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Experiences of Family Caregivers of People with Dementia during the COVID-19 Pandemic: A Qualitative Study

Demanslı Bireylere Bakım Veren Aile Üyelerinin COVID-19 Pandemisi Sürecindeki Deneyimleri: Niteliksel Bir Çalışma

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Abstract

Background: Given the rapid spread of the COVID-19 virus and an uncertain length of restrictions worldwide, it is extremely important to determine the experiences and needs of the caregivers of people with dementia (PwD).

Objectives: This study aimed to understand the experiences of family caregivers of PwD during the COVID-19 pandemic.

Methods: This study was a descriptive qualitative study using in-depth interviews. The study sample consisted of 29 caregivers of PwD from January to February 2021 in western of Turkey. The content analysis technique was used to analyze the data.

Results: A range of themes were derived from the data. The experiences of caregivers of PwD were grouped into two main salient themes: difficulties and funding solutions. The experiences of caregivers during the pandemic process varied. Also, most caregivers had multiple and serious problems.

Conclusion: This study highlights the challenges and needs for family caregivers of PwD during the COVID-19 pandemic. It is important to better tackle the rapid challenges of families living with dementia by using feasible and effective care strategies.

Keywords: Caregivers, COVID-19, Dementia, Qualitative Research.

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Öz

Giriş: COVID-19 virüsünün dünya çapında hızla yayılması ve belirsiz uzunluktaki kısıtlamalar göz önüne alındığında, demanslı bireylere bakım verenlerin deneyimlerini ve ihtiyaçlarını belirlemek son derece önemlidir.

Amaç: Bu çalışma, COVID-19 pandemisi sürecinde demanslı bireylere bakım veren aile üyelerinin deneyimlerini anlamayı amaçlamıştır.

Yöntem: Bu araştırma, derinlemesine görüşmelerin kullanıldığı betimsel nitel bir çalışmadır. Çalışma örneklemini Ocak-Şubat 2021 tarihleri arasında Türkiye'nin batısında bulunan demanslı bireylere bakım veren 29 birey oluşturmuştur. Verilerin çözümlenmesinde içerik analizi tekniği kullanılmıştır.

Bulgular: Verilerden bir dizi tema türetilmiştir. Demanslı bireye bakım verenlerin deneyimleri iki ana göze çarpan temada gruplandırılmıştır: Zorluklar ve çözüm bulma. Bakım verenlerin pandemi sürecinde yaşadıkları deneyimler çeşitlilik göstermiştir. Ayrıca, bakım verenlerin çoğunun birden fazla ve ciddi sorunları bulunmaktaydı.

Sonuç: Bu çalışma, demanslı bireylerin bakım veren aile üyelerinin COVID-19 pandemisi sürecindeki ihtiyaçları ve zorluklarını vurgulamaktadır. Uygulanabilir ve etkili bakım stratejileri kullanarak demanslı bireylerin ailelerinin sorunlarıyla hızla mücadele etmek önemlidir.

Anahtar Kelimeler: Bakım Verenler, COVID-19, Demans, Nitel Araştırma.

INTRODUCTION

The novel Coronavirus Disease 2019 (COVID-19) adversely affects millions of people worldwide, especially individuals aged 65 and over (World Health Organization, 2020). Almost all societies in the world are aging, and dementia is called the pandemic of aging societies (Fox and Petersen, 2013), with more than 50 million people with dementia (PwD) worldwide and a new case occurring every three seconds (Alzheimer's Disease International, 2019). The coexistence of dementia and the COVID-19 pandemic poses various problems for PwD and their family members. Dementia does not increase the risk of COVID-19, but PwD are more vulnerable to the virus because of their advanced age, comorbidities, and dementia-related behaviors (Wang et al., 2020). While informal caregivers of PwD struggle with many difficulties in the caregiving process, the pandemic and restrictions have exacerbated these problems and created new problems. One of the important problems recent studies have reported is that neuropsychiatric symptoms of dementia have worsened during the lockdown period because of the outbreak of COVID-19 (Cagnin et al., 2020; Giebel et al., 2021; Hwang et al., 2021; Vaitheswaran et al., 2020). These worsening behavioral symptoms may cause physical and cognitive decline of PwD and cause them to become more dependent on caregivers (Giebel et al., 2021). There has been an increase in stress and burden among caregivers during the COVID-19 pandemic (Alzheimer's Association, 2020). Caregivers have had difficulty accessing formal care, such as percutaneous endoscopic gastrostomy feeding, injections, home dialysis, colostomy and catheter care (Alzheimer Europe, 2020). Caregivers have to provide more care than before (Greenberg et al., 2020) for their relatives with reduced access to help and support (Vaitheswaran et al., 2020). In addition to all these problems encountered, they also worry about infecting their relatives with the COVID-19 virus and the fear of the absence of the paid caregiver (Cohen et al., 2020).

Given the rapid spread of the COVID-19 virus and an uncertain length of restrictions worldwide, it is extremely important to determine the experiences and needs of the caregivers of PwD who are biopsychosocially affected by the pandemic process. Scarce information is known about PwDs' and their caregivers' experiences during the pandemic (Greenberg et al., 2020). Alzheimer's Disease International and dementia experts emphasize that it is urgently important to support PwD and their caregivers worldwide (Wang et al., 2020). We believe that this qualitative study will provide some valuable insights into the experiences of caregivers of PwD.

Objectives of the Research

The aim of this study is to determine the caregiver experiences and to uncover how the pandemic, lockdown and restrictions may affect the disease management. The information gained from this study may be a guide to the planning of caregivers' support or psychoeducation programs.

Research Question

What was the experience of family caregivers with PwD during the COVID-19 pandemic?

MATERIAL AND METHODS

The type of the Research

This study was a descriptive qualitative study using in-depth interviews. Descriptive qualitative methods were used to uncover the perspectives of individuals and seek to understand the realities of events and experiences (Sandelowski, 2010). In this context, this study aimed to understand the experiences of family caregivers of PwD during the COVID-19 pandemic. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guideline, which provides guidance in reporting qualitative research, was used to report this research (Tong, Sainsbury and Craig, 2007).

The Place of the Research

This study was conducted between January and February 2021 in western of Turkey with 29 family caregivers of PwD.

The Universe/Sample of the Research

The study sample consisted of caregivers of PwD registered with the Alzheimer's Association of Izmir Branch. A purposeful sampling method was used. The target group consisted of caregivers who are 18 years of age or older, being a primary family caregivers of PwD and lived in same household, who caring for at least a year, who can use a telephone or smart phone, who speaks and understands Turkish language, who volunteered to participate in the study. Caregivers with had disability in hearing impairment were not included in the study.

Data Collection Instrument- Validity and Reliability Information

In-depth interviews with each caregiver were conducted by phone interviews using a demographics form and a semi-structured interview form developed by the investigators. The phone numbers of family caregivers who registered with the Alzheimer's Association of Izmir Branch were obtained from the archive file and listed according to including criteria. They were contacted by phone, the necessary information about the study was given, and they were asked whether they would like to participate in this study by the researcher. Verbal consent was obtained from the caregivers who agreed to participate in the study. Then, with the caregivers agreeing to participate, phone call appointments were determined whenever caregivers were available. All interviews were conducted during the daytime while the caregivers were at their homes. Permission was also obtained for the recording of the interviews. Prior to the interviews, individuals answered questions relating to their demographics and caregiving status: age, gender, marital status, education years, working status, having chronic diseases, their relationship to the relative with PwD, the relative's type of dementia, and duration of being a caregiver. In-depth interviews with each caregiver were conducted by phone using a semi-structured interview form. Three open-ended questions created by the researchers were used for the semi-structured interview: "Could you talk about your experiences while managing your relative's illness during the COVID-19 pandemic process?" "How do you think the COVID-19 pandemic affects your relative?" "How has the COVID-19 pandemic affected you?" These questions were asked of all caregivers. Additional questions were asked to obtain more detailed information according to the answers given in addition to these semi-structured questions. The data collected were in sufficient detail and responsive to the questions; therefore, no additional interviews were conducted with the same caregivers to verify the data.

Because of pandemic restrictions for in person interviews a phone conversation method was selected to collect data. Each interview lasted approximately 30 to 50 minutes. The interviews were conducted in Turkish because that was their native language. They were translated into English at the time of reporting the data. To achieve variability in data, caregivers with different genders, ages, types of dementia, and duration of being a caregiver were enrolled.

All interviews were managed by the fourth researcher. Interviews with the first and second caregivers were transcribed, and expert opinions on the interviews and interview questions were obtained from the second and third researchers. The researcher who conducted the interviews had previously conducted qualitative research and received lecture in this field. Researchers with expert opinions were very experienced in qualitative research, were giving lectures on this subject and had an educational background.

After the interviews, the records were transcribed by the first and fifth researchers. While the interviews were transcribed, the recordings were listened repeatedly. The study data reached the saturation point after interviewing 27 caregivers of PwD. Using a qualitative research method, data collection continues until the stage (saturation point) where concepts and processes that can answer the research question begin to repeat (Boddy, 2016). Then, the data collection was completed by interviewing two more caregivers to ensure data saturation was achieved. Accordingly, 29 family caregivers of PwD were included in the sample.

Evaluation of the Data

Demographics data of caregivers and PwD were analyzed as numbers and percentages. At the end of the interviews, the recordings were immediately transcribed and data were evaluated with an inductive method using content analysis. The data analysis process was carried out in six steps according to Braun and Clarke's (2006) thematic content analysis. The transcription of each interview was read several times to gain a deep understanding of the phenomenon. Words and short sentences having a meaning related to experiences were coded. A code list for each interview was created. Similarities and differences between the codes were determined. Codes related to each other were combined and categorized. Each category was named in accordance with its content. Finally, based on relationships between the categories, main themes were built. The second and third authors analyzed the data separately and agreed on the themes that best described the findings obtained in this study (Elo and Kyngäs, 2008).

Trustworthiness and Rigor

The trustworthiness of the data was achieved by adopting the criteria (credibility, transferability, consistency, confirmability, and application) defined by Colorafi and Evans (2016). The research team consisted of five geriatric nurses (one is male) experienced with family caregivers of dementia, of whom three had experience in qualitative methods. In addition, four had a PhD, and one was an MSc student. To ensure the credibility of this study, at the beginning of the interviews, the caregivers were explained that their experiences were valuable and that they could express their experiences freely. The interviews were continued until saturation of data was obtained and no new experience emerged. Also, as mentioned earlier, all the interviews were conducted by the fourth researcher, who was experienced in qualitative studies and took lectures on this subject at the postgraduate level. At the end of the interviews, the interviewer provided a brief summary of the interview and asked the caregivers to provide corrections or additions based on significant points. Credibility is ensured through participants' opinions, which were understood correctly by the interviewer in the findings section. To ensure the transferability of this study, purposive sampling was used, and variations in sampling were provided on qualifications, such as age, gender. The caregivers' statements were faithfully translated into English, and the original statements were preserved. For consistency, the purposeful sampling method was determined in line with the aim of this research. The researchers presented the data according to the emerging themes without adding comments (a thick description). All the interviews were conducted by the same researcher, who had no relationship with the participants and also had qualitative research experience using the semi-structured interview guide. Two preliminary interviews were held to review the interview questions, and these were evaluated by a professor (a geriatric nurse) who had experience in qualitative research. These interviews were included in the analysis. Interviews with caregivers continued for 30 to 50 minutes to ensure enough time for participants to thoughtfully respond to the interview questions. Although there were differences among interviewing times, sufficient answers were obtained. Interviews continued until the saturation point, where concepts and processes that could answer the research question began to repeat (Pandey and Patnaik, 2014). For dependability, the research interviewers provided consistency by using the same voice recording device and data collection forms for the interviews. Following each interview, the researcher made a summary of obtained data and asked all the participants whether they had any additional experiences to ensure that they understood them correctly. Two researchers analyzed obtained data individually. The codes were created and categorized into themes and subthemes. The Kappa test was used for the consistency evaluation of the themes obtained (Creswell and Poth, 2018). The kappa coefficient determined by the two independent raters was 1.00.

Ethical Aspect of the Research

Ethical approval was obtained for this study from the Ethics Committee of a university before this research was conducted (approval number: 2020/30-43, date: 21.12.2020), written permission (by e-mail) was received from the Alzheimer's Association of Izmir Branch (date: 23.11.2020) and also permission was obtained from the Turkish Ministry of Health, General Directorate of Health Services, Scientific Research Platform (date: 26.11.2020). The participants were informed about the aim of this study and were also informed that they could withdraw from this study. Verbal consent was obtained from the participants who volunteered to participate in this study. Interviews with caregivers of PwD were not shared with anyone, and their names remained anonymous, so anonymity and confidentiality were preserved.

RESULTS

Twenty-nine caregivers took part in this study. The majority of them were women 82.8%, with 5.69±3.46 mean years of caregiving period. The mean age of the PwD was 78.10±10.62, most of them had Alzheimer's disease 65.5% (Table 1).

The Main Themes and Subthemes

The data obtained from individual interviews revealed two main salient themes: difficulties and finding solutions.

Difficulties

Under the theme difficulties, there were eight subthemes: difficulty in sustaining protection measures, fear of being infected with and communicating the virus, difficulty in accessing healthcare services, decrease in social relations, decrease in support sources, the progress of dementia, economic burden and limitation in physical mobility.

Difficulty in sustaining protection measures

The caregivers stated that PwD had difficulty applying basic protection measures against the virus. They indicated that the people they gave care to had difficulty understanding and realizing the pandemic process and the necessity of restrictions.

He doesn't understand that he must to wear a mask. He gets furious and complaining about wearing a mask (P 21).

He throws his mask and glasses at the door even before leaving home (P 5).

As my husband refuses to wear a mask before going out, we are no longer able to take a walk with him (P 20).

Fear of being infected with and communicating the virus

Caregivers stated that they were afraid of being infected with the virus and transmitting this infection to the person they cared for.

I had dental problems but I didn't want to go to a dentist. It is because I feared that I could catch the virus and infect my husband (P 16).

I fear having physical contact with my visually impaired mother. As my mother forgets things, she always tries to hug us and we try to stop her. I have had a very hard time not being able to kiss my mother. When she got a cardiac pacemaker, I feared that she would die. I ignored all precautions and hugged her (P 26).

Difficulty in accessing healthcare services

The caregivers stated that the appointments were cancelled; they had difficulty getting a new appointment. Thus, they would not able to receive adequate healthcare services for their acute or chronic health problems because most hospitals became pandemic hospitals and they accepted few patients.

The hospital where my father's health follow-ups were is now a pandemic hospital; they have cancelled our appointments. We have had problems with arranging the medication doses and have to make our decisions ourselves (P 1).

Table 1. Characteristics of Caregivers of People with Dementia

Caregiver no	*Age*	*Gender*	*Marital Status*	*Education years*	*Working status*	*Having chronic disease*	*Relationship to relatives*	*Relatives' type of dementia*	*Caregiving period (years)*
1	53	Female	Married	15	Working	Yes	Child	VD	10
2	55	Female	Single	15	Retired	Yes	Child	PDD	2
3	86	Female	Married	11	Retired	Yes	Spouse	AD	2
4	73	Male	Married	15	Retired	Yes	Spouse	AD	10
5	72	Female	Married	5	Not working	Yes	Spouse	VD	10
6	57	Female	Single	15	Retired	No	Child	AD	6
7	55	Female	Married	15	Retired	Yes	Child	AD	9
8	63	Female	Single	5	Not working	Yes	Child	AD	5
9	48	Female	Married	5	Not working	Yes	Spouse	AD	7
10	55	Female	Married	17	Working	Yes	Spouse	AD	8
11	56	Female	Single	15	Working	Yes	Child	AD	8
12	74	Male	Married	15	Retired	Yes	Spouse	AD	4
13	71	Male	Married	15	Retired	No	Spouse	FTD	6
14	67	Female	Single	5	Retired	No	Child	AD	4
15	59	Female	Married	11	Retired	No	Child	AD	9
16	59	Female	Married	8	Not working	Yes	Spouse	FTD	7
17	68	Male	Married	15	Retired	No	Spouse	AD	4
18	71	Female	Married	11	Retired	Yes	Child	AD	6
19	59	Female	Single	15	Retired	Yes	Child	AD	13
20	60	Female	Married	15	Retired	Yes	Spouse	FTD	11
21	61	Female	Married	15	Not working	Yes	Spouse	AD	2
22	70	Female	Married	11	Retired	Yes	Child	AD	4
23	45	Female	Married	13	Not working	No	Child	AD	4
24	50	Female	Single	11	Retired	Yes	Child	VD	1
25	44	Female	Single	15	Working	No	Child	AD	1
26	49	Female	Single	15	Working	No	Child	FTD	1
27	74	Male	Married	15	Retired	Yes	Child	AD	1.5
28	61	Female	Single	5	Not working	Yes	Child	AD	7
29	65	Female	Married	15	Retired	Yes	Child	PDD	1

AD: Alzheimer's Disease, FTD: Frontotemporal Dementia, PDD: Parkinson's Disease Dementia, VD: Vascular Dementia

The most important problem I have faced in the pandemic process is being unable to get an appointment from the hospitals. My mother has chronic illnesses and she needs to be followed. However, it has not been possible to get an appointment via the electronic appointment systems of the hospitals (P 2).

Decrease in social relations

The caregivers stated that their present social relations remarkably decreased due to the restrictions; they had difficulty carrying out most activities, could not see their friends and family members and they felt lonely.

We have no social life. My friends are afraid to contact me, and I am also with them. This affects my psychology and so caregiving process negatively. It is because sometimes I have no energy left in me (P 27).

As I had assumed responsibility for my mother before the pandemic, my social circle decreased a lot. It has decreased even further in the pandemic. In addition, the activities I do with my mother have decreased, as well. We are no longer able to go out, *go to a restaurant, and walk on the beach (P 19).*

Decrease in support sources

During the pandemic, families stated that they had to dismiss paid caregivers to reduce the possibility of being infected, and this situation left them without help. Also, they indicated that other family members did not support them due to restrictions. This left them unaided and made them have difficulty in caregiving.

As our paid caregiver had to change the three vehicles to come to us, we dismissed her with the fear of COVID-19. I had to take the whole responsibility (P 18).

My elder sister used to come to us and help me on certain days. As we do not see each other now, she just calls us. I want my sister to be with me, but she cannot (P 25).

The progress of dementia

Some caregivers thought that lack of cognitive stimulation and decreased physical activity for the PwD contributed to the progression of the dementia process because the people they gave care to were always at home due to the restrictions.

The disease has remarkably progressed in the last six months. We have been completely upside down since March. My mother was never like this. For example, she used to paint, puzzles and participate in activities in the weekly meeting of the Alzheimer's Association. However, now she can do none of them. She is interested in nothing (P 18).

I believe the disease has progressed. I mean, things would be different if he were able to go out and maybe keep in touch with people. Given that he has been at home without going out for months has probably accelerated the process (P 25).

Our neighbors liked my mother a lot. We used to have a lot of guests. She would be happy when people came for a visit. As no one has visited us in this process. Loneliness has probably worsened her condition (P 28).

Economic burden

The caregivers stated that they went to private hospitals when they had new health problems during the pandemic because the public hospitals provided limited service or because they had a fear of being infected. However, this brought an economic burden.

As we cannot go to our regular hospital, we went to a private hospital and did all the tests there. They took good care of us, but we paid a lot of money, which was difficult for us (P 19).

When my mother got worse, we had to go to a private hospital. When we got discharged, we had to pay a lot of money (P 6).

Limitation in physical mobility

The caregivers stated that there was a decrease in physical mobility of both themselves and the PwD they cared for due to the pandemic restrictions. This condition led to many problems, such as constipation, weight gain, and difficulty in sustaining routines.

Our greatest problem is that we cannot go out and take a walk. As we don't walk, I have had constipation and my wife has had uneasiness (P 4).

As we cannot go out, we tried to walk inside the house. But it didn't work out. He has gradually taken a turn for the worse. Now we ride him in his wheelchair inside the house. If there was no COVID-19 and he was able to take a walk outside, he would not be atrocious (P 7).

My muscle pain has increased. It is because I used to walk every day. We cannot walk anymore (P 27).

I had lost 16 kilograms before the pandemic. I have regained the 16 kilograms due to immobility (P 24).

Finding Solutions

Almost all family caregivers stated that they had difficulty giving care to their relatives and tried to find different solutions in the pandemic process. Some caregivers tried receiving online support for care of their family member from social media and Alzheimer's Associations. Some of them received phone support from healthcare professionals they were acquainted with (doctor, nurse, pharmacist) or doctors who had followed their family member before the pandemic when they faced a health problem. Some caregivers who were afraid of being infected with the virus moved to summer houses outside the city where fewer people live and tried to reduce their contact with the outside world by doing some of their shopping online.

As we cannot go to the drugstore, we got our medicine sent by cargo (P 4).

When we had problems, I tried to manage them by talking to our doctor on the phone (P 12).

When I didn't know what to do, I talked to my friends, who are also caregivers. We exchanged advice. The advice has helped a lot (P 15).

As we cannot go out, we have begun our exercises at home. I have a bike and a treadmill at home. Now, we do it together (P 13).

We left the house in Izmir (city center) and began to live in the summer house because there were too many patients with COVID-19 in the city (P 14).

DISCUSSION

The COVID-19 outbreak has significantly disrupted everyday life worldwide. Caregivers who were responsible for PwD also had many challenges before the pandemic. Understanding the additional difficulties, experiences, and needs of the caregivers of PwD during the pandemic, is fundamental to helping them. This study was conducted to reveal the experiences of caregivers of PwD during the COVID-19 pandemic and lockdown process. Two themes were observed: difficulties and finding solutions.

Theme 1: Difficulties

The literature has demonstrated that caregivers of PwD have many difficulties that this situation is including needing health information for care of PwD, insufficient access to health and support services, and self-care (Denham et al., 2020; Zhang et al., 2021). Although restrictions slow the spread of the COVID-19 virus, they also reduce formal services for caregivers, which may result in unmet or under met needs (Savla et al., 2021). Unmet needs are common in caregivers of PwD and this situation is important in terms of adverse consequences (Zhang et al., 2021), such as reduced quality of life of the PwD and their caregivers (Janssen et al., 2020; Kerpershoek et al., 2018; Monin, Jorgensen and Vroomen, 2020), increased caregiver burden (Zwingmann et al., 2019).

In our study, caregivers stated that PwD had difficulties applying basic protection measures (e.g., physical distancing of at least 1.5 m, wearing a face mask, and eye protection from the COVID-19 virus). Unfortunately, PwD have difficulties understanding the risk of COVID-19 and taking precautions against disease. Consistent with our findings, Kobayashi et al., (2020) stated that 74.5% of the PwD did not wear face masks properly by themselves. Additionally, caregivers had to deal with the fear of being infected and protect the health of family members. Hwang et al., (2021) stated that more than 70% of caregivers expressed concerns about spreading the COVID-19 illness to their relatives, which is compatible with our findings. Vaitheswaran et al., (2020) also stated that caregivers worry about protecting their relatives with dementia and themselves from the COVID-19 virus. Having dementia is not thought to increase the risk of getting the COVID-19 virus, but the risk of being adversely affected is higher because most of the PwD are elderly and have comorbid diseases (Centers for Disease Control and Prevention, 2020; Mok et al., 2020).

In this study, caregivers of PwD reported that they could not get an appointment for routine health maintenance for the PwD and had difficulties reaching hospitals due to pandemic restrictions. They worried about what to do in case of new health or behavioral problems in the family member they cared for. These results are similar to research results in the literature (Vaitheswaran et al., 2020; Zhang et al., 2021; Kelland, 2020; Park et al., 2018). During the pandemic, caregivers of PwD are providing continuous care with little or no assistance from health care services (Kelland, 2020). In a study conducted by Vaitheswaran et al., (2020), the results showed that caregivers worried about a new health problem developing for their relatives and having to go to hospitals during the pandemic lockdown. Caregivers also stated that they had problems with the regulation of medication dosage. Many caregivers' needs were to consult dementia specialists to ask how to manage behavioral problems. A quantitative study found that 65.1% of caregivers of PwD stated unmet needs for caring for someone (Zhang et al., 2021). Providing support for managing dementia is critical to improving caregiving outcomes (Park et al., 2018). Alzheimer's Disease International and dementia experts state that PwD and their caregivers should be supported urgently worldwide.

The progression of the disease process day by day and the increase in the PwD' care needs cause most caregivers to leave their jobs or to disrupt their social and family relationships. Thus, caregivers of PwD often experience deterioration in social relations (Senturk Gonen and Kucukguclu, 2021). Caregivers of PwD have various needs for their own self-care. Caregivers noted that due to the pandemic, they had difficulty performing many activities and were unable to meet friends and family members. Missing social engagement led to increased feelings of isolation (Tuijt et al., 2021). The social relations of caregivers, which are important for them to protect their psychosocial health in this difficult process, have been adversely affected by the pandemic.

With the onset of the pandemic and the restrictions, many caregivers are unable to access support resources. Caregivers were providing care by having both formal and informal support networks before the pandemic process. Many caregivers have had to provide care alone due to various reasons during the pandemic process. Some caregivers dismissed formal caregivers and moved away from the city to reduce their chances of being infected with the COVID-19 virus. However, this adversely affected them because they perceived more loneliness and could not receive support from other members of the family. Savla et al., (2021) state that 32% of caregivers of PwD were not receiving enough support from their families. Canevelli et al. (2020) also noted that caregivers complained of poor support at the most difficult moments, resulting in their experiencing loneliness and isolation in 54% of cases (Savla et al., 2021). In this study, caregivers stated that they could only talk to their relatives on the phone or the internet, but they did not find this sufficient. Lacking informal support puts caregivers at greater risk of caregiver' role overload (Savla et al., 2021). A study observed that caregivers of PwD, more than half (61.4%), are experiencing moderate to severe loneliness (Victor et al., 2021). In the pandemic, caregivers are more likely to be juggling multiple roles. In this process, additional chores were added to existing workloads. A study reported that some caregivers needed someone for household chores, such as laundry and cooking, and to engage their relatives with dementia following the lockdown (Vaitheswaran et al., 2020). Loneliness and social isolation also significantly affect mental and physical well-being for both PwD and their caregivers. It is recommended that PwD and their caregivers remain social by paying attention to physical distancing requirements (Greenberg, Wallick and Brown, 2020). Alzheimer Europe (2020) emphasizes that caregivers of individuals with dementia should be given special attention by healthcare professionals.

This study determined that PwD were adversely affected during COVID-19 because of restrictions on their cognitive stimulation and their physical activities were greatly reduced, and these may contribute to the progression of the disease. Worsening symptoms may be due to a lack of cognitive stimulation and disrupted daily routines (Giebel et al., 2021; Keng et al., 2020). Behavioral symptoms may also result from mood changes and deterioration of cognitive functions (Volicer, 2018). Even people with advanced-stage dementia, who cannot fully understand the current situation, may notice the stress and mood changes caused by COVID-19 through the individuals and media around them (Alzheimer's Association, 2020; Alzheimer Europe, 2020). Increased behavioral symptoms may stem from restrictions and not being allowed outside (Giebel et al., 2021). A study reported that most participants reported the presence of behavioral symptoms in their relatives with dementia. Especially, the start of the pandemic, such as becoming upset about wearing a facemask, watching the news and becoming anxious, sleep disturbances and being disruptive to others at home (Vaitheswaran et al., 2020). This study has revealed that with the pandemic, PwD have problems maintaining their daily routines. Caregivers need to be creative in trying to maintain the routines of PwD to reduce the distress that can accompany cognitive decline and behavioral symptoms, where most of their time is spent in their homes with PwD (Greenberg, Wallick and Brown, 2020).

In this study, caregivers of PwD expressed their problems with financial issues. Since many public hospitals are pandemic hospitals, caregivers who are worried about getting infected with the COVID-19 virus have preferred hospitals that are relatively quiet and have less patient capacity. Caregivers stated that this was an additional burden for them. PwD and their caregivers have to deal with many financial problems (Oba et al., 2021). With the pandemic, many caregivers have had to start working from home and have economic concerns due to restrictions (Vaitheswaran et al., 2020). Financial difficulties caused by many reasons were commonly reported, with 44.1% worried about financial problems. It is important as it causes anxiety in caregivers of individuals with dementia (Hwang et al., 2021).

This study also revealed that during the pandemic process, PwD became less mobile. Vaitheswaran et al., (2020) stated that many PwD cannot go outdoors and engage in activities, which is consistent with the findings we obtained in this study. A study highlighted a decrease in mobility in PwD of 45% (Carcavilla et al., 2021). Insufficient physical activity may lead to various health problems for all age groups. Most of the PwD and their caregivers are older people living with chronic diseases. It is thought that physical inactivity may have many negative effects on the health of both PwD and their caregivers.

Theme 2: Findings solutions

Caregivers of PwD noted that there are many changes in the lives of both their own and the family members they care for due to the pandemic. This study revealed that almost all the caregivers of PwD stated that they tried to adapt to the pandemic and were looking for their own solutions. Caregivers tried to obtain information from online platforms (television, Zoom meetings, online congresses) and some of them, who were lucky, could consult with doctors on the phone. Vaitheswaran et al., (2020) stated that caregivers would like to consult healthcare professionals by phone call or video call. However, some of them stated that they did not use smartphones and computers. The vast majority of caregivers of PwD were older people who were not familiar with technology (Tsapanou et al., 2021). Health professionals are aware of the difficulty of technology use for this population and believe that psychosocial support should be provided in addition to protection from the pandemic.

The strength is that this current study is the first to our knowledge that understanding the experiences of family caregivers of PwD in Turkey during the COVID-19 pandemic. Drawing on the findings obtained in this study, the COVID-19 pandemic has affected caregivers of PwD in many ways. Caregivers encountered challenges in caring for patients in this unprecedented pandemic. Caregivers are caught between the needs of themselves and the needs of PwD they care for. Due to the pandemic and restrictions, it has been challenging for them to obtain formal and informal support. Caregivers also worry about acquiring the COVID-19 virus and spreading the disease to their relatives. The additional burden of the pandemic was added to existing burdens, such as additional caregiving duties and financial problems. These findings are essential for understanding the experiences of caregivers of PwD. Understanding the experiences of the caregivers of PwD in Turkey during the COVID-19 pandemic may help determine the content of the country-specific caregivers' support or psychoeducation programs. Comparative studies can be conducted on the experiences and needs of caregivers with PwD in different cultures. This way, culturally appropriate support programs can be developed for caregivers of PwD in other cultures.

Limitations

One of the limitations of the study is that the data were collected only from caregivers of PwD who were registered with the Alzheimer's Association of Izmir Branch. A minor concern in this study was that interviews with caregivers who agreed to participate in this study were conducted on the phone. Therefore, their facial expressions and reactions could not be evaluated.

IMPLICATION FOR NURSING PRACTICE

The mental and physical health of family caregivers is extremely critical to maintaining care for PwD. The COVID-19 pandemic and its restrictions may prevent both PwD and their caregivers from maintaining basic routines that improve their mental and physical health. Nurses should evaluate not only the needs of PwD but also their caregivers. Community resources are significant sources of support for dementia caregivers. Given the increasing support needs of caregivers during the pandemic, it is extremely crucial to be informed about this issue. Access to healthcare services can be facilitated with policy changes. However, this can be challenging to achieve. The support that caregivers need can be provided by video or phone calls. This may help provide the necessary support for some caregivers, but we should note that it does not apply to everyone. Providing health services as technologically as possible and maintaining existing services by maintaining personal protection measures and social distance are also important for caregivers who have an inability to use technology. Future research could focus on the feasibility of technology-based psychoeducation interventions for caregivers to provide the information they need during the pandemic and, in the future to provide support to better understand and manage the disease.

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