

Resilience in a Greek Sample of Informal Dementia Caregivers: Familism as a Culture-Specific Factor

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Abstract

The aim of this study was to examine the prevalence and the factors associated with resilience among a sample of 118 Greek informal caregivers (78.8% females, mean age=58.9, SD=11.6) of people with dementia. Face-to-face interviews assessed caregivers' socio-demographics, resilience, quality of life, burden, familism, and perception of services and their proxy assessments of the cognitive functioning, functional activity, and behavioral problems of people with dementia. Moderate levels of resilience were reported by 58.6% of the caregivers. Dementia-related knowledge and higher levels of familism were associated with higher levels of resilience, whereas higher frequency of dealing with behavioral problems was associated with lower resilience. Effective interventions to strengthen Greek dementia caregivers' resilience should be culture-specific, targeting both behavioral problems and caregivers' intrapersonal facilitators (i.e., dementia-related knowledge) and interpersonal interactions (i.e., familism). Healthcare professionals may have a key role in building caregivers' resilience and contribute to implications for policy and practice.

Key words: Family caregivers, familism, filial piety, solidarity, knowledge about dementia.

Introduction

The negative impact of caring on caregivers' mental health has been well-documented (1). However, little is known about the caregivers' resources (e.g., resilience), which may result in positive outcomes, such as better quality of life (2). Resilience has been defined as a process during which caregivers use internal and external assets and resources to deal with caregiving and the outcome of this process depends on both the caregiving challenges and their efforts to overcome these challenges (3).

Systematic reviews suggest that a multitude of interrelated factors are associated with caregivers' resilience (4, 5): social and cultural factors (e.g., gender, ethnicity, knowledge of dementia), the context of caring (e.g., kinship ties, social relationships, symptomology, living arrangements, time spent caring), and caregivers' psychological resources (e.g.,

coping style, personality traits). Lack of support services has also been reported (6). On the other hand, the caregivers' perceived dementia symptoms (i.e., care recipients' behavioral, psychological, cognitive symptoms) seem to jeopardise caregivers' outcome (e.g., burden) (5); they could likely jeopardise caregivers' resilience too.

Conceptualizing resilience within a cultural context is important, since there are differences between ethnic groups (e.g., Caucasian dementia caregivers were less resilient than the non-Caucasian) (5). Familism is an important aspect of the Greek culture, which might relate to dementia caregivers' resilience. It refers to strong emotional ties with the family, feelings of loyalty and solidarity and it has been related to resilience in other samples (7).

Studying factors that positively and negatively correlate with resilience is important since both are likely to cooccur. This study examined the prevalence and the potential positive and negative determinants of resilience in a sample of Greek dementia caregivers. Understanding which factors increase or decrease resilience may guide the development of appropriate interventions to support caregivers.

Methods

A purposeful sampling technique recruited 118 primary family caregivers of persons with dementia (Table 1) from various community services. After their rights were explained and consent forms were signed, questionnaires were administered through face-to-face interviews by a researcher. Socio-demographic information were asked, and caregivers' resilience was assessed with the Brief Resilience Scale (8) (6-36, $\alpha=.564$). The range of scores and the reliability coefficient of each instrument in this study is provided in parenthesis. The following instruments were administered to measure potential determinants of resilience: The WHOQOL-BREF (9) (4-20, $\alpha=.881$), the Zarit Burden Interview (10) (0-88, $\alpha=.909$), the Familism Scale (11) (14-98, $\alpha=.793$ and the Perceptions of Services Scale (PSS; 12) (13-65, $\alpha=.872$) assessed caregivers' quality of life, burden, familism, and the availability and adequacy of services for dementia people and their caregivers, respectively. The Mini-Mental

Table 1. (a) Descriptives (presented in frequencies and percentages or means and standard deviations) and (b) relationship with resilience (presented as t-test, ANOVA, or Pearson correlation coefficients) of the sociodemographic characteristics of the caregivers and the caregiving information. P values are in parentheses

Sociodemographic characteristics		Resilience (p)	Caregiving information		Resilience (p)
Sex (female)	78.8	-1.19 (.235)	Relationship with the PwD		.34 (.799)
Age	58.9 ±11.5	-0.06 (.510)	Children	62.7	
Marital status		1.39 (.242)	Spouses	25.4	
Single	5.9		Neighbour	1.7	
Married	85.6		Other	10.2	
Divorced	4.2		Help in caregiving		1.84 (.164)
Widowed	1.7		No help	29.9	
Other	2.5		Another family member	41.9	
Children (yes)	90.4	-0.70 (.487)	A formal caregiver	28.2	
Educational level		0.81 (.545)	Prevents working (yes)	61.9	-.99 (.323)
Elementary	34.4		Months of caregiving	60.2±47.1	.40 (.777)
Junior high	29.7		Hours per day	11.8±8.8	.08 (.410)
High school	20.3		Adequate info (yes)	60.3	-4.10 (.000)
University	13.6		Source of info		.70 (.692)
Employed (yes)	38.1	-2.05 (.043)	Media	35.6	
Financial situation		.62 (.542)	Professionals	26.0	
Bad	30.5		Internet	15.1	
Moderate	55.1		Seminars	6.8	
Good	14.4		Other	16.5	
Chronic disease (yes)	40.7	1.13 (.261)	Need for education (yes)	87.9	-.82 (.412)
Resilience	19.1±4.3				
Burden	46.1±17.5	-.21 (.032)			
Perception of services	36.8±10.0	.07 (.483)			
Familism	47.3±10.1	.08 (.437)			
QoL	76.5± 17.1	.39 (.001)			
MMSE*	7.4±8.5	.4 (.716)			
KATZ*	2.0±2.2	-.08 (.389)			
Lawton-Brody*	0.9±1.5	-.08 (.455)			
P.B.S. *	27.9±22.1	-.22 (.038)			

Note. Range of scores for Resilience (6-36), Burden (0-88), Perception of services (13-65), Familism (14-98), Quality of Life (QoL: 4-20), KATZ (0-6), Lawton-Brody (0-8(W)/0-5(M)), and Problematic Behavior Scale (P.B.S.: 14-98). Variables with an asterisk (*) are proxy assessments of the dementia people's symptoms by the caregivers.

State Examination (13), the Katz Index of Independence in Activities of Daily Living (14) (0-6, $\alpha=.886$), the Lawton-Brody Instrumental Activities of Daily Living Scale (15) (0-8(W)/0-5(M), $\alpha=.785$), and the Problematic Behavior Scale (16) (14-98, $\alpha=.848$) provided proxy assessments of the person with dementia for their cognitive functioning, functional capacities, independent living skills, and difficult behaviours, respectively. These variables (see Table 1) were entered in a multiple regression analysis (stepwise method) with resilience as the outcome. The study is in accordance with the Helsinki Declaration of 1975, as revised in 2000. Approval of the study was obtained from the Ethics committee of the Hellenic Mediterranean University.

Results

Despite the perceived severity of dementia symptoms (Table 1), 58.6% of the caregivers reported moderate levels

of resilience ($M=19.06$, $SD=4.27$). Although women scored higher in resilience than men ($M=19.30$, $SD=4.15$ vs. $M=18.09$, $SD=4.71$), the difference was not statistically significant ($t=-1.194$, $p=.235$). The employed caregivers, and those with adequate disease-related knowledge were more resilient compared to the non-employed (20.1 vs. 18.4, $t=-2.048$, $p=.043$), and the 'less knowledgeable' (20.3 vs. 17.1, $t=-4.10$, $p=.000$), respectively (Table 1). Resilience did not correlate with any of the caregiving variables (months of caregiving: $r=.039$; relationship with people with dementia: $r=-.063$; help in caregiving: $r=-.181$), but it did correlate with caregivers' quality of life ($r=.317$, $p<.001$). The regression model ($F(72)=6.402$, $p<.001$) predicted 24.9% of the variance in resilience. Having more information about dementia (positively), familism (positively), and dementia people's problematic behaviour (negatively) contributed to resilience (Table 2).

Table 2. Regression analysis for predicting caregivers' resilience

Variables	β	t	R ²	Adjusted R ²	SEE	R Square Change
1. Info about AD	.502	3.834**	.132	.114	4.42942	.132**
2. Problematic Behaviour	-.304	-2.377*	.210	.177	4.26935	.078*
3. Familism	.298	2.346*	.295	.249	4.07841	.084*

Note. *p< 0.05; **p< 0.01; ***p<0.001; SEE: Std. Error of the Estimate

Discussion

In line with other studies (4), the most significant determinant of resilience was caregiver's acknowledgement of having adequate disease-related information. Yet a significant proportion (nearly 40%) reported lack of knowledge, and nearly 88% reported need for more training/education, all of which have been reported as unmet needs (17). Disease-related information is a modifiable factor that can be strengthened to increase caregivers' resilience. In line with Joling's et al. (18) findings, the behavioral problems (e.g., aggressiveness, aimless wandering, restlessness) as perceived by the caregivers -and not the cognitive or functional impairment- were also negative predictors of resilience. It seems that the behavioral problems by people with dementia exceed caregivers' capacity to cope with and undermine their resilience. Similarly to studies that have shown that Latinos and women have high familism (11), in this Greek sample consisting mostly of women, familism was associated with resilience. To authors' knowledge, no other study has shown this among dementia caregivers. Given that studies have indicated that resilience has been associated with social support and meaningful relationships (2, 4, 5), it could be assumed that familism shares common features with close family relationships.

The cross-sectional nature of the study not allowing causal inferences, the use of self-report measures potentially accounting for participants' response bias, and the overwhelming participation of female caregivers not permitting generalization of the findings, are important limitations of this study. However, the study findings suggest that a culture-specific approach to enhancing resilience, targeting intrapersonal facilitators (i.e., enhancing dementia-related knowledge), barriers (i.e., controlling behavioral problems), and interpersonal interactions (i.e., enhancing familism) could be effective for the Greek informal dementia caregivers. Healthcare professionals may have a key role in supporting caregivers and building their resilience, which will have implications in the practice and policy of maintaining the home-based care of people with dementia with positive outcomes for the caregivers, the care they provide, and the care recipients.

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

Acknowledgements: We would like to thank the caregivers of the people with dementia who willingly participated in this study.

Conflict of Interest Disclosure: The authors declare no conflict of interest.

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How to cite this article: A. Kalaitzaki, S. Koukouli, S. Panagiotakis, et al. Resilience in a Greek Sample of Informal Dementia Caregivers: Familism as a Culture-Specific Factor. *J Frailty Aging* 2022; <http://dx.doi.org/10.14283/jfa.2022.31>