

Araştırma Makalesi/ Research Article

Social Media Use of Caregivers of Dementia Patients

Demans Hastalarının Bakım Verenlerinin Sosyal Medya Kullanımı

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ABSTRACT

Objective: This study was carried out to reveal the most common problems of caregivers of Alzheimer's disease and related Dementia patients by analyzing the posts in Facebook groups between January and February 2022.

Methods: In the Facebook groups, the posts of the participants were scanned with the keywords "Alzheimer", "Dementia", "care of the patient with Alzheimer "care of the patient with Dementia". Facebook has 24.912 users and 50.107 posts in nine group accounts. After the posts in the Facebook groups were determined, the modified thematic analysis of the posts was made using open and axial coding methods.

Results: According to the thematic analysis, 45.4% of the posts were written to ask for information, 32.0% to to express helplessness, 22.6 % to seek and provide support. As a result, the posts were an opportunity to share experiences, to receive/give support and help from others with similar experiences.

Conclusions: According to this study, Facebook groups are most commonly used by caregivers of patients with dementia for information seeking, dejection, support seeking, and support giving. It has been established that people use the posts as a way to exchange experiences, get and offer support, and ask for assistance from others who have gone through similar things.

Keywords: Nursing, patient care, patient with alzheimer/dementia

ÖZ

Amaç: Bu çalışma, Ocak ve Şubat 2022 tarihleri arasında Facebook gruplarındaki paylaşımları analiz ederek Alzheimer hastalığı ve ilişkili demans hastalarının bakım verenlerinin en sık karşılaştığı sorunları ortaya çıkarmak amacıyla yürütülmüştür.

Yöntem: Facebook gruplarında katılımcıların paylaşımları "Alzheimer", "Demans", "Alzheimer hastasının bakımı", "Demans hastasının bakımı" anahtar sözcükleri ile taranmıştır. Facebook'un dokuz grup hesabında 24.912 kullanıcı ve 50.107 paylaşımı bulunmaktadır. Facebook gruplarındaki paylaşımlar belirlendikten sonra paylaşımların modifiye tematik analizi açık ve eksenel kodlama yöntemleri kullanılarak yapılmıştır.

Bulgular: Tematik analize göre paylaşımların %45,4'ü bilgi istemek, %32,0'ı çaresizlik, %22,6'sı destek aramak ve destek sağlamak için yazılmıştır. Sonuç olarak paylaşımlar deneyimleri paylaşmak, benzer deneyimleri yaşayan diğerlerinden destek almak/vermek ve yardım etmek için bir fırsat olmuştur.

Sonuç: Bu çalışmaya göre, Facebook grupları demanslı hastaların bakıcıları tarafından en çok bilgi arama, umutsuzluk, destek arama ve destek verme amacıyla kullanılmaktadır. İnsanların bu paylaşımları deneyimlerini paylaşma, destek alma ve sunma ve benzer şeyler yaşamış olanlardan yardım isteme yolu olarak kullandıkları tespit edilmiştir.

Anahtar Kelimeler: Hemşirelik, hasta bakımı, alzheimer/demans hastası

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Introduction

According to DSM-V, the term dementia is defined as major neurocognitive disorder. Major neurocognitive disorder is characterized by a significant decline in at least one of the cognitive domains, such as executive functioning ability, attention, speech, learning and memory, perceptual-motor or social cognition. In addition to cognitive decline, there must also be a decline in the patient's ability to function and perform activities of daily living. (Emmady et al, 2023).

Most of the individuals diagnosed with Dementia are given home care by their family members, since many areas of their daily lives are affected. Giving care is defined as an activity and experience that includes helping and supporting relatives with services that they cannot provide for themselves. Giving care takes a lot of time for caregivers and the time devoted to care increases as the disease progresses. Both a relative's diagnosis of Dementia and the long hours of caregiving bring along many problems for caregivers. The quality of life of caregivers is also negatively affected by the caregiving process (Abdollahpour et al., 2015). In a study investigating the quality of life and care burden of caregivers of dementia patients in Türkiye, it was stated that the care burden was high and their quality of life was low (Tulek et al, 2020). Another study reported that the sleep quality of caregivers of dementia patients was poor and that this could negatively affect their psychological health (Gao et al, 2019).

It is observed that the prevalence of dementia, which creates the need for caregiving, is increasing gradually and has negative effects on caregivers. The fact that the caregiving process is stressful and affects the psychological health of the caregiver increases the importance of psychological interventions for caregivers and the need for support. In addition, it was stated that caregivers needed psychological help the most (Soner and Aykut, 2017; Yorulmaz and Dirik, 2021).

Social media provides a suitable environment for health information exchange between different socio-demographic groups. All these features make social media very convenient and popular tools for promoting and developing content sharing in the field of health as well as in every field (Gencer et al., 2019; Moorhead et al., 2013). Issues such as raising awareness of the public on health issues, improving public health, estimating epidemic and disease situations, and providing quality health services are handled more easily and quickly with social media

and internet opportunities. Social media users are reading the comments about the doctor and hospital, getting opinions from the specialist doctor about the disease, reading the posts of other people who have the same disease, examining the side effects of drugs and doing research on many other diseases. Social media brings a new dimension to healthcare as it provides a medium to be used by society, patients and healthcare professionals to communicate about health problems with the potential to improve health outcomes (Moorhead et al., 2013). One of the groups that communicate on Facebook because of the physical and psychological health problems they experience is the caregivers of patients with Dementia (Geysi, 2019; Moorhead et al., 2013). This process provides individuals with an idea about the health institution and helps them to shape their behavior (Geysi, 2019).

When the literature was searched, no studies were found that analyzed the posts of caregivers of patients with dementia on social media platforms in Türkiye. In this study, it is aimed to reveal the most common problems experienced by caregivers by analyzing the posts written in Dementia groups on Facebook, which is the most used social media platform in Türkiye.

Method Design

The research was carried out using qualitative and quantitative methods. In the research, the number and percentage distribution of posts sent to Facebook groups were evaluated quantitatively. The scope of posts sent to groups was evaluated qualitatively by content analysis.

It was conducted to examine the purposes of using Facebook groups that caregivers of patients with dementia join about their patients, and what information they search for on Facebook in Türkiye.

Prosedure

The study was conducted by comprehensively scanning groups, including caregivers of dementia patients on Facebook, one of the most frequently used social media platforms. Facebook groups were determined on Facebook with the keywords "Alzheimer", "Dementia", "Dementia patient care", "Alzheimer's and Dementia patient relatives". These groups were scanned by two independent researchers (EAG and HT) between January and February 2022.

The universe of the research consisted of all posts written in Facebook groups. The sample consisted of posts that were searched with the keywords

"Alzheimer", "Dementia", "Care of the Alzheimer's patient" "Care of the Dementia patient". Posts on Facebook individual accounts of caregivers of patients with dementia were not included in the study.

Content Analysis of The Posts

The modified thematic analysis of the posts was made using open and axial coding methods (Bradley et al, 2007; Corbin and Strauss, 2015). The open coding method involves dividing posts into common groups based on shared themes or ideas. Axis coding then categorizes all open codes into even broader themes (Bradley et al, 2007; Corbin and Strauss, 2015). The posts in the Facebook groups were copied into a word document. Transcripts were read multiple times by two (YS, EAG) researchers. Researchers continued the analysis until new themes emerged and data saturation was reached. Two researchers (YS, EAG) independently coded the transcripts and agreed on whether the sub-themes identified represented the themes. In addition, two experts experienced in qualitative research were consulted on whether the sub-themes represented the themes to ensure reliability. The themes and sub-themes were finalized in line with their suggestions. The results of the study are considered to be suitable for similar Facebook groups in different countries, and therefore it is accepted that the transferability criterion was met.

All words on Facebook posts were analyzed in the MAXQDA (version 11) software program. Numbers and percentages were used in descriptive statistics.

Ethical Statement

The data obtained in this study were obtained from publicly available sources without interacting with social media users. Ethical approval was obtained from Erciyes University Social and Human Sciences ethics committee (2022/04).

Results

Table 1 shows the number of group accounts related to Dementia on Facebook. It has been

determined that Facebook has 50.107 posts in 9 group accounts. Caregiver support groups have been established so that caregivers of patient with Dementia can share their knowledge, feelings and experiences with each other and caregivers can guide each other.

Table 1. Users in dementia group accounts across Facebook

Platform	Number of Group Accounts	Total Users	Total Number of Posts
Facebook	9	24.912	50.107

Figure 1. Shows the time trend of newly created group accounts on Facebook. There are 9 groups examined. There are two groups with 23.000 and 2.300 members in 2013, two groups with 8.608 and 8.600 members in 2015, a group with 1.900 members in 2017, and 4 groups in total with 1900, 1.822, 989, 988 members in 2019. 2013 was the year had the highest number of accounts (50.4%). 2019 was the year that was opened the most groups.

Table 2. Themes

Themes	Number of Posts	%
Request Information	22.748	45.4
Despair	16.034	32.0
Seeking and Providing Support	11.325	22.6

Theme 1: Request Information

The most common theme was "requesting information" with 22.748 posts (45.4%) (Table 2). In the sub-themes of this theme, it was determined that the caregivers of individuals with dementia requested information about their (Percutaneous Endoscopic Gastrostomy) PEG experiences, the difficulties in the symptoms of the disease, especially the home care process in the pandemic, the psychological coping methods of the caregivers, and the recommendations of the nursing home and caregiver (Table 3).

Table 3. Sub-Themes

Request Information	Despair	Seeking and Providing Support
PEG Experiences	Care Burden of the Patient	Sharing the Grief Process
Difficulties in Disease Symptoms	Financial Insufficiency	Requesting Prayer
Home Care Process in the Pandemic	Deterioration in Relationships	Financial support
Psychological Coping Methods		Spiritual Support
Nursing Home Advice		
Cargiver Advice		

PEG Experiences

In the posts (1.550 posts, %7), caregivers wanted to learn about the problems they experienced before and after PEG was opened, and their satisfaction with PEG. Some sample posts are below:

“My husband hose was inserted from the nose to the stomach, we switched to liquid food completely, but my husband's hands were very active, but he took the tube out of his nose three times. Doctors say open a PEG and your patient would live better. Can you help me, those who have their patient open a PEG before?”

“My mother got COVID-19 after PEG surgery. We stayed in the hospital for 14 days and used the drugs. Isotonic serum was applied constantly. Today she had a rash on her back and feet. Is this normal? Has anyone experienced this?”

Difficulties in Disease Symptoms

In the posts (4.200 posts, %19.4), caregivers wanted to receive information about the symptoms of their patients, such as hallucinations, aggression, body wounds. Some sample posts are below:

“My mother was diagnosed with Dementia. She is terrible right now. She is afraid, says she will be killed, she dreams, she says her dead brother has just died and cries all the time. She does not sleep at night without taking a sleeping pill.”

“My wife had a bed sore while she was intubated in the hospital. I applied the potency pomegranate for two days and it felt very good. I wanted to write in case anyone needs it. Herbalists have a potency pomegranate.”

Home Care Process in the Pandemic

In the posts (1.352 posts, %5.9), it was determined that the caregivers wanted to get information about the problems they experienced in home care during the pandemic process. Some posts are below:

“We are currently experiencing serious food shortages. Moreover, we are considering opening a PEG. It is difficult to go to the hospital during the COVID-19 period. Can home care doctors open PEG? Alternatively, can private hospitals do it?”

“Good day, my husband caught COVID-19, and then I got it. He is having a harder time. We had the second vaccine. After he got sick, his Dementia peaked. We are waiting for your prayers. May God help us; the situation in hospitals is terrible. He is spitting blood. Doctors sent him back to watch at home.”

Psychological Coping Methods

In the posts (6.278 posts, %26.6), the caregivers gave physical symptoms of psychological problems

and they wanted to learn about how they cope psychologically in this process. Some sample posts are below:

“Friends, my mother insults me a lot. Blisters formed on my body from boredom. Are any of you experiencing this?”

“As you know, looking after Alzheimer's patients is a situation that exhausts the caregiver both psychologically and physically. How do you overcome it? Experts recommend getting support. Can you get psychological support or help from someone?”

Nursing Home Advice

In the posts (4.800 posts, %21.1) caregivers wanted to learn about clean and safe nursing homes. Some sample posts are below:

“Is there a reliable, clean, full-fledged nursing home with doctor and nurse care that you can recommend on the European side of Istanbul? My mother has been with us for 2 years, but has been extremely aggressive. She attacked and injured her grandson and me. It has become very difficult to look after at home now.”

Some caregivers stated it was unbearable because of the progression of the disease and sought a nursing home.

“My father has been living with the diagnosis of bipolar since 2000, but in the last 1 year, his disease has changed course. His final diagnosis was the onset of psychosis, Dementia, and Alzheimer's. We are looking for a sheltered and safe nursing home in Izmir that accepts Dementia and Alzheimer's patients. Frankly, we are desperate and need nursing home recommendations.”

Caregiver Advice

In the posts (4.568 posts, % 20.0), the caregivers wanted to learn about the caregivers they were pleased with.

“Hello everyone, my mother has Alzheimer's disease. Thank goodness, he knows us for now he is not bedridden. I have a 7-year-old daughter; we are in primary school this year. I cannot take my mother with me because she does not come. We are together every day, but now we need to be accompanied by someone we can trust. If there are people in Izmir who have taken care of your patient before and you are pleased with them.”

Theme 2: Desperation

The second theme was “despair” with 16.034 posts (32%) (Table 2). From the posts, the caregivers of individuals diagnosed with dementia experience despair and fear because of the resistance of the patients. They do not know what to do because

of financial inadequacy, their relations with families, neighbors deteriorate, and they experience psychological problems (Table 3).

Care Burden of the Patient

In the posts (6.020 posts, %37.5), it was determined that caregivers showed resistance in receiving treatment and this situation increased the burden of caregivers and left them in despair. Some sample posts are below:

"While my father is calm and obedient during the day, he does not sleep at night and tries to shout on the balcony so that no one can sleep. Medicines never work. She is stubborn to my mother that she will not sleep too. My one-year-old daughter in my lap is too scared, we do not know what to do now."

Financial inadequacy

In the posts (3.500 posts, %21.8), it was emphasized that caregivers could not hire caregivers for their patients and take them to nursing homes because of financial insufficiency. This situation negatively affected caregivers.

"My mother is Dementia end stage. He does not want to eat, drink, and bathe. She is constantly shouting. He never sleeps day and night, and he does not put anyone to sleep. I cannot leave it alone at home. I do not have the financial situation to invest in a nursing home. I am afraid of what will happen to my mother if something happens to me."

Deterioration in Relationships

In the posts (6.514 posts, %40.7), it was determined that this disease caused deterioration in both family and neighbor relations and this situation dragged caregivers to despair. It has been stated that especially the patients disturb their neighbors and family members by shouting. Some sample posts are below:

"I am looking after my wife with Alzheimer. My age is 80. My wife is 78. She attacks me. I notice the neighbors are listening because there is a fight. I wonder if your patients have had similar crises. What will happen next?"

Theme 3: Seeking and Providing Support

The third most frequently detected theme was "Seeking and Providing Support with 11.325 (%22.6), (Table 2) posts. From the posts, it was determined that their caregivers wanted support because their patients lost and they asked for prayers from both those who lost their patients and other caregivers, provided both material (bed, chair, etc.) and spiritual support.

Sharing the Grief Process

In the posts (4.221 posts, %37.3) caregivers who lost their patients sought support by sharing their

grief process with other users in the group. Some sample posts are below:

"My mother has Dementia for 4 years. She was in intensive care for 13 days, and we lost her last Sunday night. She flew out of my hands. She was my baby. I cannot describe my pain, I am suffering, but on the other hand, I am happy that her pain has subsided."

"When my dear mother was diagnosed with the disease 8 years ago, we lost her once! Does a person ever delete her phone number from the directory while his mother is alive? Since my mom could not speak, we deleted her years ago. Even if she did not know us or understand us, how nice her presence was. We said goodbye to my beautiful mother to her eternal resting place today."

Requesting Prayer

In the posts (5.850 post, %51.7), caregivers sought support from other users by requesting prayers to recover of their patients. Some sample posts are below:

"She is not my mother; she is my child, half of my life. My mother is now in intensive care. She was intubated for respiratory distress. How many years have we overcome difficulties with my mother? My God, give her back to me. Please pray for us."

Financial Support

In the posts (664 post, %5.8), caregivers provided financial support to other users, such as beds and chairs, after they lost their patients.

"At the end of the 12-day intensive care period, we buried my mother yesterday. Our 6-year struggle has ended. I live in Izmir. I want to give my mother's sickbed and chair to a friend in need, for my mother's sake."

Spiritual Support

In the posts (600 posts, %5.2), it was determined that caregivers shared their feelings and provided spiritual support with other users who experienced similar situations.

"Hello everyone, I am a new member of the group. I realized it lately. It is so good to find people with the same problem."

In the word cloud in Figure 2, font size correlates with larger words being the most commonly used words and vice versa for smaller words. It was seen that the word 'Dementia' was the most used word in the word cloud.

Discussion

Caregivers are informal caregivers with no prior knowledge or training in dementia care. Providing access to relevant and reliable information for these

caregivers is crucial to providing continued high-quality care for the person with dementia (Soong et al., 2020). Social media can facilitate real-time communication with patients and their relatives who have similar experiences in a way that traditional media can not (Çınar and Boztepe, 2020; Duggan and Page, 2015). This study provides an overview of the social media posts used by caregivers of patients with dementia to have an idea about their perception of the disease, access to resources, patient needs, and management of the disease. In our study, we found an extraordinarily high number of users and posts on Facebook, with 9 groups, 24.912 members, and 50.107 posts about dementia patients and their relatives. Although the experience of each individual who cares for a patient with dementia is unique, in the study, caregivers used Facebook groups most frequently (45.4%) to request information. It was determined that caregivers sought information about PEG experiences, difficulties related to disease symptoms, the home care process in the pandemic, psychological coping methods of caregivers, and recommendations for nursing homes and caregivers.

Especially in the COVID-19 pandemic, which constituted a crisis period, it was determined that the caregivers of the patients questioned whether the home care services could open PEG at home, and that the cognitive status of the patients infected with the COVID-19 infection deteriorated. In a study similar to our study, the posts written by caregivers of patients with dementia to an online forum were analyzed and 48.2% of the posts were written to search for specific information about the disease and treatment services (Erdelez et al., 2019). In another study, it was stated that 70.8% of caregivers used the internet to access health-related information, and 20.8% attended online support groups (Iribarren et al., 2019). It is known that caregivers are not informed about the disease of their patients who are stigmatized by the society. Since the care needs of patients from the first stage of the disease to the last stage of the disease are constantly changing and affect patient care in acute situations such as pandemics, caregivers have difficulty in coping with the disease and turn to different sources of information (Erdelez et al., 2019). Along with the literature, our study found that caregivers wanted to know about their experiences with PEG, the challenges they faced with the disease's symptoms, the process of providing home care, particularly during the pandemic, and their psychological coping mechanisms.

In elderly individuals with dementia, cognitive impairment, progressive loss of autonomy and disease-related behavioral disorders cause, an increase in caregivers' burden (Dauphinot et al., 2015). The increase in the burden of care also causes the caregivers to experience physical, psychological, emotional, social and financial distress (Novais et al., 2017). In our study, it was determined that 32.0% of Facebook posts were written due to the increase in the care burden of the patient, financial inadequacy and deterioration of relations, and these factors created a sense of despair in individuals. The caregivers stated the symptoms of the disease increased in the last stages of the disease, the patients were constantly shouting and making noise, which disrupted their communication with neighbors and family members, and they did not have the financial capacity to invest in a nursing home. It has been determined that 2.5% of the posts aim to provide material and spiritual support to the participants. The caregivers who lost their patients stated that they could give the remaining medical supplies to their patients. They also stated that sharing with people who are in the same situation as them does not make them feel lonely and provides moral support. Similarly, a study stated that caregivers experienced burnout, despair and hopelessness due to the burden of care (Erdelez et al., 2019). The lack of emotional and psychological support of caregivers can be inferred from the caregivers seeking psychological support and trying to relax in Facebook groups. Providing professional psychological support to caregivers is important in empowering them. In addition, understanding family dynamics, determining the type of support families may need and determining which strategies can provide this support can ease caregivers' burden of care (Esandi et al., 2021). These findings shed light on the multidimensional difficulties experienced by caregivers and clearly reveal the scope of the problems faced by individuals in the process of caring for dementia patients. The burden of care leads to both physical exhaustion and emotional distress, creating feelings of hopelessness and helplessness in individuals. This situation causes caregivers to feel lonely and seek social support. Financial inadequacies and deterioration in relationships are another important dimension of the care process. It is known that relationships with neighbors and family members are damaged, especially in the advanced stages of the disease. This situation weakens the social ties of caregivers. Facebook groups stand out as a space where

caregivers share their experiences, find moral support from individuals experiencing similar difficulties, and reduce the feeling of loneliness. Providing material and moral support, and especially helping practices such as sharing medical supplies, increase the functionality of groups. Such actions strengthen both individual solidarity and community affiliation. It is important to provide professional psychological support to reduce the emotional burdens of caregivers such as burnout, helplessness, and hopelessness. This support can help individuals both protect their own mental health and provide more effective care. Developing approaches to understanding the needs of families can ensure that types of support are targeted and efficient. Customized strategies are needed to cope with family communication problems and financial difficulties. Analysis of posts in Facebook groups is a valuable source of information to better understand the needs of caregivers and develop appropriate intervention strategies.

In our study, 20.1% of the posts were gathered under the theme of seeking support, such as sharing the grieving process and requesting prayers. According to the word analysis of the posts written in the Facebook group, it was found that the words "Dementia" and "God" were written most frequently. Caregivers who lost their patients shared the loss and grief process of their patients, and sought emotional support by asking other participants to pray. In another study, it was stated that 32.5% of the posts written by the caregivers of the patients on the online forum were to seek emotional support (Erdelez et al,2019). In another study, it was stated that a religious/fatalistic perspective, believing that the disease comes from God, and praying could facilitate the management of the disease (Ar and Karanci, 2019). In Turkish society, the most powerful coping method during difficult times such as loss, mourning and illness is usually spirituality. Spiritual elements such as religious beliefs, prayer, patience and belief in fate provide individuals with support during these times. In addition, family and social solidarity play an important role. Family members, relatives and close circle complete the spiritual support by making individuals feel that they are not alone during these difficult times. This situation is closely related to the collective structure of Turkish culture and the importance it gives to spiritual values.

Limitations

Only Facebook group accounts of relatives of patients with dementia in Türkiye were included in

this study. In addition, since other social media platforms are not included in the study's scope, the results of the research can be generalized to Facebook group accounts of relatives of patients with dementia in Türkiye. Additionally, since the diagnosis is based on the statements of the patients' relatives on social media, it is not possible to know the patients' actual diagnoses or the criteria on which the diagnoses were made

Conclusion and Recommendations

Unlike previous studies, we used both quantitative and qualitative methods to examine posts in Facebook groups, a large social media network. This study provided the information that social media can be used by health professionals to inform families and reduce their anxiety by examining and taking part in disease-specific groups.

This study revealed that caregivers of patients with dementia most frequently refer to Facebook groups for information seeking, despair, seeking and providing support. It has been determined that the posts are seen as an opportunity to share experiences, receive/give support and help from others with similar experiences. Based on these results, it is recommended to organize training and awareness programs for health professionals, develop social media-based support programs, and organize local and online events and awareness campaigns to strengthen community solidarity.

Ethics Committee Approval: The data got in this study were obtained from publicly available sources without interacting with social media users. Ethical approval was got from Erciyes University Social and Human Sciences ethics committee (2022/04).

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What did the study add to the literature?

- It has been found that posts are viewed as a chance to exchange experiences, offer and receive support, and connect with others who have similar experiences.

- Caregivers of patients with dementia most commonly turn to Facebook groups for information, expressing feelings of despair, and seeking or offering support.
- This study revealed that health professionals can utilize social media to educate families and help alleviate their anxiety.

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