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UNMET REQUIREMENTS: CAREGIVERS OF PATIENTS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIA UNDERGOİIG SURGERY IN THE COVID-19 PANDEMIC*

KARŞILANMAYAN GEREKSİNİMLER: PANDEMİ DÖNEMİNDE AMELİYAT OLAN ALZHEİMER VE İLİŞKİLİ DEMANS HASTA YAKINLARI

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ABSTRACT

The study used a qualitative design to examine the experiences of caregivers of patients Alzheimer's disease and related dementia who underwent surgery during the COVID-19 pandemic. The sample of the study consisted of 21 caregivers who met the inclusion criteria of the study. The data were obtained through in-depth interviews via mobile phone. The data were analyzed by following Collazzi's seven-stage method.11 sub-themes and 3 themes were created: difficulties experienced during the pandemic period, emotions experienced during the pandemic period, and coping strategies during the pandemic period. It has been shown that caregivers, who have a high burden of care even in normal times, faced many difficulties and were negatively affected emotionally due to the surgery of their patients during the pandemic period. The nurse should know the daily life, social supports, social conditions and ways of coping with the problems of the caregiver of the elderly person with Alzheimer's disease and related dementia. If caregivers' experiences, social supports, social conditions and ways of coping with the problems and difficulties are known, home care strategies can be developed to manage these difficulties.

Keywords: Alzheimer dementia, Caregivers, Surgery, COVID-19, Life experiences

ÖZ

Çalışma, COVID-19 pandemisi sırasında ameliyat olan Alzheimer hastalığı ve buna bağlı Demans hastalarının bakım vericilerinin deneyimlerini incelemek için nitel olarak yapıldı.Araştırmanın örneklemini, dahil edilme kriterlerine uyan 21 bakım verici oluşturdu. Veriler, cep telefonu aracılığıyla derinlemesine bireysel görüşme ile toplandı.Veriler Collazzi'nin yedi aşamalı yöntemi izlenerek analiz edildi. Pandemi döneminde yaşanan zorluklar, pandemi döneminde yaşanan duygular ve pandemi döneminde baş etme stratejileri olmak üzere 3 tema ve 11 alt tema oluşturuldu.Normal zamanlarda dahi bakım yükü yüksek olan bu bakım vericiler, pandemi döneminde hastalarının ameliyat olması nedeniyle birçok zorlukla karşılaşmış ve duygusal olarak olumsuz etkilenmiştir.Hemşire, Alzheimer hastalığı ve buna bağlı Demans hastalarının bakım vericilerinin günlük yaşamını, sosyal desteklerini, sosyal koşullarını ve sorunlarla baş etme yollarını bilmelidir. Bakım verenlerin deneyimleri, sosyal destekleri, sosyal koşulları, sorunlarla baş etme yolları ve yaşadıkları güçlükler bilinirse, bu güçlükleri yönetmek için evde bakım stratejileri geliştirilebilir.

Anahtar kelimeler: Alzheimer demansı, Bakım vericiler, Cerrahi, COVID-19, yaşam deneyimleri

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INTRODUCTION

Severe acute respiratory syndrome coronavirus-19 (COVID-19) is a systemic disease seen worldwide (1).The COVID-19 virus has affected the elderly population more. The weakness of the immune system of the elderly population increases the possibility of contracting the COVID-19 virus (2,3).In the literature, it has been reported that the majority of deaths caused by COVID-19 are people over the age of 65,(4) and these people have an underlying health problems such as diabetes, hypertension, heart disease (2,5).

One of the most common problems faced by the elderly population is Alzheimer's disease and related dementia (ADRD). Worldwide, the number of patients with ADRD is more than 50 million. This number is increasing day-by-day (3). It has become more difficult to care for patients with ADRD during the pandemic period. Social distancing, isolation rules, and hygiene have become even more important within the scope of COVID-19 measures, making the adaptation process of patients with ADRD difficult. Individuals with ADRD may ignore protective measures such as hand hygiene, use of masks, and social distance. These individuals may forget the precautions to be taken. This may increase the burden of caregivers (6,7,8).

While the care of the patient with ADRD is complex even in normal times, the caregivers of patients who have to be hospitalized during the pandemic may be adversely affected physiologically, psychologically and socially. In a study conducted before the pandemic, the caregivers of the elderly with ADRD stated that the cognitive functions of their patients worsened during the hospitalization process and that the health personnel to care for the elderly with cognitive impairment were not qualified (9). In a study conducted with caregivers of elderly patients with cognitive impairment who underwent hip surgery, it was stated that caregivers experienced severe stress, their daily lives were disrupted, and they had to cope with more complex chaotic situations (10).

It is important that patients with ADRD and who have to undergo surgery should be protected from possible complications before, during, and after surgery in the pandemic period (11).Elderly individuals undergoing surgical intervention, more impairments in consciousness and cognitive level are observed compared to other age groups (12), because ADRD patients often have less mobility and poor self-care skills, which increases post-operative complications such as surgical site infection, urinary tract infection, and respiratory problems and requires caregivers (13). In this regard, caregivers and health personnel have a great responsibility because elderly patients have more consciousness changes due to surgery and its' complications (10).

Living at home and social isolation after surgery increase the care needs of these individuals. Isolation measures taken by caregivers are not understood by individuals with ADRD (6,7,8). Neuropsychiatric symptoms of ADRD patients make it difficult to maintain isolation and protect against COVID-19 (14).

Caregivers of ADRD patients during the pandemic were also adversely affected (15). In a qualitative study, caregivers emphasized that individuals with dementia had difficulty in complying with social isolation rules and were worried that they and their relatives would be infected. In addition, it was stated that caregivers were also affected by isolation and negatively affected psychologically (16).In another study, it was determined that neuropsychiatric symptoms such as despair, anxiety, and depression were observed in caregivers (17).Despite the limited number of studies examining the problems experienced by the caregivers of ADRD patients during the pandemic period, (16,17) no studies have been found on the adaptation and difficulties of caregivers ADRD patients who underwent surgery during the pandemic period. Therefore, this study was conducted qualitatively to examine the experiences of caregivers of ADRD patients who underwent surgery during the COVID-19 pandemic.

METHOD

Design

The study used a qualitative design to examine the experiences of caregivers of patients with ADRD who underwent surgery during the COVID-19 pandemic.

Participants

The COVID-19 pandemic has adversely affected the conduct of all clinical trials, and this has prompted researchers to come up with new solutions (18).

The universe of the research consists of all patients' caregivers in the "Relatives of patients with Dementia and Alzheimer's" group on facebook in Turkey. The sample of the study consisted of caregivers who accepted to participate in the study and met the inclusion criteria. Inclusion criteria for the study were as follows;1- Caregivers of patients who are included in the "Relatives of patients with Dementia and Alzheimer's" group on facebook, 2- Those who live with an ADRD patient and give primary care to the patient,3- Caregivers who have had a patient who had undergone surgery in the last 6 months, 4- consists of caregivers aged 18 and over.

Purposive sampling method was used. Caregivers of the patients who had a post in the face book group in order to seek information about the post-surgical process were asked whether they would like to participate in the study and informed about the study via private message. Telephone numbers were requested from individuals who agreed to participate in the study, and interviews were conducted via telephone. The researchers contacted 21 caregivers who met the inclusion criteria in the facebook group between November- December 2021. The study was completed with 21 caregivers when the statements obtained from the interviews were repeated and data saturation was reached. In the literature, it is stated that 12 people are sufficient to reach data saturation in qualitative studies (19) and saturation is achieved when the same codes start to appear (20). Since both these criteria were met, the study was completed with 21 people.

Data collection

Data were collected using an introductory information form and a semi-structured interview form. The introductory information form contains questions such as the ADRD patient's gender, age, type of surgery, duration of the disease. Also the introductory information form contain questions such as caregiver's age, gender, level of closeness to the patient, marital status, education level, etc.

The semi-structured interview form was developed by the authors after reviewing the relevant literature (16) and consisted of six open-ended questions (Table I).

Table I. Semi-structured interview questions

1. How has the pandemic period affected your care for ADRD patients?
2. What are the difficulties you experience while caring for ADRD patients during the pandemic period?
3. How did you cope with the difficulties you experienced while caring for ADRD patients during the pandemic period?
4. What are the difficulties you experience during the surgery of ADRD patient during the pandemic period?
5. How did the surgical process of the ADRD patient affect your compliance with the pandemic rules?
6. Have you encountered any problems after surgery during the pandemic period? What problems did you encounter? How did you deal with these problems?

The researchers analyzed the posts of caregivers of ADRD patients who had undergone surgery during the pandemic and reached these caregivers in the face book group. Interviews were conducted by the researcher, who is experienced in qualitative studies, by mobile phone. The interviews were audio-recorded with the consent of the participants. The interviews lasted an average of 30-45 minutes. Incomprehensible questions and answers were repeated.

Data Analysis

Data were analyzed using Colaizzi's seven-step data analysis method (21). 1- In the first stage, the audio recordings were transcribed word for word on the computer. 2- All written documents were read to more than once by two researchers and the important parts were underlined. 3- Meanings are formed from important expressions. 4- The meanings were grouped and as result, themes and sub-themes were formed. 5- All created themes and sub-themes were integrated with the experiences of the patient’s caregivers.6-A basic framework of caregivers' experiences has been established. 7- Finally the participants were asked whether they reflected what they wanted to say by summarizing the documents obtained at the end of the interview. All participants confirmed the essence of the phenomenon. In addition, the Consolidated Criteria for Reporting Qualitative Research checklist was followed during the study (19).

Validity and reliability

The reliability of the data was determined based on the strategies by Jiggins Colorafi and Evans (2016) (22).These strategies are confirmability, transferability, consistency, and reliability. For confirmability, the data were stored in the computer and analyzed by two independent researchers. For transferability, interviews continued until data saturation was reached. Besides, sample selection, participant characteristics and how the study was conducted were explained in detail to ensure transferability. For consistency, all interviews were audio-recorded by the same researcher, with questions from all participants in the same order. In order to ensure the reliability of the research, expert opinion was sought to confirm whether the sub-themes given under the reached conceptual theme represented the aforementioned theme. It was agreed by two experts who are experienced in qualitative study that the sub-themes given under the theme represent the mentioned conceptual category. Transcripts were not given to the experts, and they were only asked to match the themes and sub-themes.

The fact that the researcher who conducted the interview received training on qualitative research and was also a specialist psychiatric nurse ensured the sustainability of effective communication and interviews with the participants.

Ethical Considerations

Before starting the study, approval was obtained from the Erciyes University Social and Human Sciences ethics committee (Decision number: 2021/400), and verbal informed consent was obtained from the caregivers. The names of the participants were kept confidential and the codes (P1, P2, P3…) were given.

RESULTS

A total of 21 ADRD patients’ caregivers participated in the study. The demographic characteristics of the patients are presented in Table II. It was found that the

Table II. Demographic information of the patients (n=21)

Demographic Variable		n	%
Gender			
Female		16	76.2
Male		5	23.8
Age (Mean ±SD (min-max))	75.28±12.06 (42-89)		
Type of surgery			
PEG (percutaneous endoscopic gastrostomy)		13	61.9
PEG+ileostomy		2	9.5
PEG+tracheostomy		2	9.5
Hernia surgery		1	4.8
Arthroscopic surgery		1	4.8
Total hip replacement		2	9.5
Duration of ADRD (Mean ±SD (min-max))	8.04±3.05 (1-13)		
Type of ADRD			
Alzheimer's disease		11	52.4
Vascular dementia		2	9.5
Frontotemporal dementia		7	33.4
Dementia including Parkinson's disease		1	4.7
COVID-19 transmission status			
Yes		2	9.5
No		19	90.5

majority of the patients were female, the mean age was 75.28±12.06 years, and 61.9% had undergone PEG operation. The mean duration of ADRD was found to be 8.04±3.05 years. It was determined that the disease type in 52.4% of the patients was Alzheimer's disease.

Demographic information of caregivers is given in Table III. It was determined that the majority of the caregivers were female, the mean age was 54.28±10.34 years, and 42.8% of them were patients' daughters.

As a result of the study, 11 sub-themes and 3 themes were created: difficulties experienced during the pandemic period, emotions experienced during the pandemic period, and coping strategies during the pandemic period (Table IV).

Theme 1: Challenges during the pandemic

Caregivers stated that their costs increased, could not receive social support, experienced an increase in the symptoms of the ADRD, complications developed after the surgery, had difficulty in getting treatment, and had difficulty in complying with the pandemic rules. In addition, dementia symptoms made it difficult for the patient and caregivers to adapt to the pandemic process and caused them to feel more tired.

Subtheme 1. Increasing cost (n:3)

Caregivers stated that they do not want to enter the crowd during the pandemic period because they fear the risk of contamination. The majority of caregivers who had to go to the hospital during the pandemic period had to hire a private ambulance or taxi for their patients because of the fear of contamination.

> P1: "*We were afraid of infection due to the pandemic, and because we did not have a car, it was very difficult for us to go by taxi.*"
>
> P2: *"We hired a private ambulance. It is quite difficult to find in our city. We brought an oxygen ambulance from Izmir. It was quite costly."*

Table III. Demographic information of the caregivers (n=21)

Demographic Variable		n	%
Gender			
Female		15	71.5
Male		6	28.5
Age (Mean ±SD (min-max))	54.28±10.34 (28-76)		
The level of closeness			
Daughter		9	42.9
Bride		2	9.6
Partner		3	14.3
Son		4	18.9
Mother		1	4.7
Sister		2	9.6
Marital Status			
Married		11	52.4
Single		10	47.6
Occupation			
Housewife		9	42.9
Retired		5	23.9
Officer		3	14.2
Pharmacist		1	4.9
Worker		3	14.2
Nurse		1	4.9
Educational Status			
University		9	42.8
High school		9	42.8
Middle school		3	14.4

Table. IV. Schematic view of the experiences of caregivers (n=21)

Themes	Sub-themes
Theme 1: Challenges during the pandemic	● Increasing cost ● Social isolation and lack of support ● Difficulty in getting treatment ● Increase in symptoms of the ADRD ● Post-operative complications ● Non-compliance with pandemic rules during the surgery process
Theme 2: Emotions during the pandemic	● Fear of COVID-19 transmission ● Anxiety and Despair
Theme 3: Coping skills of caregivers during the pandemic period	● Spending time together and getting support from relatives ● Spirituality ● Inability to cope and psychiatric support

> P9: *"We didn't get on buses or trains. We brought the patient to the hospital in a private vehicle, of course, that had a cost."*

Subtheme 2. Social isolation and lack of support (n:14)

Caregivers stated that they could not leave the house because they were afraid of the risk of contamination, and their patients and they could not receive social support. They stated that they did not take anyone into the house because they did not know whether people who could come from outside had a virus or not. It was determined that this situation disrupted their social relations and caused a lack of support.

> P2: *"This care can never be given alone. We did not take anyone home. I didn't go out into the street."*
>
> P12: *"I can't leave the patient to anyone. Psychological I guess. I can't trust anyone because the patient will get an infection."*
>
> P20: *"The pandemic has made us very lonely. Not being able to meet with anyone has caused a lack of support and our relationships have dwindled."*

Subtheme 3. Difficulty in getting treatment (n:6)

Caregivers stated that they had difficulty in receiving treatment before and during the surgery due to the risk of contamination. Some of the caregivers stated that the home care unit did not follow the patient at home during the pandemic period. The vast majority of caregivers reported that they did not go to the hospital in non-emergency situations such as physical therapy, hindering their control, and this situation worsened the prognosis of the patients.

> P3:" Before *the pandemic, we were calling the home care doctor every month. We had to take a break from him."*
>
> P18: *"He was undergoing physical therapy, he could not go. We almost never had hospital check-ups. We could not go because of the fear of contagion. His condition got progressively worse. During the pandemic period, his controls were completely cut."*
>
> P15:"*We could not take him to the controls due to the pandemic, and this negatively affected the course of his disease."*

The pandemic process also hindered patient care after surgery due to the fear of contamination. Some of the caregivers mentioned that postoperative follow-ups were not effective.

> *P8:" It was difficult for us to have surgery during the pandemic period, we felt less support from healthcare professionals after the surgery due to the fear of contamination."*
>
> P14: *"I am a nurse, but we could not receive care from doctors and nurses due to the pandemic. They hardly ever came to the patient room. This made us very tired and forced in the care of our patient after the operation."*

Subtheme 4. Increase in symptoms of the ADRD (n:2)

Most of the caregivers stated that there was an increase in ADRD symptoms due to both the rules of the pandemic and surgical interventions. Not being visited by close relatives, especially due to the pandemic, caused the patients to feel lonely. Loneliness, on the other hand, increased the symptoms of the disease by disrupting the routines of the patients and creating an emotional void.

> *P11:" The decrease in social relations and the inability to go to the controls during the pandemic period increased the symptoms of the disease."*
>
> P14:"*It was difficult for us to take care of my mother-in-law who was newly diagnosed with Alzheimer's during the pandemic period. We have not let her go outside since the corona virus started. Because of this, she became a more irritable, quick-tempered person. She started to get angry with us and cry from time to time. Questions such as where I am and where is this place started to increase. Normally, she is a person who loves to hug his grandchildren. She is very upset why his grandchildren do not hug her and stay away. She implied that people act this way to avoid her."*

In addition, surgery during the pandemic period worsened the symptoms of the patients, both due to the use of protective equipment due to the isolation rules and sedation during the operation, blood loss, and electrolyte imbalance.

> *P5:" During the pandemic period, the protective clothing of the health personnel during the surgery caused our patient to hallucinate, thus regressing his cognitive process."*
>
> P21: ''*Surgery for hip replacement during the pandemic period disrupted Alzheimer's treatment and exacerbated the symptoms. Our patient was able to speak and respond before surgery, but no longer speaks and responds.''*

Subtheme 5. Post-operative complications (n:12)

Most of the caregivers stated that there was wound site infection and discharge from the wound site after the surgery. Patients who remained immobile for a long time after surgery developed pressure sores. Some caregivers reported difficulties in pain management.

> P6: *"There is discharge from the dressing site after surgery. How many times we have been to the doctor. No solution found.*
>
> P10*: "My mother is getting weaker day by day after surgery. Pressure sores opened. The infection has developed. There was frequent fever and vomiting."*
>
> P13*:"We could not mobilize my mother after the operation, a pressure sore developed. We could not find a solution."*
>
> P14: *"She had pain after the surgery, and she did not comply with what was wanted.''*

Subtheme 6. Non-compliance with pandemic rules (n:3)

Caregivers stated that they experienced non-compliance with pandemic rules during the surgical process due to ADRD symptoms. The caregivers stated that their patients did not wear masks in the hospital and they wanted to lie on the bed of other patients in the hospital because of the decreased cognitive functions.

> P9:*"She did not accept her bed. She called it my bed for another patient's bed. She was insisting that it is my room, why are you bringing him here? She forgot she was in the hospital. I was speaking openly. An hour later, she was forgetting. It was very difficult, very."*
>
> P14:*"We were especially worried about infection from the hospital and the surgery process, because she cannot wear masks. My mother-in-law, who nor-*

> *mally does not want to wear a mask, started to do nothing because of the change in the environment and pain caused by the surgery."*

Theme 2: Emotions during the pandemic period

Caregivers stated that they experienced fear of COVID-19 transmission, anxiety, and desperation before and during the surgery.

Subtheme 1: Fear of COVID-19 transmission (n:18)

Most of the caregivers stated that they were afraid of the risk of contamination. The non-compliance of the patients with the rules also increases their fears.

> P7: *"In the pandemic, our patient's resistance not to wear a mask during the surgery process, the fear of contagion wore us out."*
>
> P12: *''When I had to go to the hospital, he was COVID -19 positive. He had a fever. I'm pretty bored. The hospital scares me. My son's suffering scares me."*
>
> P14: *"During the COVID-19 period, we were worried about the infection from the hospital and the surgery process, and we were afraid because she didn't wear masks."*

Subtheme 2: Anxiety and Despair (n:15)

Most of the caregivers experienced anxiety and despair due to fear of contagion, social isolation and lack of support during the pandemic period. The complications they experienced after the surgical process also caused them to despair and anxiety.

> P4:*"I had a hard time. Postoperatively, the bedsores were opened. Both physically and not being able to do anything caused us deep pain. I felt helpless."*
>
> P16:*" The worsening of the course of the disease after the operation made me despair. I guess there is no getting rid of this disease.*

One of the caregivers felt regret despair that her mother died when she fell asleep.

> P10:*"I became very attached to my mother while caring. It's like my baby. It was necessary to constantly follow and I was alone. I was very tired. I never wanted to sleep. I'm so sorry for falling asleep. When I woke up, he was not breathing. I have many wishes."*

Theme 3: Coping skills of caregivers during the pandemic

Some of the caregivers stated that they coped by spending time with the patients they care for, getting support from their relatives and resorting to spirituality, while others stated that they could not cope and received psychiatric support.

Subtheme 1: Spending time together and getting support from relatives (n:12)

Caregivers stated that they spend time with the patients they care for and receive support from their relatives. Some caregivers stated that the care of patients with ADRD would not be alone and that they took care of them with the support of their first-degree relatives, and that the burden of care was shared in this way.

> P2:*"This care is never done alone. My sisters are supportive. This is how I can cope."*
>
> P9:*"We take care of each other in the same house with my sister, and reduce each other's burden. We also take time for ourselves. It helps us cope."*

Subtheme 2: Spirituality (n:5)

Caregivers stated that they applied to spirituality and that they were relieved in this way. Most of the caregivers thought that their distress was temporary and tried to relax by praying.

> P14:*"We prayed a lot during difficult times. We tried to relax, thinking that the problem we were experiencing was temporary."*
>
> P19: *"In these difficult times, I took refuge in Allah. I prayed a lot for this process to end as soon as possible."*

Subtheme 3: Inability to cope and psychiatric support (n:4)

Some of the caregivers stated that in addition to their responsibilities at home during the pandemic period, providing care to a patient with ADRD increased their burden, they could not cope with the problems, they received psychiatric support and used medication.

> P6: *"Schools were closed due to the pandemic, I took care of both my mother and grandchildren. I am psyched. I'm taking medication for therapeutic purposes."*
>
> P17: *"During the pandemic period, I was very depressed, I could not bear the burden, I had to take psychiatric support and medication.*

DISCUSSION AND CONCLUSION

Living with an individual with ADRD is accepted as a situation that has significant effects on the family (23). Family members and those around them who provide care and support to individuals with ADRD during the pandemic face some difficulties (24). In our study, caregivers stated that the cost of care increased during the pandemic, they experienced social isolation and lack of support, had difficulty in getting treatment, and experienced an increase in the symptoms of the ADRD. Similar to our study, in a study conducted with relatives of ADRD patients, caregivers experienced social isolation and had problems in accessing official services due to curfews during the pandemic process (16).

Individuals with ADRD may not follow pandemic rules such as hand hygiene, covering their mouth and nose when coughing, maintaining physical distance with others, and wearing a mask (18). In our study, both before and during the surgical process, caregivers complained that the patients did not want to wear masks and follow the rules of social distance. The non-compliance of the hospitalized patients with the pandemic rules, increases the risk of COVID-19 transmission with the decline of the immune system with age (18), especially during the surgery. In our study, the most common emotions experienced by caregivers during the pandemic process were fear of COVID-19 transmission, anxiety, and despair. Similarly, it has been reported that caregivers experience stress and anxiety due to the fear of COVID-19 transmission (16,17). Caregivers are afraid of being infected by their patients who cannot comply with the pandemic rules, and experience anxiety and despair.

In our study, some of the caregivers could not cope with the difficulties they experienced and received psychiatric support, while others coped by spending time together, getting support from their relatives, and praying. In a study, it was reported that for some families, caring for a patient with dementia is a unifying force and serves to improve family relationships, but for some families, constant disagreements in care worsen family relationships (23). In a previous study, the use of active coping methods such as social support and praying contributed to the well-being of individuals (25). It is important to know the coping methods that will be good for the caregivers, and to give individual support to the caregivers who have problems in coping.

During the pandemic period, special practices in the care of patients with ADRD due to fear of covid-19 contamination, remote working due to quarantine, job loss can force individuals economically. In the study, caregivers stated that they did not want to enter the crowd because they were afraid of the risk of contamination during the hospitalization process for surgery, they did not get on public transport and hired a private ambulance, and this process was costly. In a study, it was stated that caregivers who had to work from home due to quarantine had disruptions in their jobs and lost income (16).

In a multicenter study, it was reported that during the pandemic, 51.9% of dementia patients had worsening disease symptoms and 21.9% of families applied for a change of medication (17). Similar results were found in our study. In addition, it was found that the type of disease did not affect the burden of caregivers. Caregivers stated that there is an increase in ADRD symptoms both due to pandemic rules and surgical interventions. In our study, one of the caregivers stated that her patient upset about the social distance practice and she attributed different meanings to social distance for example people wanted to escape from herself due to ADRD. The imposition of increased hand hygiene, mask use, isolation, or restriction of visitors and activities due to the pandemic can increase cognitive symptoms (18). In addition, surgical interventions can cause delirium in individuals with ADRD, which contributes to morbidity. In our study, it was stated that a patient who was able to talk and communicate before the surgery could not speak after the surgery. It is known that especially dementia patients who have undergone surgical intervention have more impairment in consciousness and cognitive level in the long term after surgery than other patients (26).

Dementia is a pathology that requires constant care and complex treatments. The measures are taken to control the pandemic in this group of patients also led to long-term isolation and suspension of non-emergency care (27). In a study, it was stated that patients with dementia experienced an increase in co-morbid disease symptoms due to restrictions and isolation rules during the pandemic period (16). Most people with dementia have had to forgo health care services such as professional help, physiotherapy, cognitive stimulation, and welfare services such as day centres (27). Similarly, in our study, caregivers stated that they could not receive home health care services, could not go to physical therapy and routine controls during the pandemic period, and this affected the health of the patients. Also, caregivers had difficulty in getting care in the hospital during the surgery. Especially after the surgery, patient follow-up is not done very often and doctors and nurses do not come to the patient's room, and this situation makes them tiring and challenging. It is thought that there may have been a disruption in postoperative follow-ups due to reasons such as maintaining social distance, preventing contamination, postponing elective surgeries (28), and reducing health personnel resources and surgical services (29). It is known that the continuous medical care needs of dementia patients are met by their informal caregivers, and the burden of care increases accordingly (30).

Dementia patients are particularly vulnerable to complications as they depend on others for care (31). In our study, caregivers reported that postoperative pressure sores developed, they had problems in the PEG that was opened for feeding purposes, and there was a discharge in the wound area. In this period, lack of social support and patient care alone may contribute to the development of complications. As a matter of fact, one of the caregivers reported that the care would not be alone and she had problems such as pressure sores and infections because of loneliness.

Implications for Nursing Practice with Families

Findings from this study can help family health nurses, researchers, and policymakers better understand the problems and coping strategies of ADRD patients and their families who are faced with a difficult-to-manage situation such as surgery during the pandemic. The nurse should know the daily life, social supports, social conditions and ways of coping with the problems of the caregiver of the elderly person with Alzheimer's disease and related dementia. If caregivers' experiences, social supports, social conditions and ways of coping with the problems and difficulties are known, home care strategies can be developed to manage these difficulties. Since post-discharge patient care requires the technical competence of health professionals, caregivers do not have the necessary knowledge to undertake and perform certain functions and care; therefore patient-specific care training should be given. In addition, our results may help provide information on the practical application of family care models that include support systems and coping methods of caregivers of ADRD patients during acute crisis periods such as surgery. Meeting the needs of the whole family, including the patient with ADRD, is an important and sensitive undertaking.

Strengths and Limitations of the study

This study has many limitations. Firstly, face-to-face interviews could not be held due to the pandemic. Another limitation is that the type of surgery undergone patients with ADRD is heterogeneous.

In our study, it has been shown that caregivers who have a high care burden even in normal times and who care for ADRD patients face many difficulties while caring for their patients who had to undergo surgery during the pandemic period and are negatively affected emotionally. It is the first study to reveal the experiences of caregivers of ADRD patients during the surgical process which created a secondary crisis during the pandemic, and it is thought that it will make an important contribution to the literature in this respect. The most striking of these contributions is to reveal the positive or negative experiences of the caregivers of patients with neuropsychiatric co-morbidities such as ADRD, who had to be operated during the pandemic period could be guided by health personnel and caregivers in possible future pandemics.

We believe that our study will shed light on future studies on the management of the difficulties experienced by caregivers of ADRD patients who underwent surgery during the pandemic period.

Conflict of Interest

The authors declare no conflict of interest.

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