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# Delay in seeking medical help in patients with rheumatoid arthritis in India: A qualitative study

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## Abstract

**Background:** Rheumatoid arthritis (RA) is an autoimmune disease with varied articular and extra-articular manifestations. In developing countries such as India patients with RA often delay seeking medical advice which may impact prognosis and disease burden.

**Aim:** To explore perceptions and experiences of patients living in India in seeking medical help for their RA symptoms.

**Methods:** Clinician-diagnosed RA participants from different socioeconomic backgrounds were interviewed using a semi-structured topic guide. Participants were purposively selected and interviewed following an iterative approach. All interviews were recorded and transcribed by an independent company and analyzed using a thematic framework. Findings were reported in accordance with consolidated criteria for reporting qualitative research guidelines.

**Results:** Twenty participants (13 male, 7 female) with median age 40 years (35.7–46.5) were recruited. Three overarching themes demonstrating participants' experiences and reasons for delay in seeking medical help were identified. (1) "Symptoms perspectives and delay in participants' journey" narrated participants' experiences of having RA symptoms, how these were perceived, rationalized and led to delay. (2) "Participants' experience of the healthcare system" illustrated delay in referral, reaching diagnosis and treatment initiation highlighting their experiences with the health system. (3) "Recommendations for improving care" where participants made recommendations for reducing the delay at local and national levels.

**Conclusion:** This is the first qualitative study which explored perceptions and experiences of RA patients in India resulting in delay. Improved provision of rheumatology care, effective referral system and greater involvement of government at local and national levels are needed to improve the delay in seeking medical help for Indian patients.

## KEYWORDS

delay, healthcare, India, rheumatoid arthritis, symptoms perspectives

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## 1 | INTRODUCTION

In the last 2 decades, India has seen a tremendous improvement in the healthcare sector. A major focus on infectious and communicable diseases has resulted in reduced mortality rates.<sup>1</sup> Non-communicable diseases (NCDs) on the other hand have had limited investment, resulting in significant morbidity and mortality with consequent impact on economic productivity and socioeconomic development.<sup>2</sup> There is also paucity of data relating to incidence and prevalence, a lack of infrastructure in government-led organizations for delivery of high-quality healthcare in chronic conditions and lack of clear planning and policy.<sup>3,4</sup> This is a significant issue as NCDs contributed to 63% of all deaths in 2016 in India.<sup>5</sup> Cardiovascular diseases, chronic respiratory ailments, cancer, and diabetes contributed 50% to total mortality due to NCDs.<sup>5</sup> Among these chronic conditions, the burden of rheumatological diseases is still underreported and are an important cause of years lived with disability in the world. The level of disability often depends on delay in diagnosis and initiation of treatment - for example, rheumatoid arthritis (RA), a disabling disease, and a prototype autoimmune disease, affects multiple joints, resulting in erosions, damage and deformities. RA can also have significant impact on risk of cardiovascular events and other systemic complications including lung involvement with interstitial lung disease, and so on. These have significant impact on life expectancy besides resulting in high disability-adjusted life years.<sup>6,7</sup> Despite the remarkable advancement in understanding disease pathogenesis with ever increasing numbers of disease-modifying therapies, RA continues to impact quality of life, more so in developing countries such as India with underdeveloped clinical pathways. The data on RA prevalence and economic burden mainly emanate from developed countries.<sup>8,9</sup> In developing countries such as India data on prevalence are scarce and are underreported at between 0.28% to 0.7% of the general population.<sup>10-12</sup> The reason for underreporting and unaccounted disease burden could be multi-factorial. The keys issues could be either at a patient's level or at the level of healthcare structure. Diagnosis is often delayed<sup>13</sup> and this is compounded by a lack of rheumatologists in certain parts of the country.<sup>14</sup> Improvement in outcome needs addressing of these issues as limitation in service may not be the only issue that affects people seeking treatment for troublesome rheumatology symptoms. It is essential to understand the perceptions of individuals as this can contribute to helping us understand why and when individuals seek medical help.<sup>15-17</sup> A number of studies across the globe report patients' perceptions and experiences of onset of symptoms, seeking medical help and self-management strategies.<sup>18,19</sup> Most of these studies emerge from Western countries where public health systems are well organized for NCDs and are distinct from those in India. Literature shows that inherited cultural beliefs impacting upon seeking medical help can be similar among the migrated population to other countries. For example the UK rheumatology research in ethnicity has documented comparable cultural illness beliefs impacting on delay.<sup>20</sup> However, data on seeking medical advice in India are lacking and therefore this study was set up to explore the perceptions of participants with RA living

TABLE 1 Topic guide

- Experience of symptoms
- Coping and adaptation
- Health seeking
- Influence of family
- Expenses
- Referral
- Therapy
- Recommendations for reducing the delay

in India. Data from this study was used to investigate the impact of RA on work productivity which is published elsewhere.<sup>13</sup> In this paper, we focus on exploring the experiences of patients in seeking medical help.

## 2 | METHODS

### 2.1 | Participants and study design

The study protocol with time period and detailed study design including the method of reporting the data has been previously documented.<sup>13</sup> This included a qualitative thematic approach. The data have been reported in line with consolidated criteria for reporting qualitative research.<sup>21</sup> The first part of this methods section reports consolidated criteria for reporting qualitative research domains important for reporting each aspect of the study procedure. The second part focuses on data analysis and the theoretical framework procedure that took place.

Clinician-diagnosed RA participants were identified at outpatient rheumatology clinics at Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow. Purposive sampling allowed a diverse group of participants with a mix of both men and women, with varying age, educational profile, marital status, disease duration and different socioeconomic status.

Patient information leaflets in Hindi were provided and consent obtained from participants by the researcher AJ. Individual face-to-face semi-structured interviews were undertaken by AJ in a separate room within the outpatient clinics department. The interviewer had not previously come in contact with the patients. An iterative approach was followed.<sup>22</sup> Interviews were conducted until data saturation had been reached. A pre-study questionnaire captured demographic data and disease activity scores, functional status and fatigue using Disease Activity Score of 28 joints - erythrocyte sedimentation rate (DAS28-ESR), Health Assessment Questionnaire (HAQ)<sup>23</sup> and Multidimensional Assessment of Fatigue tool<sup>24</sup> respectively.

A topic guide was developed based on a literature review and discussions with patient research partners asking them to describe their journey and issues faced living with RA (Table 1). Patient research partners (AB and UJ) in India were trained by AJ. Being part of a research team and assisting in developing study documents and reflecting on results was a new concept for AB and UJ. AB, a female teacher, with a diagnosis of RA for the past 25 years and UJ, a female



shopkeeper, had been living with RA for past 15 years. The patient research partner in the UK (JH) had some experience of being part of research projects. Patient partner, JH, self-employed, had been living with RA for the past 5 years. The interviews lasted approximately 1 hour, were digitally recorded, and transcribed verbatim by an independent transcribing company. Patients were encouraged to discuss their perspectives using open-ended questions, starting from onset of symptoms, getting a diagnosis, and starting treatment at a tertiary care hospital (Table 1).

## 2.2 | Data analysis

Data were analyzed using thematic analysis.<sup>25</sup> AJ and KK independently coded all transcripts and then jointly resolved differences. Comprehensiveness, richness and credibility of data were enhanced by using the process of triangulation between the wider research team. Coding of 3 transcripts was done by patient research partners. A summary of the findings were sent to the individual participants who took part in the study for confirming the true interpretation of the interviews. The transcribed scripts into English which were typed by an independent trained and experienced company, were assessed by AJ and KK for accuracy and reliability (both bilingual researchers). A proportion of the scripts were independently assessed by JA, SD, RJ, SS, and KA. The team met for discussing the overarching themes. Part of that process has been reported in our previously published paper.<sup>13</sup> Coding categories that lacked concordance were discussed and absorbed into the coding framework. Initially, 64 codes were identified, which were then grouped into 23 categories and finally combined into 3 overarching themes (Table 2 and Figure 1).

The data have been reported in line with consolidated criteria for reporting qualitative research.<sup>21</sup>

## 2.3 | Ethics approval

Ethics approval was granted by the Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow Research Ethics Committee (IEC code 2018-95-SRF-104).

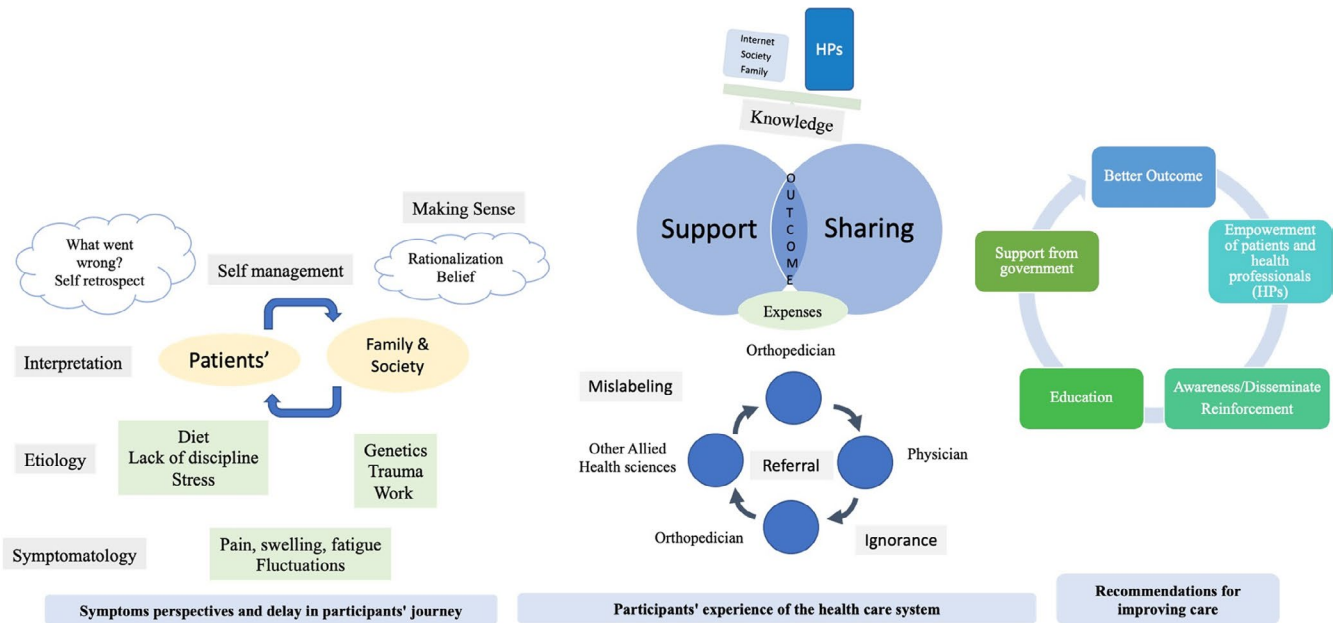
## 3 | RESULTS

### 3.1 | Patients participating in the study

Twenty participants, 13 male and 7 female, were enrolled to the study. Four patients (all male) out of 24 approached declined participation due to lack of time. Table 3 shows the demographic sheet of the participants who took part in the study. Participants from different socioeconomic backgrounds from north, central and east of India participated in the study. They belonged to upper ( $n = 4$ ), middle ( $n = 8$ ) and lower classes ( $n = 8$ ) defined using Kuppuswamy scale<sup>26</sup> and had very variant educational background levels (1 uneducated, 1 primary, 3 secondary, 8 graduate and 7 postgraduate) and religious beliefs. Median distance to hospital from their residence was 166 (119.9-210) miles. Median age at presentation and treatment duration were 40 (interquartile range [IQR]<sub>25-75</sub>, 35.7-46.5) and 5 (IQR<sub>25-75</sub>, 1.3-7) years respectively. Median DAS28 was 3.0 (2.6-3.9). Three patients had high disease activity (DAS28-ESR > 5.1), 5 moderate (DAS28-ESR > 3.2-5.1), and 9 had either low activity or were in remission (DAS28-ESR ≤ 3.2). For 1 patient,

**TABLE 2** Themes describing participants' journeys

Symptoms perspectives and delays in participants' journey		Participants' experiences of the healthcare system		Recommendations for improving care
Example of codes	Sub-categories	Example of codes	Example of codes	Sub-categories
Symptoms	Symptomatology	Lack of knowledge	Symptoms	Symptomatology
Fatigue	Making sense	Symptomatic management	Fatigue	Making sense
Diet	Etiology/interpretation	Complex referral	Diet	Etiology/interpretation
Genetics	Attitude	Lack of support	Genetics	Attitude
Work	Support	Wrong diagnosis	Work	Support
Exertion	Stigma	Expenses	Exertion	Stigma
Lifestyle	Self-management	Influence of family members	Lifestyle	Self-management
Disease of elderly	Distance	Internet	Disease of elderly	Distance
Comparison	Seeking help		Comparison	Seeking help
Symptom intensification			Symptom intensification	
Others' experiences			Others' experiences	
Support			Support	
Sharing			Sharing	
Stigma			Stigma	
Impact			Impact	
Traveling			Traveling	
Expenses			Expenses	



**FIGURE 1** Thematic diagram of rheumatoid arthritis patients' journeys in India. This diagram demonstrates their perspectives, the interplay of factors impacting on their decision to seek medical help and the delay in seeking medical help in India

DAS28-CRP (C-reactive protein) was used and in 3 cases, ESR and CRP were not available. Median (IQR<sub>25-75</sub>) HAQ and Global Fatigue Index were 1 (0.3125-1.5) and 26.3 (20.4-32.2) respectively. All patients were taking conventional disease-modifying anti-rheumatic drugs except 1 who received 1 dose of adalimumab (anti-tumor necrosis factor therapy) before presenting to us. Mean duration of treatment was  $5.4 \pm 5.7$  years when compared to mean disease duration of  $8.1 \pm 8.1$  years, highlighting the delay in treatment initiation.

Three themes emerged from the thematic analysis enhancing the understanding of participants' experiences of having develop RA and seeking medical help. The reasons for delay in seeking medical help were expressed by participants.

### 3.2 | Themes

#### 3.2.1 | Symptom perspectives and delay in participants' journeys

The most common symptoms included pain (Q1, Table 4), swelling, stiffness (Q2) with morning and winters (Q2) being particularly worse for participants; some also reported joint deformities (Q3). The fluctuating course of RA was confusing for most participants (Q3). Fatigue was experienced by most and was out of proportion to the "joint" symptom(s) although a few denied any fatigue (Q4). Participants tried making sense of their symptoms to explain the presentation and attributed work, stress, diet, lifestyle, trauma among the many other causes (Q5, Q6). Participants' understanding of RA varied, some felt that RA could be contagious (Q7) or occurred

due to chemical exposure or due to postural issues or uric acid (Q8, Q9). Most of the participants barring 1 considered the issues of joint pain to be a problem of age not recognizing this could be autoimmune (Q10) except for 2 who seem to have agreed that this can start at a young age as well (Q9). A few participants recognized that genetics could play a part in the etiology of their RA and some mentioned being surprised why no-one else had it in the family (Q11). However, despite positive family history in 2 participants, this did not seem to prompt insight that their symptoms could be RA and thus they did not seek healthcare professionals (HPs) including rheumatologists (Q12) early on when they started experiencing painful symptomology.

Often, they would rationalize and explain away their symptoms, take painkillers (Q13) or use home remedial measures like applying oil or turmeric (Q14), and move on with their life. Some of these remedies including ayurveda, naturopathy, and homeopathy, brought some temporary symptomatic relief adding to delay in seeking healthcare professional advice and support (Q15-16). However, a few participants were clear that these options mentioned above do not work (Q17). One participant reflected how he lost time trying black magic (Q16). A few were in a state of denial and disappointment wondering that they had always been healthy throughout and no family members including the "elders" had it and hence neglected it not taking it to be a serious ailment (Q18, Q19). A few including their family members blamed their "undisciplined" lifestyle (Q20). One of the participants self-diagnosed himself to have filaria in view of limb swelling.

Some cited busy life as a reason to continue coping and get along with pain till "flexibility" of joints started to get compromised (Q3). While others were oblivious of their symptoms and showed disbelief



TABLE 3 Demographic data of patients

Patient no.	Level of education	Age (y)/gender	Socioeconomic background	Marital status	Age at onset (y)	Distance from SGPGI (km)	Treatment duration (y)	DAS28 at the time of interview	HAQ	GFI	Treatment
1	Postgraduate	63/M	Upper	Married	44	222	5	2.85	0.875	29.6	MTX 7.5 mg/wk
2	Postgraduate	30/F	Middle	Married	25	193	5	2.33	0.375	0	SSZ 2 g/d and Pred 2.5 mg a/d
3	Postgraduate	43/M	Upper	Married	42	797	0.17	3.73	1	26.2	MTX 20 mg, HCQ 300
4	Graduate	28/M	Middle	Unmarried	26.5	312	1.5	3.08	0	0	MTX 17.5 mg, HCQ 300, PRED 4 mg
5	Graduate	41/M	Lower	Married	40	480	0.42	ESR not done	0.125	23.8	MTX 20 mg/wk, HCQ 200
6	Postgraduate	59/M	Upper	Married	29	258	20	2.7	1	16.2	15 mg/wk
7	Primary	45/F	Lower	Married	42	195	1.17	4.3	1.25	32.2	MTX 10 mg, HCQ 200, Pred 7.5 mg
8	Postgraduate	39/F	Middle	Unmarried	16	292	17	ESR not done	2	32.6	MTX 10 mg
9	Graduate	30/F	Middle	Married	26	276	Initiated now	5.85	0.75	25.2	Initiated now
10	Graduate	39/M	Middle	Married	33	90	6	3.33	1	13.6	MTX 20, HCQ 200
11	Secondary	35/M	Lower	Married	30	314	5	1.99	0	0	MTX 25, HCQ 300
12	Secondary	33/M	Lower	Married	32	335.8	2	2.93	0	19.5	MTX 15, HCQ 200
13	Graduate	46/M	Middle	Married	33	483	5	ESR not done	1.5	29.8	MTX 12.5, HCQ 200
14	Postgraduate	57/F	Upper	Married	49	807	8	6.83 <sup>a</sup>	1.875	43.6	MTX 15, HCQ 300
15	Graduate	37/M	Lower	Married	23	66	13.5	4.7	2.5	23.9	MTX 25, LEF 20, HCQ 300
16	Graduate	59/F	Middle	Married	48	345	8	2.22	1.125	40.6	MTX 15 HCQ 200
17	Postgraduate	46/F	Middle	Married	46	66	0.58	3.42	1.5	36.6	MTX 15 HCQ 300

(Continues)





TABLE 3 (Continued)

Patient no.	Level of education	Age (y)/gender	Socioeconomic background	Marital status	Age at onset (y)	Distance from SGPGI (km)	Treatment duration (y)	DAS28 at the time of interview	HAQ	GFI	Treatment
18	Secondary	38/M	Lower	Married	33	90	2.5	5.68	1.625	18.6	MTX 25, LEF 20, HCQ 300
19	Graduate	36/M	Lower	Married	33	246	0.83	1.96	0.875	26.6	MTX 25
20	No schooling <sup>b</sup>	48/M	Lower	Unmarried	40	193	2.17	2.17	0	20.4	MTX 20 HCQ 300
40 (35.7-46.5)			33 (29.5-42)	267 (193-338)	5 (1.3-7)	3.0 (2.6-3.9)	1 (0.3125-1.5)	26.3 (20.4-32.2)			

Note: DAS28 of greater than 5.1 implies active disease, less than 3.2 low disease activity, and less than 2.6 remission.

Abbreviations: a/d, alternate days; DAS28, Disease Activity Score of 28 joints using erythrocyte sedimentation rate (ESR); F, Female; GFI, Global Fatigue Index, where GFI of 1 means no fatigue and 50, severe fatigue; HAQ, Health Assessment Questionnaire, where < 0.3 is normal; HCQ, hydroxychloroquine; LEF, leflunomide; M, Male; MTX, methotrexate; Pred, prednisolone; SGPGI, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, India; SSZ, sulfasalazine; UP, Uttar Pradesh.

<sup>a</sup>DA S28 using C-reactive protein.

<sup>b</sup>Did not receive any formal education.

and wondered what was happening (Q19, 21), a few could not even recall the onset (Q22). For those who were unmarried, irrespective of gender, it was a challenge going to a HP due to worry about societal standing (Q23).

Depending on the pain severity and impact on functional class, most participants decided to seek a health professional. This meant years of delay for some, particularly more common for females. Opinion from family members varied with a few reinforcing the delay (Q24) while others ensured timely seeking of health care (Q25). For some lack of response to painkillers would ring a bell. A number of participants talked about expenses, need for accompaniments and travel distance to hospitals adding to delay (Q26, Q27, Q31).

### 3.2.2 | Participants' experiences of the healthcare system

Participants used other approaches before ultimately seeking help and support from HPs; these typically included orthopedic surgeons, nearby physicians, post-MBBS practitioners (Q28-31). Some of them were seeing them privately, others at primary health centers, or nearby institute including secondary or tertiary care, but none directly approached a rheumatologist. Some of the participants would visit multiple HPs citing lack of immediate relief, or an inability of a HP to reach a diagnosis or the prolonged and ongoing course of the disease or due to pressure from their relatives to seek other help (Q17, Q31-32). It was apparent that participants had low levels of understanding and education about RA (Q33-34). Participants would turn to their close social networks for trusted advice and trust the experiences of friends and families and change their HPs (Q17). Only 1 participant highlighted the need to stick to 1 HP so that their disease could be well understood and therefore more effectively managed. Participants recounted that they felt there were a few major shortcomings of HPs. These included over-reliance on symptomatic relief (Q35), tests, particularly rheumatoid factor and uric acid to reach a diagnosis and lack of forward referrals to the right specialists in time (Q36,37). One participant was told the disease is because of work (Q38).

Referral system at the government level was complex including inability to get funding and bills cleared when referred to a referral center, resulting in some patients resorting to private care or incurring expenses from their own pockets. This was perceived as a hindrance to proper healthcare provision (Q39). Despite timely referral, a few participants (Q40) did not seek further care due to symptomatic improvement (Q41) and a few cited distance and expenses as reasons. Some of them had to cut down on other expenses to compensate for medical expenses (Q42). Females were hesitant to ask for money from spouses.

A few participants found support in family members and were taken to a referral center, whereas others were left on their own with no support. HPs were the only source of disease knowledge for most. Incomplete education of participants was also reported by some and this would indirectly add to delay as it would mean lack of awareness in society in general (Q43). Participants had extremely



high opinions of doctors and considered doctors as God and hesitated to ask questions about the disease (Q44). Eventually everyone reached a rheumatologist but after prolonged delay ranging from a few weeks (3 participants) to more than 5 years for most.

Even after reaching the rheumatologists, long waiting times at outpatient clinics was troublesome. It took some time for most to understand the functioning of the hospital. Few participants would learn more about delay from each other's journey. A few participants hesitated or lacked the courage to speak to other fellow patients and felt some might perceive it as interference.

### 3.2.3 | Recommendations for improving care

Participants reflected on what was required to help improve their pathway to seeing a rheumatology specialist and many identified that there was a need for increasing awareness of the relevance of the symptoms of RA and perhaps using a campaign analogous to other common but relevant issues (Q44, Q45). Most participants compared RA to other well-known diseases like cancer, hypertension, diabetes, hypothyroidism and cited the need to achieve the same level of awareness for RA in order to reduce delay (Q45-47). Some were happy with the knowledge provided (Q48) while others quoted lack of discussion about disease and role of drugs (Q49, Q50).

Dissemination of knowledge related to primary symptoms through media like newspapers, books, pamphlets, TV, WhatsApp, posters, camps, was suggested (Q51-54). Educating the family and exchanging experiences with fellow patients should be promoted as this may serve as reinforcement and reduce further delay.

Patients highlighted lack of knowledge regarding the "rheumatology branch" and a lack of number of rheumatology practitioners including a need for empowerment of rheumatologists (Q55). They recommended a need for education of general HPs at various levels citing lack of rheumatology input at primary health centers, district levels as well as a number of tertiary centers (Q56, 57). Participants identified that the substantial impact of RA on an individual's daily life needs to be recognized more evidently by government – as this is currently not the case (Q58). They offered ideas about how the government could make practical changes, for example making smart cards for travel (Q59) and discounts for an accompanying person supporting someone who had disabilities due to RA as this would provide support and decrease expenses. Reducing expenses and better reimbursement policies could allay the general perception of tertiary hospitals being expensive and cumbersome (Q60). This is crucial as government spends only about 5% of gross domestic product on health care as compared to over 12% in Organization for Economic Co-operation and Development countries.<sup>27</sup>

## 4 | DISCUSSION

To the best of our knowledge, this is the first qualitative study to have explored RA patients' perspectives on disease symptoms, delay

and seeking medical help in India. Management of RA is complex and multi-faceted. While physical symptoms may be supported via pharmacological treatment, understanding the physical, emotional, economic and social impact of RA on an individual's life will help better design services for more effective support. The findings from our study suggest that systematic deficiencies at local and national levels are contributing to overall delay in finding appropriate medical help. The findings demonstrate how individuals living with RA in India dealt with their rheumatology symptoms and rationalized their symptoms which culminated in delay in seeking medical help (Figure 1).

In our study, there were more males as compared to females despite the gender ratio being biased toward females in RA. This could be because our cohort comprised of participants who were currently employed and the majority of women in India are home-makers. Symptom perceptions did not differ between this diverse group of participants and complemented the findings from other studies particularly focusing on symptomatology.<sup>17,28</sup> Fatigue was a common issue for most. Our findings are similar to others where participants rationalized "non-serious" aches and pains.<sup>15,17,26</sup> Self-diagnosis, self-management at home, "lay consultation"<sup>29</sup> from family members, and stigma added to the delays in presenting to the right HPs (Figure 1). Participants in our study followed multiple trajectories, most commonly the stable illness trajectory as described by Pelaez et al<sup>29</sup> until there was a significant functional compromise, loss of "flexibility" of joints and lack of relief with painkillers that compelled them to seek HPs, a finding similar to previous studies talking about delays in help seeking.<sup>17,29,30</sup> Individual interpretations, often clouded by inputs from family members in India, are both drivers and barriers to help seeking.<sup>17</sup> Family and societal role play influential parts with a lot of interference, positive and negative, in a patient's life in India. This echoed with the findings of Tiwana et al<sup>30</sup> that significant others play an important role in influencing help-seeking behavior and reflected the need for increasing symptom awareness in society. Kumar et al, in their study indicated the influence of ethnicity in delay in RA<sup>20</sup> showcasing collectivist culture in South Asia compared to an individualistic society in the UK.

Delay continued even after reaching the HPs, akin to observation by De cock et al<sup>31</sup> Participants consulted HPs of other allied health sciences, a "culture" similar to most participants elsewhere<sup>15,20,32,33</sup> but a longer delay in initiation of correct treatment meant this journey was prolonged for patients in India. Lack of education of participants also seems to be contributing to decreased dissemination of disease knowledge in society. There was a hierarchal element to the doctor-patient relationship. Lack of rheumatologists in their town or vicinity was partly to be inculcated for the same.

Most participants felt they had received good care and support from family which helped them manage well. But a few lacked this support adding to delay. This is an important aspect that needs to be contemplated as it has long-term repercussions - good understanding, sharing and decrease in delay can only be achieved with better education of the entire family over time. This finding was also raised by Simons et al in their qualitative study focusing on help-seeking in



**TABLE 4** Quotes from participants illustrating results**Theme 1. Symptoms perspective and delays in patient's journeys**

- Q1. First, when I had too much pain in the neck, I was unable to move my feet. Even when I had to get up then my Mrs will help me to get up. The problem was such that the pain was excruciating.
- Q2. First when I used to get up in the mornings, I had no problem in that. Since the disease, when I get up in the morning then I used to get pain in the feet and difficulty in walking making me late in the mornings.
- Q3. After this, roughly in 2010/11, few symptoms came but was not sure what was happening, but by 2013 my fingers were less flexible/would not turn as much and my writing was different, and I was finding it extremely hard to write and was wondering what was happening!?
- Q4. NO fatigue. Not really. I don't feel like that.
- Q5. I felt that my level of stress is high that is why I am experiencing this problem.
- Q6. They did not accept them at all. They don't take it seriously. They think it could be because of an injury. when somebody meets me for the first time, they generally ask how did I get injured? When I do tell them, they say arthritis normally happens at an older age how can it happen to you? What history can I tell him that how it happened. This is the general tendency about the disease among people.
- Q7. Yes, Dr sahib. Many people think that she has got this disease, hope she doesn't affect us or our children.
- Q8. No, not in that respect. As I said earlier that I was told my uric acid is high, and since protein has high purine and hence uric acid, I reduced my protein diet.
- Q9. It does happen in old age, but it can happen at young age as well. I was 35 when I had it and I couldn't understand why it happened to me. I couldn't find the reasons why it happened to me. One of the reasons I was told that it could be an old injury or a chemical reaction in the body or if you don't eat properly if the routine is broken then all this happens. I saw all this on the net.
- Q10. Mentally it was just that what would people think, that at this age the disease has occurred.
- Q11. I've heard it is genetic but none of my parents have got it. My mum and dad haven't got it. Neither my mum's or dad's parents had it. I went back and studied the past 3 generations.
- Q12. My mum told me that her mum had it then my mum got it so, I thought possibly it was being passed on from generation to generation
- Q13. Nothing as such. All it was, I was taking just pain killers.
- Q14. It just to hurt here and there and occasionally got swelling. I was trying to avoid things, told mum and dad and as people do, they used to apply turmeric and I used to get relief.
- Q15. Yes, Dr sahib. Many people come to the hospital and by the entrance gate people sell all kinds of medicine for arthritis for Rs120, Rs 125 and they say take it and don't pay. Only pay if you get relief. We guarantee, pay on second or third day if you benefit. Many people buy it, I feel like doing the same. They have many oils, but I don't know what's in them. They say warm it and apply to the arthritis affected area like this and my daughter said he is selling medicine for arthritis, buy it.
- Q16. They do support me but are also saddened due to the fact that I am not getting better. They keep on asking me to get examined from here or there. I have had homeopathy, Ayurveda and even magic but all in vain. I thought if friends are asking for the magic - tuna, I'll get it done although I knew it wasn't going to make a difference.
- Q17 Only Allopathy benefits, no benefit from anything else.
- Q18. Yes, I was avoiding. I thought I will carry on, But I won't take any medication in life. Until now I have had no issues. Not even fever and then suddenly all this. I didn't feel suddenly there would be so much difficulty inside me.
- Q19. How could this happen now when nobody in the family has this. Not even my maternal grandparents have this although they are really old. My nana is 86 years old but still he does all his work without any difficulty. He also looks after the cows and buffaloes. I had no idea about this kind of disease, I had heard...
- Q20. I was actually never a very disciplined fellow and always my family used to tell me that I was having no lifestyle
- Q21. Sir, initially nobody was able to understand what was wrong with me. Everyone was baffled at home.
- Q22. Sir, 5 years ago I found out about the disease but don't know how long before that the disease had been in existence.
- Q23. Avoid, because I'm not married, and people used to prohibit me from telling.
- Q24. No, he doesn't. If he supported, then I would have got examined from a better doctor in Kanpur.
- Q25. Sir, there was a lot of support. I was taking a back step from the doctors and medicine; I wouldn't have even got myself examined. I would have managed but mummy and papa insisted on...
- Q26. Support like... mum and dad are farmers; it is not much but just enough to provide food. I somehow took loans from here and there in order to come here.
- Q27. Not just the medicine, it's the travel. I don't travel alone; somebody will accompany me.

(Continues)



TABLE 4 (Continued)

**Theme 2. Participants' experiences of the healthcare system**

- Q28. I discussed it with a local orthopedic doctor, but nobody mentioned that you have an arthritis problem.
- Q29. First time my problem started at night. I went to sleep after dinner and around 1.30-2 AM I had pain in the shoulder. I took it normally and the next day I took pain killers and I had relief. After 3-4 days then pain started in the second shoulder. Then I had pain here... and that pain was unbearable so, I got examined by a local doctor.
- Q30. Yes, there should be awareness. As when the problem starts, it is in joints and generally people think to go to an orthopedic doctor, he will diagnose and start treatment accordingly but at a later stage one comes to know this condition is not within their specialization. Then he gets to the specialist when the real treatment begins.
- Q31. My disease started in 2005. I had pain and swelling in the wrist so, got examined by a doctor. It started from my fingers and wrist and because of the pain I got examined by an MBBS doctor I didn't go to any lesser doctors. His treatment continued on a monthly basis and when he couldn't understand the disease then I got examined by another doctor. I got examined at Azamgarh, I live in Rai Bareli and got treatment there.
- Q32. Mostly at the patient level because at the beginning they can't get to a good place. Like in the beginning they go to doctors with less knowledge or compounders... this takes a week or 10 days. Then they'll go to another place which may also take a week to 10 days and then they find out the result.
- Q33. The thoughts I get are like how long the medicine is going to continue? Is it ever going to finish or is it going to carry on until the end of life? These are the kind of thoughts I get.
- Q34. No, that did not happen. They just prescribed the medicine but did not tell anything.
- Q35. Well the diagnosis... I took homeopathic medicine but no relief, then Ayurvedic but no relief, then I had fever and with the fever I got burning sensation which gave me small pimples in the thigh and groin area. I also got pimples and burning sensation. Then I got admitted in Benaras and after examination found out there was a lack of blood. The fever and the treatment continued, and my hands and feet used to shake. They carried me in the lap and got me examined in Benaras. They found out my blood level was low, and they gave me 2 packets of blood. After the blood they started treatment, but they were unable to diagnose the condition.
- Q36. First it was like the blood level is low, get it checked, then hemoglobin and urine tests. People were getting various types of tests done and I was doing the same.
- Q37. I repeated my test. I got my RA negative and anti-CCP negative, there I have seen one ANA positive then again, I told my, one of my friends who is a medicine person. He told me to go for the profiling of ANA, I done my profiling at some hospital. And there it was showing that it is anti-Jo 1 positive, then I got it from outside lab, Jo 1 was negative.
- Q38. Everybody eats the same. The first doctor asked me how long I had been working at the dairy. I told him I have been working at the dairy for a very long time, since the age of 15. He said that's the reason for the disease. I said there are children aged 10-12 sitting there with the same condition, they have never done that work.
- Q39. No this wasn't from railway but from a private doctor. The problem with railway is that they don't refer soon enough. they want to do the treatment themselves but if they don't treat you correctly, there's a problem that's why one thinks to get oneself treated privately. until there is a major problem involving a lot of expense.
- Q40. Because the first doctor said that I am just writing it down for you, but you need to consult a good doctor.
- Q41. After that I continued with his medication, AND they recommended to get examined at PGI, but I thought the medicine is working, gradually everything will be fine, so I avoided it.
- Q42. Careless meaning if I had got examined by a good doctor, would have got good medicine. I am also stressed because of my husband, whatever I earn I spend on kids and live in rented house in Kanpur, whatever he earns he has his own expenses. I have also got to look after the children's education, have to think about food and rent/travel and my own expense, medicine. This is a problem why I couldn't get examined by a good doctor.
- Q43. Yes, sir. In the start no doctor explained to me that it is a life-long disease and I will have to take medicine forever. I just knew it was called RA factor or RA positive and I continued getting treatment for a few years with the hope that it will get better. Two, 3, 4 years just went past. At that time internet was not available to conduct any searches so, knowledge was obtained only through doctors. After 3-4 years only, the doctors at PGI explained that the condition is going to last for the rest of my life. You will need to take medicine for the rest of your life, but rest assured that we will make you walk so don't stress. You must take medicine for the condition and you'll be fine although occasionally you will get pain. Since then it has been going fine
- Q44. Doctors are like a form of God. This is like a temple and we come here, and we prayed to God.

(Continues)



TABLE 4 (Continued)

**Theme 3. Recommendations for improving care**

- Q44. Yes. Like here doctors said you should have come sooner. But how would I have known that I have got this disease? If I had known of the symptoms, then there is a possibility I could have spotted it sooner. So, the symptoms of the disease should be publicized.
- Q45. Yes. first of all, this is a disease and you have to tell the government this is a disease which everybody should know. Like in cancer they are doing ... You will find out they are doing many shivirs (camps), because I'm working in rural area they are checking the breasts, lungs so they are many camps are getting held up. But these sorts are not ... even in our state we don't have rheumatology
- Q46. Make people aware about the disease. Bring it onto the general platform. this disease has never been discussed on the general platform like cancer. If anyone else utters the word cancer everybody says it is such a serious disease, people getting these kind of thoughts, but with this disease people say it is just arthritis. I have heard this several times that's why I'm telling. They say it is arthritis it happens at old age and that's all.
- Q47. I have seen others on TV about cancer but not about arthritis. If that was shown, then patients may come sooner. They may go straight to the doctor.
- Q48. We had a lot of respect for him and he will provide all knowledge on the disease. I got really happy. All patients want the doctor's behavior to be good as they recover a lot quicker.
- Q49. The cause should be explained. Like this has happened to me, why has it happened?
- Q50. Please don't mind, some doctors just examine and start writing the prescription. During that time, we are not even able to ask what this medicine is for? You feel that you don't want to offend them. An improvement could be made there, and some doctors do explain.
- Q51. These days the medium of TV is quite powerful, and you can show this through advertisements.
- Q52. The government should determine where the public show their highest interest and there gradually all these things should be shared. This will raise awareness in the people. Like if the public uses WhatsApp more and through that medium even 1 out of 10 read it and forwarded it then the awareness levels could be increased. Even if nobody else finds about it but he will at least share that with his family. If somebody already had the symptoms and they read the message they will realize which disease, they have.
- Q53. While waiting here I have seen a poster and if the same poster is displayed everywhere in the primary health centers even in the working spaces of schools and colleges, it will make a difference. Although I know about the disease but following the systematic pain...
- Q54. I consider rheumatoid arthritis has less awareness in public. They just know what arthritis is. But RA has many types, so I will suggest having a TV advert or pamphlets in hospitals locally telling people to take precaution about things such as if these are the symptoms this could be the disease, discuss all that and tell them to come here. Something like that...
- Q55. I would say any government of UP or center, they should keep their health department at number one. Our doctors should have full facilities for the diagnosis/ tests, if they only have half of the things, what can they do? They should be provided all machines (equipment) and medicine.
- Q56. It may happen, but I feel that it could be mostly happening in smaller cities as there aren't enough doctors. They don't have the facilities to diagnose the disease. However, in bigger cities the doctors are good like here at PGI and they can diagnose the condition much quicker.
- Q57. There are several patients of RA all over India. Many people in the interior are not aware that they've got RA. If the govt. discusses a little about this disease at PHC, district hospitals level, then that will be beneficial for the patient and for the govt.
- Q58. First of all, the government needs to be told that this is a disease. They need find a permanent solution so that it doesn't happen again.
- Q59. Like if I could get a travel pass and also if I could get some concession in the medicine.
- Q60. In the bank certain diseases like cancer etc the hospitalization costs, bills are reimbursed generally on hospitalization but this disease (RA) doesn't require hospitalization, it is a long-life disease. The initial hospitalization bills were reimbursed. They don't reimburse continuous medicine bills. I told them this was a long-term disease so for some time they have started reimbursing the medical bills.

new-onset RA.<sup>34</sup> Diagnosis and initiation of treatment thus took time. This is much protracted when compared to median delay of 23 weeks between symptom onset and assessment by a rheumatologist in the UK.<sup>35</sup> This highlights the medical ignorance in Indian patients with symptoms often attributed to myriad factors including diet, stress, excess work and lifestyle among many other causes. Thus, lack of disease awareness, fewer numbers of rheumatologists and delayed referral resulted in a prolonged journey (Figure 1), something that is different from European populations and similar to other developing nations. "Doctor shopping", partly due to HPs not clearly conveying appropriate accessible education about the disease during consultation, and poor referral system added to delay and poor management. Our study suggests that in contrast to developed nations, patients in India experience delays at multiple levels; the journey started with delay in reaching HPs when they had not reached a diagnosis and the delay continued even after reaching HPs including a delay before disease-modifying therapies were finally commenced. This indirectly highlights the healthcare system in India which has no proper referral system. India has a mixed healthcare system, with most tertiary care being provided by the private sector and primary healthcare services being provided mainly by the government.<sup>36</sup> Most of the referrals to both private and

public sector sub-specialists are by word of mouth and based on experiences of friends and family. But lack of accountability,<sup>37</sup> poor referral, and lack of all subspecialties even at tertiary levels result in a prolonged journey for most patients.

Disease course in itself was a learning curve for most of them and interviews concluded with recommendations to improve the consultation pathway. Recommendations made by the participants represented changes at 2 levels: the local as well as national level. Patients highlighted how the initial delay could be dealt with by spreading awareness through media, camps, pamphlets, targeting health centers at towns and villages. This was similar to findings from a paper focusing on South Asians in the UK.<sup>20</sup> Participants drew parallels with other chronic conditions and highlighted how government was spreading awareness and a similar model needs to be adopted for RA. A need for greater numbers of rheumatologists, education of health professionals locally as well as society for better penetration of rheumatological services are essential. There is a need for a bottom-up approach to improve care and disease outcomes from the ground level. This will help undiagnosed patients reach the right clinician. There is also a need to improve the present curriculum for undergraduate as well as postgraduate



students of medicine and pediatrics, as it is deficient in rheumatology training.<sup>38,39</sup> This can be only be achieved by engaging with all stakeholders including medical councils and the government. National rheumatology societies will have to play a major role. Governments should focus on improving the health infrastructure for easier access to patients. Better patient and family education, concept of patient partners and discussions with fellow patients could mean institution of treatment, in time reducing delay. These should have long-term ramifications on reducing the delay and designing a better consultation pathway. This study highlights the need for large cross-sectional quantitative studies to investigate the impact of delay in RA on economic burden in India.

#### 4.1 | Limitations

We note a few limitations to this study. Qualitative studies with small patient numbers are subject to significant biases and difficulties in extrapolating findings to the general population; however, the results of our study make strong recommendations for the future. Our part 1 study aimed at exploring the impact of RA on work productivity. Since these data are continuous from that, therefore we might not have captured the views of RA and level of delay in home-makers. The study was done only at 1 center and since India is the 7th largest country with richly diverse cultures, there may be variance in the patient perspectives. However, SGPGI, a tertiary hospital, does serve patients from central, north, and east India. Another limitation could be a recall bias as most of the patients had long disease duration. Despite these limitations, these data suggest further research is required in India.

#### 5 | CONCLUSION

This study has highlighted the perceptions of Indian participants with RA in seeking medical advice. Rationalization, signposting of symptoms, lack of appropriate doctor advice, influence of/and lack of education in family, following traditional beliefs, poor referral and lack of rheumatologists contributed to delays. The recommendations made by patients could help in planning pathways to reduce delay.

It is essential to target primary healthcare givers at the village level, and towns including orthopedics and medical graduates to develop greater knowledge on the impact that delay could have on a patient's life and RA prognosis. There is an urgent need to increase the number of trained rheumatologists with better regional distribution and knowledge sharing to reduce delay. Finally, greater involvement of government with improved policies is required.

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#### CONFLICT OF INTEREST

The authors have no conflicts of interests to declare.

#### AUTHOR CONTRIBUTIONS

KK, AA, JA, RJ, SD, KA and SS developed the protocol for the study. AJ conducted the study, AJ and KK analyzed the data and prepared the manuscript. AA, JA, RJ, SD, KA and SS verified the data analysis. AA, JA, RJ, SD, KA and SS modified the drafted manuscript. KK is the guarantor of this paper.

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