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Work productivity loss among rheumatoid arthritis patients in India: a qualitative study

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Abstract

Objective. To explore to what extent rheumatoid arthritis (RA) impacts on work productivity loss in patients living with RA in India.

Methods. Face to face semi structured interviews took place in 13 male and 7 female patients attending outpatient clinics at Sanjay Gandhi Postgraduate Institute of Medical Sciences, India living with RA. Patients currently working were recruited. Data were audio recorded, transcribed by an independent translation company and were analysed using the framework method of thematic analysis.

Results. Four themes that explained patients' experiences of coping with work whilst having RA were identified. These included [1] "Balancing act of work and RA" where participants expressed their day to day struggle living with RA and coping at work. [2] "Work place adaptation after RA": here participants shared insights into communicating with employers and their efforts to adapt at work place. [3] "Support from others and information to manage RA and work": here participants had considered seeking support from different sources that would help them cope at work and understand RA. [4] "Wanting a better support mechanism": here participants made recommendations that could help them cope at work.

Conclusion. This is the first study to have explored the impact of RA on patients' work productivity in India. Patients may have different support needs compared to previous studies in other countries. Patients seem to be employing additional coping strategies not addressed by current interventions or country systems, which may not be sufficient to support patients in staying employed. Patients made future recommendations.

Key words: Rheumatoid arthritis, South Asians, Work productivity loss, India

Rheumatology Key messages

- RA has negative effects on work productivity and career aspirations of patients in India.
- RA strategies were mainly self-developed, indicating a need for education for both clinicians and employers.
- The government needs to reflect on developing better reimbursement policies for patients with RA.

Introduction

Rheumatoid Arthritis (RA) is a chronic inflammatory disease that typically affects people of working age [1]. Advances in treatment have improved disease control and aims to result in better quality of life for patients [2]. Employment and work disability have a significant influence on quality of life in patients with RA [3]. Work disability is an umbrella term encompassing a spectrum of disability including reduced productivity at work referred to as presenteeism through to transient absenteeism (one or more days of sickness absence) and complete loss of work or permanent work disability or unemployment [4]. Work disability is a continuous process and may not parallel disease activity [5]. Therefore, the impact of the disease and status of remission needs to be perceived from patients' perspective as this might have different meaning for patients than clinicians [6]. Pioneering work by Bury [7] around chronicity of diseases framework highlighted the disruptive nature of RA diagnoses, acknowledging that patient experiences are not only influenced by people's social context but also by the nature of their symptoms. Moreover, his work notes that stigma and discrimination about chronic illnesses such as RA which can lead to disability, are noted to be more of an issue in certain cultures [8]. In turn this stigma may influence experience of illness, coping strategies and remaining in work.

We have some understanding that people with RA have more work related disability than people who do not have RA [9]. In RA, studies from 32 countries enrolled 8,039 patients from high gross domestic product (GDP) (>24K US dollars (USD) per capita) and low-GDP countries (<11K USD). Countries including Argentina, Brazil, Canada, Denmark, Egypt, Estonia, Finland, France, Germany, Greece, Hungary, India, Ireland, Italy, Japan, Kenya, Kosovo, Latvia, Lithuania, Morocco, The Netherlands, Norway, Poland, Romania, Russia, Serbia, Spain, Sweden, Turkey, United Arab Emirates, the UK, and the US [9] suggest people with RA who are in paid employment have higher level of disability resulting in absenteeism (time off work). This has a direct impact on costs to society. For people with RA, their symptoms can include increased pain, disability in hand joints, fatigue and depression [5] also negatively impact on work productivity. Sokka et al [9], highlighted that in low-GDP countries, people remain working with high levels of disability and disease activity and were found to be associated with disease duration, worse physical function, high active joint count, low educational level, gender, erosive disease and manual work [9]. Sokka et al, further concluded that cultural and economic differences between societies were also noted. However, full explanations of these differences were not documented. Work from the UK on minority ethnic

population particularly people from South Asian origin living with RA were found to have specific health beliefs that led to poor adherence to medications have also been shown to influence disease outcomes [10]. It is possible that the inter-relationship between disability and work workplace and relationships with employers are also different for people in India mainly because of the nature of work, social factors such as family support and lack of governmental policy on the employment of patients living with long term conditions.

India is an emerging economy with a young workforce. The prevalence of RA is about 0.5% in a population of 1.2 billion [11]. Thus, there are a large number of patients with RA who face work related problems. In addition, due to poor access to health care, patients' disease control is not optimal and as a consequence patients incur further out of pocket expense on health care [11]. More recently, the government has provided some financial support for medical expenses through various schemes, but there is not much support in terms of disability or unemployment. Many patients struggle to meet the financial burden of long term chronic disease leading to despair. Since very little is known about the impact of RA on work productivity and employment in India we conducted this study to explore the impact of RA on work productivity.

Methods

The data has been reported in line with consolidated criteria for reporting qualitative research (COREQ) [12]. The first part of this method section will report COREQ domains important for reporting each aspect of the study procedure. Second part will focus on data analysis and the theoretical framework.

Eligible participants were identified during attendance at routine outpatient rheumatology clinics. Clinician diagnosed RA participants were invited to take part in the study by clinical staff from Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow between Oct 2018 to Jan 2019. Sanjay Gandhi Postgraduate Institute of Medical Sciences is a government run hospital that captures patients predominately from middle to lower socioeconomic status. Patient information leaflets in Hindi were provided to them and consent taken to participate in individual face-to-face semi-structured interviews. We took consecutive participants attending the outpatient clinic. A purposive sampling strategy was adopted by means of a sampling frame [13]. Participants in employment were purposively sampled for a range of age, gender, occupations and disease duration (see Table 1). Interviews were arranged by the researcher

(AJ), a male researcher, from Indian background, trained in qualitative methods by UK researchers (KK, JA, KA). These researchers have extensive experience in conducting qualitative research. AJ visited the UK for training. AJ was able to communicate in Hindi during the interviews and built rapport with participants. The interviews took place at Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow in a quiet room designated for research. Interviews were conducted until data saturation had been reached. A pre-study questionnaire captured demographic data and disease activity scores (see Table 1). Disease activity assessment to give us an indication of disease severity was calculated by using DAS28_{ESR}, [14] functional status and fatigue were assessed using Health assessment Questionnaire (HAQ) [14] and Global Fatigue Index using Multidimensional Assessment of Fatigue tool respectively.

A topic guide was developed based on a literature review and discussions with patient research partners from India (AB and UJ) and the UK (JH) (see Table 2). Patient research partners AB, a female and a teacher by occupation, with a diagnosis of RA for past 25 years and UJ, a female and a shopkeeper, who had been living with RA for past 15 years were both from India. The patient partner from the UK, self-employed, had been living with RA for the past five years. Having patient research partners from two countries allowed researchers to explore support mechanisms to see what could be implemented in India. Pilot interviews took place to detect any logistical issues. Interviews followed an iterative process, with new concepts emerging during data analysis being explored in subsequent interviews. The interviews lasted approximately one hour, were digitally recorded, and transcribed verbatim by an independent transcribing company.

Ethics approval was granted by the Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow Research Ethics Committee (IEC code 2018-95-SRF-104). At the beginning of each interview, the purpose of the study and the consent process were fully explained in Hindi by AJ and each participant signed a consent form. Participants' safety and comfort during interview was imperative. The participants were reassured that their participation would not affect their routine healthcare services.

Data analysis

Since our study was not based on grounded or other phenomenology framework, data were analysed using a form of thematic analysis, the Framework method is commonly applied to qualitative health research [15]. The framework approach is noted for its systematic yet flexible

nature, particularly suited for use by multidisciplinary research teams. This allowed the development of themes to be derived entirely from the raw data to provide rich descriptions of how patients experienced their condition in relation to issues of employment and productivity. This involves a series of five key stages: familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation [15]. The thematic analysis was developed by two of the authors (AJ and KK) who independently coded all transcripts and then jointly resolved differences of interpretation as the analysis progressed (see Figure 1). We did not use software for organising data analysis because we were concerned that this would exclude the Indian research team who did not have access to such resources. The transcripts were typed by an independent translation company who is familiar in translating material in different languages. Transcripts in Hindi were back translated in English by the trained and experienced company. Researchers AJ and KK (both bilingual researchers) listened to a selection of the audio recorded interviews to ensure accuracy, reliability and validity of the typed scripts by the independent translation company. The data analysis approach involved each interview being analysed individually and compared with earlier or subsequent interviews to determine South Asian participants' perspectives of having RA and working.

Rigour was achieved through a process of reflexivity and by documenting all analytic decisions, leaving an audit trail. The following steps were taken: The first and last authors (AJ& KK) became familiar with data and analysed all the transcripts where data were subjected to line-by-line coding. Patient research partner, AB, UJ and JH, were given instructions on coding, they independently coded three transcripts to develop reliable and inclusive themes informed by multiple perspectives. Patient research partners (AB, UJ and JH) were able to reflect on the findings generated from this study and their past experiences of working with RA. Moreover, AB, UJ and JH resonated with findings after having diagnosed for years. Memos that summarised the findings were sent to individual patients who took part in the study for agreement.

A meeting to discuss the coding framework took place between researchers [13]. Coding categories that lacked concordance were discussed and absorbed into the coding framework (see Figure 1). The initial codes were then grouped into the most noteworthy and frequently occurring categories so that mapping of interpretation of data could be charted. As validity check and to ensure quality, trustworthiness of the data, a percentage of transcripts were analysed by other authors (a multidisciplinary group with different expertise - rheumatologists

(AA, India and SD, UK), Occupational Health expert (SS, UK), Social policy expert (KA, UK), epidemiology expert (RJ, UK), and health literacy expert (JA, UK) and patient partner (AB, UJ and JH). This triangulation process ensured that the research findings were robust, rich, comprehensive, and well-developed. The team independently read transcripts and identified the experiences of RA to be presented as a separate paper. The themes presented in this paper surrounding work experience were agreed with no additional themes. The core themes extracted and presented here focus on patients' experience of working while living with RA. Initially, 160 codes were identified, which were then grouped into 30 categories and finally combined into four overarching themes. The four predominant themes enhanced our understanding of patients' experiences of working while having RA.

Results

Four themes emerged enhancing the understanding of RA patients' experiences of living with RA and coping with work in India. Table 1 show the demographics of the patients who participated in the study. We approached 24 patients, of whom 20 agreed to participate in the interview. Four patients (male) could not participate due to lack of time. There were 13 male and seven female patients, from North, central and East India participated in the study. The median age at presentation was 40 years (IQR, 35.7 - 46.5) median duration of treatment was five (IQR, 1.3-7) years respectively. Patients with different level of education and varying type of employment ranging from skilled to non-skilled, public sector to private sector jobs, were interviewed (See table 1). DAS28_{ESR} was available for most patients however not in four cases. For one patient, DAS28_{CRP} was used and in three cases, DAS was not available. Three patients had high disease activity (DAS28_{esr} > 5.1), five moderate (DAS28_{esr} > 3.2- 5.1), and nine had either low or were in remission (DAS28_{esr} ≤ 3.2). Median (IQR), HAQ and GFI were 1 (0.3125-1.5) and 26.3 (20.4-32.2) respectively. All participants were on conventional disease modifying anti-rheumatic drugs and no patient was on biologic except one who received one dose of adalimumab (monoclonal Anti-TNF Therapy) before presenting to the department. Each theme is illustrated with participant quotes (Table 3).

Balancing act of work and RA

Several participants talked about the positive aspects of work relative to RA and how work served as a healthy distraction, a place for accomplishment and self-worth (Q1&2). However, in some cases participants reported that future aspirations were altered (Q3,4&5). Some talked

about how their family and friends encouraged them or were the main reasons driving them to work (Q6&7). Many participants indicated they worked after having the diagnosis of RA, choosing to concentrate on aspects of their jobs that best utilised their strengths. Participants had diverse patterns of work and changes after learning about their RA diagnosis including changes to their work schedules (Q8, 9&10). Self-initiated adjustment to work schedule ranged from reducing hours, taking days off, regular breaks between tasks, taking extra time to complete tasks, newer targets, change of jobs and changing mode of travelling to work (Q11, 12 &13). All participants displayed a clear sense of responsibility towards their job, family and employer (Q14, 15&16). Participants made every effort to motivate themselves to continue working and expressed tolerability in their employment despite having a feeling of “damaged identity” after RA. A number of participants spoke about how their experience with RA gave them a different perspective on how relevant work was in their lives. Several men in particular talked about a transformation from overworked to a more balanced approach (Q17). Moreover, a few men saw being at work after diagnosis of RA as sustaining family responsibilities and to avoid stigma. This was further linked with young bachelors who had to demonstrate normality in health for future marriage (Q18). In comparison, the women with RA saw being at work more as a means of distracting from unhappy thoughts and escaping from social isolation (Q19). Being at work with RA freed them from the feeling of dependency and being a burden to others. Also, it helped them to restore their social status and demonstrate their capabilities in society. However, it came at a cost for some, as they found it difficult to strike a balance between work and home life (Q20). Not surprisingly, fatigue was a major deterrent for the patients adding to despair and change of working style and pattern. (Q21).

Examples of patients' quotes:

Q1. I am a junior engineer with the railways and my work is of particularly supervision. I enjoy my job and look forward to coming every day. [Male, 28, Junior Electric Engineer].

Q2. When the condition was really bad then I was concerned but since I have got here, I have confidence that I will be able to work and do well. [Male, 35, Construction worker].

Q3. The slight tension is... what the disease flares and it does worry me about the future. My promotion will be affected [Male, 45, Security guard].

Work place adaptation after RA

A number of participants were deterred from discussing their health issues with managers, mainly for fear of being seen as unfit for work and being dismissed (Q22). A few were equally

hesitant in telling their employer and colleagues about RA. The latter was linked to fears that their ill health would reach management and have a detrimental effect on their employment and financial stability (Q23). Some participants in manual jobs stated that health matters were never discussed at work because there was no prevailing culture for open discussion. When disclosing RA to others, only a few found their employers and colleagues to be sympathetic and helpful (Q24). For some this support was found to be linked to the type of job participants were associated with. For example, participants who were more educated and in high ranked government jobs expressed extensive support from junior staff and had better financial stability and positive relationships with their employer compared to those who were in manual or daily wage earners (Q25&26). A farmer had advantages in being their own boss however, working to full capacity meant ignoring daily symptoms in order to complete tasks and sometimes requiring family members' help from time to time (Q27). The ability to make such accommodations was certainly a factor that influenced staying in the job but clear struggles were displayed (Q28).

Examples of patients' quotes:

Q22. There is always fear that if I told my boss about this disease no one would give me a job and they would dismiss me from work. I can't afford to do that instead I struggle to do the work but I do manage to complete it. [Male 39, Fire Fighter].

Q23. I try not to tell my manager anything because they would take a cut from my wages. I don't earn that much anyway and if I told them about the disease then that would impact my pay. [Female, 30, Teacher].

Q24. Some of my work colleagues are very kind they will not let me lift heavy things and they will find someone else to do that bit. They care about me all day at work. [Male, 39, Fire Fighter].

Support from others and information to manage RA and work

Most of the participants had received little information of the disease, duration of treatment, potential complications, and prognosis. This made it hard for them to perform effectively when being at work. The majority of participants wanted to seek further information to know if their working life could be maintained (Q29&30). The fear of damaging joints was at the forefront for many participants. They had little information from the clinic about the impact of RA on working life, their health state and the suitability of their job for conditions and symptoms (Q31&32). Participants declared that doctors had not provided them with much information

about disease and work rather more focus was on controlling inflammation. In contrast, the participants who had some information about their disease were able to manage to work more successfully. About half of the participants attempted to seek information either from family, friends or the internet while some spoke with fellow patients (Q33&34). Some employed focused strategies like regular exercise and yoga so that they could maintain work productivity. In contrast, about a half of the participants reported to use ayurvedic and homeopathic remedies in order to balance their symptoms. (Q35 &36).

Examples of patients' quotes:

Q29. I didn't know much at all about this condition. Especially it goes up and down you don't really understand the pattern and you don't understand what will happen at work today. If I had known a bit more then I could have managed it better. [Female 30, Teacher].

Q30. The doctor sahib told me that this is a lifelong disease. It can be suppressed, but it can flare up at any time. You would always have to take medication. I felt that it would be extremely difficult if you are working and you never will know how to change your life. [Female, 46, Beautician].

Q31. I am fearful of using my joints too much in case I damage them. [Male, 35, Construction worker].

Wanting a better support mechanism: patients' recommendations

Understanding of RA symptoms varied between individuals from a lack of insight into the onset, pattern and nature of RA symptoms. Recommendations made by participants' were geared towards clinicians, employers, government and themselves. All participants recommended more awareness of RA and not just amongst the public but also to the local government departments that link with health care systems (Q37,38 &39). Participants made reference to there being better general understanding of cancer and diabetic diseases and felt that less was known about RA (Q40&41). Participants expressed a great need for increasing rheumatologist capacity and empowerment of health professionals across states since many had travelled out of their areas to get treatment (Q42). This resulted in financial losses for participants. Most of the participants talked about the importance of emotional support in their work. This could mean a lot of different things: encouraging people at work, respecting one's autonomy at work, giving hope, employers appreciating the patients' abilities at work, revision of targets, job flexibility and accepting RA patients at work (Q43). Participants made recommendations for doctors to discuss employment issues more openly during consultations,

better patient education and need for discussion with the employers though the opinion was divided for latter (Q44&Q45). Participants made recommendations for better financial incentives to help support their travel for hospital appointments and treatments so that they can remain in work and expressed the need for disability allowance (Q46). Participants made recommendation for more information related to occupational rehabilitation and physiotherapy advice during hospital visits. Participants showed willingness to be part of patient support groups (Q47). Participants made recommendations for more effective pathways through which doctors could engage in more useful communications with employers and ultimately act as patient advocates (Q48).

Examples of patients' quotes:

Q37. Make such a medicine that it doesn't take that long and the benefits are good. Because we can't get all medicines here. It is costly about double, triple the price. Sir, I think many people would be from a labour background they won't be able to afford. The government should support us with this cost. [Female 30, Teacher].

Q38. Pt: The government should determine where the public views most on TV things should be shared. This will raise awareness in the people. Like if the public uses WhatsApp more and through that media even one out of ten read it and forwarded it then the awareness levels could be increased. [Male, 39, Construction worker].

Q39. Please raise awareness to show a disability certificate, managers will recognise that but in all kind of disease we have difficulty every day. They just think we can't walk they don't understand the problem inside our body. [Female, 39, Teacher].

Discussion

To the best of our knowledge this is the first qualitative study to have explored the impact of RA on working lives of South Asian patients. Understanding the impact of RA on work productivity is complex. Absenteeism and presenteeism are problems among participants living with RA in India. Our findings resonate with chronicity framework of RA by Bury [7]. Overall our findings indicate there is an appreciation for continuing to work while living with RA however lack of education about the disease, lack of support from clinicians and lack of opportunity to fully engage with employers presented challenges on a daily basis. The impact of RA on their cognition, mood and physical abilities within the workplace were commonly reported. Specific examples of work-based tasks affected by this have been reported in our study.

In our study, we recruited more males than females despite disease being prevalent in female gender with a ratio of 2-3:1. This could be either because of increased number of males in employment in India or due to higher risk of work disability in females. A higher median HAQ and GFI when compared to DAS28 (ESR or CRP) score suggested an indication of higher level of fatigue and functional disability. This is important due to 2 reasons: 1) disease activity score may not be a true embodiment of the symptomatic presentation of RA and measurement of fatigue is not a component of disease activity assessment for most inflammatory conditions. 2) Damage and functional assessment cannot be measured by disease activity scores. HAQ is an important determinant for predicting work disability (or instability) [16]. All participants reported that fatigue was the symptom that impacted most on their work ability. Other research of employed adults with RA also found that participants found fatigue as the most challenging aspect of their condition limiting their employment and impacting on many aspects of work functioning [17]. Addressing fatigue through interventions and appropriate accommodations by health care professionals and employers may help to validate experiences of fatigue, improve self-management of symptoms and enhance work functioning [6, 18]. It may also be important to target health care professionals' time and resources for those who experience fatigue early post diagnosis to facilitate development of strategies that can be used in response to variations in the course of a disease such as during a flare.

Our findings echo with other researchers where most participants have cited employment as a driving force helping them to distract from daily fluctuant symptoms and kept them motivated [19]. Similar findings [4, 9, 20], where participants viewed work to be active, helped them maintain self-esteem and indirectly helped them to adhere better to medications. Moreover, we found for some participants work to be a necessity as they were the sole bread-winners for the family and provided family's financial support. Similarly, other studies have highlighted factors including desire, motivation to work in the view of financial burden, underlining the significance of work in patients' life [4, 9, 20].

We report presenteeism to be more common rather than absenteeism and added to that a sense of responsibility towards the employers.

A published systematic overview on work and arthritis, showing a comprehensive overview of seven themes and subcategories considered important by patients while working [9]. Table 4 highlights the similarities including novelties found in our study. The novelties heightened by our participants included concepts like: disease awareness, concern about disclosing RA to

family and employers, lack of wider support from a multidisciplinary team for example, allied health professional support, advice from physiotherapy or occupational therapy, employer fear and education, awareness about the level of support available from government and lastly, stigma were noted to be predominant. The concept of stigma for females contributed to challenges for women to strike a balance between work, home and family life. Some of these tasks at home defined an “Indian woman” and added misery for women if they failed to strike a balance. A study by Verduin et al [21] also found some participants had given a new meaning to life after RA in which work was viewed differently [21]. In our study participants reported future aspirations to be affected including promotion. Participants working in a public sector viewed the threat to be less of an issue as promotion was usually guaranteed in this sector. However, the impact of RA on those who were in less fortunate positions for career progression was disheartening. For example; the type of job hierarchy at work, participants’ and employer’s flexibility and extent of autonomy were some of the main factors which impacted upon the extent patients could adapt to working with RA.

The extent of knowledge about RA was clearly an important consideration some expressed limited discussion around the disease course of RA. Many participants were confused about the chronicity of RA. Past work demonstrates that patients who understand that RA can be controlled tend to engage more in management than those who expect a cure [10]. In our study some participants had sound knowledge about RA which they acquired over time however, most resorted to various lay modes outside of the clinic to learn about RA.

The recommendations made by the participants living in India appeared to be twofold; immediate and long term. Most of the participants felt the need for increasing RA awareness including early diagnosis and better patient education to help them understand as this could lead to better self-care. A number of ways to increase awareness were suggested including use of media, organising lectures, also camps particularly in areas where there are limited rheumatologists. Participants were attentive to other chronic disease awareness like cancer and diabetes and aspired for an increased understanding from the government on the seriousness of RA. Studies showing results of better educated patients demonstrate full engagement in RA management and patients becoming active partners in shared clinical decision making [22]. Participants expressed a desire for better pathways through which they can discuss RA with employers to create long lasting effect and changes at work place. A need for emotional support at work with more flexibility and acceptance was suggested. Need for better work organization

and awareness of the involvement of psychosocial factors have been emphasized in previous studies [23]. In our study, participants advocated need for better reimbursement policies, smart cards for patients which allow an entitlement to benefits like concession on travel, medications and medical tests.

A need for more rheumatologists and improved infrastructure for better referral system empowering health professionals to improve health facilities was highlighted. A distinction between the role of Orthopaedics and Rheumatology was valued since many of our participants reported delays in obtaining the diagnosis of RA by visiting the wrong clinician. A number of them were regretful of not having had discussion with fellow patients and almost none of them had heard of patient support groups. Future recommendation was to operationalise these support groups to newly diagnosed patients with RA. Studies have shown where sharing patients' fellow support had a positive impact of coping with RA [23].

We collected data from an institute that is known as a centre of excellence in rheumatology practice capturing patients from a wide range of geographic areas in India. Our findings may be transferable in countries where similar welfare structures exist. Moreover, this study provides encouragement for others around the globe to explore local barriers and find solutions within their countries. Building on from the work of Sokka et al in 32 countries [9], researchers might want to adopt our approach in seeking patients' recommendations that may help support work in patients with RA.

There were some limitations noted in our research. Although we were successful in recruiting from range of geographical areas around Lucknow, our selection of recruitment could have included more participants from rural areas since their experience of living with RA with limited resources could have had a different impact on work productivity. Only one of our participants had received biologics and this makes it difficult to compare our findings with other European studies as these studies usually include patients prescribed advanced medications like biologics. However, multiple studies looking at the changes in work productivity with the advent of biologics have shown mixed results ranging between no differences between groups using cDMARDs or biologics. Despite these limitations we have been successful in recruiting South Asian patients from a wide geographical area around Lucknow region.

Conclusion

This is the first qualitative study to explore the impact of RA on work productivity in India. Our study provides important direction for future work. It demonstrates a definite need for employment assessment during consultation at early stages. The participants described how RA impacted cognition, physical abilities and mood ultimately affecting work productivity. Our study discussed specific work tasks affected by RA for people living in India. The study reports management strategies that were mainly self-developed by participants, indicating a need for formalised education on management strategies in clinic and at the workplace. Moreover, there is an imperative need for medical undergraduate and postgraduate degrees to incorporate the topic of health and influence on work in curriculum. The rheumatology community in India needs to design clear referral pathway to services, timely diagnosis and initiation of treatment. The government also needs to reflect on developing better reimbursement policies and workplace benefits.

References

- 1.van Tuyl LH, Sadlonova M, Hewlett S, Davis B, Flurey C, Goel N, et al. The patient perspective on absence of disease activity in rheumatoid arthritis: a survey to identify key domains of patient-perceived remission. *Ann Rheum Dis.* 2017;76(5):855-61.
- 2.Smolen JS, Landewe R, Breedveld FC, Dougados M, Emery P, Gaujoux-Viala C, et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs. *Ann Rheum Dis.* 2010;69(6):964-75.
- 3.Young A, Dixey J, Kulinskaya E, Cox N, Davies P, Devlin J, et al. Which patients stop working because of rheumatoid arthritis? Results of five years' follow up in 732 patients from the Early RA Study (ERAS). *Ann Rheum Dis.* 2002;61(4):335-40.
- 4.Verstappen SM. Rheumatoid arthritis and work: The impact of rheumatoid arthritis on absenteeism and presenteeism. *Best Pract Res Clin Rheumatol.* 2015;29(3):495-511.
- 5.Cochrane A, Higgins NM, Rothwell C, Ashton J, Breen R, Corcoran O, et al. Work Outcomes in Patients Who Stay at Work Despite Musculoskeletal Pain. *J Occup Rehabil.* 2017.
- 6.Hewlett S, Carr M, Ryan S, Kirwan J, Richards P, Carr A, et al. Outcomes generated by patients with rheumatoid arthritis: how important are they? *Musculoskeletal Care.* 2005;3(3):131-42.
- 7.Bury M. Chronic illness as biographical disruption. *Sociol Health Illn.* 1982;4(2):167-82.
- 8.Bury M. Health care and chronic illness: a sociological view. *Health Care Anal.* 1994;2(3):240-3.
- 9.Sokka T, Kautiainen H, Pincus T, Verstappen SM, Aggarwal A, Alten R, et al. Work disability remains a major problem in rheumatoid arthritis in the 2000s: data from 32 countries in the QUEST-RA study. *Arthritis Res Ther.* 2010;12(2):R42.
- 10.Kumar K, Raza K, Nightingale P, Horne R, Chapman S, Greenfield S, et al. Determinants of adherence to disease modifying anti-rheumatic drugs in White British and South Asian patients with rheumatoid arthritis: a cross sectional study. *BMC Musculoskelet Disord.* 2015;16(1):396.

11. Misra DP, Agarwal V, Negi VS. Rheumatology in India: a Bird's Eye View on Organization, Epidemiology, Training Programs and Publications. *J Korean Med Sci.* 2016;31(7):1013-9.
12. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care.* 2007;19(6):349-57.
13. Dixon-Woods M, Agarwal S, Jones D, Young B, Sutton A. Synthesising qualitative and quantitative evidence: a review of possible methods. *J Health Serv Res Policy.* 2005;10(1):45-53.
14. Kirwan JR, Reeback JS. Stanford Health Assessment Questionnaire Modified to Assess Disability in British Patients with Rheumatoid-Arthritis. *British Journal of Rheumatology.* 1986;25(2):206-9.
15. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol.* 2013;13:117.
16. Lacaille D, White MA, Backman CL, Gignac MA. Problems faced at work due to inflammatory arthritis: new insights gained from understanding patients' perspective. *Arthritis Rheum.* 2007;57(7):1269-79.
17. Backman CL. Employment and work disability in rheumatoid arthritis. *Curr Opin Rheumatol.* 2004;16(2):148-52.
18. Hewlett S, Ambler N, Almeida C, Cliss A, Hammond A, Kitchen K, et al. Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. *Ann Rheum Dis.* 2011;70(6):1060-7.
19. Mattila K, Buttgerit F, Tuominen R. Impact of morning stiffness on working behaviour and performance in people with rheumatoid arthritis. *Rheumatol Int.* 2014;34(12):1751-8.
20. Looper KJ, Mustafa SS, Zelkowitz P, Purden M, Baron M. Work instability and financial loss in early inflammatory arthritis. *Int J Rheum Dis.* 2012;15(6):546-53.
21. Verduin PJ, de Bock GH, Vliet Vlieland TP, Peeters AJ, Verhoef J, Otten W. Purpose in life in patients with rheumatoid arthritis. *Clin Rheumatol.* 2008;27(7):899-908.
22. Xu RH, Wong EL. Involvement in shared decision-making for patients in public specialist outpatient clinics in Hong Kong. *Patient Prefer Adherence.* 2017;11:505-12.
23. Dures E, Almeida C, Caesley J, Peterson A, Ambler N, Morris M, et al. Patient preferences for psychological support in inflammatory arthritis: a multicentre survey. *Ann Rheum Dis.* 2016;75(1):142-7.

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Figure legend

Figure 1: Thematic diagram of South Asian participants' impact of RA on work.

Table 1: Demographic data of patients interviewed

Patient no	Gender	Level of education	Age (year)	Type of Employment**	Age at onset (year)	Treatment duration (years)	DAS28 at the time of interview	HAQ	GFI	Treatment
1	M	Post-Graduation	63	Advocate	44	5	2.85	0.875	29.6	MTX 7.5mg/week
2	F	Post-Graduation	30	Teacher	25	5	2.33	0.375	0	SSZ 2g/d and Pred 2.5mg A/d
3	M	Post-Graduation	43	Doctor and Govt Service	42	0.17	3.73	1	26.2	MTX 20mg, HCQ 300
4	M	Graduation	28	Junior Electric Engineer	26.5	1.5	3.08	0	0	MTX 17.5mg, HCQ 300, PRED 4MG
5	M	Graduation	41	Security	40	0.42	ESR not done	0.125	23.8	MTX20mg/week, HCQ 200
6	M	Post-Graduation	59	Bank Clerk	29	20	2.7	1	16.2	15mg/week
7	F	Primary	45	Housemaid	42	1.17	4.3	1.25	32.2	MTX 10mg, HCQ 200, Pred 7.5MG
8	F	Post-Graduation	39	Teacher	16	17	ESR not done	2	32.6	MTX 10mg
9	F	Graduation	30	Police Constable	26	Initiated now	5.85	0.75	25.2	Initiated now
10	M	Graduation	39	Fire Fighter	33	6	3.33	1	13.6	MTX 20, HCQ 200
11	M	Secondary	35	Construction worker	30	5	1.99	0	0	MTX 25, HCQ 300
12	M	Secondary	33	Shopkeeper	32	2	2.93	0	19.5	MTX 15, HCQ 200
13	M	Graduation	46	Ayurveda & Homeopathy practitioner	33	5	ESR not done	1.5	29.8	MTX 12.5, HCQ 200
14	F	Post-Graduation	57	Professor of Mathematics	49	8	6.83*	1.875	43.6	MTX 15, HCQ 300
15	M	Graduation	37	Driver	23	13.5	4.7	2.5	23.9	MTX 25, LEF 20m HCQ 300
16	F	Graduation	59	Nurse (Ayurveda)	48	8	2.22	1.125	40.6	MTX 15 HCQ 200

17	F	Post-Graduation	46	Beautician	46	0.58	3.42	1.5	36.6	MTX 15 HCQ 300
18	M	Secondary	38	Aircraft technician	33	2.5	5.68	1.625	18.6	MTX 25, LEF 20m HCQ 300
19	M	Graduation	36	Shopkeeper	33	0.83	1.96	0.875	26.6	MTX 25
20	M	No schooling	48	Farmer	40	2.17	2.17	0	20.4	MTX 20 HCQ 300
Median + [IQR ₂₅ - IQR ₇₅]			40 [35.7-46.5]		33 [29.5-42]	5 [1.3-7]	3.0 [2.6-3.9]	1 [0.3125-1.5]	26.3 [20.4-32.2]	

DAS28, Disease activity Score using Erythrocyte Sedimentation rate (ESR); DAS28 of greater than 5.1 implies active disease, less than 3.2 low disease activity, and less than 2.6 remission; *DAS28 using C-reactive protein. HAQ, Health assessment Questionnaire, where <0.3 is normal; GFI, Global Fatigue Index, where GFI of one means no fatigue and 50, severe fatigue; [HCQ, Hydroxychloroquine]; [LEF, Leflunomide]; [MTX, Methotrexate]; [Pred, Prednisolone]; [SSZ, Sulfasalazine]. ** Term Manual labour has been used for elementary occupation defined by Modified Kuppuswamy Socioeconomic Scale 2018 requiring skill level I as per International Standard Classification of Occupations (ISCO).

Table 2 – Topic Guide

- Experience of having RA and work
- Nature of job
- Adaptations
- Future aspirations
- Communications with employer and other
- Seeking help
- Recommendations for future support to stay at work

Table 3: Quotes from participants illustrating results

Balancing act of work and RA

Q1. I am a junior engineer with the railways and my work is of particularly supervision. I enjoy my job and look forward to coming every day. [Male, 28, Junior Electric Engineer].

Q2. When the condition was really bad then I was concerned but since I have got here, I have confidence that I will be able to work and do well. [Male, 35, Construction worker].

Q3. The slight tension is... what the disease flares and it does worry me about the future. My promotion will be affected [Male, 45, Security guard].

Q4. I have been in service only 10 years. I have to spend the rest of life in service yet. How many years can I carry on like this? If I couldn't work, then future is in trouble. This has become a tension. [Female, 30, Police Constable].

Q5. Yes. I cannot think progressively. I think because of the disease the future path has disappeared. I cannot think outwardly just inwardly. [Male, 46, Ayurveda & Homeopathy practitioner].

Q6. My parents are very supportive and always encourage me to do carry on working. Even on the days I have a flare they still motivate me. [Female, 30 Teacher].

Q7. I have to go to work because of supporting my children. My children and wife are always taking care of me. I get a lot of encouragement from that. [Male, 37, Driver].

Q8. Yes. I was in greater pain, Instead of standing for too long I used to sit in between my teaching. I got used to a pattern and would follow that to get through the day. [Female, 30 Teacher].

Q9. I have used to walk to work but now I have a lift so that I have more energy at work. I do get my junior colleagues to type my letters and I just do the jobs I can do. [Male, 63 Advocate].

Q10. You can tell it that I always used to think I have to carry all the burden on my shoulders, I have reduced that focus. I have started distributing works to others and a little bit I see... I'm not indispensable. Now I understand myself more that I can't do this. [Male, 43, Doctor].

Q11. I find now that I have shortened my days I feel less tied. [Female 45, Housemaid].

Q12. I know that I can get rest of the day so try to do much as I can in the first part of the day. I have more energy and in that way I am not so irritated with everyone around me. [Male, 59, Bank Clerk].

Q13. It does take me longer to do the work now but I have to put extra hours in my day to complete the task. [Male 28, Junior Electric Engineer].

Q14. Everybody used to keep on saying take leave but still I went to college as how much leave could I have taken and I know I have a duty towards my job [Female, 57, Professor of Mathematics].

Q15. I have to work to earn for my family. I have little children who are dependent on me so I need to work. [Female, 45, Housemaid].

Q16. I don't think about anything. I only just hope God keeps me healthy so I carry on working as much as I can. I am not sorrow. Male, [48, Male, Farmer].

Q17. I come to work to keep my mind balanced not think about this disease all the time. [Male, 35, Construction worker].

Q18. I can't stay off work for too long. I was concerned about having the disease at such a young age, whole life is ahead of me, what will happen in the future what would be the condition. [Male, 28, Junior Electric Engineer].

Q19. I am happy at work I am with people I need to help that gets me away from my isolation. [Female, 59, Nurse Ayurveda].

Q20. I had to reduce my hours at work because my home life was suffering. I couldn't do the full time. [Female 46, Beautician].

Q21. I feel very tired and sometimes it makes me very upset. I have to think about the hours I do and always think about different ways to doing my work so that I can get through the day. [Female, 57, Professor of Mathematics].

Work place adaptation after RA

Q22. There is always fear that if I told my boss about this disease no one would give me a job and they would dismiss me from work. I can't afford to do that instead I struggle to do the work but I do manage to complete it. [Male 39, Fire Fighter].

Q23. I try not to tell my manager anything because they would take a cut from my wages. I don't earn that much anyway and if I told them about the disease then that would impact my pay. [Female, 30, Teacher].

Q24. Some of my work colleagues are very kind they will not let me lift heavy things and they will find someone else to do that bit. They care about me all day at work. [Male, 39, Fire Fighter].

Q25. I have a lot junior staff who can take the delegation and I feel that helps me so many ways. Filing and other writing jobs can be done by my junior colleagues I don't worry about that too much. [Male, 63, Advocate].

Q26. I don't really want to display my condition at work because I know my colleagues will not help and my manager will ask me what is wrong. I don't want to tell anyone about this condition. Some days it gets better and sometimes not. [Female, 45, Housemaid].

Q27. I get all support because the people work with me so I don't need to worry too much. [Male, 48, Framer].

Q28. The only difficulty comes when I do too much. I think the symptoms are controlled but it only comes too soon and I have to slow down. That is hard because you can't get things done as I wished [Male, 48, Framer].

Support from others and information to manage RA and work

Q29. I didn't know much at all about this condition. Especially it goes up and down you don't really understand the pattern and you don't understand what will happen at work today. If I had known a bit more then I could have managed it better. [Female 30, Teacher].

Q30. The doctor sahib told me that this is a lifelong disease. It can be suppressed, but it can flare up at any time. You would always have to take medication. I felt that it would be extremely difficult if you are working and you never will know how to change your life. [Female, 46, Beautician].

Q31. I am fearful of using my joints too much in case I damage them. [Male, 35, Construction worker].

Q32. The disease comes and goes and sometimes it is very hard to control it. But we don't really know how to help ourselves the clinic is too far to come. Sometimes I don't work until I visit here at the clinic. [Male, 59, Bank Clerk].

Q33. My son has a look at the internet for me to understand this condition. He always tells me to do my work in different ways. I don't feel the swelling then. I didn't get much information from here at the clinic. [Male, 33, Shopkeeper].

Q34. When I come to clinic here I do talk to other patients. It helps to know some things and what others are going through. I hear their stories as well. Male, 37, Driver].

Q35. I do a lot walking and exercise. I find this gives me more energy. I do yoga in the morning to strength my joints and that keeps me fit for the day.

Q36. I have tried ayurvedic, and homeopathic remedies. Some have worked but some haven't worked. It is all about balance at the end of the day. [Male, 46, Ayurveda & Homeopathy practitioner].

Wanting a better support mechanism": patients' recommendations

Q37. Make such a medicine that it doesn't take that long and the benefits are good. Because we can't get all medicines here. It is costly about double, triple the price. Sir, I think many people would be from a labour background they won't be able to afford. The government should support us with this cost. [Female 30, Teacher].

Q38. Pt: The government should determine where the public views most on TV things should be shared. This will raise awareness in the people. Like if the public uses WhatsApp more and through that media even one out of ten read it and forwarded it then the awareness levels could be increased. [Male, 39, Construction worker].

Q39. Please raise awareness to show a disability certificate, managers will recognise that but in all kind of disease we have difficulty every day. They just think we can't walk they don't understand the problem inside our body. [Female, 39, Teacher].

Q40. Sir, there is plenty of awareness about cancer and diabetes but no one has heard about this disease. No one in my family or at work knows. People say it is old person disease but how can we have it. I think we need more about this disease I feel it is worse because it is affected my joints. [Male, 41, Security guard].

Q41. TV is important is for other things like cancer, so it is important for this too. Media is essential. It should go on multimedia channels and mobiles. If it reaches people that you may have this condition, get blood tests done. If the doctor explains, then definitely the patients would listen. [Male, 38, Aircraft technician].

Q42. There isn't enough doctors and clinics like this one. We have to come from very far to get treatments. I was going to the wrong doctor all this time. If we had this service everywhere then we can avoid all that wasting time. [Male, 39, Fire Fighter].

Q43. There is no emotional support for this disease. I felt very depressed and low mood went on for days. I feel if there was some reinforcement from the government to employers then we could get more support to do our work. [Female, 57, Professor of Mathematics].

Q44. It would be good to have a letter from the department to my employer because they would take that seriously. Right now this isn't taken seriously. [Female, 30, Police Constable].

Q45. I fear that if my employer finds out then I would be out of a job. I know we can't live from the government so I don't want my boss to know this. [Male, 41, Security guard].

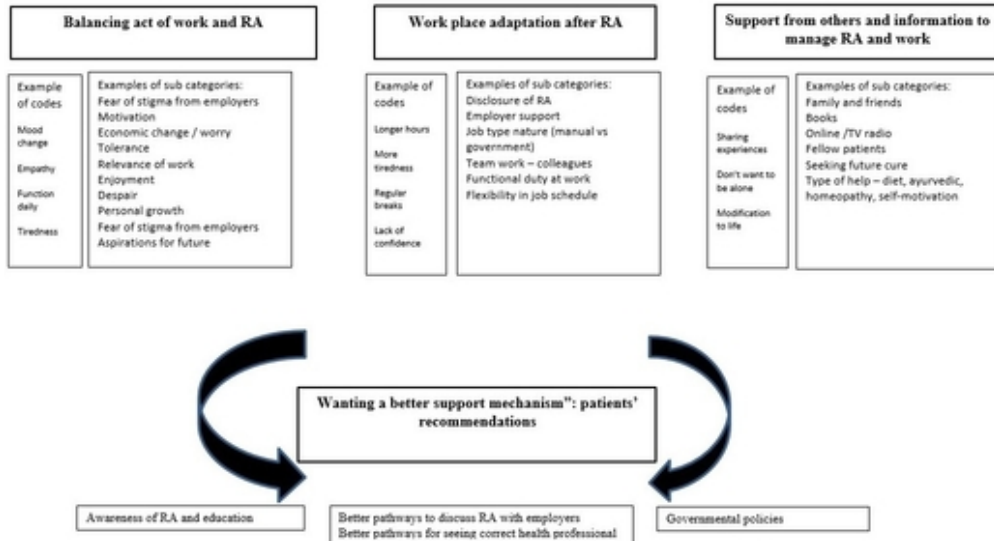
Q46. Travelling is very expense. It is an expense for me, there should be some sort of concession for travelling to clinic and medication costs. But we don't get anything. [Female, 30, Teacher].

Q47. I have never had physiotherapy for my care. I have never heard of an occupational therapist before this. If these people can help us, then we should have them. We can't afford expensive medications anyway so we should get some support to manage this long term disease. [Male, 59, Bank Clerk].

Q48. The government should give more power to doctors so that they can help us to stay at work. If they send letters to managers they will have to give more support at the moment it seems a battle. [Female, 46, Beautician].

Table 4 Similarities between our study and others and novelties found in our study.

Similar subcategories between our and other studies	Concepts heightened in our study	Concepts not found in our study
Fatigue and energy Pain and stiffness Physical limitations Unpredictability Desire, value and motivation to work Importance of worker role and identity Concentration coping, understanding, adapting and managing disease Awareness of limitations and abilities, balancing work and leisure activities Importance of assertiveness, importance of planning Flexibility Desire of contact or information from others with disease Relationship with colleagues Family and work balance Reluctance to disclose	Disease awareness Concern for family Stigma Patient support groups limited Occupational health department limited Designated department for physiotherapy limited Employer and family education absent Multiple recommendations for the government	Opportunities for part-time work or disability benefits Ergonomic assessment and ergonomic adjustments to workplace Employer help/advocacy/policies regarding career planning, (re)training



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