



Life and Medical Sciences

Social Media Use of Solid Organ Transplant Patients: Sharing Unmet Needs

Solid Organ Nakli Hastalarının Sosyal Medya Kullanımı: Karşılanmayan Gereksinimlerin Paylaşılması

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Abstract

The aim of this study was to analyze the posts of patients with solid organ transplant Facebook groups and to reveal the most common problems experienced by them. The study was conducted with a comprehensive search of solid organ transplant patients' Facebook groups. Posts of the participants were scanned with the keywords "organ transplant patients", "life after organ transplant", "organ transplant information", "kidney transplant", and "liver transplant". Qualitative data were evaluated by inductive content analysis. All words of the post were analyzed in the MAXQDA (version 11) software program. There were 18,722 users in 10 groups related to solid organ transplantation and 478 posts were shared. Five main themes were determined: Seeking information/giving information, seeking support/providing support, seeking a partner for cross-transplantation of those waiting for organ transplants, financial issues and experiences related to COVID-19. It has been determined that 59.8% of individuals most frequently refer to Facebook groups for information seeking/giving information. The posts are seen as an opportunity to share experiences, to seek support/provide support, and help from others with similar experiences. Social media can be used by health professionals to inform individuals and reduce their anxiety by examining and participating in disease-specific groups.

Keywords: Solid organ transplantation, Transplanted patient, Social media.

Özet

Bu araştırma organ transplantasyonu yapılan hastaların dahil olduğu Facebook gruplarındaki gönderilerin analiz edilerek bireylerin en çok yaşadıkları sorunların ortaya çıkarılması amacıyla yapılmıştır. Çalışma en sık kullanılan sosyal medya platformlarından Facebook'ta solid organ nakli olan hastaların dahil olduğu grupların kapsamlı taramasıyla yürütülmüştür. Katılımcıların gönderileri "Organ nakli/transplantasyonu yapılan hastalar", "Organ nakli sonrası yaşam", "Organ nakli bilgilendirme", "böbrek nakli" ve "karaciğer nakli" anahtar kelimeleriyle taranmıştır. Nitel veriler tümevarımsal içerik analizi ile değerlendirilmiştir. Facebook gönderilerindeki tüm kelimeler, MAXQDA (sürüm 11) yazılım programında analiz edilmiştir. Solid organ nakli ile ilgili 10 grupta toplam 18.722 kullanıcı olduğu ve 478 gönderi paylaşıldığı belirlenmiştir. Bilgi

arama/bilgi verme, destek aramak/destek sağlamak, organ nakli bekleyenlerin çapraz nakil için uyumlu verici araması, maddi konular ve COVID-19 ile ilgili deneyimler olmak üzere 5 ana tema belirlenmiştir. Bireylerin %59.8 oranında en sık bilgi arama/bilgi verme nedeniyle Facebook gruplarına başvurduğu belirlenmiştir. Sonuç olarak gönderilerin, deneyimleri paylaşma, benzer deneyimlere sahip başkalarından destek ve yardım alma/verme fırsatı olarak görüldüğü belirlenmiştir. Sosyal medya, sağlık profesyonelleri tarafından hastalığa özgü grupları inceleyerek ve bunlara katılarak bireyleri bilgilendirmek ve kaygılarını azaltmak için kullanılabilir.

Anahtar Kelimeler: Solid organ nakli, Nakilli hasta, Sosyal medya.

Introduction

Organ transplantation is the treatment of the patient by transplanting a healthy organ taken from a living or dead person instead of damaged organs. Currently, there is no other treatment method other than organ transplantation to resuscitate the patient for some conditions [1].

Another point that is as important as the transplantation of the organ in transplantation practices is to provide the donor and recipient care under the best conditions, to increase their quality of life in the later period and to meet their information needs [2]. Although health-related quality of life increases after transplantation, it cannot reach the level of quality of life of healthy people [3]. After transplantation, individuals may experience many problems including pain due to surgery, nausea and vomiting because of the immunosuppressive drugs, susceptibility to infection, loss of concentration, hair loss, loss of sexual desire, and depressive feelings. These symptoms may negatively affect the individual's quality of life and impair their adherence to treatment [4,5].

Post-transplant patients need information about their condition and the risks and benefits of their treatment [6]. In a study, patients after liver transplantation thought that symptoms such as nausea-vomiting, aphthae in the mouth, and diarrheal constipation were caused by drugs, but they admitted that they did not know the side effects of drugs well [7]. Interaction with other patients and participation in support groups can positively affect the compliance of patients by increasing information exchange after transplantation [8]. In a study, it was stated that the transplanted patients benefited from talking to people who had similar experience with them [7]. In another study, a support group was formed in patients who underwent liver transplantation,

and it was found that the knowledge level of the patients increased, the symptom level decreased, and the quality of life increased after the support group was formed [5].

Social media platforms are technology tools capable of enhancing digital opportunities that bring individuals together for networking and communication. One of the reasons for their popularity is that communication via social media can reach their target audience instantly without the lag time associated with traditional print media [9,10]. The use of social media to promote organ donation is spreading rapidly. The transplant community has discovered that the general public can be reached through on-line platforms and social media, and that education and campaigns can be organized in this way [10,11]. In the studies, social media platforms were used to encourage people to donate organs, to provide education and to increase the donation rate [12,13]. In the literature, there are studies that analyze the sharing of health personnel and surgeons on organ donation on on-line platforms [12,14]. No study has been found in the literature that analyzes the social media shares of organ transplant recipients with patients who have had similar experiences. This study was conducted to examine the purposes of using Facebook groups of organ transplant patients and what information they searched for on Facebook [15].

Material and Method

Type of research and procedures

The research was carried out using qualitative and quantitative methods. In the study, Facebook posts of Turkish-speaking solid organ transplant recipients living in Türkiye were analyzed in January- April 2022. The study was conducted by comprehensively scanning solid organ transplant patients' groups on Facebook. First of all,

Facebook groups related to solid organ transplant patients were determined. In the Facebook groups, the posts of the participants were scanned with the keywords "organ transplant patients", "life after organ transplant", "organ transplant information", "kidney transplant", and "liver transplant". The posts shared in the groups formed the universe of the research. The posts were examined one by one, and the posts thought to be related to the research topic constituted the sample of the research and were copied to the word page. Posts of patients with solid organ transplants on their individual Facebook accounts were not included in the study.

Data analysis

Quantitative data are given as number, mean, standard deviation and percentage. Qualitative data were evaluated by content analysis. The coding of the data that emerged as a result of the examination of the primary data was carried out with inductive content analysis. Inductive Content analysis uses the process of abstraction by grouping data so that researchers can answer study questions using concepts, categories, or themes. The researcher reviews the data to identify codes. Sub-concepts are combined with other code containing similar content to create categories and themes. Identified concepts, categories and themes form the basis for reporting content analysis results [16]. The data were read multiple times and systematically coded by one of the authors (YS) experienced in qualitative study. Considering the purpose of the research, themes and sub-themes were created to increase the depth of analysis. Identified themes and sub-themes were reviewed by all authors, differences were discussed, and themes and sub-themes were interpreted together to minimize inconsistencies. Words in Facebook posts were analyzed, and word cloud made in the MAXQDA (version 11) software program.

Reliability

The reliability of the data was obtained based on the strategies determined by Jiggins Colorafi and Evans [17]. Some of these strategies are reliability and transferability. In order to confirm the reliability of the research, whether the sub-

themes given under the conceptual theme reached in the research represent the mentioned conceptual category, expert opinion was sought. The results obtained from analyzes performed on this sample group are considered to be suitable for use in similar sample groups in different environments, and therefore it is accepted that the transferability criterion is met.

Ethical Statement

The data were obtained from publicly available sources without interacting with social media users. Usernames were not included in the study. In addition, the meaning of the quotations has been preserved by changing the spelling errors and abbreviations, and translated into English, against the risk that the quotations may be obtained by using a search engine that will jeopardize the anonymity of the quotations [18].

Results

There were 18,722 users in 10 groups related to solid organ transplantation and 478 posts were shared. Five main themes were determined: Seeking information/giving information, seeking/providing support, seeking a partner for cross-transplantation of those waiting for organ transplants, financial issues and experiences related to COVID-19. It has been determined that 59.8% of individuals most frequently refer to Facebook groups for seeking/giving information (Table 1). In the word cloud in Figure 1 font size indicates that the larger words are the most commonly used words and the smaller words the less used words. As a result of the word cloud analysis, 63 frequently used words were determined and the most frequently used word was "Transplantation and organ".

Theme 1: Seeking information / giving information

Most frequently, 59.8% shared posts to Facebook groups about seeking and providing information about organ transplantation. Patients sought general information about drug effects and side effects, post-operative care, seek information about the problems they encounter after solid organ transplantation, and give information about the post-transplant health care services received by the organ transplant recipients, the problems they experience, and solution suggestions. In

addition, patients gave information about current and technological developments and scientific studies related to organ transplantation (Table 2).

Sub-theme 1(1): *General information search*

In this theme, there are posts of both patients who are waiting for organ transplantation and those who have had organ transplants. In general, most of the patients asked what they should pay attention to in the early and late postoperative period, whether they would use a corset and how long they would use it. Most of the patients sought information about the side effects of using painkillers and steroid drugs after transplantation.

"Hello dear friends. I would like to ask you, if you share your experiences about what we should pay attention to in the early and late periods after the operation, I would appreciate how many months we need to wear a corset."

Sub-theme 1(2): *Searching for information about post-transplant health problems*

Most of the patients with liver transplantation stated that they experienced abdominal edema and itching after transplantation and sought information on this subject. Some of the patients stated they had bleeding problems after liver transplantation and sought information about it.

"My father had a liver transplant 2 months ago, and today it started to itch. Has anyone experienced this situation?"

"What causes swelling in the abdomen after liver transplantation? We have an appointment on Tuesday. It has been 3 months since the operation"

"Does anyone experience seizure-like complications after liver transplantation and have a brain hemorrhage?"

Most of the kidney transplant patients shared post-transplant elevations in Glomerular filtration rate (GFR) and creatinine levels.

"Friends, what is your kidney working (GFR) level and how long have you been transplanted? It has been 1 year, do you think my 70% GFR is normal? Creatinine is at 1.20 level"

Most of the patients had problems such as postoperative wound problems, incisional hernia, insomnia, fatigue, diarrhea and asked the reason

for these problems and the possibilities for solutions. Cancer was developed in some of the patients as a complication of immunosuppressive drugs after transplantation and patients sought information about the diagnosis and treatment process of cancer.

"Good evening friends, it has been 6 months since liver transplant. I've been having diarrhea for the last 1 month, it doesn't go away, has it happened to you, I wonder what causes it"

"Does anyone have Kaposi sarcoma after kidney transplant? It is more common in people who have had a kidney transplant. I would appreciate it if anyone who has experienced or survived the disease can provide information. Thank you"

Sub-theme 1(3): *Post-transplant information*

The patients shared information about the services of the home care units they received such as home blood analysis, after the transplantation. In addition, the patients gave information about the problems and solutions they experienced after the transplant and warned the patients to have their follow-up regularly.

"You can call the health officers to your home and have many blood tests done. If available, they measure the tacrolimus level for Prograf users. If you say hemogram, they will come prepared and perform your blood draw in that direction. You will see your results on the same day."

"Hello friends, I have been a transplant patient for 10 years. I had abdominal pain for about 3 months. As a result of the tomography, a suspicious tumor was found in my old kidney, liver, and bones. The last doctor asked for a PET, I had a full body cancer screening. Tumors were found only in the old kidney and other regions were clean. I had such an adventure for 3 months. I was very bad. My advice to you is to have your old kidneys checked frequently."

Sub-theme 1(4): *Current developments in organ transplantation*

Some of the patients shared the information that scientists have produced bionic/artificial kidneys with the advancement of technology for patients waiting for organ transplantation, and that patients can get rid of dialysis in this way.

"More than two years ago, scientists at Vanderbilt University said they aimed to be able to implant an artificial kidney in the bodies of people suffering from kidney failure. New developments in nanotechnology could make such a life-saving system possible."

Some patients shared posts to make their voices heard to the Ministry of Health and organized through social media posts to accelerate the studies of artificial organs from stem cells.

"Is there anyone who knows about the stem cell artificial organ studies circulating on the internet or who works in these studies? What is the situation? Let us create an agenda for all patients waiting for transplant, let us get organized on social media. Let us tag the ministry of health and the places we can reach and let our voice be heard by creating an agenda for them to speed up the work of these artificial organs. How do you think?"

Theme 2: Seeking / providing support

Organ transplant patients applied to Facebook groups second most frequently with a rate of 24.9% to seek and provide support. Patients who had to receive immunosuppressive treatment after organ transplantation shared in Facebook groups to ask for and provide drug support to each other. In addition, the patients motivated each other and provided psychological support by sharing the positive situations they experienced during the treatment process (Table 2).

Sub-theme 2(1): Asking / providing drug support

The majority of patients request and give drugs. Especially when patients could not reach the drug in pharmacies, when they were out of town and had no drug left, or when they could not reach the drug due to financial difficulties, they asked for drugs.

"Hi guys, I need Myfortic 180 mg or 360 mg urgently. I cannot find it in any pharmacy for a week. They say it is not in stock. We have no drugs for tomorrow. Even if it is 2 pieces, it can meet our needs."

Sub-theme 2(2): Providing psychological support

Most of the patients motivated the patients who had similar problems by stating that years

have passed since the organ transplantation and that they are continuing their lives in a healthy way and that everything will be all right if they do not lose their faith. They stated that being positive and not losing faith facilitates disease management.

"Two years after the transplant, I gave birth to a baby. Those who are transferred, never fear anything, God (*Allah*) is with us."

"What will be the benefit for patients like us by rebelling or distressing in chronic disease? The best medicine is to be positive, not to worry, to learn to live as if I am not sick, to be conscious. It is years of experience."

In addition, some of the donor patients stated that organ donation does not impair their health and shared to encourage organ donation.

"As a liver donor, I wanted to write to relieve people who will be donors. I had surgery 28 days ago and gave my liver. The recipient and I are very well and healthy. I returned to my social life without even a month."

Theme 3: Seeking a partner for cross-transplantation of those waiting for organ transplants

The third most common reason for patients waiting for organ transplant to apply to Facebook groups was to search for a partner for cross transplant. The patients, who could easily reach the patients who had similar problems with them, through Facebook groups, sought a partner to increase their chances of cross-transplantation (Table 2).

"Hi, first, get well soon; unfortunately, a liver transplant is needed due to cirrhosis. Only our daughter's blood type is compatible with our family, but unfortunately, she cannot be a donor due to her vascular structure. We are waiting for cross transplant for recipient A (+) donor B (+) blood group. If there are people who are waiting for a cross transplant, like us, whose blood type is compatible, we can contact you."

Theme 4: Financial issues

Most of the patients who had an organ transplant reported that some of the drugs they used after transplantation were not covered by insurance and their costs were high, and some

asked whether the drugs were covered by insurance. In addition, they asked whether they could obtain financial aid thanks to the disability report they received after the organ transplant, and whether they could buy a car with a tax deduction.

“Did you know they started taking money from Cellcept ? They take 100 TL per drug; can it be true?”

“Is there anyone who bought a car after receiving a disability report due to liver transport? What are the terms? What is the disability rate to buy a car?”

Since some of the patients thought that they would fully regain their health after kidney transplantation, they asked whether their disability pension would be cut.

“Is the disability pension of those who have kidney transplants cut off?”

Theme 5: *Experiences related to COVID-19*

Under this theme, it was shared whether the patients with organ transplants were vaccinated against COVID-19, which vaccine they preferred, and how the patients who were positive for COVID-19 went through the process. Experiences of those with chronic diseases during the pandemic were shared about whether they started working due to restrictions (Table 2).

Sub-theme 5(1): *Vaccination experiences*

Organ transplant patients asked other patients whether they had the COVID-19 vaccine, which vaccine they preferred, how many doses they received, and whether any side effects developed after the vaccine.

“Hi friends, I have chronic liver failure, esophageal varicose veins. Those who have these diseases, which one did you have as the COVID-19 vaccine? I will be very happy if you write”

“Friends with organ transplants, will you get the COVID vaccine? Has your doctor made any recommendations in this direction?”

Sub-theme 5(2): *Experiences of COVID-19 positive patients*

Some of the organ transplant patients shared whether they got COVID-19 infection after vaccination, which drugs can and cannot be taken after transplantation, and whether their blood values deteriorated after COVID-19.

“Does anyone have two doses of vaccine with kidney transplant and have COVID-19? If so, did you take any medicine, could you tell me?”

“It has been 3 months since my transplant, I got COVID-19 today and my blood values are high. Do any of you have COVID? What path did you follow? Does it affect the disease a lot?”

Sub-theme 5(3): *Getting to work in the pandemic*

Most of the organ transplant patients were exposed to curfew due to their chronic diseases. It has been shared about when they will start work.

“Do any of you go to work, friends? There is a curfew for those with chronic diseases.”

“Friends of public employees who have had an organ transplant, have you started your work? Is there any information especially for those working in the Health sector?”.

Table 1. Themes related number of posts and percentage.

Themes	Number of posts	Percentage (%)
Seeking information / Giving information	286	59.8
Seeking support / Providing support	119	24.9
Seeking a partner for cross-transplantation of those waiting for organ transplants	41	8.6
Financial issues	18	3.8
Experiences related to COVID-19	14	2.9

Table 2. Themes and sub-themes.

Themes		Sub-themes	
Theme 1	Seeking information / Giving information	1.1	General information search
		1.2	Seeking information about post-transplant health problems
		1.3	Providing post-transplant information
		1.4	Current developments in organ transplantation
Theme 2	Seeking / Providing support	2.1	Asking/providing drug support
		2.2	Providing psychological support
Theme 3	Seeking a partner for cross-transplantation of those waiting for organ transplants		
Theme 4	Financial issues		
Theme 5	Experiences related to COVID-19	5.1	Vaccination experiences
		5.2	Experiences of COVID-19 positive
		5.3	Getting to work in the pandemic



Figure 1. The “word cloud” created from posts collected on Facebook.

Discussion

Social media provides a medium for communication between the community, patients and healthcare professionals about health issues and improving health outcomes. This situation brings a new dimension to health services [19]. One of the groups that communicate on Facebook due to the physical and psychological health problems they experience is the groups of patients who have had organ transplants.

Kidney and liver transplantation are among the most common solid organ transplantations all over the world and affect patients physically, psychologically, and socially after transplantation

[20]. After organ transplantation, patients need information about the problems they experience, their general condition, and the side effects of their treatment [6]. In our study, the Facebook groups of the patients who had solid organ transplants were examined and the patients used the groups most frequently with a rate of 59.8% to seek and provide information. According to the word cloud analysis, the most written word was transplantation. The patients sought general information about drug effects and side effects, what should be considered after surgery, and information about the complications they encountered after transplantation. Organ

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transplant recipients gave information about the health service they received after the transplant, the problems they experienced and the solution suggestions. In addition, it was determined that the patients gave information about current and technological developments and scientific studies about organ transplantation. In a study protocol, a Facebook group was established by the healthcare team for adolescents who will undergo kidney transplantation, and it was reported that they aimed to improve the satisfaction level, self-esteem and knowledge level of the patients compared to the control group by sharing information about drug compliance and treatment process for 3 months thanks to this group [21]. The problems experienced after solid organ transplantation do not completely disappear, and new problems are added to the already existing problems such as fear, anxiety, and fatigue [22]. In our study, some of the liver transplant patients shared about the itching and bleeding problems, and some of the kidney transplant patients shared due to the change in creatinine and GFR. In addition, information was sought on issues such as postoperative wound problems, hernia, insomnia, fatigue, and cancer development. It is thought that sharing the complications and solutions they have experienced with patients who have similar experience with them, by ensuring that they do not feel alone, will positively affect their adherence to treatment, increase their level of knowledge, and facilitate the management of the disease.

The uses and gratifications theory (U&G) states that the use of social media is primarily based on meeting personal needs [23]. The U&G theory is based on the idea that individuals are active users of various communication channels and they consciously choose channels to satisfy their perceived needs and desires [24]. Similarly, in our study, the participants used Facebook groups at a rate of 24.9% to seek and provide support. Patients who had to receive immunosuppressive treatment after organ transplantation asked for drugs when they could not reach the drug in pharmacies, when they were out of the city and had no drug left, or when they could not reach the drug due to financial difficulties. 3.8% of the Facebook posts in our

study consisted of financial issues. Along with the advantages of social media, it also brings with it unprecedented health risks. False or misleading health information on social media can spread more easily than scientific information and threaten the health of individuals [10,25]. As a result of our study, it was determined that individuals demand and give drugs from each other, and it was thought that this situation could put their health at risk. But it's not safe and they should not use drugs without the knowledge and approval of organ transplant centers.

In our country, practices such as financial aid and tax exemption are provided to disabled individuals, their families, and other individuals who take care of them [26]. In the study, individuals who had an organ transplant with a disability report asked whether they could obtain financial aid and whether they could buy a car with tax deduction. It has been seen that individuals try to learn about their rights given to them by the state through social media.

Psychosocial problems after organ transplantation disrupt the compliance of patients and affect the results of treatment [27]. In our study, patients motivated each other and provided psychological support by sharing the positive situations they experienced during the treatment process in Facebook groups. In this context, social media offers the opportunity to provide support to each other for patients who need financial and moral support, and this is thought to be important in the management of the disease.

The 3rd most frequent reason for referral to Facebook groups of patients awaiting organ transplantation, with a rate of 8.6%, was to seek a spouse for cross transplantation. The patients who could easily reach the patients who had similar problems with them through Facebook groups sought a partner to increase their chances of cross-transplantation. In other studies, similar to our study, it has been revealed that social media is used to find donors [9,12,13].

Although the COVID-19 pandemic affects many patient groups, patients with organ transplants have a more severe disease and may be at high risk for poor outcomes. In a study

conducted with patients who underwent solid organ transplantation and were positive for COVID-19 at the beginning of the pandemic, it was determined that 76% of the patients were hospitalized and treated, and 35% of these patients were followed on mechanical ventilators [28]. In our study, patients with organ transplants also shared their experiences during the COVID-19 period in Facebook groups. Especially, ideas were exchanged on how patients with COVID-19 positive went through the process. Patients with COVID-19 have mentioned that their blood values have deteriorated.

In our study, individuals had asked each other whether they were vaccinated and their COVID-19 vaccination preferences. Vaccination is an important practice to prevent infections and the morbidity and mortality they cause. However, the safety, efficacy, and duration of the COVID-19 vaccine response in patients undergoing organ transplantation are unknown, as COVID-19 vaccine trials have not been conducted in this group [29]. In some studies, it has been stated that the vaccine can be administered before transplantation or it can be administered three to six months after transplantation, when immunosuppression reaches its lowest level [29-31]. It is clear that patients' use of Facebook groups is beneficial in terms of eliminating the lack of information and encouraging vaccination. However, it is thought that it is important to

consult scientific information from responsible physicians in reaching accurate and precise information.

Transplant patients are often accompanied by underlying diseases such as hypertension or diabetes, which cause severe transmission of COVID-19 [32]. In our study, individuals who had an organ transplant during the pandemic period and had chronic diseases shared their experiences about whether they started working due to restrictions.

This study has some limitations; only Facebook group accounts of solid organ transplant patients in Türkiye were included in this study. In addition, since other social media platforms are not included in the scope of the study, the results of the study can be generalized to Facebook group accounts of solid organ transplant patients in Türkiye.

Conclusion

This study revealed that organ transplant patients apply to Facebook groups most frequently to seek information/give information, to seek support/provide support, to seek a spouse for organ transplant awaiting cross-transplantation, financial issues and to share experiences related to COVID-19. The posts are seen as an opportunity to share experiences, to seek support/provide support, and help from others with similar experiences.

Conflict of interest: The authors declare that there is no conflict of interest. The authors alone are responsible for the content and writing of the paper. **Financial disclosure:** There is no financial support for this study. **Practice implications:** Unlike most previous studies, posts from organ transplant patients in Facebook groups, a large social media network, were examined. It is thought that this study will contribute to the literature, as it is the first study to show the reasons why patients with organ transplantation apply to social media platforms, on which subjects they share their experiences and lack of knowledge. This study provided the information that social media can be used by health professionals to inform individuals and reduce their anxiety by examining and participating in disease-specific groups.

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