of scattering was the same for all fitted values and the residuals were almost parallel to the y axis, respectively. A problem of non-normality was found only for the dependent variable 'PB', which was resolved after removing one case; this handling resulted in slightly improved results (β's and p values and the R^2). VIFs did not reveal any multicollinearity problem, since all values were very close to 1 indicating that there was no correlation between the independent variables.

Results of the three separate multiple regression analyses with the three subscales of PSS being the dependent variables are presented in Table 4. Only variables having a statistically significant relationship with the three subscales in the correlational analyses were included in the regression models as independent variables. The AAS factor was found to be significantly associated with three variables explaining 34.4% of the variance: 'Caregiving impedes work', the 'environment' domain of the Quality of Life scale and the overall score on 'familism' scale. Caregivers who considered that caregiving tasks hindered their work were less satisfied with their quality of life related to their environment and had stronger ties with their families were more likely to evaluate negatively the availability and adequacy of services. Five variables were significantly associated with the 'COMP' index: 'Adequate information about dementia', the 'Problematic Behavior Scale', the 'Social relationships' domain of Quality of Life, being employed and gender, explaining 42.5% of the variance. Those who were women, non-employed, inadequately informed, cared for a PwD with problematic behavior, and had less satisfying social relationships and networks, were more likely to be less confident in physician's diagnostic and therapeutic abilities related to dementia. Finally, the only two variables significantly associated with the 'PB' factor were both related to the functional status of the PwD, explaining 24.0% of the variance: the 'Katz' index and 'Problematic Behavior Scale'.

Discussion

Perceptions and evaluation of health and social care services by the caregivers of PwD are critical and may lead to the subsequent use of these services or the reluctance to use them (Lloyd et al., 2016; Roelands et al., 2008). Therefore, the two principal objectives of this community-based study were: (a) to identify significant factors associated with the perception of services available for community-dwelling PwD by the informal caregivers and (b) to investigate the association of a cultural trait (familism) with the caregiver's perceptions, as, to the best of our knowledge, there are few studies exploring this relationship.

Participants rated 'the availability and adequacy of services' moderately, perception that may reflect the actual deficits of the health and social care systems in Greece. Indeed, there are few available health and social care services for PwD and their caregivers, and those are mainly provided in large cities, with the rural areas being largely underserved (Dimakopoulou, Sakka, Efthymiou, Karpathiou, & Karydaki, 2015). Furthermore, there is a lack of networking of the existing services, lack of medical specialty in Geriatrics or official sub-specializations in the field of dementia or gerontology and absence of continuing education programs for healthcare professionals on dementia (Ministry of Health, 2014). The state's rationale was to rely mainly on informal caregivers. Rather recently a National Action Plan was launched to confront these problems (Ministry of Health, 2014) as the rise in female workforce participation along with the increasingly aging population will lead to a shortage of unpaid carers for PwD in the years to come.

One important finding was that a set of predisposing and enabling factors were significantly associated with caregiver's perception of services (the AAS and COMP subscales). Only the variance of the third subscale (PB) was

Table 4. Multiple regression analyses with dependent variables AAS, COMP, and PB[a] (standardized regression coefficients).

AAS (dependent)	β	p	COMP (dependent)	β	p	PB (dependent)	β	p
Caregiving impedes work	−0.405	.000	Adequate info for disease	0.350	.000	KATZ	0.385	.000
QoL4 – Environment	0.233	.014	PBS	0.412	.000	PBS	−0.334	.001
Familism (total score)	−0.220	.019	QoL3 – Social relationships	0.213	.031			
			Employed	0.251	.006			
			Gender	0.209	.020			

[a] Note. AAS, adequacy/availability of services; COMP, competence of physicians; PB, professionals' behavior.

exclusively explained by two need factors. These results are in line with previous research demonstrating that enabling factors are as important as need variables in explaining the use of community services; for example, beliefs in negative outcomes for the PwD from service use have been found to be associated with use of neither day care nor residential respite care (Phillipson, Magee, & Jones, 2013; Phillipson et al., 2014).

Familism significantly correlated with PSS and explained a proportion of the variance of the AAS. In all cases it correlated negatively with the caregivers' perception of the services meaning that the stronger the identification with the family, the worse the assessment of services provided. Despite the socio-economic changes of the last decades and disparities between urban and rural regions, traditional collectivistic values continue to be strongly rooted in the Greek cultural background (Hofstede Insights, 2019; Papastylianou & Lampridis, 2016). In this sample of dementia caregivers, the score on familism scale was high and comparable to that from similar populations in other cultures (Losada et al., 2006). Higher levels of familism imply greater engagement of the caregiver in behaviors that fulfil family obligations toward the more vulnerable members, and reliance on family for social support. Therefore, one possible explanation for the moderate evaluation of the services might be that the dementia caregivers have high expectations from the formal services, and probably believe that the family provides better care for their loved one than the existent formal network of services. Another explanation could be that the family members are reluctant to admit they need support from a formal system of services for a problem that the family network should deal with.

Women participants were more critical than men of physicians' competence to treat a person with dementia. This finding may be well related to familism as to gender roles. The predominance of women in caregiving (60–70%; Alzheimer's Association, 2014) may indicate that there is a cultural expectation worldwide that women will assume the caregiving role (Godfrey & Warshaw, 2009). These values have been found to directly impact on the ability of predominantly female caregivers to access informal and formal dementia support care (Benedetti, Cohen, & Taylor, 2013). Moreover, it was found that the experience of caregiving differs between genders (Greenwood & Smith, 2015). Males adopt more independent, task-orientated and problem-solving attitudes, while females use more emotion-focused strategies, provide more intensive and complex care and have difficulty in balancing caregiving with other responsibilities; also, women report poorer physical health and higher levels of emotional distress, and burden than men (Robinson, Bottorff, Pesut, Oliffe, & Tomlinson, 2014; Schultz et al., 2012).

The impact of caregiving on participants' ability to work was a strong correlate of AAS: more limitations of their capacity to work due to caregiving were associated with worse evaluation of services. Particularly when patient's illness trajectory worsens and when losses in caregivers' social life, family relations and leisure activities occur, including their capacity to work, their degree of tolerance is weakened (Brodaty & Donkin 2009) and demand more assistance from the network of community services. The perceived inadequacy of those services to support them effectively may be a source of discontent leading to negative evaluation.

A significant proportion of the sample (40%) reported lack of knowledge about the disease, corroborating previous findings which underscore the caregivers' need for sufficient, precise, and comprehensible information (Stephan et al., 2018; Werner et al., 2014). Additionally, lower levels of knowledge about the disease were associated with a more negative evaluation of physicians' competence. In a qualitative study, Laparidou & Middlemass (2019) found that caregivers strongly believed that there was a need to educate health care professionals about dementia, and that, especially family physicians, lacked understanding of how dementia affects patients and their caregivers and knowledge on how to best help them. Besides, Greenwood, Mackenzie, Habibi, Atkins, and Jones (2010) found that, nine in 10 GPs believe that they are insufficiently trained, and approximately half of them lack confidence that they are meeting carers' needs.

Two QoL domains significantly correlated with the perception of services. The higher the quality of the 'environment' the caregivers were living in (e.g. financial resources, accessibility and quality of health and social care, physical environment) the better their perception of services (AAS). Additionally the better 'social relationships' the carers had, the more likely they were to evaluate positively physicians' competence. As found in other studies (Daley et al., 2019) contact with family and social networks is highly valued by carers, allowing them to offload emotionally, overcome isolation, and discuss shared concerns. It might be that the worse quality of these networks puts more pressure on physicians to compensate for this deficiency.

Additionally, higher levels of caregivers' objective burden (e.g. high dependency of the patient on caregiving for the basic activities of daily living, and exacerbation of troublesome behaviours), were related with more dissatisfaction with professionals' behavior. A possible explanation may be that they actually exhibit negative and discriminative behaviors toward the PwD when the symptoms are worsening. The expression of negative attitudes and beliefs by healthcare professionals toward the PwD may serve as a barrier for the use of services, while showing respect, valuing their capacity and rights and addressing their needs are considered facilitators (Stephan et al., 2018). Another explanation might be related to the typical negative feelings, emotional vulnerability, and feelings of helplessness of the caregivers when the health status of the care recipient is deteriorating, affecting their relationship with the healthcare professionals as well (Ornstein & Gaugler, 2012). It has been reported that the 'behavioral disturbances' of the PwD (e.g. verbal and physical aggression, agitation, psychotic symptoms, oppositional behavior, wandering) are more stressful for the caregivers than cognitive and functional problems. This is principally due to the unpredictable trajectory of the disease as well as the personality alternations that may occur in the PwD, leaving the caregiver less prepared to handle them adequately (Ornstein & Gaugler, 2012). It is well documented that behavioral problems are associated with more caregiver anger and resentment toward the patient, increased caregiver stress and worse psychological health (Croog, Burleson, Sudilovsky, & Baume, 2006). In our sample the 'Problematic Behavior Scale' correlated positively with the perceived burden and negatively with psychological health (quality of life dimension). However, in line with previous research on service use (Roelands et al., 2008), subjective burden was not a significant correlate of the service evaluation by the caregivers.

Limitations

Despite its strengths, this study has a number of limitations, which are worth mentioning. Although one could acknowledge the difficulty in recruiting a sample of dementia caregivers, who are usually extremely overwhelmed and burdened, still the small sample size constitutes a limitation of the study. Additionally, as this was a convenience sample collected through formal service networks of both the public and voluntary sectors, there might have been an underrepresentation of those who had fewer or no contacts with these networks and possibly were more dissatisfied or reluctant to use the services. Furthermore, the present findings cannot be generalized, as the data collection was restricted to one geographic area of Greece. Since the regression analyses explained between 24.0% and 42.5% of the variance in service perception, it seems that future studies should consider additional correlates to account for the whole picture.

Conclusion

This study aimed to understand the factors influencing the perception of services by caregivers of PwD and identify barriers and enablers toward the use of community services by them. Familism and gender were two predisposing factors found to affect perception of services. These seem to be important in the Greek culture and they may be in any other collectivistic culture where the individuals are interdependent, value, and rely on the family. Therefore, perception of services may not be influenced by their adequacy and availability *per se*, but also by the cultural values of the perceiver, and should be taken into consideration in relative studies.

Also, being employed and/or able to work despite caregiving tasks was essential for the study participants. Restrictions in these roles affected perceptions negatively, underscoring the importance of further developing respite care community services to alleviate the burden suffered by the dementia carers. Additionally, those who needed more information about the disease evaluated more negatively physicians' competence and skills, corroborating relative international findings about the need of carers for training and consultation on how to cope with the patient in the different stages of the disease. Furthermore, health decline of the PwD was related with worse evaluation of the health personnel's behavior toward the care recipient suggesting underlying stigma and the need for more sensitization and education of professionals.

Understanding these patterns is important in order to identify possible barriers and direct interventions that facilitate the appropriate use of community services, to effectively support the PwD and their caregivers and possibly postpone institutionalization.

Disclosure statement

No potential conflict of interest was reported by the authors.

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References

Abdollahpour, I., Nedjat, S., Salimi, Y., Noroozian, M., & Majdzadeh, R. (2015). Which variable is the strongest adjusted predictor of quality of life in caregivers of patients with dementia? *Psychogeriatrics*, *15*(1), 51–57. doi:10.1111/psyg.12094

Abo Jabel, H., & Werner, P. (2018). Examining Israeli Arab dementia family caregivers' perceptions regarding services for persons with dementia. In International *conference on health policy and research*, Tel Aviv.

ADI. (2018). *World Alzheimer Report 2018. The state of the art of dementia research: New frontiers*. Retrieved from https://www.alz.co.uk/research/WorldAlzheimerReport2018.pdf.

Alzheimer Europe. (2013). *Greece: The prevalence of dementia in Europe*. Retrieved from https://www.alzheimer-europe.org/Policy-in-Practice2/Country-comparisons/2013-The-prevalence-of-dementia-in-Europe/Greece

Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. *Alzheimer's and Dementia*, *10*(2, e47-92. doi: 10.1016/j.jalz.2014.02.001

Andersen, R. M., & Davidson, P. L. (2007). Improving access to care in America: Individual and contextual indicators. In R. M. Andersen, T. H. Rice, & G. F. Kominski (Eds.), *Changing the U.S. health care system: Key issues in health services policy and management* (pp. 3–31). San Francisco, CA: Jossey-Bass.

Bastida, J. D., Esteve, M. N., Font, S. J., & Eickhoff, A. F. (2016). Relation between the burnout and the quality of life of the caregiver of persons with dementia. [Relación entre el burnout y la calidad de vida del cuidador de personas con demencia]. *Gerokomos*, *27*(1), 19–24.

Benedetti, R., Cohen, L., & Taylor, M. (2013). 'There's really no other option': Italian Australians' experiences of caring for a family member with dementia. *Journal of Women & Aging*, *25*(2), 138–164. doi: 10.1080/08952841.2013.760330

Bieber, A., Nguyen, N., Meyer, G., & Stephan, A. (2019). Influences on the access to and use of formal community care by people with dementia and their informal caregivers: A scoping review. *BMC Health Services Research*, *19*(1), 88. doi:10.1186/s12913-018-3825-z

Brodaty, H., & Donkin, M. (2009). Family caregivers in dementia. *Dialogues in Clinical Neuroscience*, *11*, 217–228.

Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatrics Psychiatry*, *20*(6), 537–546. doi:10.1002/gps.1322

Carers UK. (2015). *Alone and caring: Isolation, loneliness and the impact of caring on relationships*. Retrieved from https://www.carersuk.org/for-professionals/policy/policy-library/alone-caring

Cheng, S. T., Lau, R. W., Mak, E. P., Ng, N. S., & Lam, L. C. (2014). Benefit-finding intervention for Alzheimer caregivers: Conceptual framework, implementation issues, and preliminary efficacy. *The Gerontologist*, *54*(6), 1049–1058. Retrieved from doi:10.1093/geront/gnu018

Croog, S. H., Burleson, J. A., Sudilovsky, A., & Baume, R. M. (2006). Spouse caregivers of alzheimer patients: Problem responses to caregiver burden. *Aging & Mental Health*, *10*(2), 87–100. Retrieved from doi:10.1080/13607860500492498

Daley, S., Murray, J., Farina, N., Page, T. E., Brown, A., Basset, T., … Banerjee, S. (2019). Understanding the quality of life of family carers of people with dementia: Development of a new conceptual framework. *International Journal of Geriatric Psychiatry*, *34*(1), 79–86. Retrieved from doi:10.1002/gps.4990

Dassel, K. B., & Carr, D. C. (2016). Does dementia caregiving accelerate frailty? Findings from the health and retirement study. *Gerontologist*, *56*(3), 444–450. doi:10.1093/geront/gnu078

Dimakopoulou, E., Sakka, P., Efthymiou, N., Karpathiou, N., & Karydaki, M. (2015). Evaluating the needs of dementia patients' caregivers in Greece: A questionnaire survey. *International Journal of Caring Sciences*, *8*(2), 274–280.

European Commission. (2018). *The 2018 ageing report. Economic & Budgetary Projections for the 28 EU Member States (2016–2070)*. Institutional Paper 079, May 2018.

Eurostat. (2016). *A look at the lives of the elderly in EU today*. Retrieved from https://ec.europa.eu/eurostat/cache/infographs/elderly/index.html

Fountoulakis, K. N., Tsolaki, M., Chantzi, H., & Kazis, A. (2000). Mini mental state examination (MMSE): A validation study in Greece. *American Journal of Alzheimer's Disease and Other Dementias®*, *15*(6), 342–345. Retrieved from doi:10.1177/153331750001500604

Gallagher-Thompson, D., Bilbrey, A. C., Apesoa-Varano, E. C., Ghatak, R., Kim, K. K., & Cothran, F. (2020). Conceptual framework to guide intervention research across the trajectory of dementia caregiving. *Gerontologist*, *60*, S29–S40. doi:10.1093/geront/gnz157

Godfrey, J. R., & Warshaw, G. A. (2009). Toward optimal health: Considering the enhanced healthcare needs of women caregivers. *Journal of Women's Health*, *18*(11), 1739–1742. doi:10.1089/jwh.2009.1720

Gonçalves-Pereira, M., Zarit, S. H., Cardoso, A. M., Alves da Silva, J., Papoila, A. L., & Mateos, R. (2020). A comparison of primary and secondary caregivers of persons with dementia. *Psychology and Aging*, *35*(1), 20–27. Retrieved from doi:10.1037/pag0000380

Greenwood, N., Mackenzie, A., Habibi, R., Atkins, C., & Jones, R. (2010). General practitioners and carers: A questionnaire survey of attitudes, awareness of issues, barriers and enablers to provision of services. *BMC Family Practice*, *11*(1), 100. doi:10.1186/1471-2296-11-100

Greenwood, N., & Smith, R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. *Maturitas*, *82*(2), 162–169. Retrieved from doi:10.1016/j.maturitas.2015.07.013

Hofstede Insights. (2019). Retrieved from https://www.hofstede-insights.com/models/national-culture/

Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *JAMA*, *185*, 914–919. doi:10.1001/jama.1963.03060120024016

Kim, H. J., Kehoe, P., Gibbs, L. M., & Lee, J. A. (2019). Caregiving experience of dementia among Korean American family caregivers. *Issues in Mental Health Nursing*, *40*(2), 158–165. Retrieved from doi:10.1080/01612840.2018.1534909

Koukouli, S., Pattakou-Parasyri, V., & Kalaitzaki, A. E. (2014). Self-reported aging anxiety in Greek students, health care professionals, and community residents: A comparative study. *The Gerontologist*, *54*(2), 201–210. Retrieved from doi:10.1093/geront/gnt036

Laks, J., Goren, A., Dueñas, H., Novick, D., & Kahle-Wrobleski, K. (2016). Caregiving for patients with Alzheimer's disease or dementia and its association with psychiatric and clinical comorbidities and other health outcomes in Brazil. *International Journal of Geriatric Psychiatry*, *31*(2), 176–185. doi:10.1002/gps.4309

Laparidou, D., & Middlemass, J. (2019). Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study. *Dementia*, *18* (7-8), 2526–2542. doi:10.1177/1471301217751226

Lawton, M. P., & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist*, *9*, 179–186. Retrieved from doi:10.1093/geront/9.3_Part_1.179

Lloyd, J., Patterson, T., & Muers, J. (2016). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia*, *15*(6), 1534–1561. Retrieved from doi:10.1177/1471301214564792

Losada, A., Robinson Shurgot, G., Knight, B. G., Márquez, M., Montorio, I., Izal, M., & Ruiz, M. A. (2006). Cross-cultural study comparing the association of familism with burden and depressive symptoms in two samples of Hispanic dementia caregivers. *Aging & Mental Health*, *10*(1), 69–76. Retrieved from doi:10.1080/13607860500307647

Magaña, S. (1999). Puerto Rican families caring for an adult with mental retardation: Role of familism. *American Journal on Mental Retardation*, *104*(5), 466–482. doi:10.1352/0895-8017(1999)104<0466:PRFCFA > 2.0.CO;2

McCleary, L., & Blain, J. (2013). Cultural values and family caregiving for persons with dementia. *Indian Journal of Gerontology*, *27*(1), 178–201.

Ministry of Health. (2014). *National action plan for Dementia–Alzheimer's Disease*. Athens: Ministry of Health.

Nápoles, A. M., Chadiha, L., Eversley, R., & Moreno-John, G. (2010). Developing culturally sensitive dementia caregiver interventions: Are we there yet? *American Journal of Alzheimer's Disease and Other Dementias*, *25*(5), 389–406.

National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. Washington, DC: The National Academies Press. Retrieved from 10.17226/23606

Ornstein, K., & Gaugler, J. E. (2012). The problem with "problem behaviors": A systematic review of the association between individual patient behavioral and psychological symptoms and caregiver depression and burden within the dementia patient–caregiver dyad. *International Psychogeriatrics*, *24*(10), 1536–1552. Retrieved from doi:10.1017/S1041610212000737

Papastylianou, D., & Lampridis, E. (2016). Social values priorities and orientation towards individualism and collectivism of Greek university students. *Journal of Beliefs & Values*, *37*(1), 40–54. doi:10.1080/13617672.2016.1141528

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583–594. doi:10.1093/geront/30.5.583

Phillipson, L., Jones, S. C., & Magee, C. (2014). A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice. *Health and Social Care in the Community*, *22*(1), 1–12. doi:10.1111/hsc.12036

Phillipson, L., Magee, C., & Jones, S. (2013). Why carers of people with dementia do not utilise out-of-home respite services. *Health and Social Care in the Community*, *21*(4), 411–422. doi:10.1111/hsc.12030

Robinson, C. A., Bottorff, J. L., Pesut, B., Oliffe, J. L., & Tomlinson, J. (2014). The male face of caregiving: A scoping review of men caring for a person with dementia. *American Journal of Men's Health*, *8* (5), 409–426. Retrieved from doi:10.1177/1557988313519671

Roelands, M., Van Oost, P., & Depoorter, A. (2008). Service use in family caregivers of persons with dementia in Belgium: Psychological and social factors. *Health & Social Care in the Community*, *16*(1), 42–53. Retrieved from doi:10.1111/j.1365-2524.2007.00730.x

Rote, S., Angel, J., & Hinton, L. (2019). Characteristics and consequences of family support in Latino dementia care. *Journal of Cross-Cultural Gerontology*, *34*(4), 337–354. Retrieved from doi:10.1007/s10823-019-09378-4

Sabogal, F., Marín, G., Otero-Sabogal, R., Marín, B. V., & Perez-Stable, E. J. (1987). Hispanic familism and acculturation: What changes and what doesn't? *Hispanic Journal of Behavioral Sciences*, *9*(4), 397–412. Retrieved from doi:10.1177/07399863870094003

Schultz, R., Beach, S. R., Cook, T. B., Martire, L. M., Tomlinson, J. M., & Monin, J. K. (2012). Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging & Mental Health*, *16*(6), 712–721. Retrieved from doi:10.1080/13607863.2011.651439

Stephan, A., Bieber, A., Hopper, L., Joyce, R., Irving, K., Zanetti, O., … Meyer, G. (2018). Barriers and facilitators to the access to and use of formal dementia care: Findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC Geriatrics*, *18*(1), 131. doi:10.1186/s12877-018-0816-1

The WHOQOL Group. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. *Psychological Medicine*, *28*(3), 551–558. doi:10.1017/s0033291798006667

Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of loneliness associated with being an informal caregiver: A qualitative investigation. *Frontiers in Psychology*, *8*, 585. Retrieved from doi:10.3389/fpsyg.2017.00585

Vecchio, N., Fitzgerald, J. A., Radford, K., & Fisher, R. (2016). The association between cognitive impairment and community service use patterns in older people living in Australia. *Health & Social Care in the Community*, *24*(3), 321–333. Retrieved from doi:10.1111/hsc.12212

Wang, X. R., Liu, S. X., Robinson, K. M., Shawler, C., & Zhou, L. (2019). The impact of dementia caregiving on self-care management of caregivers and facilitators: A qualitative study. *Psychogeriatrics*, *19*(1), 23–31. Retrieved from doi:10.1111/psyg.12354

Weber, S. R., Pirraglia, P. A., & Kunik, M. E. (2011). Use of services by community-dwelling patients with dementia: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias*, *26*(3), 195–204. Retrieved from doi:10.1177/1533317510392564

Werner, P., Goldstein, D., Karpas, D. S., Chan, L., & Lai, C. (2014). Help-seeking for dementia: A systematic review of the literature. *Alzheimer Disease and Associated Disorders*, *28*(4), 299–310. Retrieved from doi:10.1097/WAD.0000000000000065

Wimo, A., Gauthier, S., & Prince, M. (2018). *Global estimates of informal care*. London: ADI.

Wolfs, C. A. G., de Vugt, M. E., Verkaaik, M., Verkade, P. J., & Verhey, F. R. J. (2010). Empowered or overpowered? Service use, needs, wants and demands in elderly patients with cognitive impairments. *International Journal of Geriatric Psychiatry*, *25*(10), 1006–1012. doi: 10.1002/gps.2451

Zaganas, I. V., Simos, P., Basta, M., Kapetanaki, S., Panagiotakis, S., Koutentaki, I., … Vgontzas, A. N. (2019). The Cretan aging cohort: Cohort description and burden of dementia and mild cognitive impairment. *American Journal of Alzheimer's Disease & Other Dementias®*, *34*(1), 23–33. Retrieved from doi:10.1177/1533317518802414

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*, 649–655. doi:10.1093/geront/20.6.649

Zhang, X., Clarke, C. L., & Rhynas, S. J. (2019). What is the meaning of filial piety for people with dementia and their family caregivers in China under the current social transitions? An interpretative phenomenological analysis. *Dementia*, *18*(7–8), 2620–2634. Retrieved from doi:10.1177/1471301217753775