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Fibromyalgia as a Popular Public Health Problem: Analysis of Instagram Posts in Türkiye

Popüler Bir Halk Sağlığı Sorunu Olan Fibromiyalji: Türkiye'deki Instagram Gönderilerinin Analizi

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ABSTRACT Objective: This study aimed to analyse the fibromyalgia (FM) posts shared on Instagram in Türkiye and to raise awareness on this subject. **Material and Methods:** FM-related hashtags (#fibromiyaljisendromu, #fibromyalji, #fibromiyalji, #yumusakdokuromatizması, #yumuşakdokuromatizması, #yumusakdokuromatizmasi, #yumuşakdokuromatizmasi) obtained from Instagram on 07.10.2023 were analysed. For each hashtag evaluated, the "Top 9" and the 30 most recent posts were included in the study. The Global Quality Score (GQS) of the posts was calculated. The type of posts (photo or video), their content, user information, and number of likes and views were evaluated. **Results:** 91 posts were included in this study. 51 (56%) of the posts were photos, and 40 (44%) were videos. 35 (38%) of the posts were shared by physicians, 31 (34%) by non-physician medical staff and 25 (27%) by others. Of the physicians who shared posts, 22 (63%) were physical medicine and rehabilitation (PMR) physicians, and 13 (37%) were physicians of other branches. GQS value was significantly higher in the physician and non-physician medical staff group than in the others ($p<0.05$). Among physicians, the GQS value of posts shared by PMR physicians was significantly higher than the GQS value of other physicians ($p=0.035$). The median GQS value of all posts was 2 (minimum=1, maximum=5). **Conclusion:** This study revealed that Instagram posts were insufficient and of low quality, in line with the needs of patients. It may be important for physicians, especially PMR physicians, to take a greater role and produce high-quality content in line with the needs of patients.

Keywords: Fibromyalgia syndrome; Instagram; social media; Türkiye

ÖZET Amaç: Bu çalışmada, Türkiye'de Instagram'da paylaşılan fibromiyalji (FM) gönderilerini analiz etmek ve bu konuda farkındalığı artırmak amaçlanmıştır. **Gereç ve Yöntemler:** 07.10.2023 tarihinde Instagram'dan elde edilen FM ile ilgili hashtag'ler (#fibromiyaljisendromu, #fibromyalji, #fibromiyalji, #yumusakdokuromatizması, #yumuşakdokuromatizması, #yumusakdokuromatizmasi, #yumuşakdokuromatizmasi) incelendi. Değerlendirilen her hashtag için "Top 9" ve en son 30 gönderi çalışmaya dâhil edildi. Gönderilerin Küresel Kalite Puanı [Global Quality Score (GQS)] hesaplandı. Gönderilerin türü (görüntü veya video), içerikleri, kullanıcı bilgileri, beğeni sayıları ve izlenme sayıları değerlendirildi. **Bulgular:** Bu çalışmaya 91 gönderi dâhil edilmiştir. Gönderilerin 51'i (%56) görüntü, 40'ı (%44) video'dur. Gönderilerin 35'i (%38) hekimler tarafından, 31'i (%34) hekim olmayan tıbbi personel tarafından, 25'i (%27) başkaları tarafından paylaşılmıştır. Gönderi paylaşan hekimlerin 22'si (%63) fiziksel tıp ve rehabilitasyon (FTR) hekimleri iken 13'ü (%37) diğer branş hekimleridir. GQS değeri hekim ve hekim olmayan tıbbı personel grubunda diğerlerinden anlamlı olarak yüksekti ($p<0,05$). Hekimler arasında bakıldığında FTR hekimleri tarafından paylaşılan gönderilerin GQS değeri diğer hekimler tarafından paylaşılan gönderilerin GQS değerinden anlamlı daha yüksekti ($p=0,035$). Tüm gönderilerin medyan GQS değeri 2'ydi (minimum=1, maksimum=5). **Sonuç:** Bu çalışma, hastaların ihtiyaçları doğrultusunda Instagram gönderilerinin yetersiz kaldığı ve kalitesinin düşük olduğunu ortaya koydu. Hekimlerin özellikle FTR hekimlerinin daha fazla rol alarak hastaların ihtiyaçları doğrultusunda ve yüksek kalitede içerikler üretmesi önemli olabilir.

Anahtar Kelimeler: Fibromiyalji sendromu; Instagram; sosyal medya; Türkiye

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The use of social media is gradually increasing and affects people's daily lives very closely. In 2021, the number of social media users worldwide will be approximately 4.20 billion, 53% of the world population.[1] Approximately 90% of young adults aged 16-34 in the UK use social media.[2] Social media platforms are a powerful communication tool that can be used to educate patients and raise public awareness about many diseases and health problems. Social media is changing the nature and speed of healthcare interactions between individuals and healthcare professionals.[3] Social media platforms are a cost-effective and efficient way to create and publish information.

Fibromyalgia (FM) is a very common condition that causes chronic musculoskeletal pain. In North America, approximately 4% of the population lives with FM, a condition characterized by widespread pain and fatigue.[4] Muscle and joint stiffness, insomnia, fatigue, mood disorders, cognitive impairment, anxiety, sadness, diffuse tenderness, and the inability to perform normal daily activities are the main symptoms of this disease.[5] FM is a heterogeneous condition frequently associated with infections, psychiatric or neurological diseases, endocrine diseases such as diabetes, and rheumatic diseases.[6] Some patients with FM cannot be diagnosed because of the complex symptom scale, lack of clinical awareness, and absence of objective diagnostic criteria.[7]

Individuals affected by FM have frequent hospital admissions and benefit continuously from health services.[8] This may be due to the lack of an optimal option in the treatment of FM. FM treatment is controversial, and pharmacological treatment may be inadequate for the majority of FM patients. Considering the different mechanisms of pain sensitivity, treatments should include multidisciplinary programs for peripheral, central, and cognitive-emotional causes of chronic pain in FM.[5]

Individuals diagnosed with FM are concerned about their complaints being perceived as a psychiatric disorder and "feel stigmatised by the medical and nonmedical community alike, especially given that treatment centres on symptom relief rather than the management of a disease process".[9] In a previous study, it was reported that patients with FM used the internet as their main source to access information.[10] However, since the social media environment is an information-oriented open communication channel, it is known that false information can be disseminated as well as correct information.[11]

In this study, we aimed to analyse the FM posts shared in Türkiye on Instagram (Meta Platforms, Inc., United States), a mobile and internet-based application where more than 800 million users can upload a photo or video, follow each other's streams, tag the photos with a location name, and raise awareness on this issue.[12]

MATERIAL AND METHODS

The data for the research was obtained from Instagram on 07.10.2023. Hashtags, which are keywords, were determined to find posts about FM. Multiple hashtags were used to identify posts related to the subject. These are: #fibromiyaljisendromu, #fibromyalji, #fibromiyalji, #yumusakdokuromatizması, #yumuşakdokuromatizması, #yumusakdokuromatizmasi, #yumuşakdokuromatizmasi. The number of posts for each hashtag was recorded. For the analysis, the "Top 9" post set and the last 30 posts of each queried hashtag were evaluated.[13] Instagram automatically generates the "Top 9" post set and the list of the most recent posts with a unique algorithm. It was also recorded, whether the post was a photo or a video.

The posts were analysed in two groups according to whether they were photos or videos. Those who shared the post were divided into three groups: physicians, non-physician medical personnel, and others. If the post was made by a physician, the sharer of the post was divided into two groups: physical medicine and rehabilitation (PMR) and others. The identity information of the users was evaluated according to the information reported on their Instagram accounts or linked websites.

Post content types were divided into four categories: educational, patient experiences, advertising, and humor. If a post contained content suitable for more than one category, it was included in each category separately. Post content was categorized as eti-

ology, diagnosis, symptoms, treatment, and differential diagnosis. In each post mentioned, the treatments mentioned were indicated separately. The Global Quality Score (GQS) of the posts was calculated. GQS is a scoring scale from 1-5. The GQS value is 1 when the content is of low quality, missing most information, poorly flowing and not useful for patients; 2 when the content is of overall low quality, some information is present but many important topics are missing, poorly flowing, and of limited use for patients; 3 when the content is of moderate quality, has sub-optimal flow, some important information is emphasized but others are not, and is useful to some extent for patients; 4 when the content is of good quality and overall good flow, the most relevant information is present but some topics are omitted and is useful for patients; and 5 when the content is of excellent quality and flow and is very useful for patients.[14]

The like numbers for the posts were recorded. If the posts were videos, the number of views was recorded. Repeated posts linked to the same account, posts in a foreign language other than English, irrelevant posts, and posts that did not mention dry sarcasm in their visual or textual content were excluded from the study. The posts were reviewed by Burak Tayyip Dede and Muhammed Oğuz. In controversial posts, Ebru Aytekin and Fatih Bağcıer's opinions were also taken into consideration and joint decisions were reached. All reviewers were physicians.

Due to the public accessibility of Instagram data, it was not subject to assessment by the ethics committee.

STATISTICAL ANALYSIS

Statistical analysis was performed using the IBM SPSS version 22.0 software (IBM Corp., Armonk, IL, USA). Normal distribution was evaluated with kurtosis-skewness values and Kolmogorov-Smirnov/Shapiro-Wilk test. Since normal distribution was not observed, a comparison between groups was performed by the Kruskal-Wallis test. Descriptive values were presented as median (minimum-maximum). p values below 0.05 were considered as statistically significant results.

RESULTS

The "Top 9" and the most recent 30 posts (n=214) were analysed for authorship and content type. Of these posts, 91 met the inclusion criteria. 51 (56%) of the posts were images, and 40 (44%) were short videos. 35 (38%) of the posts were shared by physicians and 31 (34%) by non-physician medical personnel. Others shared 25 (27%) posts. Of the physicians who shared posts, 22 (63%) were PMR physicians, and 13 (37%) were physicians of other branches. Of the short videos, 23 were shared by physicians, 12 by non-physician medical personnel, and 5 by others.

Content analysis of the posts showed that posts with educational messages were the most popular (71.4%, n=65), followed by advertisements (38.4%, n=35). Content analysis of the posts showed that 46 (50.5%) mentioned treatment, 39 (42.8%) mentioned symptoms, 13 (14.2%) mentioned etiology, 8 (8.7%) mentioned diagnosis and only 3 (3.2%) mentioned differential diagnosis. Content analysis showed that eating habits were the most popular of the treatment posts (39.1%, n=18). Exercise was the next most popular (37%, n=17) (Figure 1).

The GQS and like counts of the posts and the number of views of the videos were compared between physicians, non-physician medical staff, and others. The GQS value showed a statistically significant difference between the three groups ($p<0.001$) (Table 1). When analysed pairwise between the groups, the GQS value was significantly higher in the physician and non-physician healthcare personnel

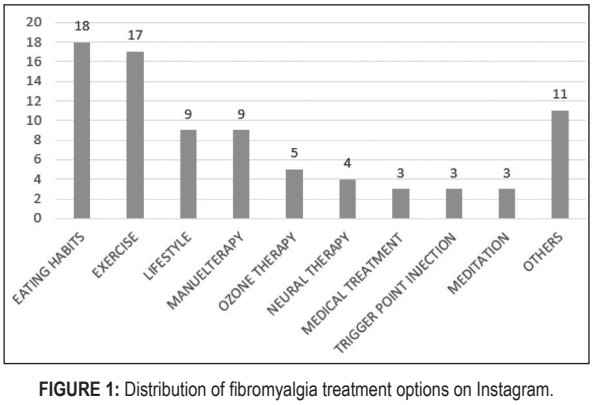

FIGURE 1: Distribution of fibromyalgia treatment options on Instagram.

TABLE 1: Comparison of the post analyses.

	Physicians Median (IQR)	Non-physician medical staff Median (IQR)	Others Median (IQR)	p value
GQS^+	2.0 (1.0)	2.0 (2.0)	1.0 (0.0)	0.000
Like number^*	244 (1,211)	45 (238)	69 (682)	0.002
Number of video views	17,528 (40,762)	10,588 (54,520)	967 (26,3111)	0.966

^The significant difference between physicians and others; +The significant difference between non-physician medical staff and others; *The significant difference between Physicians and non-physician medical staff; IQR: Interquartile range; GQS: Global Quality Score.

groups compared to the others ($p<0.001$, $p<0.001$, respectively). However, there was no significant difference in the GQS value in the physician and non-physician healthcare personnel groups ($p=0.875$). Among physicians, the GQS value of posts shared by PMR physicians was significantly higher than the GQS value of other physicians ($p=0.035$). The median GQS value for PMR physicians and other physicians was 2 (minimum=1, maximum=5) and 1 (minimum=1, maximum=3), respectively. The median GQS value of all posts was 2 (minimum=1, maximum=5).

The like number of posts shared by clinicians was significantly higher than those shared by non-physician medical staff and others ($p<0.05$). Although the number of views of videos shared by physicians and non-physician medical personnel was higher than those shared by others, there was no statistically significant difference ($p>0.05$) (Table 1).

DISCUSSION

In recent years, medical journals have emphasized the importance of social media in disseminating advice on public health information and disease prevention.[15] Although health professionals have been accused of being slow to adopt social media, it has been stated that there is a need to change from traditional models to models driven by social media.[16] Because social media provides patients with a better understanding of their condition and information to cope with their illness. This leads to improvements in the disease and a reduction in complications, thus reducing the cost of the disease.[17]

FM patients use the internet as a source of information to better understand their disease and to have an idea about the management of their disease.[10] This may affect patient management positively or negatively.[18] At this point, having information about the available information about FM on Instagram may benefit healthcare professionals. In a previous study, it was reported that 91% of FM patients used the internet to get information. It was reported that 87% of the patients searched about treatment, 85% about resources, 81% about symptoms, 79% about effects, and 79% about coping methods. However, it was stated that 93% of the participants were skeptical about the reliability of the information.[10] When we look at the data in this study, we see that 46 (50%) of the most popular posts mentioned treatment, and 39 (43%) mentioned symptoms. These results were well below the expectations of the patients. Therefore, if physicians are aware of the issues frequently raised by patients, they can improve the quality of life of patients and prevent unnecessary concerns with appropriate answers and education on this subject.[19]

FM is a syndrome characterized by chronic and widespread musculoskeletal pain, often accompanied by other symptoms including fatigue, bowel disorders, sleep, and mood changes.[6] With the increasing recognition of the validity of FM, it has been underdiagnosed, misdiagnosed, or overdiagnosed. A complete medical history and physical examination are mandatory in the evaluation of a patient with chronic widespread pain to confirm the diagnosis of FM or to differentiate similar symptoms from FMS. A differential diagnosis should be made with simple tests to determine other diseases that may cause similar symptoms and findings.[20] In this study, it was observed that only 8 of the submissions mentioned diagnosis and 3 mentioned differential diagnosis. This may cause patients with similar symptoms to be misled by social media.

In this study, 35 (38%) of the submissions were made by physicians, and 22 (25%) of these were made by PMR physicians. However, it has been reported in a previous study that the diagnosis and management of FM, which may show similar characteristics to many chronic pain syndromes, should be carried out by PMR physicians.[21] However, in this study, the proportion of PMR physicians among those who shared posts on Instagram was quite low. At this point, it may be important for PMR physicians to be more prominent on Instagram.

In a previous study, the content, quality, and readability of Spanish websites providing information about FM were evaluated.[22] In this study, it was stated that the quality of the websites was at a medium-low level, very low in terms of content, and somewhat difficult to read. In addition, it was stated that the content lacked scientific evidence and was out of date.[22] In this study, we evaluated the quality of the posts with GQS. The median GQS value of the posts was 2, which was low. In a study analyzing Instagram posts on chest pain, it was reported that posts shared by physicians and healthcare professionals were more accurate and reliable than others. In this study, the post quality of physicians and non-physician healthcare professionals was higher than others. PMR physicians also had higher post quality than other physicians.

Currently, there is no curative treatment for FM. The main aims of treatment are to reduce symptoms, improve quality of life, and maintain functionality.[23] In a previous review, exercise was reported to be a strong recommendation.[23] In this study, only 17 of 46 posts mentioning treatment mentioned exercise. It was stated that there are no nutritional, supplement, and complementary medicine products for FM, except for achieving target weight and healthy eating. However, this study's most popular posts about treatment were about eating habits.[23,24] Medical agents are frequently used in the treatment of FM. At this point, it was previously reported that FM patients were concerned about the side effects of the drugs used.[19] In this study, we found that medical treatment was mentioned in only 3 of the posts mentioning treatment. Therefore, it would be appropriate to provide accurate evidence-based information about the eating habits that patients are interested in in treatment-oriented posts. It may also be wise to mention points with strong recommendations and points of concern for patients.

Considering the demand of FM patients for the internet about their disease, the evaluation of posts about FM on Instagram, a social media application, made this study special. In addition, this study, which emphasises the need to improve the quality of information about FM on Instagram, may provide feedback for users who post about FM and contribute to the development of strategies for sharing better quality information.

There were some limitations in this study. The Instagram hashtags analysed were only analysed on a specific date and not on different dates, and only posts shared in Türkiye were analysed.

CONCLUSION

In this study, we conducted content analysis by analysing Instagram posts related to FM. This study revealed that Instagram posts were insufficient and of low quality, in line with the needs of patients. Considering the number of likes of the posts and the number of views of the videos, it can be said that the posts made by physicians are more interesting. At this point, it may be important for physicians, especially PMR physicians, to take a greater role and produce high-quality content in line with the needs of patients. These posts on Instagram might be especially helpful for people who have just been diagnosed with FM or are still getting tested by a doctor and may not have enough face-to-face support because their condition is controversial and unclear.[12]

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

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