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Feature Article

The effects of support groups on dementia caregivers: A mixed method study

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ABSTRACT

The aim of this qualitative and quantitative study was to understand the effects of support group interventions on the caregiving burden of individuals providing care for people with dementia. This study used the Caregiver Burden Inventory, and focus group interviews (18 caregivers), which were conducted using a semi-structured interview form. The initial study sample was 37 primary caregivers; however, the final analysis included 30 caregivers. The quantitative data were analyzed by paired sample *t*-test. The interviews being analyzed using content analysis. It was found that there was a significant decrease in the scores for total burden ($p = 0.049$), social burden ($p = 0.008$) and emotional burden ($p = 0.000$) after the intervention. The content analyze revealed three main themes (“having knowledge,” “calming down,” and “acceptance”). Overall, it was concluded that support groups are effective in reducing caregiver burden.

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Introduction

As the percentage of older people rises in many countries, there has been a commensurate rise in the number of people with dementia. In 2015, there were 46.8 million people with dementia in the world, with the number of older adults with dementia predicted to double every 20 years.¹ In line with these global figures, the number of people with dementia (PWD) is also increasing in Turkey. A study conducted in 2009 found that dementia prevalence in people aged 55 years and above was 8.4% which increased in parallel with age in Middle Anatolia.² In the study, which was conducted in Izmir (the city in which the present research was conducted), Keskinoglu, Yaka, Uçku, Yener, Kurt (2013) found that the percentage of dementia in individuals 65 years of age and older was 12.9%.³ Since that time, there have been no further prevalence studies in Turkey.

Dementia has long been recognized as a public health priority; when cognitive impairment is accompanied by disruptive and aggressive behavior and failing functional capacities, it becomes more difficult to care for PWD, which places greater burden on caregivers. Therefore, caregivers need appropriate support programs such as support group interventions.

Background

Dementia is a syndrome that results in progressive cognitive, functional and behavioral changes, all of which make home care difficult because the needs of PWD typically increase over time, with most eventually becoming fully reliant on the caregivers^{4,5}; therefore, caregiving can be an all-consuming job.

Turkish culture and society traditionally promotes strong family bonds and familial care for those in need; therefore, family care plays a significant role for people with dementia as many older adults with dementia are cared for at home.⁶ The Alzheimer's Association (2016) estimated that there were approximately 600,000 informal caregivers in Turkey. Generally, as institutional care is not yet culturally and socially acceptable in Turkey, the oldest daughter or son is expected to become the primary caregiver.⁶ Unfortunately, as there is not enough formalized structured home care service within the Turkish

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healthcare system, families receive little support when providing home care to PWD; therefore, caregivers are trapped between the cultural social pressure and their caregiving responsibilities and find giving care a burden because of the lack of support. Therefore, priority should be given to support for home care.

Because the caregiver burden increases the longer the caring continues,⁷ there is a need to develop and implement effective intervention strategies.⁸ In many studies conducted with caregiver's emphasis is put on the negative results of care such as the burden, depression, coping difficulties, and low quality of life.^{7,9–11} Therefore, developing and providing support services has become increasingly important. Interventions to assist PWD caregivers have been of interest for many years and various intervention programs have been implemented, such as psycho-education, technology-based interventions, multicomponent interventions, psychotherapy, and cognitive behavioral therapy.^{12–14} One of the important intervention for caregivers has been “support groups,” which is where people who are facing the same problems, share their experiences and provide mutual support through a planned sequence of actions.^{15–17} Support groups have been found to provide a comfortable environment for the sharing of emotions and anxieties, thereby decreasing the caregiver's burden and stress levels, alleviating depression, preventing feelings of social isolation, and increasing their coping skills, well-being, and quality of life.^{8,14,18–20} The World Alzheimer Report (2015) reported that strengthening support and services for PWD caregivers was vital in reducing caregiver burden, and pointed out that all healthcare professionals need to be aware of the needs of not only the patients but also the caregivers, who are of vital importance for the patient's continuing care process.²¹

There are many caregivers in Turkey; however, the services available to them are currently insufficient. Many studies have been conducted in other countries to evaluate the effectiveness of support groups on dementia caregivers.^{20,22,23} However, there has been little research in Turkey on the effectiveness of support groups, and studies that have been done have tended to only use quantitative study designs, with very few using mixed methods.

This study used mixed methods (qualitative and quantitative) to examine the effect of support groups on the caregivers' burden. The underlying assumption of mixed methods research is that it can more comprehensively address some research questions than using either quantitative or qualitative methods alone.²⁴ The integration of different types of data can generate insights into a research question, resulting in an enriched understanding of complex health research problems.²⁵ The purpose for using mixed methods in this study was to reinforce the results revealed in the quantitative scale with statements from the caregivers. In accordance with the aims of this study, the following hypothesis was tested: Support group intervention is effective in reducing the burden on PWD caregivers. The present study was also conducted to understand the Turkish caregivers' experiences of the support groups. Therefore, a qualitative design was appropriate as it enabled the researcher to understand the subjects' direct experiences.²⁶ It is hoped that the findings from this study can facilitate culture-oriented family care planning and cross-cultural comparisons.

Material and methods

Design and sample

A quasi-experimental quantitative and descriptive qualitative mixed method was used for the study. Treatment fidelity was evaluated based on study design, the training of interventionists, and the delivery and receipt of the interventions.²⁷ While there was strong support for all areas, there were some concerns about the receipt of the intervention, primarily because the characteristics of Turkish

culture restrict the free expression of emotions; therefore, subjects may not find it easy to express negative emotions and thoughts about their family PWD care burdens. To overcome these possible problems, a comfortable, supportive environment was provided so that the caregivers felt safe to participate in the discussion, and nursing researchers attended all sessions for treatment fidelity.

The sample consisted of primary caregivers who cared for PWD registered at dementia and geriatrics outpatient clinics of a university hospital for at least 4 h in a day over at least six months. The National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDS-ARDRA) criteria for AD diagnosis was used.²⁸ Subjects were recruited in two ways; research announcements were placed on the walls of outpatient clinics, and physicians working in these outpatient clinics invited caregivers to the support group. A meeting was held with forty-two volunteers to give detailed information about the research and to explain the study method. After the meeting, five caregivers said that they would be unable to complete the planned research period. Therefore, there were 37 caregivers willing to participate in the study; however, as only those who participated in at least seven of the sessions were included in the final analyses, seven further participants were excluded, and the quantitative data for the analyses obtained from 30 caregivers. The reasons for the missing data was that the subjects moved to another town ($n = 2$), the patient died ($n = 2$), there was a change in primary caregiver ($n = 2$), and there was an unwillingness to continue ($n = 1$). Eighteen caregivers participated in the qualitative section of the study; ten from the first group and eight from the second group volunteered to participate in the focus group interview, all of whom had participated in last sessions.

Data collection

The “Socio-demographic Features Questionnaire” and the “Caregiver Burden Inventory” (CBI) were used. The CBI is a 24-item self-rating questionnaire, the validity and reliability of which was examined by Küçükgüçlü, Esen, Yener (2009)²⁹ for a Turkish population where the Cronbach's alpha subscale values were found to be: 0.94 for time-dependency burden; 0.89 for developmental burden; 0.90 for physical burden; 0.76 for social burden; and 0.96 for emotional burden, with the whole inventory Cronbach's alpha value being 0.92; therefore the CBI showed very high internal consistency for a Turkish population. In this study, the inventory was applied twice; shortly before the start of the support group intervention and after the support group intervention. Two focus group interviews were held in the last session using a semi-structured group interview method. In the focus groups, two members of the research team asked open ended questions about the caregivers' experiences in the support group. The interview questions were as follows: “What have you experienced since the first day you participated in the support group meetings?”; “Would you please broadly summarize the whole process of the support group meetings?”; and “What did you gain from these meetings?” The support group sessions were held at the nursing faculty building in which two of the researchers worked. The interviews took place in a quiet room with no interruptions, lasted for 60–95 min, and were digitally audio recorded. The data were collected between September 2014, and June 2015.

Intervention

The participants were divided into two groups; the first group consisted of 19 PWD caregivers and the second group consisted of 18 PWD caregivers. Due to nonattendance, each session had approximately 11 individuals. Ten sessions were held in two week intervals, with each session lasting 2 h. All participants were encouraged to

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