**Delay in seeking medical help in patients with Rheumatoid Arthritis in India: a qualitative study**

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**Key words:** Rheumatoid arthritis, South Asians, Patient perspectives, delay, India

**Authors’ Contribution**

KK, AA, JA, RJ, SD, KA and SS developed the protocol for the study. AJ conducted the study, AJ and KK analysed 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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**Conflict of Interest**

The authors have no conflicts of interests to declare.

**Running head**

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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 socio-economic backgrounds were interviewed using a semi-structured topic guide. Participants were purposively selected and interviewed following iterative approach. All interviews were recorded and transcribed by an independent company and analysed using thematic framework. Findings were reported in accordance with COREQ 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, rationalised and led to delay. [2] “Participants’ experience of the health care system” illustrated delay in referral, reaching diagnosis and treatment initiation highlighting their experiences with health system. [3] “Recommendations for improving care” where participants made recommendations for reducing the delay at local and national level.

**Conclusion**

This is the first qualitative study which explored perception 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**

Rheumatoid arthritis, Delay, Symptoms' perspectives, India, Healthcare

**Introduction**

In the last two decades, India has seen a tremendous improvement in the health care sector. A major focus on infectious and communicable diseases has resulted in reduced mortality rates. 1 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.2 There is also paucity of data relating to incidence and prevalence, a lack of infrastructure in government led organisations for delivery of high quality healthcare in chronic conditions and lack of clear planning and policy.3,4 This is a significant issue as NCDs contributed to 63% of all deaths in 2016 in India.5 Cardiovascular diseases, chronic respiratory ailments, cancer, and diabetes contributed 50% to total mortality due to NCDs.5 Among these chronic conditions, the burden of rheumatological diseases is still under reported 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 include lung involvement with interstitial lung disease, etc. These have significant impact on life expectancy besides resulting in high disability adjusted life years. 6,7 Despite the remarkable advancement in understanding disease pathogenesis with ever increasing number 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 the RA prevalence and economic burden mainly emanates from developed countries.8,9 In developing countries such as India data on prevalence is scarce and is under-reported to between 0.28% to 0.7% of the general population.10–12 The reason for under- reporting and unaccounted disease burden could be multi-factorial. The keys issues could be either at a patient’s level or at the level of health care structure. Diagnosis is often delayed 13 and this is compounded by a lack of rheumatologists in certain parts of the country.14 Improvement in outcome needs addressal of these issuses 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.15–17 A number of studies across the globe report patients’ perceptions and experience of onset of symptoms, seeking medical help and self-management strategies.18,19 Most of these studies emerge from western countries where public health systems are well organised for NCDs and 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.20 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 in India. Data from this study was used to investigate the impact of RA on work productivity which is published elsewhere.13 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 documented previously13. This included qualitative thematic approach. The data have been reported in line with consolidated criteria for reporting qualitative research.21 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 socio-economic 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 outpatient clinics department. The interviewer had not come in contact with the patients previously. An iterative approach was followed22. 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 DAS28ESR, Health Assessment Questionnaire (HAQ)23 and Multidimensional Assessment of Fatigue tool24 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 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 five years. The interviews lasted approximately one hour, were digitally recorded, and transcribed verbatim by an independent transcribing company. Patients were encouraged to discuss their perspectives using open ended question, starting from onset of symptoms, getting a diagnosis, and starting treatment at a tertiary care hospital. (Table 1)

**2.2 Data analysis**

Data were analysed using thematic analysis.25 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 three 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.13 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 three overarching themes. (Table 3 /Figure 1)

The data have been reported in line with consolidated criteria for reporting qualitative research (COREQ).21

**2.3 Ethical Approval**

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

1. **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 2 shows the demographic sheet of the participants who took part in the study. Participants from different socio-economic background from north, central and east of India participated in the study. They belonged to upper (n=4), middle (n=8) and lower class (n=8) defined using Kuppuswamy scale (28) and had very variant educational background level (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 (IQR25-75, 35.7 - 46.5) and 5 (IQR25-75, 1.3-7) years respectively. Median DAS28 was 3.0 [2.6-3.9]. Three patients had high disease activity (DAS28esr > 5.1), five moderate (DAS28esr , > 3.2- 5.1), and nine had either low or were in remission (DAS28esr ≤ 3.2). For one patient, DAS28crp was used and in three cases, ESR and CRP were not available. Median (IQR25-75) HAQ and Global Fatigue Index (GFI) were 1 (0.3125-1.5) and 26.3 (20.4-32.2) respectively. All patients were taking conventional disease modifying anti-rheumatic drugs (DMARDs) except one who received one dose of adalimumab (Anti-TNF Therapy) before presenting to us. Mean duration of treatment was 5.4 ± 5.7 years when compared to mean disease duration of 8.1 ± 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 Symptoms perspectives and delay in participants’ journey**

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) though 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 one considered the issues of joint pain to be a problem of old not recognizing this could be autoimmune (Q10) except for two who seem to have agreed that this can start at 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 else had in the family (Q11). However, despite positive family history in two 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, bought some temporary symptomatic relief adding to delay in seeking health care 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 the time trying black magic (Q16). A few were in a state of denial and disappointment wondering that they have 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 other were oblivious of their symptoms and showed disbelief 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)

* + 1. **Participants’ experience of the health care system**

Participants used other approaches before ultimately seeking help and support from HPs; these typically included orthopaedic surgeons, nearby physicians, post MBBS practitioners (Q28-31). Some of them were seeing them privately, others at primary health centres, or nearby institute including secondary or tertiary care, but none approached a rheumatologist directly. 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 one participant highlighted the need to stick to one 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 (RF) and uric acid to reach a diagnosis and lack of forward referrals to the right specialists in time (Q36,37); One participant was told 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 centre resulting in some patients resorting to private care or incurring expenses from their 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 the family members and were taken to a referral centre 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 disease (Q44). Eventually everyone reached a rheumatologist but after prolonged delay ranging from a few weeks (three participants) to more than five years for most.

Even after reaching the rheumatologists, long waiting time 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. (Q49,50).

Dissemination of knowledge related to primary symptoms through media like newspaper, 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 individuals’ 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 countries26.

**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-facetted. Whilst 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 level 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 rationalised 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 unfavourable to female in RA. This could be because our cohort comprised of participants who were currently employed and majority of women in India are home-makers. Symptoms perception did not differ between this diverse group of participants and complemented the findings from other studies particularly focusing on symptomatology.17,27 Fatigue was a common issue for most. Our findings are similar to others where participants rationalised “non-serious” aches and pains. 15,17,28 Self-diagnosis, self-management at home, “lay consultation”29 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 29 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.17,29,30 Individual interpretations, often clouded by inputs from family members in India, are both drivers and barriers to help seeking.17 Family and societal role play an influential role with lot of interference, positive and negative, in a patient’s life in India. This echoed with the findings of Tiwana et al30 that significant others play an important role in influencing help-seeking behaviour and reflected the need for increasing symptom awareness in the society. Kumar et al, in their study indicated the influence of ethnicity in delay in RA20 showcasing collectivist culture in South Asia compared to individualistic society in UK.

Delay continued even after reaching the HPs, akin to observation by De cock et al.31 Participants consulted the HPs of other allied health sciences, a “culture” similar to most participants elsewhere15,20,32,33 but a longer delay in initiation of correct treatment meant this journey was prolonged for patients in India. Lack of education to participants also seems to be contributing to decreased dissemination of disease knowledge in society. There was hierarchal element to doctor patient relationship. Lack of rheumatologists in their town or vicinity was partly to be inculpated 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 entire family over time. This finding was also raised by Simons et al in their qualitative study focusing on help-seeking in new onset RA.34 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 rheumatologist in UK.35 This highlights the medical ignorance in Indian patients with symptoms often attributed to myriad factors including diet, stress, excess work and lifestyle amongst many other causes. Thus, lack of disease awareness, a fewer numbers of rheumatologists and delayed referral resulted in prolonged journey (Figure 1), something that is different to European population 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 suggest that in contrast to developed nations, patients in India experiences delay at multiple levels; journey started with delay in reaching the 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 health care system in India which has no proper referral system. India has a mixed health-care system, with most of tertiary care being provided by the private sector and primary health care services being provided mainly by the government.36 Primary health care services are provided mainly by the government. Indian health public system was designed with primary, secondary and tertiary level of health services. But lack of accountability37, poor referral, and lack of all subspecialties even at tertiary levels results in prolonged journey for most of the patients resulting in delay.

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 two levels: local as well as national level. Patient highlighted how the initial delay could be dealt 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 UK.20 Participants drew parallel 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 number of rheumatologists, education of health professionals locally as well as society for better penetration of rheumatological services are essential. There is a need for bottom-up approach to improve care and disease outcomes from ground level. This will help undiagnosed patients reach the right clinician. There is also a need to improve present curriculum for undergraduate as well as post-graduate students of medicine and pediatrics, as it is deficient in rheumatology training.38,39 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.

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 one study aimed at exploring the impact of RA on work productivity. Since this data is 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 one centre and since India is the 7th largest country with richly diverse culture, there may be variance in the patient perspectives. However SGPGI, a tertiary hospital, does serve patient from central, north, and east India. Another limitation could have a recall bias as most of the patients had long disease duration. Despite these limitations, this data suggests further research is required in India.

**Conclusion**

This study has highlighted the perceptions of Indian participants with RA in seeking medical advice. Rationalisation, 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 health care givers at village level, and towns including orthopedicians and medical graduates to develop greater knowledge on the impact that delay could have on 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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**Figure 1: Thematic diagram of RA patients’ journey in India.** This diagram demonstrates their perspectives, the interplay of factors impacting on their decision to seeking medical help and the delay in seeking medical help in India.

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