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Caregiving Self-Efficacy in Family Caregivers of People with Dementia: The Role of Knowledge of Dementia and Perceived Social Support

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ABSTRACT

Purpose: To examine the role of perceived social support and knowledge of dementia in family caregivers of people with dementia (PwD) regarding caregiving self-efficacy.

Design: Descriptive, cross-sectional, and predictive design was used.

Methods: The study was conducted with caregivers of PwD (n:102) between March and May 2022. Data was collected using the following forms: a socio-demographic characteristics form, the revised scale for caregiving self-efficacy (RSCSE), the dementia knowledge assessment scale (DKAS) and the revised form of the multidimensional scale of perceived social support (RFMSPSS). Data was assessed through descriptive statistics and multivariate regression analysis.

Findings: The participants' RSCSE, DKAS and RFMSPSS mean scores were 1125.89 ± 417.18 (range:0–1800), 15.70 ± 6.06 (range:0–34), and 52.72 ± 20.07 (range:12–74), respectively. Analysis indicated that DKAS and RFMSPSS predicted positive caregiving self-efficacy scores but it was not statistically significant for DKAS ($R^2:0.209$, $F:13.077$, $p < 0.001$). These variables accounted for 21% of total variance of caregiving self-efficacy. RFMSPSS predicted positively and statistically significantly ($\beta:0.461$, $p < 0.001$) the total score of the self-efficacy scale.

Conclusions: The perceived social support of caregivers of PwD is an important predictor of the self-efficacy level of caregivers.

Clinical Evidence: In order to enhance improving the quality of the caregiving process, caregivers should be strengthened, and caregiving self-efficacy should be comprehensively evaluated to enable assistance to the caregiver. The social support of caregivers is an important predictor of caregiving self-efficacy. Therefore, social support should be taken into consideration when engaging in appropriate initiatives.

Introduction

Dementia is one of the leading causes of disability and dependency in people aged 65 years and over worldwide. The majority (more than 60%) are individuals from low- and middle-income countries. Approximately more than 10 million people are diagnosed with dementia each year (World Health Organization, 2023). As the prognosis of dementia worsens, people with dementia (PwD) need more help from others due to impaired cognitive and physical functions and behavioral problems. The care needed is usually given in two forms, formal and

informal. Formal caregiving is the care given by occupational groups that provide health care and personal care services at home or in an institution. Formal home care providers are mostly nurses, physiotherapists, social workers, dietitians and home care assistants. Informal caregiving refers to the care provided by family members or friends who live with a relative in need of care, take on the role of helping, meet their basic needs, follow up on their medical care and doctor or hospital relations, and provide home care without payment (Alzheimer Association, 2022).

Needs of PwD are met mostly by their family members. Caregivers (mostly family members and friends) provide daily care to PwD for five hours on average. Caregivers of PwD are described as “hidden patients” (Alzheimer Association, 2023).

Caregivers prioritize the needs of their loved ones over their personal needs and lifestyle preferences. Although many caregivers often stress the importance of health-promoting activities, they have difficulty in allocating time for self-care, going to doctor, and asking for help from other family members (Lindeza et al., 2020). Caregivers suffer from cognitive losses, emotional burden, negative family relationships, depression, care burden, anxiety, job losses, financial difficulties, and low quality of life (García-Castro et al., 2022; Lindeza et al., 2020; Tan et al., 2021).

The self-efficacy of individuals who face the caregiving-associated problems decreases over time and their perceptions of the caregiving process become more negative. The concept of self-efficacy, which is involved within the scope of the social cognitive learning theory developed by Albert Bandura, is defined as one’s belief in his or her capacity to fulfill a challenging activity (Bandura, 2002). The concept of self-efficacy is multidimensional and includes processes for caregivers such as taking time for themselves, performing their self-care activities, managing disturbing patient behaviors well, and controlling distressing thoughts about care. When caregiver self-efficacy is mentioned, it is necessary to consider the processes for the care of the patient as well as the caregiver’s own self-care activities. In this sense, although attempts to increase caregiver self-efficacy are directly aimed at caregivers, they also indirectly affect individuals with dementia.

As the concept of self-efficacy has gained importance, the number of studies on the self-efficacy of caregivers has increased. The studies conducted with caregivers of PwD have highlighted that these caregivers do not have the required level of self-efficacy (Frias et al., 2020; Tan et al., 2021). They do not allocate sufficient time for themselves and are not able to manage disturbing patient behaviors, leading to impairment of their self-efficacy (Steffen et al., 2019).

Increased self-efficacy of caregivers may have a positive effect on their health since caring for PwD is challenging. When the self-efficacy levels of caregivers of PwD are elevated, this may be useful in alleviating their burden and depression (Cheng et al., 2013). Also, caregiving self-efficacy is inversely correlated with depressive symptoms (Grano et al., 2017) and protects against the risks of diseases (Schönfeld et al., 2016). Caregivers with high self-efficacy are more likely to adopt healthy living behaviors and have a high quality of life, resulting in coping better with the behavioral symptoms of PwD and having higher self-confidence and self-esteem (Crellin et al., 2014; Crespo & Fernández-Lansac, 2014; Nogales-González et al., 2015). In their study, George and Steffen (2014) revealed that caregivers with higher self-efficacy levels had better mental and physical health. Higher self-efficacy of caregivers has an important role in reducing problems experienced in caregiving and in promoting their own health. Therefore, it is of great importance to understand the effect of caregiving-related factors on caregiver self-efficacy (Tan et al., 2021).

Caregivers’ perception of social support and dementia knowledge level are important variables that affect caregiver self-efficacy (Merrilees et al., 2020; Shiba et al., 2016; Tan et al., 2021). In the literature, it is emphasized that it is important to address the lack of caregivers’ knowledge about dementia, its treatment and care practices (Merrilees et al., 2020). It was found that caregivers getting high scores in dementia knowledge had better positive attitudes toward dementia, psychological well-being of caregivers, and the individual-centered approach (Dai et al., 2020; Wang et al., 2022). It is emphasized that if caregivers have a low level of knowledge about dementia, it negatively affects their self-efficacy level (Merrilees et al., 2020).

In the study conducted by Tan et al. (2021) using RSCSE, they stated that there was no study using the revised caring scale which is specific to caregivers of PwD and assesses more than one self-efficacy domain. The aim of this study is to examine the role of perceived social support and knowledge of dementia in family caregivers of PwD regarding caregiving self-efficacy.

Research Questions

- (1) What is the self-efficacy level of family caregivers of PwD?
- (2) Does the knowledge level of family caregivers of PwD about dementia affect their self-efficacy level?
- (3) Does the perceived social support of family caregivers of PwD affect their self-efficacy level?

Methods

Design

This study was conducted based on descriptive, cross-sectional, and predictive design.

Participants and setting

The study was conducted with the caregivers of PwD who were followed up in the neurology outpatient clinic of a university hospital in Turkey between March and May 2022. The sample consisted of 102 family caregivers who were aged 18 years and over, were primarily responsible for the care of a PwD (diagnosed by a specialized neurologist), provided care for at least four hours a day, were literate and agreed to participate voluntarily in the study. Caregivers who did not speak Turkish and had hearing and/or speaking impairment were excluded from the study. A nonrandom sampling method (convenience sampling) was used in the study. As a result of the post-hoc analysis, it was found that the power of the study was 98% in the regression analysis performed with two independent variables in the G-power 3.1.9.4 software, the effect size was $d = 0.15$, the significance level was less than 0.05, and the sample size was 102.

Dependent and independent variables

While RMFSPSS (perceived social support) and DKAS (dementia knowledge of caregivers) mean scores were the independent variables, the RSCSE (self-efficacy) mean score was the dependent variable. Self-efficacy has three domains; SE-OR: self-efficacy in obtaining respite (first subscale, 5 items, min:0, max:500 point), SE-RBD: self-efficacy in responding to disruptive patient behaviors (second subscale, 8 items, min:0, max:800 point) and SE-CUT: self-efficacy in controlling upsetting thoughts about caregiving (third subscale, 5 items, min:0, max:500 point). Each item in the scale assesses caregiver confidence related to each subscale.

Instruments

Demographic characteristics form

The demographic characteristics form was prepared by the researchers to collect data on the socio-demographic characteristics of the caregivers. It had questions about the caregivers' age, gender, educational status, relationship with the PwD, working status, income status, and the length of caregiving.

The Revised Scale for Caregiving Self-Efficacy (RSCSE)

The Revised Scale for Caregiving Self-Efficacy with 14 items was developed by Zeiss et al., in 1999 to assess the self-care/self-efficacy and problem-solving/self-efficacy of caregivers. Steffen et al., revised the scale in 2002 to 18 items specific to caregivers of PwD (Steffen et al., 2002). The scale was adapted

into Turkish by Özgül and Akpınar Söylemez (2021). It has three subscales; SE-OR: self-efficacy in obtaining respite (first subscale, 5 items, min:0, max:500 point), SE-RBD: responding to disruptive behaviors (second subscale, 8 items, min:0, max:800 point), and SE-CUT: controlling upsetting thoughts (third subscale, 5 items, min:0, max:500 point). Each item in the scale assesses caregiver confidence related to each subscale. The scale is scored from “0” point (caregiver does not feel confident at all to do the given activity) to “100” points (caregiver feels absolutely confident to do that activity). Total scores range between 0–1800 points. The higher the score on the scale, the higher the self-confidence of the caregiver in the caregiving process. The Cronbach’s Alpha value of the Turkish version of the scale is 0.82 (Özgül & Akpınar Söylemez, 2021). The Cronbach’s alpha value of the scale in this study is 0.92.

Dementia Knowledge Assessment Scale (DKAS)

The Dementia Knowledge Assessment Scale (DKAS) was developed by Annear et al. (2015) to assess people’s knowledge of dementia (Annear et al., 2015). Akyol et al., adapted the scale into Turkish in 2021. DKAS is a 5-point Likert-type scale (True, Probably True, Don’t Know, False, Probably False) consisting of 25 items. For true statements, the respondent gets 2 points for the “true” option and 1 point for the “probably true” option. For false statements, the respondent gets 2 points for “false” option and 1 point for “probably false” option. The response “I don’t know” gets 0 points. Accordingly, the minimum and maximum scores of each item are 0 points and 2 points, respectively. The Turkish version of the scale consists of 17 items and total scores vary between 0 and 34 points. The higher the score, the higher the knowledge level the person holds about dementia. The Cronbach’s Alpha value of the Turkish version of the scale is 0.83 (Akyol et al., 2021). The Cronbach’s alpha value of the scale in this study is 0.74.

Revised Form of the Multidimensional Scale of Perceived Social Support (RFMSPSS)

The Multidimensional Scale of Perceived Social Support (MSPSS) is an easy-to-use, short scale that subjectively assesses the adequacy of social support from three sources (Zimet et al., 1988). The scale has three subscales: family, friends, and significant other. Eker et al., conducted the Turkish validity and reliability study of the Revised Form of the Multidimensional Scale of Perceived Social Support (RFMSPSS) in 2001. The scale consists of 12 items and each item is rated between 1 and 7 points (1: Absolutely No, 7: Absolutely Yes). Total scores range from 12 to 74 points. The higher the score on the scale, the higher the perceived social support level of the person. The Cronbach’s Alpha value of the Turkish version of the scale is 0.89 (Eker et al., 2000). The Cronbach’s Alpha value of the scale is 0.93 in this study.

Data analysis

IBM SPSS Statistics Premium Academic Pack-Concurrent User V 25 was used to carry out statistical analysis of the data. Number and percentage distributions of the descriptive data were used. Multiple regression analysis was applied to examine how the selected independent variables affected the RSCSE scores of the caregivers. Multivariate regression analysis was used to assess which factors (level of dementia knowledge and perceived social support) predict caregiving self-efficacy of caregivers of PwD. Sociodemographic characteristics (sex, age, education etc.) were adjusted. Independent variables (level of dementia knowledge and perceived social support) with a variance inflation factor (VIF)-a measure of multi-collinearity-less than 10 and a tolerance greater than 0.20 were included in the model. The significance level was accepted as 0.05.

Ethical Considerations

Written permission from the Neurology Department of University X Hospital and approval from Ethics Committee of X University (approval number:2022/05-04; date:09.02.2022) were obtained. The caregivers were informed about the aim and design of the study and their verbal and written consents were obtained.

Results

It was found that while 83 (81.4%) of the caregivers in the sample were female, 19 (18.6%) were male. The mean age of the participants was 55.29 ± 10 years and 57.8% were children of PwD (Table 1). A total of 52% of the patients were female, 66% had Alzheimer-type dementia, and 32.4% suffered from dementia for more than 5 years.

The SE-OR, SE-RBD, SE-CUT, and SE-total mean scores of the participants were 306.70 ± 178.83 (range:0-500), 515.55 ± 203.12 (range:0-800), 303.82 ± 155.06 (range:0-500), and 1125.89 ± 417.18 (range:0-1800), respectively. Their mean scores were 15.70 ± 6.06 (range:0-34) for DKAS and 52.72 ± 20.07 (range:12-74) for RFMSPSS. Table 2 shows the results of multiple regression analysis done within the scope of the study. The model which included the mean scores of RFMSPSS and DCAS accounted for 19.30% of the self-efficacy levels of the caregivers. When the variables were analyzed, it was found that the mean score of RFMSPSS predicted the level of self-efficacy in a statistically significant and positive manner ($\beta: 9.58, p=0.001$). This result showed that the perceived social support of the caregivers with PwD was an important predictor of their self-efficacy level. The mean score of DKAS predicted positively the level of RSCSE, but a statistically significant difference was not found ($\beta:1.58, p:0.801$). In other words, the higher the level of knowledge of the caregivers about dementia, its treatment and management, positively affected the self-efficacy level of caregivers.

Table 1. Descriptive characteristics of the family caregivers (n: 102).

	n	(%)
<i>Sex</i>		
Female	83	81.4
Male	19	18.6
<i>Educational status</i>		
Primary school	28	27.5
High school	29	28.4
University	45	44.1
<i>Relationship with the PwD</i>		
Spouse	28	27.5
Daughter/son	59	57.8
Others	15	14.7
<i>Working status</i>		
Employed	36	35.3
Unemployed	66	64.7
<i>Financial status</i>		
Income lower than expenses	38	37.3
Income equal to expenses	48	47.1
Income higher than expenses	16	15.6
<i>Caregiving period</i>		
Less than 1 year	6	5.9
1-5 years	66	64.7
6 years or more	30	29.4

$p < 0.05$; PwD: People with Dementia.

Table 2. Factors affecting the self-efficacy of caregivers: Multiple regression analysis ($n = 102$).

	Model	B	Std Error	β	t	p
SE-OR	DKAS	-.0222	2.927	-.008	-.076	.0940
	RFMSPSS	2.277	.884	.256	2.576	.011*
	Constant	190.149	73.861		2.574	.012*
SE-RBD	DKAS	.858	3.314	.026	.259	.796
	RFMSPSS	2.765	1.001	.273	2.762	.007*
	Constant	356.317	83.627		4.261	<.001*
SE-CUT	DKAS	.914	2.138	.036	.428	.670
	RFMSPSS	4.535	.646	.587	7.025	<.001*
	Constant	50.352	53.946		.933	.353
SE-Total	DKAS	1.589	6.283	.023	.253	.801
	RFMSPSS	9.588	1.898	.461	5.052	<.001
	Constant	595.40	158.572		3.755	<.001

SE-OR: ($R = 0.047$, $R^2 = 0.066$, $F = 3.505$, $p = 0.034$).

SE-RBD ($R = 0.072$, $R^2 = 0.054$, $F = 3.863$, $p = 0.024$).

SE-CUT ($R = 0.037$, $R^2 = 0.324$, $F = 25.196$, $p < 0.001$).

SE-Total ($R = 0.193$, $R^2 = 0.209$, $F = 13.077$, $p < 0.001$).

* $p < 0.05$, β : Beta, Std Error: Standard Error.

DKAS: Dementia Knowledge Assessment Scale.

SE-OR: self-efficacy in obtaining respite, SE-RBD: responding to disruptive behaviors, SE-CUT: controlling upsetting thoughts, SE-

Total: The Revised Scale For Caregiving Self-Efficacy.

RFMSPSS: Revised Form of the Multidimensional Scale of Perceived Social Support.

Discussion

The number of PwD is rising rapidly worldwide and thus the need for caregivers of these individuals is also increasing. One of the important components of care of PwD is the self-efficacy of their caregivers. The studies conducted with caregivers of PwD emphasized that the caregivers did not have the desired level of self-efficacy (Söylemez et al., 2023). In this study, after the evaluation made using the RSCSE, it was found that the family caregivers had a moderate level of self-efficacy. In the literature, Yang et al. (2019) and Leung et al. (2020) reported that the caregivers had a moderate level of self-efficacy which is compatible with the present study. Community health nurses can play a key role in providing care to PwD by supporting informal caregivers and increasing their self-efficacy.

One of the components of the concept of self-efficacy defined within the frame of the Social Cognitive Learning Theory developed by Albert Bandura is successful past experiences. If individuals have accomplished a skill in the past, their self-confidence, i.e., self-efficacy, would be higher when trying to accomplish that skill again. The first successful experience of the caregiver while providing care activities is important for subsequent care activities. Here, it is emphasized that it is important to identify the training needs of the caregiver before the first experience to elevate their level of knowledge (Bandura, 2002). Knowledge can empower the individual to accomplish the skill. In this study, the dementia knowledge of caregivers of PwD was evaluated using the DKAS. The multiple regression analysis showed that the mean score of DKAS predicted positively the level of self-efficacy, but there was no statistically significant difference. In their study, Tan et al. (2021) concluded that the dementia knowledge scale had a significant effect on the subscale of misconceptions about dementia and the subscale of responding to disruptive behaviors of RSCSE, and had a positive effect on the other subscales, but it was not statistically significant. Since the Turkish version of the DKAS has a unidimensional structure, it was not compared. In their study, Mason et al., emphasized that a low level of knowledge about dementia negatively affected the perception toward care and lowered the level of self-efficacy, and they also recommended that self-efficacy of caregivers could be improved through trainings (Mason et al., 2020). In a systematic review, Tang et al., reviewed the studies involving psychosocial interventions to improve the self-efficacy of caregivers and determined that improving the level of knowledge and skills for caregiving positively affected self-efficacy of caregivers (Tang & Chan, 2016). Community health nurses should regularly assess the knowledge of dementia of caregivers and implement any necessary educational initiatives.

Perceived social support level and self-efficacy are two significant concepts for psychosocial life of individuals that positively affect each other (Lee & Oh, 2020; Neneh, 2022). In this study, caregivers of PwD had a high level of perceived social support, which was an important predictor for the level of caregiving self-efficacy. When the studies in the literature are examined, their findings are compatible with the findings of the present study (Adashek & Subbiah, 2020; Au et al., 2009; Park et al., 2019; Tan et al., 2021; Tang & Chan, 2016). Perceived social support is an important factor for caregivers to allocate time for self-care and to avoid upsetting thoughts about care (thoughts about what they have missed in their lives after assuming the role of caregiver, thoughts that life treats them unfairly, etc.) and accordingly improves the self-efficacy of caregivers (Tan et al., 2021). A systematic review by Adashek and Subbiah (2020) emphasized that the perceived social support of caregivers had a positive effect on their level of well-being, quality of life and their level of self-efficacy. Accordingly, perceived social support is an important factor in elevating the self-efficacy levels of caregivers and crucial to provide the caregivers with both formal and familial help. Thus, elevating the level of caregiver self-efficacy may allow them to provide better care.

Given that self-efficacy is a multidimensional concept, the examination of the factors affecting caregiver self-efficacy can provide guidance in the planning of initiatives to improve self-efficacy. Accordingly, the present study examined the effect of the perceived social support and the knowledge level of dementia, on the self-efficacy of caregivers. For improving caregiving self-efficacy, knowledge of dementia and perceived social support of caregivers of PwD by community health nurses should be comprehensively evaluated. It is recommended to conduct further studies with larger samples from multiple centers. Qualitative studies can also be used to analyze the effect of knowledge of dementia and perceived social support on self-efficacy of caregivers.

Conclusion

The perceived social support of caregivers with PwD is an important predictor of the self-efficacy level of caregivers. In order to enhance improving the quality of the caregiving process, caregivers should be strengthened and therefore caregiving self-efficacy should be comprehensively evaluated. Community health nurses can integrate multiple activities into their practice and caregiving plans for caregivers of PwD, which can enable them to support them both formally and informally. Nurses should inform caregivers about dementia and how to manage it. Also, it is recommended that caregivers be aware of their social support systems and be educated about the significance of the involvement of all family members in the caregiving process.

Limitations

In this study, the sample was recruited via convenience sampling and the participants were purposefully selected. Also, the inclusion and exclusion criteria of the study did not include confounders such as the stage of the disease of PwD, the presence of comorbidities, the presence of another individual that the caregiver is responsible for taking care (for example, a child) that may affect the caregiver's self-efficacy level. Therefore, the results of this study may not be generalizable to all family caregivers of PwD in Turkey.

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Data availability statement

Data and supplementary material related to this article can be obtained from the corresponding author upon request.

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