

Original Article

Lives with Pain: Pain-Related Experiences of Ankylosing Spondylitis Patients

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Abstract

Background: One of the most serious and common problems experienced by patients with ankylosing spondylitis is pain. Pain is an important problem that negatively affects people's quality of life.

Aim: This study was conducted to determine the experiences of patients with ankylosing spondylitis about pain shared on Facebook.

Methods: In this study, qualitative phenomenological research design was used. The study was conducted through a comprehensive review of groups on Facebook that included patients with ankylosing spondylitis. Each comment with "pain", "ache" and "soreness" in the groups was included in the analysis.

Results: A total of 1,152 posts containing this words were reached. After the analysis, three themes were formed: "seeking before diagnosis and helplessness", "the effect of pain on activities of daily living" and "factors that increase or decrease pain and methods used in pain management".

Conclusions: The patients with ankylosing spondylitis shared various posts about the disease and its management from social media groups. The most common symptom experienced and asked by individuals is pain, and individuals are struggling to adapt to life with pain. Communicating with people who have had similar experiences could make individuals feel that they are not alone and can provide psychological relief. Moreover, it may create awareness in eliminating the factors that do not attract the attention of the individual and increase the severity of their pain. However, it is important to obtain expert opinions about the methods to be used to prevent complications.

Keywords: Ankylozon spondylitis, Facebook, nursing, pain, pain management

Introduction

Ankylosing Spondylitis (AS) is an autoimmune, inflammatory and rheumatic disease that can affect the spine and sacroiliac joints, causing back pain, joint stiffness and a decrease in quality of life (Liang et al., 2021). Clinical symptoms of the disease include back pain and progressive spinal stiffness, as well as inflammation of the hips, shoulders, peripheral joints, and fingers/toes (Zhu et al., 2019). One of the most serious and common problems experienced by patients with AS is pain (Kim et al., 2020; Zhou et al., 2021). It is stated that 16-54% of AS patients with chronic low back pain experience neuropathic pain (Kim et al., 2020). Although 75% of the

patients admitted to the hospital with the complaint of low back pain, it is also stated that they have difficulty in localizing the pain due to the blunt character of the pain. Since the pain felt especially at night does not decrease with rest, it causes patients to feel the desire to move (Li et al., 2012). In studies, the presence of pain in individuals with AS has been revealed (Kim et al., 2020; Zhou et al., 2021) and the effects of these pains on various aspects of individuals' lives have been investigated (Liu et al., 2020; Ogdie et al., 2019).

With the increase in digitalization, it is seen that the use of information obtained from the internet and social media groups in the control

of the disease and its symptoms has increased (Suarez-Lledo & Alvarez-Galvez, 2021). However, social media is not only used to research disease information and share disease experiences. Individuals also use these tools for different purposes such as getting suggestions about healthy living and making the right decisions about hospitals and doctors (McNab, 2009). Social media platforms have become a powerful educational resource in the digital age. These platforms have become an environment that helps individuals use their health information and make decisions regarding their subsequent health behaviors (Dudley et al., 2019). With social media, people in different continents can communicate with each other (Talaue et al., 2018). There are many social media groups that enable AS patients to communicate and exchange information with each other. Patients in these social media groups share their disease experiences and problems. Therefore, in this study, it was aimed to determine the experiences of AS patients about pain shared on Facebook, one of the most used social media networks. In the literature, a limited number of studies have been found that qualitatively evaluate both the level of complaints related to pain and methods of coping with pain in individuals with AS (Alhabeeb, 2021). Moreover, in today's world where social media is used at a high level, it is thought that knowing what the posts of individuals with AS in these groups are will give important messages to health professionals on many issues such as health protection, disease and management.

Research questions:

- What are the pain experiences of individuals with AS?
- What is the effect of these pains on their daily living activities?
- How do individuals with AS cope with these pains?

Method

Study design: This study was conducted based on phenomenological approach to reveal the pain-related experiences and the meanings hidden in the experiences of the individuals diagnosed with Ankylosing Spondylitis. Phenomenology is a qualitative research method that allows people to express their understanding, feelings, perspectives

and perceptions about a particular phenomenon or concept and is used to describe how they experience that phenomenon (Creswell & Creswell, 2018). Phenomenology has been preferred because it provides a suitable research ground for studies aiming to investigate cases that we frequently encounter on a daily basis, but that we do not fully understand and do not know about the problems they cause (Tekindal & Uguz Arsu, 2020). The Consolidated Criteria for Reporting Qualitative Research checklist was followed during the study (Tong et al., 2007).

Participants: The study was conducted with a comprehensive examination of groups including AS patients on Facebook, one of the most frequently used social media platforms. Purposive sampling method was used in sample selection. Facebook groups with members from different countries of the world were selected to ensure the representativeness and data saturation of the sample. The inclusion criteria were as follows: (1) Groups established on behalf of Ankylosing Spondylitis patients, (2) having at least 10 members, (3) groups that have been sent posts about pain. Groups were searched with the keyword "ankylosing" between November and December 2022. Around 200 groups were found worldwide, including AS patients. In qualitative studies, it is accepted that the data are saturated if the new participants in the sample repeat the previously mentioned concepts without revealing new themes (Kyngäs vd., 2019; Sandelowski, 1995). For this reason, the research was terminated when it was determined that new concepts and themes did not emerge in the newly joined groups. The study was carried out on the posts in 26 groups that are open to everyone or become a member.

Data collection: In January 2023, the groups were searched with the keywords "pain", "ache" and "soreness" by the first author and an observer other than researchers. These two individuals conducted the search independently of each other. In this study, the posts made by individuals in Facebook groups in the last five years were included in the research. Each comment with "pain", "ache" and "soreness" was included in the scope of the research. However, the posts on the individual pages of patients with AS were not included in the study. In order to facilitate re-

checking the data, coding was done by writing the name of the group and the date of the posts. After independent scanning, the data were compared and the deficiencies were corrected. The first researcher completed her doctorate in nursing. She is an instructor at a Health Sciences Faculty. She has conducted and published multiple qualitative studies before.

Data analysis: Colaizzi's seven-stage method was used in the analysis of the data. Colaizzi's method is a structured data analysis method to help participants identify and address the meanings of experiences by identifying key themes between their narratives and allows for rigorous analysis (Colaizzi 1978). In the first stage, the transcript in which the data was recorded was read multiple times and the data was recognized. In the second and third stages, all expressions directly related to the phenomenon were identified and the meanings were formulated by careful evaluation of these expressions. In the fourth stage, common themes were formed from the defined meanings. The formulated meanings are grouped into clusters of 3 common themes and 8 sub-themes. In the fifth step, the basic structure of the pain-related experiences of individuals with AS is defined. At the last stage, transcripts, themes and sub-themes were sent to two experts and their opinions were taken.

Rigour and trustworthiness: The criteria used in qualitative research for ensuring reliability of the research and rigour of the results are credibility, dependability, confirmability, and transferability (Speziale et al., 2011). In this study, various measures were taken by the researchers to minimize or eliminate the factors that threaten the validity and reliability (Creswell and Miller 2000). Social media platforms are a natural environment that allows individuals to express their experiences and feelings clearly. It is thought that real experiences are reached by collecting the research data from this natural environment and this is important in ensuring the internal validity of the qualitative data obtained in the research. The participants of the research were formed from groups of suitable individuals who would contribute to the purpose of the research. To ensure reliability, the researchers independently read the transcripts repeatedly and classified the

expressions. In order to increase the reliability of the data, direct expressions were used depending on the originality of the data. In providing external validity, the research model, study group, data collection, data analysis and how the findings were organized are explained in detail. Since the Facebook groups included in the research were examined in detail and the accessed correspondence was recorded, the internal reliability was tried to be increased by preventing the loss of the data obtained. The data were read independently by two researchers. In addition, the themes and sub-themes created during the content analysis were checked by two experts and researchers. While creating the themes, a consensus was reached among the researchers. For ensuring dependability, all translated transcripts were reviewed by two bilingual experts fluent in English and Turkish who were experienced in qualitative research and were aware of the subject of the study.

Ethical consideration: The data to be obtained from this research were obtained from publicly available sources without interacting with any institution, organization, or person. Researchers applied to the University Ethics Committee to obtain ethics committee approval. However, since the data were obtained from publicly available sources, it was stated that the study could be conducted without the approval of the ethics committee (2022/244). While participating in the groups, the purpose of the research was explained. The names of individuals were never included in the data, their information was kept confidential.

Results

The AS groups investigated were established between 2009 and 2023 and have 71,864 members. When a search was made with "pain", "ache" and "soreness" in the "search within the group" section, a total of 1,152 posts containing this words were reached. The participants used this social media network to get information from each other about the disease, to share each other's experiences, to share their experiences about drugs, non-drug methods and their effects used in disease and pain management.

The questions that individuals frequently ask each other are listed below.

- What kind of disease is AS?
- Does everyone experience intense pain?
- Which doctor should I go to?
- What should I eat and what should I not eat?
- Is thermal water good?
- Does your pain increase/decrease when you use things that will strengthen your immunity?
- Should I have cupping and leech therapy?
- Is it okay if I use antidepressants?
- Are shortness of breath and chest pain due to this disease?

Theme 1. Seeking before diagnosis and helplessness

Although most of the individuals experience many symptoms in AS, they stated that the diagnosis and initiation of appropriate

treatment for the disease is too late. Some participants even stated that the symptoms were confused with other diseases and that they received ineffective treatments for the wrongly determined disease. In fact, some individuals stated that it took many years for the correct diagnosis to be made. In this process, individuals stated that they experienced helplessness and boredom.

“The diagnosis of AS was made last year. But I had pain for 20 years. The diagnosis has just been made. They called it the beginning of hernia and dismissed it.” (P1)

Theme 2. The effect of pain on activities of daily living

Individuals with AS stated that they experience severe pain due to the disease and that these pains affect them physically, psychologically and socially. Table 1 shows the metaphors that individuals frequently use for the pain they experience.

Table 1. Metaphors frequently used by individuals for the pain they experience

Metaphors	Expressions of Individuals
Stone	<ul style="list-style-type: none"> • I have pain in my rib cage, it is as if a stone has been tied to my chest, my breathing is difficult. What should I do? • What other drug should I take? Starting from the hips all the way down to my fingers, I'm like a stone. • I have been experiencing cramping pain from the hip to the fingers for 1 month. I've been petrified.
Magnet	<ul style="list-style-type: none"> • It's like my body is in pain like a magnet.
Rolling pin	<ul style="list-style-type: none"> • It's like I swallowed a rolling pin. I can't make sudden movements. From my back to my hips, the parts of my chain bone are held, I cannot bend.
Like a truck hit	<ul style="list-style-type: none"> •why do I feel like I got hit by a truck? Fatigue and pain radiating almost throughout the body.
Like a dog bite	<ul style="list-style-type: none"> • It's always the same pain whether I lie down or stand up or sit. It's like a dog has bitten its teeth and it doesn't leave the left side of my waist.
Electric shock	<ul style="list-style-type: none"> • I have pain all over. Something happens in my feet, in my hands, in my arms, as if I were getting an electric shock.
Down-and-out Like a car ran over me	<ul style="list-style-type: none"> • ... every morning, I woke up as if I had been beaten, as if a car had run over me.
Sinking of the back bones into the lungs	<ul style="list-style-type: none"> • The bones of my back are sinking into my lungs, it's like I don't want to breathe. The pain between my legs, the middle of my waist, my flanks, the tips of my fingers and toes, my shoulders, my heels, and the bottom of my feet can't stand the pain. The drug is not enough anymore, I think it used to be very good before.

Subthema 2.1. Physical effects

Individuals stated that the pain they experienced completely negatively affected

their quality of life, they had difficulty in walking/sitting/sleeping, and they had sleep problems due to pain. Many patients stated that they experienced shortness of breath, had difficulty breathing, and experienced pain while breathing. Some individuals stated that they experienced various side effects due to the drugs they used.

"...zero quality of life, severe pain day and night, I will go crazy from not being able to sleep anymore" (P3)

"All your ribs hurt, you cannot turn from one side to the other in bed, you are afraid to sneeze, when I sneeze, all your bones collide...(P4)

"Drugs are good for me, my pain is almost non-existent. However, I have had aphtha for three months. Have you ever experienced such a situation? (P6)

Some participants mentioned that the pain and other symptoms they experienced made even their personal needs a torment.

"Even our personal needs often become torture. I can't turn from right to left without help. My screams make the neighborhood groan." (P7)

"Walking, eating, getting up is like torture. I am afraid of waking up when I sleep." (P8)

Subthema 2.2. Psychological effects

Some patients stated that the disease affected them psychologically very negatively and they had difficulty in coping. Some patients said that they could not endure the pain and even thought of suicide, and some said that they attempted suicide.

"There wasn't a day I didn't cry until I was diagnosed not out of pain but out of desperation. I even thought of committing suicide." (P9)

"I couldn't stand it anymore and attempted suicide twice"(P10)

Many participants stated that the people around them did not believe in the pain and other symptoms they experienced, and therefore they experienced intense anger.

"They don't believe in the pain we're going through...I take drug, I fall asleep crying,

when I wake up in the morning, I can't wake up for the first half hour or 40 minutes." (P12)

"Nobody understands me, they even make fun of me when I say I get tired quickly. I am literally suffering from burnout." (P13)

Some individuals stated that they received psychological support.

".....I am crying, I am getting psychological support." (P14)

Subthema 2.3. Social effects

Since they had multiple complaints during the disease process, some individuals said that they felt tired of the people around them, and some said that they were alone. Some participants even reported that they could not work.

"My family abandoned me. My brothers no longer look at me. People are tired of me." (P15)

"I got tired of all the family members in the house by saying bring this and take this. I can't meet any of my needs. I'm tired of living dependent on others all the time." (P16)

Theme 3. Factors that increase and decrease pain and methods used in pain management

It was observed that the individuals in the groups made many suggestions to each other that reduced the pain and shared their experiences.

Subthema 3.1. Nutrition

The vast majority of individuals stated that they discovered foods that increase or decrease their pain through experience. Individuals stated that they noticed that their pain decreased when they did not consume these foods.

"Gluten and sugary foods increase the severity of attacks." (P17)

"I eliminated red meat and sugar from the diet. I got rid of the pain by applying alkaline water and herbal cure." (P19)

"I stopped eating gluten, refined sugar, milk, packaged products. I continue to eat

vegetables, legumes, meat, fruits and nuts, my pain has stopped. CRP have returned to normal. The disease has slept, my pain is gone.” (P20)

Some individuals have stated that especially salt and salty foods increase their pain a lot, and they feel relieved when they control the salt.

There is salt in everything we eat. If attention is paid to the use of salt, the pain is greatly reduced.” (P21)

In addition, some individuals stated that they were relieved by the autophagy diet. One individual stated that he realized that his autophagy diet was good because of salt restriction.

“The cure for this disease is autophagy diet, not drug.” (P22)

“I did autophagy, I spent 72 hours with warm water. Feels good. Later I learned that the reason why autophagy is good is that salt does not enter the body for 72 hours.” (P23)

Apart from the products or foods specified, individuals used black herb, rosehip seeds, cherry stem, nettle, lemon, kefir, ginger, turmeric, flaxseed, potato juice, rock salt, boron products, oils (thyme, mint, flaxseed, rosemary oil, calendula oil and tea), eggs, raw nuts, protein, collagen and fish oil. In addition, many participants also stated that minerals such as vitamin D-K-B and magnesium relieve them.

“After I started raising my vitamin D levels, my hip pain gradually went away.” (P31)

One individual stated that garlic, ginger and lemon increased their pain.

“... when I use things like garlic, lemon, ginger, my pain increases. I don't understand why that is.” (P32)

Subtheme 3.2. Weather conditions

Some of the participants, who said that they were affected by seasonal changes, stated that they were adversely affected by cold and some by heat. Some participants stated that seasonal changes did not affect them.

“The cold feels good, the heat increases my pain.” (P33)

“Muscle aches are more common in winter. My hips, waist and back hurt so much all the time, it's like knives are being stuck.” (P34)

“I have no problem with the air” (P35)

One of the most frequently asked questions by individuals was whether the spas are good for their pain. The statements of the participants regarding this issue differ.

“Although spas may cause adverse reactions in some patients, they are good for others. For example, I relax. I specifically asked the doctor. We don't recommend it, but there are some good ones, he said. (P4)

“It's been very good for me and I go three times a year. All my pain is gone, I'm like cotton. But the sea is like my enemy. When I dive into cold water, my whole body locks up.” (P36)

“Too hot and too cold are not good for our disease. That's why it's not right to go to hot springs/spa. I made that mistake once by going to the hammam. I stayed for a long time both in the hot water and in the hammam so that I would benefit.” (P37)

Subtheme 3.3. Hijamah-Leech Treatment

Some individuals stated that they had hijama treatment and some leech therapy and they were relieved.

“I had two hijama and once a leech done. My pain has decreased.” (P38)

“I was relieved thanks to leech and hijama. I got up. My pain is still there, but it's not as unbearable as it used to be.” (P39)

Some individuals stated that such practices did not provide any benefit.

“It didn't help me at all, on the contrary, my CRP ratio increased.” (P41)

“I had leech and hijama done twice, but I did not find any benefit.” (P42)

Subthema 3.4. Exercise

In general, most of the participants stated that the exercises were beneficial and relieved to

slow the disease's progression and reduce the pain experienced. It was observed that the participants did and recommended various exercises for AS such as physical movements, yoga, swimming, massage, pilates, and walking.

"I try to keep my pain under control with regular exercise. If I neglect sports for three or four days, the pain starts immediately. Pilates, yoga and swimming. It's my only medicine." (P43)

"Do sports. When you keep your muscles strong, the disease cannot catch you." (P44)

"Make pilates, you will see a lot of benefits. I was bent double, now I am better thankfully." (P45)

One participant stated that she tightly wrapped her aching limbs and relaxed.

"Apply a little pressure too. I also have pain in my legs. I wrap it tightly with a cheesecloth, so don't cut off the blood circulation completely, but wrap it tightly and you'll get some relief." (P46)

Subthema 3.5. Other Methods

Some participants stated that they benefited from many methods such as ozone therapy, cupping therapy, acupuncture, manual therapy, breathing exercises in reducing their pain.

"Breathing exercise is essential. Besides, it is necessary to lie face down for half an hour every day." (P47)

"I have regular ozone therapy, thank goodness your joints are starting to improve." (P48)

Discussion

Many studies have been conducted to evaluate the frequency of pain and the effect of pain on sleep, quality of life, and functionality in individuals with AS (Gravaldi et al., 2022; Li et al., 2019; Yang et al., 2016). Although there are a limited number of studies on the painful experiences of individuals and how they manage it (Alhabeeb, 2021), no study has been found on how they use social media

networks in disease management and what shares they share. In this study, the posts of individuals with AS in Facebook groups were examined and their posts about their feelings, thoughts and experiences about the pain they experienced in AS were examined.

Facebook connects the world by allowing people from different places to meet, discuss various topics, and build relationships (Gaddy & Topf 2021). It is seen that there are patient groups for various diseases on Facebook and that people actively follow these pages to be informed (Apperson et al., 2019). In the study, it was seen that the participants used this social media network to get information from each other about the disease, to share each other's experiences, to share their experiences about drugs, non-drug methods, and their effects used in disease and pain management. With this interaction, individuals benefit from each other's experiences. Individuals exchange ideas with each other, especially in initiatives to be tried for the first time.

In this study, it was seen that the problems related to pain management in AS were discussed in Facebook groups created for AS patients. Because pain management is an important part of AS treatment (van der Heijde et al., 2017). Pain is the most commonly reported symptom of AS, and pain reduction is a priority for patients (Haroon et al., 2018; Gudu & Gossec 2018; Garrido-Cumbrera et al., 2017). Although pain in arthritis is predominantly secondary to inflammation, residual, non-inflammatory pain is also common and is thought to result from joint damage or peripheral and central sensitization of pain receptors (Boyden et al., 2016). In this study, it was observed that the patients complained of severe pain related to AS.

Unfortunately, pain can cause many problems beyond just affecting individuals physiologically. It is a known fact that pain affects individuals in many physical, psychological, social, and spiritual areas (Demir Dikmen, 2019). In this study, individuals with AS stated that they experienced severe pain due to the disease and that these pains affected them physically, psychologically, and socially. Individuals stated that the pain they experienced completely negatively affected their quality of

life, they had difficulty in walking/sitting/sleeping, and they had sleep problems due to pain. Some participants mentioned that the pain and other symptoms they experienced made even their personal needs a torment. Shahba et al (2021) emphasized the importance of pain as the main problem that complicates life for patients with AS. According to the Disease Activity Index and Functional Index, patients have physical, social, and work-related limitations that often prevent them from achieving their goals. In addition, in the same study, it was stated that AS patients struggled with negative emotions such as fear of pain and inability to take care of themselves (Shahba et al., 2021).

It is stated that AS patients often suffer from psychological disorders such as anxiety or depression (Jo et al., 2018; Park et al., 2018). It is stated that the physical dysfunction experienced by the patients can also cause various degrees of mental disorders (Oh et al., 2018; Roberts et al., 2018). According to a study conducted in Sweden, it was stated that the probability of developing clinical depression in AS patients is much higher (Meesters et al., 2014). Li et al (2020) stated that patients with lower levels of chronic pain acceptance are more likely to become depressed (Li et al., 2020). The physical symptoms and psychological complications of AS can interact and create a vicious circle (Kelly, 2021). Patients who experience more severe AS symptoms, such as intense pain, morning stiffness, and difficulty standing up without support, perceive less self-control and experience higher levels of anxiety and depression (Baysal et al., 2011; Martindale et al., 2006). The reverse is also true. Depression and perceived helplessness also have significant effects on the physical symptoms of AS, such as the intensity of pain (Brionez et al., 2010; Kelly, 2021). As a matter of fact, in this study, some patients stated that the disease affected them psychologically very negatively and they had difficulty in enduring this situation. Some patients said that they could not stand the pain they suffered and even thought about suicide, and some said that they attempted suicide. Some individuals who talked about the unbearable pain they experienced said that they preferred to die. These posts can affect everyone in the group

both positively and negatively. Patients who do not know what their future will be like and cannot bear the symptoms of the disease may be affected by the discourse of other patients and harm themselves. As a matter of fact, it is stated in the literature that the suicide of one can be a trigger for another (Walling, 2021). On the contrary, individuals who think of harming themselves can be directed to appropriate therapies by others in the group, and their quality of life can increase. It is thought that the inclusion of health professionals who are experts in these subjects in such groups will positively affect individuals. Professional posts by health professionals can help patients to have a positive mood, improve their social and psychological adaptation, and feel confident in overcoming the disease. In this sense, rehabilitation nursing can be done using step-by-step scientific methods to achieve the best results (Oh et al., 2018; Roberts et al., 2018). Many studies in the literature include applications that AS patients can do in disease and symptom control (Yu et al., 2021; Pecourneau et al., 2018; Hu et al., 2020; Gravaldi et al., 2022; Souza et al., 2017). It is thought that posts the results of this study in groups will create awareness in patients.

Individuals benefit from each other's experiences in these groups. In this study, it was seen that the messages about the drugs used by the individuals in the groups, the methods that reduce and increase their pain, the ways of coping with the pain, and the satisfaction with these methods used for pain were shared. It has been observed that people who will experience any method gain knowledge from the experiences of people who have used this method before. It is a clear fact that the methods used are affected by individual factors. For example, it was written that hot and cold weather affect AS differently in groups. Some patients stated that they were uncomfortable with the heat and some with the cold. In the literature, it has been stated that rheumatic patients feel more comfortable in a hot and dry climate (Maraver et al., 2021). In this study, it was also questioned whether the spa treatment of the individuals was good for the individuals. While some individuals stated that the spa treatment was good, some individuals stated that it adversely affected the symptoms of the disease. The treatment of AS

is very complex. Although it was stated in a study that a complex three or four-week spa rehabilitation program showed positive cost-effectiveness and cost-benefit ratios compared to standard exercise therapy alone (Mustur, 2022); it is recommended that the spa rehabilitation program be strictly individualized, primarily according to the stage and disease activity, previous treatment, and the general condition of the patient (Rosu et al., 2014).

In the research, it is seen that individuals use many methods to reduce the symptoms of the disease. These methods include pilates, massage, balneotherapy, yoga, tai chi, acupuncture, nutritional support and hypnotherapy (Kocyigit et al., 2022). In a study by Cinar et al., (2021), it was stated that 40% of AS patients used various complementary and alternative treatments. It is stated that these methods used include natural products, massage therapies, spa relaxation techniques, prayer/spiritual approach, cupping, daydreaming, naturopathy, acupuncture, and yoga. In addition, it was determined that the most frequently used method in this study was natural products, including many herbal products. In this study, it is seen that AS patients use many methods such as yoga, swimming, massage, plates, natural products, nutritional support, ozone therapy, cupping therapy, acupuncture, manual therapy, breathing exercises, hijama-leech to get rid of their pain. It has also been determined that people use many herbal products among natural products. The point to be considered here is to use the method that is suitable for the person. As a matter of fact, it is stated in the literature that many complementary and alternative treatments that are used incorrectly affect the health of people negatively (Keene et al., 2019). In this study, it is also seen that a method suggested by some patients is not good for other patients and is not recommended.

It seems that social media has become an important tool used for the control of disease and symptoms. The important issue here is whether each post is suitable for people. For this reason, it is thought that it is of great importance for individuals to have a good level of digital health literacy to prevent

possible harm. In this regard, nurses can help patients use their digital health information and play an important role in correcting misunderstandings about their diseases that may arise from the inability to interpret the information obtained from the internet correctly.

However, to provide better health service and health education to both individuals and society, nurses must first have a good level of digital health literacy. Nurses with a good level of digital health literacy can play a more active role in the disease management of the patients they care for (Temur & Aksoy 2022).

Limitations: In this study, only the posts of patients who participated in the determined Facebook groups were examined. The fact that elderly individuals who are not members of these groups and especially those who do not use social media could not be included in this study is an important limitation of this study.

Conclusion: As a result of this study, it was seen that AS patients shared various posts about the disease and its management from social media groups, the most common symptom they experienced and asked was pain, and individuals were struggling to adapt to life with pain. It has been determined that this pain affects individuals in various physical, social, and psychological aspects, and individuals use many methods to slow down the disease and relieve or alleviate their symptoms. Posts with people who have had similar experiences can make individuals feel that they are not alone and can relax psychologically.

Moreover, it can create awareness by eliminating the factors that do not attract the attention of the individual and increase the severity of their pain. However, it is important to obtain expert opinions about the methods to be used to prevent complications. Negatively, a method used by one individual may result in a negative effect on another and damage the trust of the individual. For this reason, it is recommended to include health professionals in social media groups with various patient groups and to increase the digital health literacy levels of patients.

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