

Original Article

The Relationship between Caregiver Burden and Psychological Resilience in Caregivers of Individuals with Dementia

Seher Gonen Senturk, PhD

Assistant Professor, Department of Internal Medicine Nursing, Faculty of Health Sciences Cankiri Karatekin University, Cankiri Turkey

Merve Aliye Akyol, MSc, PhD Student

Research Assistant, Department of Internal Medicine Nursing, Faculty of Nursing Dokuz Eylul University, Izmir Turkey.

Ozlem Kucukguclu, PhD

Professor, Department of Internal Medicine Nursing, Dokuz Eylul University Faculty of Nursing, Inciralti, Izmir, Turkey

Correspondence: Ozlem Kucukguclu, Professor, PhD Department of Internal Medicine Nursing, Dokuz Eylul University Faculty of Nursing, Inciralti, Izmir, Turkey E-mail:ozlem.kguclu@deu.edu.tr

Abstract

Background: Caring for individuals with dementia can be a strain on the caregiver. Despite, the experience of caring for individuals with dementia is not entirely negative. The positive emotions and thoughts of caregivers of individuals with dementia in spite of the difficulties they experienced may be associated with their high psychological resilience.

Objective: This study aimed to examine the relationship between caregiver burden and psychological resilience in caregivers of individuals with dementia.

Methodology: The sample of this descriptive cross-sectional study consist of 103 caregivers of individuals with dementia who attended outpatient neurology department in a university hospital between February 2016 and February 2017. In the study, sociodemographic characteristics form, Caregiver Burden Inventory (CBI), and Resilience Scale for Adults (RSA), Mini Mental State Examination (MMSE), Blessed Dementia Scale (Blessed ADL1) and Blessed Orientation-Memory-Concentration Test (Blessed ADL2) were used. Sociodemographic data are shown in number, percentage and means. Spearman correlation analysis was performed to examine the relationship between caregiver burden and psychological resilience.

Results: The mean age of caregivers is 56.5 ± 9.91 , 85.4% of them are women, 42.7% of them provide care for their mother, 50.5% of them provide care for their family member between 1-5 years. The mean age of individuals with dementia is 75.60 ± 9.69 , 52.4% of them are female, 49.5% of them are primary school graduate, and 69.9% are Alzheimer type dementia. The total mean score of the CBI was 44.88 ± 19.01 , and the total mean score of the RSA was 111.25 ± 23.94 . There was a statistically significant negative correlation between the total mean score of the CBI and RSA scales ($p < 0.05$).

Conclusions: The caregiver burden can be reduced by increasing the psychological resilience level of caregivers. Psychological resilience levels can be enhanced by providing social and formal support to caregivers, enabling the development of effective coping skills and developing their strengths. Increasing the psychological resilience levels of caregivers are thought to help reduce the caregiver burden.

Keywords: Dementia, caregiver, caregiver burden, psychological resilience

Introduction

Dementia is defined as a syndrome in which memory, thought, behavior, and the ability to perform daily life activities are impaired. The majority of caregivers of individuals with dementia in the world are family members

(WHO, 2017). Caregivers of individuals with dementia are experiencing caregiving burden, emotional stress, depression and trait anxiety due to the problems that the care process creates, also they experience various health problems, job loss and financial difficulties (Abdollahpour et al., 2012, Givens et al., 2014; Pioli, 2010; Ozyesil,

Oluk & Cakmak, 2014). Despite negative aspects, the experience of caring for a loved one with dementia is not entirely negative (Bekhet & Avery, 2018). It has been pointed out that caregivers have found meaning in this process, that their personal development and commitment to the individual they provide care for have increased, that caregivers have rediscovered and identified themselves, that they are happy in the care process and see this process as an opportunity to nurture the relationship with the patient (Butcher, Holkup & Buckwalter, 2001; Joling et al., 2016; Quinn, Clare & Woods, 2012). It is stated that the positive emotions of caregivers of individuals with dementia in spite of the difficulties they experienced may be associated with their high psychological resilience (Dias et al., 2015; Wilks et al., 2011). Psychological resilience is defined as the ability of a person to successfully overcome and adapt to negative conditions despite the difficult circumstances, satisfaction with social network and social support, psychological well-being, strength, and healthy life (Dias et al., 2015; Masten & Coatsworth, 1998). It is stated that individuals will be more easily able to overcome the problems they encounter, or they will be able to get rid of these stresses with the least harm by improving their psychological resilience levels (Oz & Bahadır Yılmaz, 2009). In one study, it was stated that caregivers with a high psychological resilience did not consider institutionalizing the individuals with dementia they thought continuing to provide their care at home (Gaugler, Kane & Newcomer, 2007). In the literature, the importance of increasing the psychological resilience is emphasized to reduce the caregiver burden. However, it is indicated that there is insufficient information about the relationship between psychological resilience and caregiver burden in the literature (Scoot, 2013). For this reason, this study aimed to investigate the relationship between caregiver burden and psychological resilience of caregivers individuals with dementia.

Methodology

Study Design and Sample

This cross-sectional descriptive study was conducted between February 2016 and February 2017 in the outpatient neurology department of one university hospital. The sample selection was carried out using nonprobability convenience sampling. A total of 103 caregivers of individuals

with dementia were recruited into the study. Caregivers who a family member of the patient (spouse, daughter, son, sister, etc.); the primary person responsible for caregiving; providing care for at least 6 months and twenty hours in a week and is agree to participate voluntarily were included to study. Caregivers were having visual, hearing or speech impairments were excluded. Patients were diagnosed as having dementia by a neurologist, who based the diagnosis on according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria.

Instruments

Sociodemographic Form

It consists of two parts, which belong to caregivers and patients. First part; the caregiver's age, gender, educational years, relationship with the patient, income status, duration of caregiving. Second part; patient's age, gender, educational years, duration of diagnosis, type of dementia.

Caregiver Burden Inventory

Caregiver Burden Inventory (CBI) was developed by Novak and Guest (1989) in Canada to measure the impact of caregiving on caregiver relatives of the patients. This inventory is the first developed and most commonly used scale to measure the caregiver burden of caregiver of patients with cognitive impairment in the literature (Novak & Guest, 1989; Novak & Guest, 1992). The caregiver burden inventory of caregivers is also examined in five subscale (time-dependence, developmental, physical, social and emotional burden). Each subscale scores between 0 and 20 points. The total score of each individual range from 0 to 100. A high score indicates a high-level burden, and a lower score indicates a low-level burden. Kucukguclu, Esen & Yener (2009) carried out the validity and reliability this scale and Cronbach's alpha value was found to be 0.94. The Cronbach's alpha value of the scale was found to be 0.90 in this study.

Resilience Scale for Adults

Friborg et al. (2003) developed resilience scale for adults (RSA) which consists of six subscale (structured style, perception of future, family cohesion, perception of self, social competence and social resources). The scale is a 5-point Likert scale with a maximum score of 165 and a minimum score of 33. A high score indicates a high-level psychological resilience. The validity and reliability studies were carried out by Basım & Cetin (2010) in our country.

The total Cronbach's alpha coefficient of the scale was 0.86. The Cronbach's alpha value of the scale for this study was calculated as 0.82.

Mini Mental State Examination

The Mental State Examination (MMSE), first published by Folstein, Folstein & McHugh (1975), is a test used to assess quantitatively cognitive performance within the standard neuropsychiatric examination methods. Gurgen et al. (2002) found that MMSE is valid and reliable in dementia diagnosis in Turkish society.

Blessed Dementia Scale (Blessed ADL1) and Blessed Orientation-Memory-Concentration Test (Blessed ADL2)

Developed by Blessed and his colleagues in 1968, it consists of two parts. The first part assesses daily life activities and behavioral characteristics, and the second part assesses cognitive status (Blessed, Tomlinsin & Roth, 1968).

The first part has been remodified by Katzman and his colleagues (Katzman, Brown, Fuld, 1983). The validity and reliability of the scales were performed by Akca Kalem's colleagues in our country (Akca-Kalem, Oktem, Emre, 2002).

Statistical Analysis

The data analysis was carried out using SPSS (SPSS Inc. Chicago ILdate) 22.00.

Sociodemographic data are given in numbers and percentage.

Spearman correlation analysis was performed to determine the relationship between caregiver burden and psychological resilience. A value of $p < .05$ (95% confidence interval) was considered statistically significant.

Ethical Considerations

The study was consonant with the World Medical Association Declaration of Helsinki and was approved by the local Ethical Committee for the Noninvasive Research Ethics Board (Ethical Consideration Number: 2016/05-09).

Participants were informed about the study and if they agreed to take part in the study, their written permission was received.

Results

Characteristics of Caregivers

The mean age of caregivers is 56.5 ± 9.91 , 85.4% of them are female, 42.7% of them have an undergraduate degree, 42.7% of them provide care for their mother, 60.2% has an equal income to expense, 50.5% provide care for their patients between 1-5 years (Table 1).

Characteristics of Individuals with Dementia

The mean age of the individuals with dementia is 75.60 ± 9.69 , 52.4% of them are female, 49.5% are primary school graduates, 69.9% have Alzheimer type dementia, 45.6% are duration of diagnosis 1-5 years, and MMSE mean score is 15.81 ± 6.51 , Blessed ADL1 mean score is 5.57 ± 4.59 , and Blessed ADL2 mean score is 8.04 ± 5.61 (Table 2).

Subscale and Total Mean Scores of Caregiver Burden Inventory

The mean score of time-dependence subscale of the CBI is 13.18 ± 5.35 , the mean score of developmental burden subscale is 11.33 ± 5.09 , the mean score of physical burden subscale is 9.95 ± 5.92 , the mean score of social burden subscale is 5.21 ± 5.06 , 5.18 ± 4.66 , and the total mean score is 44.88 ± 19.01 (Table 3).

Subscale and Total Mean Scores of Resilience Scale for Adults

The mean score of the structured style subscale of the RSA is 12.53 ± 3.61 , the mean score of the perception of future subscale is 12.15 ± 3.86 , the mean score of the family cohesion subscale is 20.95 ± 4.94 , the mean score of the perception of self subscale is 20.00 ± 6.15 , ± 4.69 , the mean score of the social competence subscale is 21.80 ± 4.69 , the mean score of the social resources subscale is 23.80 ± 5.68 , and the total mean score is 111.25 ± 23.94 (Table 4).

The Relationship Between the Caregiver Burden and the Psychological Resilience

A statistically significant and negatively strong relationship was found between the CBI and the RSA score averages ($r = -0.869$, $p < 0.001$). Accordingly, as the psychological resilience mean scores of caregivers increased, the mean scores of the caregiver burden decreased statistically significantly.

Table 1. Characteristics of Caregivers

Characteristics	Caregivers (n=103)
	X ± SD
Age (years)	56.5±9.91
	N (%)
Gender	
Female	88 (%85.4)
Male	15 (%14.6)
Education	
Illiterate	1 (%1.0)
Literate	3 (%2.9)
Primary education	26 (%25.2)
High school	25 (%24.3)
University	44 (%42.7)
Masters degree	4 (%3.9)
Relationship with the patient	
Spouse	38 (%36.9)
Mother	44 (%42.7)
Father	17 (%16.5)
Relatives	4 (%3.9)
Working	
Working	28 (%27.2)
Not working	75 (%72.8)
Income	
Income less than expenditure	20 (%19.4)
Income equal to expenditure	62 (%60.2)
Income more than expenditure	21 (%20.4)
Caregiving period	
Less than one year	13 (%12.6)
1- 5 years	52 (%50.5)
6 years and more	38 (%36.9)

Table 2. Characteristics of Individuals with Dementia

Characteristics	Individuals with Dementia (n=103)
	X ± SD
Age (years)	75.60±9.69
	N (%)
Gender	
Female	54 (%52.4)
Male	49 (47.6)
Education	
Illiterate	4 (%3.9)
Literate	12 (%11.7)
Primary Education	51 (%49.5)
High school	16 (%15.5)
University	18 (%17.5)
Masters degree	2 (%1.9)
Types of Dementia	
Alzheimer's Dementia	72 (%69.9)
Vascular Dementia	18 (%17.5)
Frontotemporal Dementia	13 (%12.6)
Duration of diagnosis	
Less than one year	10 (%9.7)
1-5 years	47 (%45.6)
6 years and more	46 (%44.7)
	X ± SD
MMSE	15.81±6.51
Blessed ADL1	5.57±4.59
Blessed ADL2	8.04±5.61

Table 3. Caregiver Burden Inventory and Its Subscales Mean Scores

	X ± SD
Time-dependence burden	13.18±5.35
Developmental burden	11.33±5.09
Physical burden	9.95±5.92
Social burden	5.21±5.06
Emotional burden	5.18±4.66
Caregiver burden	44.88±19.01

Table 4. Psychological Resilience Scale and Its Subscales Mean Scores

	X ± SD
Structured style	12.53±3.61
Perception of future	12.15±3.86
Family cohesion	20.95±4.94
Perception of self	20.00±6.15
Social competence	21.80±4.69
Social resources	23.80±5.68
Psychological Resilience	111.25±23.94

Discussion

This study was conducted to determine the relationship between the caregiver burden and the psychological resilience of caregivers of individuals with dementia. It was found that there was a negatively strong correlation between caregiver burden and psychological resilience ($r = -0.869$, $p < 0.001$). According to this, as the psychological resilience mean scores of the caregiver increases, the caregiver burden mean scores decreases statistically significantly.

In the literature stated that higher levels of resilience were associated with decreased burden (Bekhet, 2013; Scott 2013; Fernández-Lansac et

al., 2012; Gaugler et al., 2007; Joling et al., 2015). Resilient people enjoy challenges and prefer changes rather than stability, and life travails provide opportunities to develop skills and self-knowledge (O'Rourke et al., 2010). The caregiving process can be perceived by many caregivers as stressful and difficult, annoying and can lead to depression by creating negative emotions (Bekhet & Avery, 2018). However, resilient individuals can see the caregiving process as a process that matures them (Butcher, Holkup & Buckwalter, 2001; Joling et al., 2016; Quinn, Clare & Woods, 2012).

Caregiving makes individuals vulnerable to physical and metabolic conditions that disturb

their health (Yesil et al., 2016). Resilience is also defined as becoming a more powerful, more flexible, and healthier person day by day (Bekhet & Avery, 2018). It is found that individuals with a high level of psychological resilience have a higher level of physical well-being and higher self-perception of health status (Dias et al., 2015; Zauszniewski, Bekhet, & Suresky, 2009). In the caregiving process, family relationships may break down, and economic and social problems may arise (Kucukguclu et al., 2009). Individuals with a high level of psychological resilience are reported to have social support source and better interpersonal relationships, and they are less likely to experience psychosocial problems (Donnellan, Bennett & Soulsby, 2015; Wilks & Croom, 2008; Dias et al., 2015; Zauszniewski, Bekhet & Suresky, 2009).

It is thought that individuals with high psychological resilience are more likely to respond positively to the caregiving experience, to view this process as an acquisition and adapt to change more quickly, also have less burden because of their higher social relations and resources.

Conclusion

Results of this study suggest that caregiver burden correlated with psychological resilience in caregivers of dementia in Turkey. Resilience is promising for caregivers of individuals with dementia. Psychological resilience levels can be enhanced by providing social and formal support to caregivers, enabling the development of effective coping skills and developing their strengths. Increasing the psychological resilience levels of caregivers are thought to help reduce the caregiver burden.

Study Limitations

The present study has some limitations. The sample was different types of dementia caregivers and nonrandom. The sample was limited to only one region of the country, and therefore the findings may not be generalizable to other parts of Turkey.

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