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Assessing Symptoms and Knowledge Levels among Caregivers of Children Receiving Treatment for Rheumatic Diseases

Romatizmal Hastalık Tanısı ile Tedavi Gören Çocukların Bakım Vericilerinin Hastalıklara Yönelik Semptom ve Bilgi Düzeyinin Belirlenmesi

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ABSTRACT

The study aimed to assess knowledge level of caregivers responsible for children with rheumatic diseases regarding both their symptoms and diseases themselves. This descriptive study, including 115 caregivers of children diagnosed with rheumatic diseases at the pediatric rheumatology outpatient clinic of hospital in the xxxx Region of Türkiye, was conducted between January 20 and June 10, 2023. Data were collected "Participant Information Form" and "Symptoms and Knowledge Level Form for Rheumatic Diseases." In the analysis of the data, number (n), percentage (%), mean, standard deviation, and independent sample t-test were used. The average age of the children was 10.58 ± 4.43 years, Juvenile idiopathic arthritis accounted for 40.9% of the medical diagnoses. The onset of symptoms occurred at 36.13 ± 34.59 months and the treatment duration was 30.04 ± 31.80 months (min: 1 month; max: 156 months). 73% of caregivers were women, mostly mothers, and 59.1% experienced joint pain associated with rheumatic diseases. 81.7% of participants received verbal information or education from their doctor, while 25.2% primarily sought information online (95.4%) due to perceived inadequacy in the provided education. Caregivers who obtained information from the internet demonstrated a higher level of knowledge about the disease compared to those who did not ($p < 0.05$). It is recommended that health professionals implement scheduled and systematic health training sessions for caregivers, and there should be support for academicians, professional organizations in establishing websites aimed at providing accurate information to caregivers about diseases via the internet.

Keywords: Caregiver, Knowledge level, Child, Rheumatic disease, Symptom

ÖZ

Bu çalışmada romatizmal hastalığa sahip çocukların bakım vericilerin romatizmal hastalıklarda görülen semptomlar ve hastalığa yönelik bilgi düzeylerinin belirlenmesi amaçlandı. Çalışma Türkiye'nin xxx Bölgesi'ndeki bir bölge hastanesinin 20 Ocak – 10 Haziran 2023 tarihleri arasında çocuk romatoloji polikliniğinde romatizmal hastalık tanısı alan 115 çocuğun bakım vericisi ile tanımlayıcı tipte yürütüldü. Veriler "Katılımcı Bilgi Formu" ve "Romatizmal Hastalıklara Yönelik Semptomlar ve Bilgi Düzeyi Formu" kullanılarak toplandı. Verilerin analizinde sayı (n), yüzde (%), ortalama, standart sapma ve bağımsız gruplarda t testi kullanıldı. Çocukların yaş ortalaması 10,58 ± 4,43 yıl olup, tıbbi tanıların %40,9'unu juvenil idiyopatik artrit oluşturmaktadır. Semptomların başlangıcı 36,13 ± 34,59 ayda gerçekleşmiş olup, tedavi süresi 30,04 ± 31,80 aydır (min: 1 ay; maks: 156 ay). Bakım verenlerin %73'ü kadınlardan oluşmakta olup, çoğunluğu annelerden oluşmaktadır ve %59,1'i romatizmal hastalıklarla ilişkili eklem ağrısı yaşamaktadır. Katılımcıların %81,7'si doktorlarından sözel bilgi veya eğitim alırken, %25,2'si sağlanan eğitimin yetersizliği nedeniyle öncelikle çevrimiçi olarak bilgi aramıştır (%95,4). İnternetten bilgi edinen bakım verenler, almayanlara kıyasla hastalık hakkında daha yüksek düzeyde bilgi sahibi olduklarını göstermiştir ($p < 0,05$). Sağlık profesyonellerinin bakım verenlere yönelik planlı ve sistemli sağlık eğitimleri düzenlemeleri, bakım verenlere internet üzerinden hastalıklar hakkında doğru bilgi vermeyi amaçlayan web sitelerinin oluşturulması konusunda akademisyenler ve meslek örgütlerinin desteğinin sağlanması önerilmektedir.

Anahtar Kelimeler: Bakım verici, Bilgi düzeyi, Çocuk, Romatizmal hastalık, Semptom

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The study adhered to ethical guidelines, obtaining approval from the xxxxxxxx Scientific Research Ethics Committee (Decision No. E-24237859-386).

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INTRODUCTION

Chronic diseases encompass a range of conditions causing ongoing functional disruptions, curtailing daily life activities, and persisting over extended periods. [1-3] While commonly associated with the elderly, these conditions are prevalent among children as well. [4] Studies indicate that in the United States, one in every five children, and in China, 200 million children, suffer from chronic disorders leading to recurrent pain and limitations in daily activities. [5, 6] Some of the most common chronic diseases, especially in school-age children in Turkey, are asthma, cancer, cystic fibrosis, cerebral palsy, chronic renal failure, malnutrition, diabetes, cancer hypertension and epilepsy. [7-9] In addition, it is known that 698,406 children between the ages of 0-19 have chronic diseases in Turkey.[10] Rheumatic diseases are chronic musculoskeletal and vascular disorders characterized. by persistent pain, stiffness, inflammation, and long-term structural impacts on various organs, significantly impeding quality of life. [11-13] Among children and adolescents, juvenile idiopathic arthritis (JIA) stands as the most prevalent rheumatic disease. [14] Research conducted in Türkiye highlights the prevalence of JIA at 64/100,000 and familial Mediterranean fever (FMF) at 1/1000, particularly prominent among children residing in the Black Sea Region. [10, 15]

Early diagnosis and appropriate treatment play a crucial role in managing childhood rheumatic diseases to prevent potential complications, including severe organ involvement and joint amputations in the future. [9, 10, 16] Caregivers are often the first to identify symptoms related to these diseases, follow the physician’s instructions in the treatment process, and actively participate in providing necessary care for children. [16] Therefore, a key strategy in managing childhood rheumatic diseases is ensuring that caregivers possess sufficient knowledge about the condition. [17] Despite the prevalence of rheumatic diseases in children in the Black Sea Region of Türkiye [15], there is a notable gap in research regarding the level of knowledge among caregivers of children with rheumatic diseases about the symptoms of the condition in this region. Understanding the symptoms and having adequate knowledge about these diseases is critical for caregivers to contribute effectively to preventing future complications related to childhood rheumatic diseases. Given this gap in research, this study aims to assess the level of knowledge among caregivers of children with rheumatic diseases regarding both the symptoms and general knowledge about these conditions.

MATERIALS AND METHODS

Study Design

The study was conducted in descriptive type.

Population, Sample, and Sampling Method

The study population comprised 150 patients with rheumatological diseases and their respective caregivers who were under the care of the pediatric rheumatology outpatient clinic at a tertiary care regional hospital in the xxxxx Region.

The sample size was determined to be 109 patients, calculated with 95% power and a 5% type I error, utilizing the OpenEpi program with the universal sampling method.

The study was ultimately conducted with 115 caregivers who visited the outpatient clinic between January 20 and June 10, 2023. Participants were required to have no visual, auditory, or perceptual impairments and voluntarily express their willingness to partake in the study.

Data Collection

Data collection involved face-to-face interviews conducted in the pediatric rheumatology outpatient clinic room, utilizing two forms: the “Participant Information Form” and the “Symptoms and Knowledge Level Form for Rheumatic Diseases.”

The Participant Information Form Researchers designed this form in line with existing literature to gather information on key characteristics of both the child and the caregivers, like age, gender, medical diagnosis of the child, onset duration of symptoms and treatment, as well as the age, gender, education level, and relevant knowledge about rheumatic diseases for the caregivers.[6-9]

The Symptoms and Knowledge Level Form for Rheumatic Diseases

The form has two parts. In the first part, caregivers’ knowledge about symptoms related to rheumatic diseases was assessed.[10-15] Responses were categorized as “yes,” “no,” or “no idea.” In the second part, caregivers’ overall knowledge about rheumatic diseases was evaluated using 15 questions. Face validity was ensured by consulting two measurement and evaluation experts, while content validity involved the input of five experts. The content validity index was determined to be 0.897 using the Lawshe technique. To assess the comprehensibility of the knowledge test created for caregivers, a pilot study was conducted with five caregivers diagnosed with rheumatic diseases and undergoing treatment in the relevant hospital. These caregivers were not included in the main study. Following their participation, feedback was gathered, and the comprehensibility of the questions was re-evaluated. Some questions were reorganized based on the feedback received. The finalized form was structured to have a single correct answer determined by the researchers for each question. Responses were categorized as “yes, no, or don’t know”. A scoring system was implemented, where the correct answer received “1” points, while incorrect and “Don’t know” answers were assigned “0” points to be used in the statistical analysis. The highest and lowest scores to be taken on the knowledge test are 0 and 15. Participants’ knowledge levels were categorized based on their scores: low: 0-5 points; moderate: 6-10 points; and high: 11-15 points.[10-15]

Ethical Considerations

The study adhered to ethical guidelines, obtaining approval from the xxxxxxxx Scientific Research Ethics Committee (Decision No. E-24237859-386). In order to conduct the study, institutional permission was obtained from xxxxxxxx (Decision No. E-44710342-044-7051).Caregivers were verbally informed about the study’s purpose, and their verbal and written informed consent was obtained prior to data collection. The study was conducted in accordance with the Declaration of Helsinki.

Statistical Analysis

The data underwent analysis using SPSS 22 software for Windows version 22.0. The normal distribution of the data was assessed through the Kolmogorov-Smirnov test. Descriptive statistics, including number (n), percentage (%), mean, and standard deviation, were employed. The independent sample t-test was utilized for data analysis, with statistical significance set at $p<0.05$.

RESULTS AND DISCUSSION

The child’ mean age was 10.58±4.43 years (min: 2/max: 15), with 55.7% being girls. 40.9% had a medical diagnosis of juvenile idiopathic arthritis (JIA), and 15.7% had at least one comorbidity, primarily uveitis (42.9%). The duration of disease-related complaint onset was 36.13 ± 34.59 months (min: 3 months; max: 168 months), and the treatment duration was 30.04 ± 31.80 months (min: 1 month; max: 156 months). Notably, 42.6% experienced a disease-related attack in the past year (58%), 87% attended school, and school-going children were absent for an average of 19.43 ± 25.59 days (min: 2/max: 90) annually due to disease-related complications, 12.2% received psychiatric supportive treatment, and 80% attended hospital controls regularly (Table 1).

Table 1. Sociodemographic Characteristics of Children

Features	n	%
The child' mean age	10.58±4.43 (min:2/maks:15)	
Gender		
Female	64	55.7
Male	51	44.3
Medical diagnosis		
IgA Vasculitis	27	23.5
PFAPA syndrome	12	10.4
JIA	47	40.9
Systemic Lupus Erythematosus	4	3.5
FMF	25	21.7
The duration of disease-related complaint onset (months)	36.13±34.59 (min:3 / maks:168)	
The treatment duration (months)	30.04±31.80 (min:1 / maks:156)	
Comorbidity		
Yes	18	15.7
No	97	84.3
If your answer is yes, comorbid disease		
Üveitis	5	35.7
FMF	1	7.1
Autism spectrum disorder	2	14.3
Other*	10	53.9
Attended school		
Yes	100	87.0
No	15	13.0
Average number of absences of children attending school (days)	19.43± 25.59 (min:2 / maks: 90)	
Having had a disease-related attack in the past year		
Yes	49	42.6
No	66	57.4
If your answer is yes, how many attacks?		
Once	28	58.3
Twice	13	27.1
Three times or more	8	25.6
Psychiatric supportive treatment		
Yes	14	12.2
No	101	87.8
Regular visits to controls		
Yes	92	80.0
No	23	20.0

JIA: Juvenile Idiopathic Arthritis, **FMF:** Familial Mediterranean Fever. *: hypertension, asthma, chronic renal failure.

Presents the sociodemographic characteristics of the caregivers. The caregivers' mean age was 40.06+5.94 (min:27/maks:62), 73% of caregivers were female and the mothers of the children. 49.6% had primary education, and 25.2% had a monthly income below the minimum wage. Additionally, 44.3% had a relative diagnosed with osteoarthritis (37.3%). 81.7% of caregivers received verbal information or education from their doctor about their child's disease. However, only 25.2% of those who received information believed that the education provided was sufficient. Among those who found education insufficient, 95.4% attempted to supplement their knowledge by searching on the Internet. Concerning specific areas of information, 79.3% of caregivers felt they lacked knowledge about the side effects of drugs, 76.7% about regular drug use, and 62.8% about joint protection. Additionally, 80.2% expressed a desire for information or training about the side effects of drugs, 75.6% about regular drug use, and 69.8% about the approach to pain (Table 2).

Table 2. Sociodemographic Characteristics of Caregivers

Features	n	%
The caregivers' mean age	40.06±5.94 (min:27 / maks:62)	
Gender		
Female	84	73.0
Male	31	27.0
Level of intimacy		
Mother	84	73.0
Father	31	27.0
Education level		
Literate	7	6.1
Primary education	57	49.6
High school and above	51	44.3
Income rate		
Income less than expenses	29	25.2
Equal income and expenses	43	37.4
Income more than expenses	43	37.4
The presence of another person with rheumatic disease in the family		
No	64	55.7
Yes	51	44.3
Mother/father	19	37.3
Sister/brother	16	31.4
Other*	16	31.4
If your answer is yes, the medical diagnosis		
Osteoarthritis	19	37.3
FMF**	18	35.3
Other***	14	27.4
Receipt of information or education about the disease		
Yes	94	81.7
No	21	13.8
Person from whom information was obtained		
Doctor	94	100.0
Satisfaction with the information or education		
Yes	29	25.2
No	86	74.8
If your answer is no, where did you get the information****		
Internet	83	95.4
Other patient relatives	21	24.1
Television	41	47.1
Social media	40	46.2
Topics thought to be lacking information****		
Regular drug use	66	76.7
The side effects of drugs	69	79.3
About joint protection	54	62.8
Time for warm/cold applications	38	44.2
Exercises that can be done	39	45.3
Approach to pain	50	58.1
Treatment duration	36	41.9
Subjects on which you would like to receive information or training		
Regular drug use	65	75.6
The side effects of drugs	69	80.2

About joint protection	59	68.6
Time for warm/cold applications	46	53.5
Exercises that can be done	48	55.8
Approach to pain	60	69.8
Treatment duration	55	64.0

*: Aunt, uncle, cousin, **: Familial Mediterranean Fever, ***: Fibromyalgia, rheumatoid arthritis, ankylosing spondiot, Systemic lupus erytomatosus. ****: More than one option is marked.

Table 3 illustrates caregivers' understanding of symptoms associated with rheumatic diseases. It was determined that 59.1% of participants recognized pain in the joint area, 53.0% identified swelling in the joint area, and 51.3% acknowledged fatigue as a symptom of rheumatic diseases. Conversely, 34.8% believed that enlargement of the spleen/liver, 32.2% weakness in the arms/legs, and 30.4% wounds in the genital area and blood in the feces were not indicative of rheumatic diseases. It was found that 65.2%, 63.5%, and 62.6% of the participants were not aware that dry eyes, difficulty swallowing and chewing food, and dry mouth symptoms could manifest in rheumatic diseases (Table 3).

Table 3. Caregivers' Knowledge of the Symptoms of Rheumatic Diseases

Symptoms	**Yes**		**No**		**No idea**	
	n	**%**	**n**	**%**	**n**	**%**
Pain in the joint area	68	59.1	12	10.4	35	30.4
Swelling in the joint area	61	53.0	18	15.7	36	31.3
Weakness	59	51.3	12	10.4	44	38.3
Fatigue	52	43.2	15	13.0	48	41.7
High fever	49	42.6	19	16.5	47	40.9
Redness in the joint area	48	41.7	19	16.5	48	41.7
Weight loss	42	36.5	20	17.4	53	46.1
Bruising on hands in cold weather	37	32.2	21	18.3	57	49.6
Difficulty in movement	36	31.3	26	22.6	53	46.1
Skin rash	29	25.2	24	20.9	62	53.9
Abdominal pain	29	25.2	31	27.0	55	47.8
Pain in the muscles	29	25.2	34	29.6	52	45.2
Pain in legs	26	22.6	32	27.8	57	49.6
Wounds in the mouth	25	21.7	26	22.6	64	55.7
Chest pain	21	18.3	34	29.6	60	52.2
Hair loss	20	17.4	32	27.8	63	54.8
Changes in nails	19	16.5	34	29.6	62	53.9
Back pain	19	16.5	30	26.1	66	57.4
Seızure after hıgh fever	18	15.6	30	26.1	67	58.3
Weakness in the arms/legs	16	13.9	37	32.2	62	53.9
Wounds in the genital area	15	13.0	35	30.4	65	56.5
Difficulty swallowing	14	12.2	28	24.3	73	63.5
Dry mouth	14	12.2	29	25.2	72	62.6
Blood in the ürine	13	11.3	33	28.7	69	60.0
Swelling in lymph nodes	13	11.3	33	28.7	69	60.0
Dry eyes	12	10.4	28	24.3	75	65.2
Blood in the feces	11	9.6	35	30.4	69	60.0
Difficulty swallowing and chewing food	10	8.7	32	27.8	73	63.5
Enlargement of the spleen	9	7.8	40	34.8	66	57.4
Enlargement of the liver	8	7.0	40	34.8	67	58.3

*: More than one option is marked

Table 4 outlines the caregivers’ knowledge about rheumatic diseases. The caregivers’ total score on the knowledge test averaged 7.56 ± 3.45 (min: 0; max: 15). The distribution of knowledge levels revealed that 28.7% of caregivers had a low level, 51.3% had a moderate level, and 20% had a high level of knowledge. Only 54.8% of participants were aware that rheumatic diseases are chronic, 53.1% knew about the necessity of a salt-free diet due to the drugs used in treatment, and 44.3% were aware that rheumatic diseases could damage organs such as the lungs and heart (Table 4).

Tablo 4. The Caregivers’ Knowledge About Rheumatic Diseases

Questions	**Yes**		**No**		**I dont know**	
	n	**%**	**n**	**%**	**n**	**%**
Genetic tests are required for some rheumatic diseases.	79	68.7	6	5.2	30	26.1
If there is rheumatic disease in your family, it may occur in you too	72	62.6	17	14.8	26	22.6
Infectious diseases can cause rheumatic diseases	71	61.7	9	7.8	35	30.4
Stress factor can cause rheumatic diseases	67	58.3	14	12.2	34	29.6
Rheumatic diseases are chronic diseases	63	54.8	15	13.0	37	32.2
A salt-free diet is due to some drugs used in treatment.	61	53.1	12	10.3	42	36.6
Rheumatic diseases could damage organs such as the lungs and heart	51	44.3	25	21.7	39	33.9
Smoking in the family is a risk factor for rheumatic diseases	43	37.4	25	21.7	47	40.9
Consanguinity marriages increase the incidence of some rheumatic diseases.	40	34.8	22	19.1	53	46.1
Rheumatic diseases are treated with analgesia and muscle relaxants.	28	24.3	42	36.5	45	39.1
Rheumatic diseases are more common in children with obesity	24	20.9	37	32.2	54	47.0
Rheumatic diseases only damage the joints.	21	18.3	54	47.1	40	34.6
In the treatment of rheumatic diseases, using only drugs is sufficient.	14	12.2	43	37.4	58	50.4
Rheumatic diseases are contagious.	13	11.3	78	67.8	24	20.9
Rheumatic diseases are women's diseases, they are not seen in men	12	10.4	82	71.3	21	18.3
Total score on the knowledge test averaged: 7.56+3.45 (min: 0 /maks:15)						

Table 5 explores the relationship between certain caregiver characteristics and their level of knowledge about rheumatic diseases. No statistically significant differences were found based on the gender of the caregivers, the presence of another person with rheumatic disease in the family, regular visits to controls, receipt of information or education about the disease, and satisfaction with the information or education ($p>0.05$). However, caregivers who obtained information about the disease from the Internet demonstrated a higher level of knowledge about rheumatic diseases ($p<0.05$) (Table 5).

Tablo 5. Comparison of the Relationship Between Some Characteristics of Caregivers and Their Level of Knowledge About Rheumatic Diseases

Features	Knowledge level means ranks	t; p
Gender		
Female	7.57±3.43	p: 0.975[a]
Male	7.54±3.56	
The presence of another person with rheumatic disease in the family		
Yes	8.01±3.08	p:0.209[a]
No	7.20±3.70	
Regular visits to controls		
Yes	7.43±3.54	p:0.420[a]
No	8.08±3.08	
Receipt of information or education about the disease		
Yes	7.78±3.32	p: 0.145[a]
No	6.57±3.90	
Satisfaction with the information or education		
Yes	7.92±3.45	p: 0.786[a]
No	6.05±3.32	
Obtained information about the disease from the Internet		
Yes	7.77±3.41	**p: 0.034[a]**
No	4.00±3.36	

a: Independent-Samples T test

The insufficient knowledge of caregivers regarding the symptoms of rheumatic diseases and their overall understanding of the disease can cause to delays in seeking medical care, overlooking changes during the disease progression, and providing inadequate care during the treatment process. [14, 16] This study aimed to assess the knowledge level of caregivers whose children were diagnosed with rheumatic diseases in the Black Sea Region of Türkiye regarding the disease. Consistent with the study's findings, JIA emerged as the most prevalent rheumatic disease in children. This aligns with existing literature, where JIA is frequently identified as the most common rheumatic ailment in the pediatric population. [13, 16, 18, 19] Failure to diagnose rheumatic diseases, especially JIA, in their early stages may lead to joint damage, chronic pain, and disability. [20] Consequently, children with rheumatic diseases require more intricate care due to potential disabilities and activity limitations as they age. [13] This circumstance emphasizes the growing need for caregivers to acquire comprehensive information about rheumatic diseases. In line with the study's results, it was observed that a significant number of caregivers turned to the Internet for additional information, indicating dissatisfaction with the education provided by healthcare professionals. Despite receiving verbal information and education from doctors about their child's disease, caregivers sought supplementary knowledge online. This highlights the importance of addressing caregivers' informational needs to enhance their understanding of rheumatic diseases and ensure better care for children with these conditions. Furthermore, the study revealed that caregivers expressed a desire for education on various aspects, including information about the side effects of medications, regular usage, and an approach to pain. Woolnough et al. also found that caregivers were predominantly interested in information regarding the regular use and side effects of drugs. Similarly, a study by Correll et al. in the USA identified a desire for information about drug side effects, disease-related attacks, and the etiology of the disease. [21, 22] Correspondingly, a study involving patients and caregivers in the Netherlands indicated a preference for education about drug treatment and pain management, and in another study conducted with children diagnosed with rheumatic diseases in the United Kingdom, children expressed a primary interest in learning about new treatment methods and drug usage. [23, 24] In the context of rheumatic disease diagnosis, caregivers play a pivotal role as observers of their children's symptoms, actively contributing to the early detection of the disease. Despite this crucial role, the study found that only half of the caregivers were aware that rheumatic diseases are characterized by symptoms such as joint pain, swelling, and weakness, and a significant proportion lacked knowledge about various symptoms associated with these diseases. A similar trend was noted in a study conducted in Saudi Arabia, where participants demonstrated limited awareness of symptoms related to rheumatic diseases, with pain being the most commonly recognized symptom, while other symptoms remained largely unknown. [25] Moreover, some studies have indicated that caregivers often initially seek assistance from orthopedics and dermatology outpatient clinics when observing symptoms such as joint pain, swelling, and skin rashes in their children. [14, 26] Consistent with the findings of our study, it was identified that an average of six months elapsed between the onset of disease-related symptoms in children and the time of diagnosis and initiation of treatment. Recognizing that failure to diagnose rheumatic diseases early can lead to organ involvement, growth deformities, visual impairment, and joint damage-related amputations. [20, 27] Given these implications, health professionals should design and implement health education programs focusing on rheumatic diseases and their associated symptoms, particularly targeting caregivers of children with rheumatic diseases. The evaluation of caregivers' knowledge about rheumatic diseases, conducted through a questionnaire developed by the researchers, revealed that participants generally possessed a moderate level of knowledge. Unlike our study, community-based investigations in Egypt, Syria, the Netherlands, and Portugal found that a majority of participants lacked sufficient knowledge about rheumatic diseases. [12, 28-30] This disparity may be attributed to the fact that our study specifically involved participants with children diagnosed with rheumatic diseases, ensuring regular check-ups and a prolonged duration of follow-up, which likely contributed to a better-informed caregiver population. Furthermore, the use of different questionnaires to measure participants' knowledge levels could contribute to variations in the observed knowledge levels. The study findings indicated that the gender of caregivers did not significantly impact their knowledge about rheumatic diseases. This contrasts with numerous community-based studies where women generally exhibited higher knowledge levels than men. [12, 26] Additionally, receiving information or education about the disease from physicians did not significantly affect caregivers' knowledge levels in our study. In contrast, existing literature suggests that training provided to caregivers of children with chronic diseases can enhance their knowledge about the respective conditions. [1-3, 27] This discrepancy may stem from the nature of the education provided, which might not be verbal or implemented according to a structured plan. Given the demanding work conditions of physicians, patients often consult health personnel only during scheduled check-ups. A noteworthy finding from the study was that caregivers sought additional information on the Internet when they found the provided training insufficient. Significantly, caregivers who obtained information through the Internet demonstrated a statistically higher level of knowledge about rheumatic diseases. The increasing use of the Internet and social media has contributed to a rise in individuals seeking information about specific health conditions. In a qualitative study conducted by des Bordes et al. involving patients diagnosed with rheumatoid arthritis, it was observed that participants frequently turned to the Internet to gather information about their diseases. [31] Koçyiğit et al. similarly found that patients diagnosed with ankylosing spondylitis used Internet sources, particularly YouTube, to acquire information about exercises, and they generally considered these sources reliable. [32] In alignment with our study, Gordon et al. discovered in their research that individuals with rheumatic diseases sought information from the Internet, often learning new information previously unknown to them, and perceived obtaining information from the Internet as more convenient than consulting healthcare professionals. [33] The findings collectively highlight that a significant proportion of patients with chronic diseases, especially in developed countries, choose to obtain information through the Internet due to its accessibility and convenience.

CONCLUSION AND RECOMMENDATIONS

The results obtained from the study underscore the pivotal role of Internet use as a valuable source of health-related information. In conclusion, the study revealed that a significant number of caregivers whose children were diagnosed with JIA lacked awareness of the symptoms of the disease, and an average of six months elapsed between the diagnosis and the initiation of the treatment process. Furthermore, most caregivers demonstrated a moderate level of knowledge about rheumatic diseases, and those who sought information from the Internet exhibited a higher level of knowledge. To address these findings, health professionals must provide systematic and targeted health education to caregivers, focusing on potential complications associated with rheumatic diseases, particularly the use of medications. Additionally, there should be support for academicians and professional organizations to establish websites that serve as reliable sources of information for caregivers seeking accurate and comprehensive details about their children's diseases on the Internet.

Limitations of the study

The only limitation of the study is that it was conducted with a patient population from a specific region of Türkiye. Therefore, the finding cannot be generalized

Conflict of Interest

The authors declare that they have no conflict of interest.

Funding Declaration

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Author Contributions

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