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Patients' perceptions of rheumatoid arthritis and their behaviour towards medications in Saudi Arabia: a qualitative study

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ABSTRACT

Background Medication preferences and associated challenges remain unexplored in Saudi patients with rheumatoid arthritis (RA).

Objectives To explore the perceptions, beliefs and experiences of patients with RA regarding the disease and its treatment in Saudi Arabia.

Design Three focus groups were created in Riyadh, Saudi Arabia through purposeful sampling. Discussions were recorded and transcribed. Subsequently, thematic analysis was performed.

Participants The groups included women, aged 35–50 years (n=6), men (n=4) and women above 50 years (n=5).

Results The identified themes included stress and losing a loved one as the primary factors inducing RA, delay in diagnosis and beliefs about certain foods that triggered RA flare-ups. The most common adverse effects were weight gain, nausea and fungal infections. The participants were open to starting new medications. Stiffness was the main unmet need among the participants. Adverse effects, pain management and fertility problems were key factors affecting treatment transitions. Younger participants expressed concerns about prices and availability of medications. Physical exercise and therapy were identified as important complementary therapies for improving the quality of life. The lockdown during the pandemic may have positively impacted patients' symptoms. Younger women highlighted challenges related to the transition of treatment before and after contraception, losing their jobs, meeting their children's and family's needs and pursuing their dreams. Men expressed concerns about fertility and a fear of needles. Psychological and social challenges were the main theme among older participants.

Conclusion This study identified patient preferences and needs that could guide future educational initiatives for physicians and communities.

STRENGTHS AND LIMITATIONS OF THE STUDY

- ⇒ This is the first study to explore the beliefs of Saudi patients with rheumatoid arthritis regarding their illness and treatment.
- ⇒ The study highlights participants' experiences across diverse cultural and societal backgrounds.
- ⇒ The focus groups represented men and women individuals from different age and educational backgrounds.
- ⇒ This study sheds light on the impact of the pandemic on patients with rheumatoid arthritis.

INTRODUCTION

Rheumatoid arthritis (RA) is a chronic inflammatory disease that affects physical activity and may lead to disability and early mortality. It significantly impacts patients' social and mental well-being.[1 2] Its estimated prevalence in Saudi Arabia is 2.2 per thousand people, with high occurrences observed among women and older individuals.[3] Despite advancements in RA treatment, patients' decisions regarding their treatment often deviate from the recommended guidelines.[4]

Moreover, a disparity exists between how patients and physicians evaluate disease activity.[4] Patients perceive pain as the primary determinant of disease activity, whereas physicians rely on the number of tender joints.[4 5] Many patients express their concerns regarding disease-modifying antirheumatic drug (DMARD), particularly regarding their potential long-term side effects.[6] However, medication adherence is influenced by individuals' perceptions of medication benefits, concerns about potential adverse effects and the balance between these factors.[7]

Furthermore, cultural background significantly influences patients' responses to their illness and treatment. Some patients express concerns about the overuse and potential harm of medications in general.[8 9] Additionally, patients believe that natural herbs do not disrupt the body's balance and have fewer side effects than conventional medications.[10] Religious beliefs also influence patients' understanding of disease development,[11] while other factors such as age and educational level influence their concerns about medication. Older patients and those with lower educational backgrounds tend to express greater apprehension about DMARDs.[6 9 10]

The aforementioned factors greatly influence patients' treatment preferences, adherence and outcomes.[6] Several qualitative studies have explored various aspects of patients with RA, including delay in diagnosis, physical capacity and well-being, emotional challenges, social life changes, coping strategies and support needs.[12–14] However, to the best of our knowledge, no study has addressed the disease-related concerns and beliefs of patients with RA in Saudi Arabia or the Middle East. In Saudi Arabia, healthcare for chronic illnesses, such as RA, is primarily provided through governmental (public) hospitals, where all types of disease-modifying agents are available for disease management. Given the diverse cultural beliefs and perspectives within this healthcare system, understanding and considering these factors is crucial for treating patients. This study aimed to explore the perceptions, beliefs and experiences of patients with RA in Saudi Arabia regarding their disease and treatment.

METHODS

Study design, settings and participants

We conducted a qualitative study comprising three focus groups involving patients with RA via Zoom meeting. No new themes emerged after the creation of the three focus groups, which were then defined as points of data saturation.[15]

The study was reported following the COnsolidation criteria for REporting Qualitative (COREQ) studies.[16] To ensure maximum sampling variation, we considered factors such as age, education level and sex. Each focus group included participants of similar age ranges and sex, but different educational and socioeconomic backgrounds.

Rheumatology clinic records indicated that most patients with RA were female, aged ≥35 years, whereas male patients with RA were fewer in number and typically aged >50 years. Therefore, female participants were subcategorised according to their age, resulting in two female groups (group 1: 35–50 years and group 2: >50 years) and one male group (>50 years). Focus group recruitment and interviews were conducted from January 2021 to May 2021.

Recruitment and interview procedure

Participants were initially recruited using purposive sampling[17] by clinic personnel or staff from a rheumatology association (nurses or social workers). If a participant agreed to be contacted by the research team, their contact information (phone number) was shared with the principal investigator (LAJ) to schedule a Zoom meeting.

Participants who met the inclusion criteria were sent an information sheet and consent form via WhatsApp. The inclusion criteria were a minimum age of 18 years and a confirmed RA diagnosis for at least 6 months based on the American College of Rheumatology/European League Against Rheumatism 2010 diagnostic criteria.[18] Participants aged<18 years, as reported in medical records or those having difficulty communicating verbally in Zoom meetings, were excluded. Participants were recruited from the databases of specialised rheumatology clinics affiliated with King Saud Medical City and its affiliated university, and the Charitable Rheumatology Association in Riyadh, Saudi Arabia. Subsequently, we arranged a convenient date and provided Zoom meeting links to all consenting participants. A semistructured topic guide, developed and reviewed by LAJ, HA and MAO (online supplemental material 1: topic guide), was used to facilitate discussions. The guide covered three key domains: illness, disease experience with therapy expectations and patient–physician relationships. The topic guide was piloted with three patients with RA prior to its use in the study. The pilot participants were excluded from the study. The guide comprised open-ended questions that enabled participants to express their perceptions and ideas to guide coding trajectories. Two facilitators, LAJ and HA, guided the focus groups.

Patient and public involvement

The participants or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Analysis procedure

Interviews with each focus group were audio-recorded and transcribed verbatim in Arabic. The transcripts were checked for accuracy, and all identifiers were removed (transcription was performed by research team members, LAJ, ShA and SuA). Inductive thematic analysis of the transcripts was conducted based on the themes explored using the topic guide, and codes were generated accordingly (online supplemental material 2: coding index). Thematic analysis followed a structured process, involving data review and familiarisation, developing a coding index of related quotes, generating themes, reviewing themes and naming themes.[19] No special software was used for the analysis. Independent, duplicate thematic coding was performed on a sample of the transcripts by the following faculty members in pharmacy: LAJ (female, PhD, with professional training in qualitative research) and HA (female, PhD, with clinical rheumatology experience). LAJ trained HA to conduct thematic coding. MAO (male, SF Rheum, consultant rheumatologist) facilitated data collection and patient contact. Primary themes were identified and analysed to capture participants' perceptions and beliefs about illness and treatment (table 1).

RESULTS

The focus group included 15 participants, comprising women participant aged 35–50 years (PW, n=6), men participants (PM, n=4) and women participants above 50 years (PWE, n=5). The average duration of interactions

Table 1 Thematic analysis and data validation using a stepwise approach

Steps	Substeps	Explanation
Step 1: data collection	Audio recording	Each focus group was audio-recorded.
	Transcription	Transcripts were created verbatim in Arabic by the research team (LAJ, ShA and SuA).
	Accuracy check	Transcripts were checked for accuracy by listening to the audio recording.
	Anonymisation	Identifiers were removed from the transcripts.
Step 2: familiarisation of data	Data familiarisation	The research team reviewed the transcripts to get a deep understanding of the data. The transcripts were read multiple times to ensure immersion and familiarity with the data.
	Identification of keywords	Initial notes were taken on recurring ideas, patterns and noteworthy points.
Step 3: generating initial codes	Code generation	Descriptive labels (codes) were assigned to segments that capture key aspects of the data.
	Coding index	The list of codes identified was grouped based on the domains of the topic guide, and a coding index was developed.
	Validation of the coding index	Independent, duplicate thematic coding was conducted on a sample of transcripts by the pharmacy to ensure understanding of the coding index, and a meeting was conducted to discuss any discrepancies in coding. ► LAJ: female, PhD, with professional training in qualitative research. ► HA: female, PhD, with rheumatology clinical practice experience.
	Independent coding	Transcripts were systematically coded by highlighting significant segments of text and tabulating the text using Excel.
Step 4: combining codes into themes	Grouping	Group-related codes were organised into broader themes that reflected meaningful patterns in the data. All coded data extracts relevant to each theme were collated.
	Primary theme identification	Primary themes were identified from these patterns by developing a thematic map to visualise the relationships between the themes.
	Theme naming	Themes were named.
Step 5: reviewing themes and validation strategies	Theme review	► Themes were refined by checking their coherence and consistency with the data. ► Themes were reviewed for accuracy and relevance to the research questions.
	Themes validation	► The entire data set was reread to confirm the validity of the themes. ► The themes were examined to record and analyse participants' perceptions and beliefs about illness and treatment.

ranged from 59 to 101 min. The disease duration ranged from 6 to 18 years (table 2).

Based on the analysis, five main themes were generated related to patients' beliefs about the illness, impact of the COVID-19 pandemic, medication use experiences and preferences, patient–physician relationships, and the use of complementary medications to treat RA (figure 1).

Additionally, several subthemes and issues emerged across different groups, including psychological and social challenges, fertility concerns in male individuals, family planning within the context of their diseases and DMARD use, barriers to pursuing their careers, dislike for self-injection or needles and limitations in performing daily activities (figure 2).

Table 2 Demographic characteristics of the participants

		Female focus groups	
Focus groups (n=3)	**Male focus group**	**<50 years**	**>50 years**
Number of participants (n=15)	4	6	5
Age, years (SD)	40.75 (5.6)	38.4 (1.8)	56.2 (3)
Duration of the disease, years (SD)	6 (3)	11.3 (5.5)	17.8 (4)
Number of participants with children	0	4	5
Number of participants with a bachelor's degree	1	4	1
Number of participants with higher education certificate	0	1	0
Number of participants who underwent primary schooling	0	0	2
Duration of interaction with the focus group, mins	79	101	59

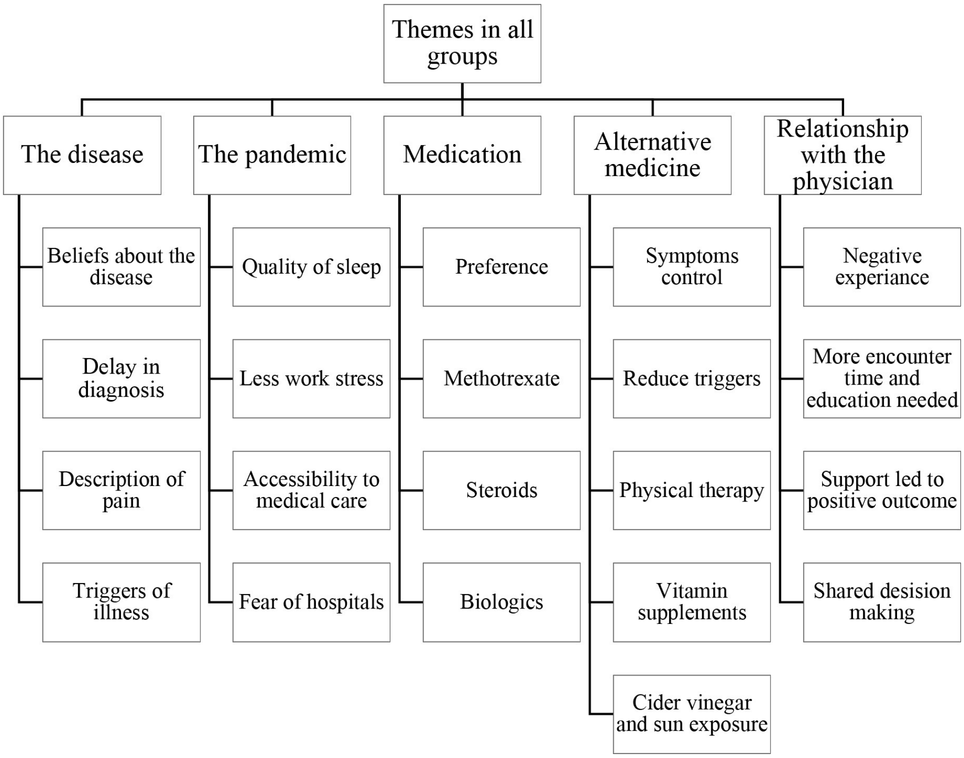

Figure 1 Themes and subthemes used for the three interviewed groups.

Theme 1: the disease (signs, symptoms and progression)

The participants across all the groups shared their beliefs about the nature of the disease based on their experiences. A common belief was that they viewed it as a lifelong condition with no remission.

> PWE-5: This is a disease that you will live with, and there is no definitive treatment for it. …. Because when I started and went to the hospital, I saw people telling me that there are patients here, and that they had the disease for 18 and 20 years, and I used to say, Oh God, is it possible that there is no cure? ….”

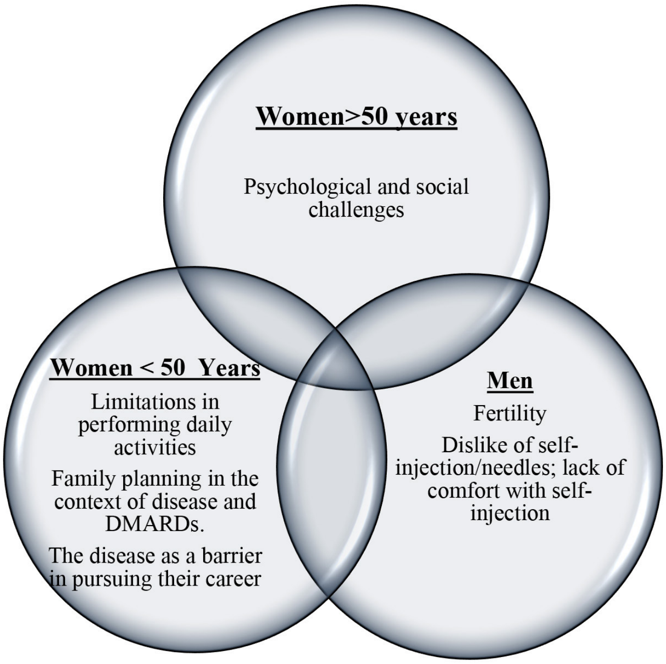

Figure 2 Differences in themes used for the three groups. DMARDs, disease-modifying antirheumatic drugs.

Participants frequently linked the onset of the disease to stressful life events that caused physical or emotional trauma, such as accidents, falls, fires, or losing a loved one.

> PW-6: I was almost diagnosed when I was 17 years old, and I now have the disease for about 10 years. My illness is related to an accident that happened when I was almost 12 years old, I accidentally got burnt with gas, starting from my leg, the pain was so severe that it hindered my movement for 5 years. I woke up the morning after the accident to find that I was unable to straighten both my legs.

Participants also shared their personal experiences of how the illness affected various organs over time and how the symptoms fluctuated between good and bad days.

> PWE-5: That’s it. This is a disease that you will live with; sometimes it will get worse, and sometimes it will ease. Sometimes you will feel like you are not having any disease….
>
> PM-1: …I mean the effect of rheumatoid on my lungs, and….
>
> PW-2: ……and I had other symptoms, vitamin D is deficient, and my blood is coming down (anemia), so all came at once. ….

Participants described pain in different ways, such as sensations of cold air, being hit by a door or wall and needle pricking. They also described it as an overall feeling of immobilisation that restricted their daily activities.

> PWE-1: I feel my hand has cold air inside it and it start to freeze, when I rub it and straighten the air goes away…
>
> PWE-3: I feel like pins and needles pricking my knees…
>
> PM-4: I feel the pain as bruises in my elbows, or the lines on the palm. It is like you've been hit by a door…

Participants also indicated that the illness caused body stiffness.

> PW-3: I lived with stiffness for my whole life, whether on medication or without. On good days it lasts for an hour, and if I'm in flare (active disease), stiffness lasts for more than two hours….

All participants shared their experiences of how the disease began and their efforts to obtain a conclusive diagnosis for their disease by visiting multiple physicians. They expressed facing delays in diagnoses or misdiagnoses. The duration of their symptoms ranged from 2 months to 10 years.

> PW-1: I was diagnosed with RA 21 years ago around the start of 2000. It came shortly after the distressing news of my one year-old daughter being diagnosed with diabetes, just two months after I started to experience pain. …. Every time I go to the doctor, they would tell me that it could be a Vitamin B or D deficiency. Around the five year mark, I developed plantar fasciitis in my foot, causing excruciating pain that kept me awake at night. Seeking relief, I consulted an orthopedist who conducted x-rays and blood tests. The sedimentation rate was about 300 and all my other tests were abnormal. He suggested that I see a rheumatologist. Within the first 10 minutes he told me that I could probably have RA. …. I had been suffering from it for a long time. By then, I had been grappling with symptoms for 6 years, and x-rays revealed deformities in two of my fingers.
>
> PM-3: It started with me for 16 or 15 years, my joints, hands and legs hurt, then I went to a private hospital and a government hospital they did not give me a result….
>
> PM-1: It started with me about 2 years ago and a little bit. I mean, I started with the symptoms, but I didn't know what they were exactly. I mean it started to be inflammation in the joints the… Elbow Ah. Swelling and pain I expected from the computer session, for example, the table or the… It lasted with me for about 3 months, moving between the joints of the hand and the elbow….

The participants shared different triggers that initiated their flare-ups, such as inadequate sleep, a protein-rich diet, stress or trauma, and excessive physical exertion.

> PM-4: …when my sleeping hours decrease to 3 hours, or when I stay up late with the guys, … and I'm exhausted. I haven't had enough sleep. …. when I am controlling my sleep, and do not exert myself, the attacks are less frequent. I mean, I can almost say that I have recovered by the grace of God Almighty. ….
>
> PWE-1: I developed the illness after my mother died.
>
> PW-5: The illness started after I had an accident when I was 12. The pain started form(from) my leg and it moved to other body parts.
>
> PW-3: Proteins are friends with RA. Eating lentils, particularly black lentils, may trigger flare-ups ….

Regarding the spiritual aspects of the illness, the participants expressed strong religious beliefs, attributing the course of their illness to faith.

> PM-1: thank God anyway, thank God for everything….
>
> PM-3: At first I didn't feel anything, …. there is no improvement, I mean was assisted by Allah almighty, then the painkillers"

Theme 2: impact of the COVID-19 pandemic on the disease

Participants shared how the COVID-19 pandemic had affected their illness. Most of them agreed that the pandemic had a positive impact on the disease, such as improving their sleep and reducing work-related stress, which they believed triggered their symptoms.

> PW-4: For me, this was the best period (COVID period). I was basically at home, and I started working from home; no one would say anything to me. I was relaxing at home, engaging in my hobbies and raising my children, and things were fine, no stress or anything.

The participants shared the challenges they faced during the pandemic, such as limited access to certain medications and missing out on appointments, though they were scheduled virtually at the beginning of the pandemic. Many reported being unable to follow-up with their physicians regularly, and some expressed their fear regarding going to hospitals for follow-up appointments and dispensing their medication.

> PW-3: Yes, I stopped taking the injections. They called me and told me to come and get them. I was afraid to go, to be honest, but after the attacks got worse, … I stopped taking them for about 6 months… most of my medicines were delivered to me except the injections, I have to go to the hospital. …."

Theme 3: experiences with medications

Participants across the groups described their experiences with medications, highlighting their preferences regarding effectiveness, safety and cost. They emphasised the need for medications to control joint pain, swelling and stiffness. They pinpointed swelling and stiffness as the most prevalent unmet medical needs, noting that their medications often failed to adequately control these symptoms.

> PW-6: … I always have a feeling that there is no medicine for swelling; when the attack returns the limbs will be swollen and red. It comes and goes by itself. It is often accompanied by stiffness (no treatment for it)…

The participants also emphasised the need for safe medications devoid of major side effects, particularly those affecting the kidneys and liver. Female participants specifically expressed frustration with side effects such as hair loss and skin pigmentation.

Additionally, the participants preferred a reduced number of medications, preferably the ones administered at home, as some medications such as rituximab require hospital administration. They also reported issues related to medication availability in hospitals. Additionally, they expressed concerns about high costs that have rendered some treatments unaffordable.

> PW-2: We suffer from lifelong diseases. I mean, our medicines are well known and have been prescribed since a very long time. Why do we always face issues in getting our full prescription regardless of the hospital? …. The prescription was given to me for three months. They gave me methotrexate for three months only.
>
> PW-3: Yes, this is the case with my insurance every month. Imagine that every month I go to the hospital and stay there for 2 or 3 hours to get medicine.
>
> PW-2: Even without insurance. The pharmacist told me that you should go to the doctor to renew it for you. The second thing is regarding the prices of injections; there is no alternative. The prices are ridiculous. I don't know if there are alternative plans. I mean, a person does not have a guarantee for thirty or forty years that he will be able to afford all these medicines. I am worried about whether the insurance is continuing.

The participants also highlighted the challenges faced in transitioning between medications, primarily driven by the need to control their symptoms, ensure safety, minimise side effects, plan pregnancy and address issues related to medication availability.

Subtheme 1: experience with methotrexate (MTX)

The participants shared their experiences with MTX, and male participants agreed that it did not relieve pain. Most male participants in the focus group reported experiencing severe nausea. Female participants in the younger age group reported similar experiences regarding medication efficacy. However, the side effects differed among them; they experienced anxiety and continuous stress, which subsided once they stopped taking MTX.

> PW-4: When I started taking methotrexate, it was very good for me in relieving the pain and the severity of the attacks. I felt the difference after six to eight weeks. Then I got pregnant and had to stop methotrexate. I could observe a clear difference in my psychological state and in the stress that I experienced both the times that I stopped using methotrexate. It felt strange. I don't know if it was psychological. But I noticed a strong association with methotrexate. It increases the tension inside me….
>
> PW-1: Do you feel like you are always running
>
> Moderator: PW-1, are you suffering from the same problem?
>
> PW-1: I feel like it might be from methotrexate. I stopped taking it since three months now, and I'm very relaxed. As she says, you feel like you are always running and stressed. It may be due to methotrexate.
>
> PW-6: but it is a lovely medication!

In contrast, the participants in the male focus group disagreed about MTX's efficacy in relieving pain.

> PM-3: I took eight methotrexate pills a week. I felt that it frankly did no good for me. The pain still comes and goes, and I have attacks. …. It also hurts my stomach. …. Whenever I see my doctor, I convey that I am tired of the medicine. But the doctor always insists on continuing the medicine. One day I came to him and said, I can no longer take the pills. In fact, the pills made me feel nauseous. He transferred me to Methotrexate 15 milligrams injections. Unfortunately, even that did not relieve the pain. I continued the treatment for 9 months with no improvement in pain or nausea and eventually stopped it.

Subtheme 2: experiences with steroids

The participants across all three groups agreed that steroids helped manage their pain but that the pain would resurface after the medication was stopped. They were well aware of the side effects of steroids and described them in detail. One participant described how he started treatment with non-steroidal anti-inflammatory drugs and hydroxychloroquine, but after 6 months with no improvement in pain, he switched to steroids.

> PM-3: After that, he started putting me on cortisone, The cortisone relieved my pain by perhaps 80 percent of the pain that was present.
>
> …I continued it for maybe three months, then I gradually stopped it and the pain completely disappeared from me. Unfortunately, maybe a month and a half later, the pain returned; but I mean, thank God, it was less than before.

Subtheme 3: experiences with biologics

Many participants, especially female individuals, expressed openness towards using biologics owing to their positive experiences regarding their efficacy in relieving pain. However, some concerns remained.

> PW-1: I mean, they say that you should check if you have cancer before using biologics.
>
> PW-5: Yes, the doctor told me the same thing. I have a tumor in my uterus that is approximately (one cm) in size. It is small and I am afraid that it will grow.
>
> PW-3: I took it (biologics) for a year and a half, I saw improvement. The experience was very beautiful. ……I stopped it for a year and a half after the disease subsided. This was about 4 years ago I became pregnant…the doctor started me on Humira after 19 days of giving birth. I have completed 3 years on it before the doctor suggested that I go back on Actemra. I did not prefer it, by God, because it involves admission to the hospital.

Conversely, male participants perceived biologics as risky and believed that they should be a last resort.

> PM-4: I am not a specialist, but according to my knowledge, it is a difficult treatment that should be given in the late stages.

Despite concerns, the participants were open to trying new medications and linked this with trusting their physician.

> PW-2: I am willing to try anything new as long as it has a benefit or it might be a benefit.

Theme 4: use of alternative medicines

Participants attributed their positive experiences to various alternative and complementary treatment options in managing their symptoms and controlling disease. These included healthy diets, avoiding foods that trigger the disease, engaging in physical therapy such as walking and bicycling and consuming vitamins and supplements such as vitamin D, vitamin B complex, iron, calcium and omega-3. They also emphasised the importance of adequate sleep, physiotherapy, exposure to sunlight, social support through WhatsApp groups and use of cider vinegar to alleviate gastrointestinal side effects related to medication.

> PWE-5: Do not say that you have grown up, God willing, look at people who are seventy or eighty, and if there is vitamin D, you say it is deficient. …. Go out if you have a yard and sit in the sun for 20 minutes a day, it is better than a hundred pills. …. I went through this dizziness for a year. Then they gave me medicines for inflammation. I did not get better except with special exercises for this thing. It subside(d) like this.

Theme 5: relationship with the physician

The participants recounted their interactions with their physicians, pinpointing specific factors influencing the patient–physician relationship. This included insufficient time allocated by physicians to gather a comprehensive medical history and adequately educate patients about their condition, medications and available treatment alternatives. In addition, several physicians omitted physical examinations during these interactions. Other points of disconnection from physicians included a lack of empathy and a judgemental attitude towards patient complaints. Some physicians did not take the patients seriously at the beginning, which led to a delayed diagnosis.

Conversely, physicians who provided support and involved patients in decision-making were viewed positively, contributing to improved health outcomes.

> PM-3: I have seronegative rheumatoid… I told him (rheumatologist) that I couldn't sleep at night because of the pain. He gave me a sleeping medication… I went to another doctor, and she told me that some patients imagine that they are sick. Unfortunately, she said this even when I had already been diagnosed and on methotrexate. And she is a specialist!
>
> PM-2: Oh, there is a doctor …he is also a professor. I swear to God, he sits down while I am on the chair and examines me… and overwhelms me with his kindness and respect unlike the other doctors who seem a bit too serious when I visit them.
>
> PWE-5: My first session with him and I asked him several question(s) while he patiently said and told me, Ask, you have the right to ask.

Other emerging themes

Different themes emerged across the three focus groups.

Female group (20–50 years)

Female participants aged 20–50 years emphasised the importance of discussing family planning with their physicians before starting any medications, as they considered switching from one medication to another as a time-consuming process that could affect the childbearing age.

> PW-1: I am spontaneous and do not like planning. When I decide that I will become pregnant, I do not want to plan that I will become pregnant and wait for three months while I cleanse my body. I do not want to decide that I will get pregnant, so I do not want medicine that could restrict me. I do not want to wait for my body to be cleaned.
>
> PW-5: What scares me is that if I get pregnant, I will have to wait a certain period.

Another theme was the physical limitations faced due to the illness in managing household responsibilities, from hugging their children to hosting and serving guests.

> PW-5: Of course, it was difficult for me to take the baby from his crib to my bed, and it was difficult for me to breastfeed him. ….

The participants also shared how the illness put their lives on hold at such a young age.

> PW-1: Of course, the disease is already present. It is difficult to deal with sickness, especially during pregnancy and childbirth. It is also a crucial age filled with several responsibilities: work, leisure, family, etc. At the peak of the age when the person wants to exert all their energy to achieve their goals and dreams, the opposite happens. Every day I struggle with how to wake up. …… I mean, it's not the case that I wake up every day and cry because I can't even breastfeed my daughter…. I fell into depression because of RA.

Female group (≥50 years)

Female participants aged >50 years cited the psychological and social difficulties they experienced after their diagnosis, including divorce, raising children, loneliness and family struggles, which impacted their symptoms. They also expressed concerns about relying on others. They supported each other by giving advice.

> PWE-5: Advice from me while I am still going through circumstances that are a million times more difficult than yours: take care of yourself, get to know people, two Qur'an circles….
>
> PWE-1: I have, I have friends, and I have the support of several people around me.
>
> PWE-5: Do your job. If you are sick and in bed and unable to get up, no one will ask where you are. There is no one but your children to see you. Sometimes even the children do not see you. Pay attention to yourself. You must be your own doctor.

On many occasions, participants emphasised how walking and exercise improved their symptoms and mental health.

> PWE-4: If I reduce walking and movement, I will no longer be able to move.
>
> PWE-1: I see nothing better than walking.
>
> PWE-3: Where should we walk? By God, I cannot walk on my feet.
>
> *Everyone*: Try, you must try.
>
> PWE-5*:* I mean, even if it is difficult, it will get better. If you walk ten steps tomorrow, you will walk 15 the next time and 20 another time. But if you come to sleep and sit like this saying 'I can't, I can't,' it increases the problem. I've been in a similar situation when I didn't feel better until I got up. …but I read that it is necessary to exercise, even if you engage in simple movements in the morning. I mean, now I have severe pain here, you know?… I'm not giving up. If you give up, it'll be over….

Male group

Male participants shared their experiences in managing the illness and its treatments. The predominant theme revolved around the adverse effects of medications, such as depression and fertility challenges.

> PM-2: There is a treatment and I can't recall its name, but it is an orange pill that I used to take twice a day. It affected my fertility; it rendered my sperm nonviable. There is no benefit in it…. I changed the treatment but it was of no use. Maybe this is what God has written for us.
>
> PM-3: I used the orange pills; they are like capsules. I used them and they affected my ability to conceive. I requested for a change in medication, but unfortunately, they caused a deformity in the sperm.

Another theme unique to the male group was the aversion to self-injections and needles. When asked about the most significant challenges faced by a patient with rheumatoid disease concerning medications and treatments, one participant highlighted the sentiment as stated below:

> PM-2: the needles, I take the needle at home. I am familiar with the process, and I know how to inject myself. But I hesitate. It is not because of the pain. It is the sight of two needles in front of me: one for the abdomen and other for the thigh. It is a thing that I am unable to explain.
>
> Moderator: What feeling
>
> PM-2: Fear. …. every time….

The male participants emphasised the importance of raising awareness about the disease and its treatments among the public, as well as the role of patient associations and health professionals in supporting patients.

> PM-4: Now, we have become aware about the disease through personal efforts and the collective efforts of hospitals, committees, and various associations. They dedicated their time and efforts to rheumatoid patients and the public.

Cultural differences highlighted in this study across the groups are presented in table 3.

DISCUSSION

This study is the first to address the experiences and expectations of patients with RA in Saudi Arabia and the Middle East using a qualitative approach. It highlights the cultural aspects of the Saudi population and the unique patient–physician relationship.

Several themes emerged from the focus groups. The first was the difficulties that the participants experienced during the initial diagnosis of the illness and the delays they faced. This is a common issue worldwide, as multiple factors may affect the time from symptom onset to confirmed diagnosis.[20] A possible explanation for the delay in diagnosis could be the late referral to specialised

Table 3 Different perceptions and beliefs highlighting cultural differences within the population

Triggers of immunity	Death of a loved one	Postdelivery	Burn accident
Exercises that alleviate symptoms	Cycling	Walking	
Complementary medicine/therapy used	Natural products (cider vinegar, omega 3, protein-rich diet)	Supplements (calcium, vitamin D and iron)	Other (physiotherapy, social support groups)
Medications used	Conventional synthetic (methotrexate, hydroxychloroquine and leflunomide)	Biologics (adalimumab, etanercept and tocilizumab)	Steroids and non-steroidal anti-inflammatory drugs (celecoxib, naproxen)
Feared and experienced adverse drug reactions	Experiencing hair loss and hyperpigmentation	Experiencing depression and anxiety	Experiencing nausea and vomiting
	Fear of renal side effects	Experiencing an allergy	Fear of steroid-induced diabetes mellitus
	Fear of hepatic side effects	Fear of pulmonary side effects	

physicians, as indicated by participants in one of the focus groups. Another influencing factor may be the severity of the symptoms.

Another aspect that the participants discussed was the perceived connection between disease onset and traumatic or negative life events, linking these to immunological triggers.[21] Additionally, they discussed how pain impacted their mobility.[22] This study was conducted after the outbreak of COVID-19, an event that positively influenced symptoms in patients with RA. The patients reported improved sleep and less work-related stress, which were contradictory to previous findings.[23 24] This interesting finding reveals a possible link between the pandemic and RA, both of which are influenced by stress-related factors.[25 26]

Regarding their experience with medications, participants complained that certain medications did not relieve their joint pain or swelling. They expressed concerns about adverse drug reactions, especially with methotrexate, steroids and biologics, citing some bothersome side effects such as hair loss and skin pigmentation. Medication cost and availability were also significant concerns. The participants expressed aversion to MTX. Interestingly, male and female participants reported varying psychological symptoms when using MTX, without documented efficacy from their perspective. Previous studies have reported a high rate of MTX intolerance among Saudi patients with RA, primarily due to psychological intolerance.[27 28] Notably, while participants talked positively about steroid therapy, its adoption was often stigmatised due to its widely publicised side effects. Female participants shared positive experiences with the use of biologics. However, this positive experience was counterbalanced by the fear of self-injection reported by male participants. A systematic review on patients' attitudes and experiences towards DMARDs reported similar findings in qualitative research,[7] highlighting fears related to MTX therapy, poisoning and toxicity from these medications.

An important emerging theme was the use of alternative medicines, which is common among patients with rheumatic diseases.[29] In Saudi Arabia, the prevalence of complementary and alternative medicine for patients with RA was reported to be as high as 70%.[30] Participants primarily used these methods to control symptoms and prevent flare-ups. From a qualitative perspective, the participants reported that different alternative treatment approaches, such as physiotherapy and the use of cider vinegar, might help reduce disease triggers and control symptoms.

The influence of cultural factors varied drastically across the focus groups. However, this has rarely been evaluated in previous studies.[31] Religion has been reported to influence how patients with RA perceive and manage their pain. Engaging in religious activities, such as prayer and seeking spiritual support, has been linked to improved pain management and quality of life.[32] These practices provide emotional comfort, a sense of control and hope, which positively affect patients' well-being and adherence to treatment.[33] Positive religious coping is associated with low levels of depression and anxiety, which are common in patients with RA.[34] Incorporating patients' religious beliefs into clinical practice can strengthen therapeutic relationships, improve patient outcomes and enhance overall satisfaction with care.[35]

The fear and concerns that men possess regarding infertility and its cultural significance in Saudi Arabia should be addressed in further qualitative research. Previous studies have noted that changes in the attitude of Middle Eastern women towards family planning contributed to declining fertility rates, while the perspectives of men have been largely overlooked.[36]

In this study, the male participants exhibited a fear of self-injection, which could be attributed to several psychological factors, including an unnatural feeling, stigmatised by illicit drug use and the expectation of pain.[37] However, this fear was not linked to sex-based differences. Other studies have reported the presence of psychological, emotional and physical barriers among female patients with RA.[10]

The study findings revealed a complex patient–physician relationship. Although some participants reported challenges such as diagnostic delays, most of them highlighted the importance of support provided by their physicians,[4] which introduces practical implications. Thus, there is a need to improve the patient–physician relationship. Furthermore, patients should be educated on what to expect from medications. Patients mainly expect medications to reduce pain; however, they must understand that DMARDs not only reduce pain but also hamper further progression of the illness and improve long-term health outcomes. Moreover, patients should be educated on self-injection techniques. This study could inform physicians about the issues that need to be addressed among patients with RA in Saudi Arabia.

Overall, all themes reported in this study were similar to those reported in the studies of the USA and Europe, with key differences including sex-based variations, the impact of religious beliefs and the unexpected appreciation of the pandemic on reducing stress related to RA.[10]

This study is the first to address the perceptions and experiences of patients with RA in Saudi Arabia and the Middle East. It is also the first to shed light on potentially positive experiences during the COVID-19 pandemic and sex-based differences in medication use and experience. In addition, the study included male and female participants from different age groups and educational backgrounds. These findings can guide healthcare professionals in educating about their disease and treatment options while raising awareness on the importance of early diagnosis. Furthermore, it may direct healthcare teams to inquire about complementary medicine use, family planning and other concerns that the patient might have. This may not only be beneficial for patients living in Saudi Arabia but also for those in countries with similar cultural and religious beliefs and Saudi nationals living abroad. Nevertheless, this study has some limitations. First, this study included a limited sample size. Second, the COVID-19 pandemic had a positive impact on alleviating work-related stress. Third, self-selection bias may have existed, as participation was voluntary. Finally, the absence of an older adult male group may have caused a bias in the results.

Conclusion

Participants with RA in Saudi Arabia had experiences and expectations similar to those in other countries. Participants experienced pain, stiffness, diagnostic delays and difficulty in controlling their symptoms. The participants strongly believed in the efficacy of complementary medicine and reported issues or side effects with steroids and MTX. However, Saudi patients with RA differed in their experiences during the pandemic and had sex-based differences in their experiences with biologics and MTX.

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Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants. The study complies with the declaration of Helsinki and all participants were aware of the study procedure. Participants provided electronic consent and agreed on having the interviews recorded. The study is under restrictions of King Saud University institutional review board approval (IRB Approval of Research Project no. E-20-5316 application date 22 November 2020). Participants gave informed consent to participate in the study before taking part.

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