

Life of Indian Women with Rheumatoid Arthritis: A Qualitative Study

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ABSTRACT: Rheumatoid arthritis (RA) is a chronic progressive joint disorder with unpredictable symptoms and painful course. RA can affect person in younger age and cannot be cured permanently. RA may lead to undesirable consequences in personal and professional life of patients which includes restrictions to pursue one's career goals, reduced social engagements and altered family responsibilities. Researches with biomedical perspective majorly discuss various biomedical interventions and their health outcomes. However, very few publications are available in the arthritis pain literature which study patient's life experiences with RA and discuss the health outcomes of various psychosocialspiritual pain management strategies employed by patients. To the author's best knowledge, in India the Rheumatoid arthritis has been very scarcely investigated from patient's point of view and psychosocial perspective. Therefore, the present research aims to give a comprehensive account of impact of RA on patient's lives and the strategies employed by patients to live with this painful chronic disease. This research consisted of semi-structured interviews of 9 women suffering from Rheumatoid arthritis and the thematic analysis was conducted to analyse the data. Results of the study showed that RA affects the patient's life significantly and there is a pressing need of creating awareness about Rheumatoid arthritis among Indian population for timely diagnosis. Themes emerged from the interviews indicate that psychosocialspiritual factors played an important role in pain management which include pain acceptance, self-management, social support, spiritual and philosophical teachings. The findings of this study highlight the need for clinicians to consider patient's perspective in disease management and to evaluate the potential of psychological, social and spiritual coping mechanisms for enhancement of health outcomes.

KEY WORDS: Rheumatoid Arthritis, Pain acceptance, psychological, social, spiritual coping mechanisms.

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I. INTRODUCTION

Rheumatoid arthritis (RA) is a chronic, progressive, autoimmune disease which is characterized by morning stiffness, painful and swollen joints, and joint deformity. (Bitch, 2010) The key features of this disease pain, stiffness, fatigue, physical limitations create a greater impact on the person's ability to engage in meaningful activities in domains of work, family and leisure. At present RA cannot be cured completely but the inflammation and the progression of the disease can be controlled through medical intervention (The Kings Fund 2009). Unpredictability of symptoms, painful course and limitations in performing activities in various aspects of life create significant psychological impact on the person making the life challenging for an individual to live with this disease. (Dixon, Keefe, Scipio, Perri & Abernethy, 2007). Reduced physical function was associated with decreased participation in leisure and social activities triggering the feelings of dissatisfaction about life and depression. (Neugebauer, Pasch and Katz, 2003). The data gathered from qualitative researches has provided the insight about experiences of patients with RA. Lempp et.al (2006) have demonstrated that RA affects the public and private identity of patients. Diminished capacity to fulfil social roles affects the self-esteem of patients. (Plach et.al 2004). Several qualitative researches exploring the experience of RA patients have identified themes like dependency, functional limitations, uncertainty, impact on social roles, accepting limitations, self-management of symptoms, praying etc which highlighted the impact of RA on person's life and the coping strategies employed by patients

(Iwasaki & Butcher, 2004).

There are number of researches which demonstrated the associations between psychosocial factors and its impact on the physical and psychological well-being. Coping strategies like Active coping are found to be associated with lower intensity of pain, whereas passive coping in face of pain is associated with severe depression (Brown & Nicassio, 1987). Chronic pain patients showing catastrophizing tendencies indicated higher level of physical and psychosocial disability (Turner et.al, 2000). The way person attach subjective meanings to their physical impairments determines person's psychological well-being rather than person's

actual physical impairment (Neugebauer et al 2003). These studies empirically support the biopsychosocial model of disease which proposes the interaction between physical, psychological and social factors. Qualitative researches emphasizing on positive experiences of the disease have explored how patients live with this disease. Research by Iwasaki & Butcher (2004) with older women and men with Arthritis suggested that patients use wide number of stress-coping strategies like staying active and busy, gaining education of the disease to deal with the symptoms. Subsequent research has also demonstrated that flexibility in usage of wide number of coping strategies indicated better psychological well-being (Sinclair & Blackburn, 2008). Patients who reported positive life experience with RA have considered RA as a part of their life “something they used to live with” and see the symptoms of disease as a challenge. (Stamm, 2008).

However, the large body of literature on Rheumatoid arthritis is based on the studies conducted on the non-Indian population. There are very few studies in India who explored the patient’s experiences of living with RA. In India, the prevalence rate of RA in adult population is around 0.92% and the disease occurs more frequently in females. (Gupta, et.al, 2018). Scientometric assessment of Indian publications on Rheumatoid arthritis research during 2007-2016 have shown that highest publication share is from the field of Medicine followed by pharmacology, toxicology, pharmaceuticals, biochemistry, genetics and molecular biology, immunology and microbiology and chemistry. (Gupta, et.al, 2018). This assessment demonstrates that in India there is sparse research on patient’s experiences of living with RA. Therefore, the objectives of the current study are to qualitatively explore Indian patient’s experience of living with RA which includes emotional reactions towards diagnosis, impact of RA symptoms on various domains of life and the coping strategies patients employ to accommodate the disease in their day-to-day life.

II. METHODS

2.1 Participants

In this study, the semi structured interviews of 9 patients diagnosed with RA were conducted. The patients were recruited from Rheumatology support group from Pune. Informed consent was obtained from each participant before interviews were conducted. The inclusion criteria were: RA diagnosis for minimum six months, the age range from 18 years to 65 to explore the experiences of patients from different age groups and absence of terminal disease and psychotic disorder. The sample composed of patients ranging from age 35 to 65. The patients were contacted through Rheumatoid Arthritis patients support group in Pune. The patients who agreed to participate in the study were interviewed at their house. Interviews lasted from 40 min to 90 min. Patients were asked question: Can you please describe your experience of Rheumatoid arthritis from beginning? Through follow up questions, the impact of disease on one’s mental health, family, work and leisure was explored; the strategies patients employed to live with this disease were identified.

2.2 Data analysis

The audiotapes were transcribed into the verbatim. Pseudonyms were used to maintain confidentiality. The data was analysed by applying thematic analysis. The key research questions in semi-structured interview were used to find out the main themes by using deductive analysis. Further each main theme was analysed to explore the subthemes.

III. RESULTS

3.1 Delay in diagnosis and in treatment

Few patients received early diagnosis and started their treatment from Rheumatologist.”. The patients who received the late diagnosis, have suffered a lot due to excruciating pain from long period and expressed the sense of relief after getting diagnosis. Not having clarity of cause was more distressing for them. The causes for late diagnosis of RA and delayed treatment were neglect from patients and doctors also. Patients attributed pain to “work” and “temporary illness because of body exertion”. When the patients recognized their pain and referred to general practitioners, some of the patients received the diagnosis of RA. But even after getting diagnosis by undergoing blood tests, patients continued to take medical treatment in the form of “pain killers” from their general practitioners and resisted to go to the Rheumatologist out of fear of taking “steroids and their negative effect on the body”. Patients avoided to go to Rheumatologist and resorted to alternative treatments like Ayurveda and Homeopathy. When they did not experience expected pain relief from the alternative treatment modalities and their health condition worsened, they left with no option but to undergo treatment from Rheumatologist. Some patients also complained that their general practitioner did not refer them to Rheumatologist immediately after getting diagnosis of RA rather continued to treat patients on their own with pain medicines which evoked anger in patients. Delayed diagnosis and treatment have led to decreased mobility and feeling of despair. Many patients visited more than one doctor before visiting to Rheumatologist.

“When I started getting severe pain, I went to my family doctor. I got diagnosis of RA. My family doctor prescribed me some pain killers and did not refer me to Rheumatologist. I felt better temporary and I started taking Ayurvedic medicines. I avoided going to Rheumatologist because of side effects of Steroids. But at one

point my pain worsened so much that I became bed-ridden. I was scared about my future. Then I went to Rheumatologist and started my treatment. My family doctor should have suggested me earlier to go to Rheumatologist.” (Meera)

Patients who got delayed diagnosis experienced the sense of relief as they got clarity about the causes of pain and also they experienced pain relief in short time due to pain-directed treatment by Rheumatologists.

“At least I have got diagnosis. Earlier it was not detecting only. That was more important.” (Sanika).

“I experienced pain relief in one week after I started my treatment from Rheumatologist. My conditioned improved little bit.” (Meera).

In case of patients with younger age and who got early diagnosis experienced the sense of “shock” as most of them did not suffer from any severe pain and hence did not expect to be getting diagnosed with chronic disease in young age. These patients experienced emotional turmoil due to “why me” question after realizing the chronicity of the disease.

“I went for normal blood test before my sports tournament. I got detected with RA in my blood. I was right away disqualified to take part in running tournament. That was a major blow.” (Sakshi)

For some patients, the need of taking medications from younger age elicited the feelings of grief and distress.

“I had to start taking steroids I was shattered. Two words ‘steroids and arthritis will not go made me disturb emotionally. I have actually cried a lot when I had to take dose of steroid. Arthritis is not going till end of my life made me cry. When I got to know that without taking medicines I cannot function properly and compulsion of taking medicines created avoidance for medicines. I feel what happened to body.” (Rajani).

3.2 Impact of RA symptoms on day to day life.

Just after the diagnosis and in the initial phase of treatment, patients suffered from severe pain, stiffness in multiple joints, fatigue. Patients experienced a great deal of immobility which put tight restraints on their independence to perform daily living activities like going to wash-room, brushing, taking bath, dressing up, combing hair etc. Getting dependent on others to perform basic daily living tasks triggered the feelings of guilt, anger, frustration, fear and sadness. Many patients felt that their diminished ability to fulfill their social roles as a mother, spouse, daughter-in-law etc has threatened their identity as a woman. Many of them experienced the sense of grief due to inability to become a part of important events in the lives of their loved ones.

“One of the biggest struggles is to go to toilet in morning as in morning there is lot of stiffness...To get up from the bed and go to the toilet is a big problem.... Now I have become so dependent. Without the help of my maid I cannot go to washroom also. This dependency is very distressful. Now for small things you need to depend on other person” (Sakshi Jog)

“I could not walk even small steps. My cooking stopped. I could not lift small utensils also. My grip got worsened. I could not mix batter for making ‘chapati’. I had to hire maid for that. I had difficulty to perform daily chores like wearing clothes, in doing bath, brushing. I had stopped wearing sari. I could not go out.”(Vidisha)

“I love playing with kids. I have always played children of my relatives. After the birth of my daughter I got RA symptoms. Now I am having my own daughter, but now I can’t run behind her and can’t play with her. This hurts me a lot. I feel guilty.” (Rajani)

Grief of not being able to perform duties associated with one’s role was colored with expectations of culture and society. One-woman participant expressed:

“I could not lift my baby in my lap. Therefore, I used to carry my baby in baby carrier. At that time people looked at me with lot of questions, I used to feel very weird and that added my distress” (Sakshi Jog)”

Physical limitations due to RA have also disrupted their long-term career goals and ambitions which further more mounted their frustration.

“It took me lot of time to absorb the first shock. It was big blow till then I did not know what is failure. It was so intense in that age when I got to know about my disease. It was big blow to my passion. I was state-level runner and I was about to get opportunity at national level. But in Medical test I got RA positive. I was not allowed to participate at national level. I lost my opportunity because of RA even though I had capacity.” (Sakshi Jog)”

“I love cooking. But due to the disease I cannot cook. I had to stop. Dance was my passion. From childhood it was my dream to have dance shows. After pregnancy I had plans to have my shows. But all my plans came to halt.” (Divya)

3.3 Emotional reactions

Negative emotions like shock, sadness and fear were provoked when patients experienced the period of acute pain at the time of diagnosis during which patient's daily living activities and mobility was affected. Increase in irritability was reported by many patients especially in initial phases when patients are trying to adjust with the painful course of disease and the limitations in mobility.

"At the beginning I did not have any habit to tolerate the pain and perform all day-to-day tasks. I used to get irritated because I could not perform my tasks properly because of mobility problem. I used to get tired easily and then got angry on my family members." (Shalini).

During this phase, the patients questioned their fate with "Why me" question and also associated their disease with their "misdeeds". Patients started losing hope due to persistent pain. Some of them even consulted to Astrologer and resorted to religious rituals for pain relief.

"I have never fallen so sick throughout my life. I was not able to do anything which made me feel depressed. I felt why God has given me this disease. I kept fasts to get some pain-relief and even discussed with Astrologer about my destiny..." (Vidisha)

Most patients reported that they experienced depressive symptoms for brief period of time especially when the disease activity was high which made them almost bed-ridden. Patients started feeling scared about having bad impact on family and developing the dependency on others for whole life to perform daily-living tasks.

"When I could not walk at all because of pain, I was very disturbed. I had to stay in bed for whole day and even I could not sleep at night. I felt depressed that what will happen to me and my family in future if this condition persists like this" (Meera)

3.4 Coping strategies

3.4.1 Taking medications

Initially most of the patients referred to their family doctors or orthopedics which prescribed them pain-killers. Consumption of pain-killers created temporary pain-relief and conditioned worsened over the period of time. All the patients reported that they visited the Rheumatologist when the disease has substantially affected their daily living and found difficult to perform daily chores. After started taking medications prescribed by Rheumatologist, most of the patients experienced substantial pain relief and reduced the disease-activity to some extent. Patient acknowledged that the pharmacological treatment benefited them a lot to resume to the daily living activities and helped them to regain their confidence that they can function properly like earlier.

"I could not function. I was bedridden. But when I have started taking medications prescribed by Rheumatologist, I have started feeling better. My pain started reducing. I could start doing my all tasks. I felt relieved " (Vidisha D)

Especially some of the patients who got diagnosed in young age expressed the fear of steroids and its side effect. They also experienced good amount of emotional distress while accepting the fact that they need to take medicine whole life to function properly.

"I was very upset with the thought of taking medicines every day. I even tried to miss my doses. But soon realized its impact on my body." (Radhika)

Few patients have also discontinued the treatment from Rheumatologist due to fear of dependency on steroids and not experiencing the desirable effect. Therefore, they resorted to other forms of treatment.

"I started my treatment with one of the Rheumatologist in Pune but I discontinued in between because I did not see proper effect. Hence, I started again with pain-killers prescribed by my family doctor. But those pain-killers were also not effective for me. So, someone suggested me to refer to my current Rheumatologist. Now, I am feeling much better because of his treatment" (Shalini)

However, after observing the failure of other forms of treatment in creating the desirable effect, they again referred back to pharmacological treatment from Rheumatologist and experienced pain-relief.

Therefore, though taking medicines every day was emotionally distressing for patient, but the pharmacological treatment from Rheumatologist indeed played key role to alleviate symptoms and slower the progression of disease.

3.4.2 Acceptance of the disease

It was observed that the pharmacological treatment alleviates excruciating pain and severe joint stiffness. However, the patients experience flare-ups, some amount of pain and limitations to perform day-to-day activities and work-related tasks. Many patients stopped performing day-to-day living tasks and other activities meaningful for them due to fear of exacerbating the pain and getting "RA attack" or flare-ups. This phase was characterized by significant amount of emotional distress, depressive symptoms for brief period, future worries due to impact of disease on their work and family and patients found very difficult to accept the chronicity of disease.

"I was very nervous when doctor told me that this disease is going to be forever. I was scared that any time "RA attack" can come. I was depressed and my mind was occupied by fears about suffering of my family and children because of this disease. It was very difficult for me to accept the fact that this disease will never go" (Shubha).

However, majority of the patients have expressed that over a period of time they got habituated to pain and came to terms with the fact that this disease cannot be cured completely and they will be living their life with this disease. In this phase, patients mainly realized the chronicity of the disease.

"I have realized that this pain is not going to end permanently. Even if I stay in bed it is going to pain. So better I move around and I will do things which are important for me. I can take a pill if I get pain afterwards." (Meera).

"I have understood that this pain is going to be part of my life. So slowly my body as well as mind started accepting it. Since then I am not at all scared of pain" (Shalini).

"I understood that I am going to have pains due to disease and this disease is going to be with me till the end of my life. Getting sad and crying will not reverse my medical condition. So there is no point in getting upset due to pain" (Sakshi).

The narrations of the patients mainly reflected the sentiment that accepting the chronicity of the disease does not make them feel helpless rather empowers them to resume back to their "normal life" by performing the activities meaningful to them.

"I have accepted that this disease is going to be part of my life. Earlier I used to get very upset because of pain and felt ashamed to confess that I have Rheumatoid arthritis in front of people. I did not move out of my house because of this disease. But now I am not ashamed of my disease. Since I have accepted the disease I go out for work and also perform all activities. Even if my specific joint pains, I just perform my activities with the joints which are not paining" (Sulakashana).

Patients also shared that accepting the disease have motivated them to explore alternatives to manage the disease and to take some serious measures to prevent progression of the disease.

"Acceptance of the disease does not mean that giving up efforts. Not putting any efforts and only depending on God to take care of my disease will only exacerbate my pain. So, I started taking care of myself by going for walk, following diet, going for water walk, reducing weight etc. I don't want to ruin my life because of my lack of efforts rather I am taking efforts to make my life better." (Sangita)

"I have realized that I need to work on my anger which I felt increasing my pain. Therefore, I started following Happy thoughts which helped me to change my thought process and perspective to look at the world." (Shalini)

After realizing the inevitability of pain, the patients redefined their life-goals in light of new limitations due to disease. Over the period of time, the patients also learned the ways to manage pain on their own and hence, they pursued their interests and indulged in meaningful activities without being worried about pain. One patient shared her story which reflected the changing in life goals in light of physical limitations and determination to pursue interests by self-managing the pain.

"I was a professional runner, but I could not continue with running due to RA. Therefore, I started playing table-tennis in which I won lot of medals. I have also participated in boating races. I have completed many treks in Himalayas and Maharashtra. I balanced between rest and activity" (Sakshi Jog)

"I loving go out for movies and have fun. But I see that I do not go evening since I feel tired in the evening. I make it point to plan going out during day time. If my son insists on going to mall in the evening, I take the pain-killer and go out." (Divya)

Accounts of experiences of many women reflected the determination to continue their meaningful activities involving leisure, work and family in best possible way and also the willingness to face pain after doing strenuous activities and handle it by taking pain-killers and rest.

3.4.3 Social support

All the patients have reported that their family and friends played very important role in coping with symptoms, limitations and emotional distress. Especially all the patients emphasized the contribution of their husband and children in helping the patients to perform daily chores and in pain management.

"My husband took my care. He used to seat beside my bed after my operation. My husband accepted my disease." (Sakshi Jog)

"At times my joints stiffen so much that I cannot do any household work. In such condition, my husband and children perform all daily chores in house from cooking to cleaning without complaining. Because of this support, I am leading a happy life." (Shubha)

One of the patients has shared that her children and husband have also understood the exact nature of Rheumatoid arthritis which included the aspects like flare-ups and management of flare-ups. Therefore, their family members have also guided patients to deal with flare-ups without getting panic.

"My daughter has studied my disease thoroughly by reading different articles about my disease. So now she exactly knows Do's and Don'ts in treatment of RA. Whenever I have severe pain, at times I am very distressed and cannot think of any pain-management technique. In such condition, my daughter understands my pain and guides me by advising various pain management techniques like applying ice pack, exercise, oil-massage etc." (Meera).

Support of family members also included the emotional stability of care-givers in face of severe pain of patients which maintain positive environment in family which ultimately prevents depression in patients.

"My family members supported me a lot and consoled me. They helped me to think positively. My family did not allow me to get into depression". (Rajani)

"My parents and in-laws supported me tremendously. They take care of me. They do all the things for me. Overall family environment was positive which helped me to recover." (Divya)

Not only family members, but also friends and colleagues helped the patients to keep the optimism during the painful course of disease and motivated them to adapt to the life-style changes in light of limitations. One patient who was a teacher by profession shared that:

"My friends and teachers supported me lot to deal with first shock of diagnosis and did not allow me to get into depression. They encouraged me to come for trekking and helped me during trek. When I had to cut my hair short and had to change my dressing style, I was very hesitant and was feeling very shy. But all my friends and students encouraged me to adapt new dressing style by giving me positive compliments about my new look." (Sakshi Jog)

"My friends circle helped me lot in this phase. My friends helped me to come out of this nervousness by saying positive things." (Sanika)

One of the very important sources of social support was perceived by all the patients in this study in the form of interaction with their doctor or Rheumatologist. All the patients placed high value on the support of their doctor which helped them to maintain their morale in painful course of disease, to understand the nature of disease and to facilitate the acceptance among patients. Most of the patients reported that their doctors explained them the nature of the disease and told that this disease is not curable. But at the same time patients were told positive things like painful course is not permanent, it is possible to do all the work. All the patients shared that positive interaction with their doctor reduced their fear of disease and increased their confidence to manage their lives along with disease.

"My interaction with doctor were positive. My doctor did not tell in one shot that you have to live with the disease, but he told me slowly. He told me your disease will be there, but it would be silent. My earlier doctor was very negative. He told me lot of restrictions which made me scared a lot. I was feeling low because of that. I felt I have got something very serious and it is end of life. I used to feel when I will come out of this. Then I changed my doctor. My current doctor talked very positively with me. He told me no restrictions. He said whatever you want eat. He told me to live the life the way I used to live. At one point I forgot I got this disease. He told me only to drink water regularly. I felt very happy, confident and "I am normal". From then I am living normal life. (Divya)

"Changing the doctor helped me a lot. My earlier doctor used to say negative things like you are not going to recover. My current doctor motivated me by saying my disease won't go but I will become better. Whatever my doctor told it happened in same way, that is why I believe him. His positive thinking helped me to regain my confidence." (Sanika)

In case of three patients, they changed their Rheumatologist because they perceived their interaction with Rheumatologist negative. According to some patients, positive communication of chronicity of the disease encouraged the patients to continue performing the activities which maintained normalcy in their life.

3.4.4 Self-management

When patients were asked the question, "How do you manage your life with the disease? most of the patient reported that they have never stopped working completely due to the symptoms of disease. Patients learned to balance between activity and rest. Patients preferred to continue doing their household activities as per the pace their disease activity allowed.

"I know that due to disease I cannot function fast. So, whenever any preparation for any event has to be done, I start in advance so that I can complete my tasks without straining my body." (Meera)

"I used to do all my works in the house. But I have decided a strategy of doing works in breaks at my speed. Doing things at my speed helped me to avoid burden." (Sanika)

Inner quest to recover from the disease in order to handle the responsibilities associated with one's social role as wife, daughter-in-law, mother motivated women to search for ways to manage the symptoms as well as to perform their duties. Participant discussed that they made changes in the ways of performing daily chores as per the physical limitations. Gradually, participants understood the nature of the disease and developed 'practical' solutions to perform their duties which were affected by disease. Many participants made

changes in their dressing pattern, sleeping habits, household duties like cooking and also started performing these duties by taking small break to relax instead of working continuously.

"I have started finding solutions. Instead of using heavy utensils in cooking, I started using smaller and lighter utensils. To manage morning stiffness in my wrists, I dip my hands in warm water." (Rajani)

"I had long hair which I could not comb in the morning hours due to joint stiffness. Therefore, I cut my hair short so that I can comb my hair easily." (Sakshi)

Most of the women sought information about the Rheumatoid arthritis in internet, health magazines and through discussion with health professionals. Getting more and more aware about the disease also helped them to reduce their anxiety and to deal with symptoms more effectively. Some of the patients also monitored their own bodily symptoms and drew some of the inferences about their flare-ups. Patients became knowledgeable about the effects of medications and according to that they set up timings for taking painkillers as per their needs. In order to live healthy life with RA, the patients made changes in their life-style which included adapting healthy eating habits, maintaining fitness, changing perspective to look at the world and self, time-management and prioritizing.

"I have read a lot about this disease in internet. After reading, I have realized that I am not the one who got this disease. But there are other younger or older people who are functioning well. So I have realized that it is not life threatening and that much dangerous than I have imagined. I am not the one who is suffering from this disease. I have felt I can overcome disease and live with it. My fear got reduced substantially" (Rajani)

"I have studied that an acidity plays an important role in flare-ups of RA. Therefore, I follow diet to prevent acidity and don't consume foods in large quantity which can trigger acidity. If I eat junk food, next day I exercise more and have light meals. I also go for walk regularly." (Sangita)

"I have realized that I need to work on my mind if I want to manage my disease. I get angry easily. I felt I need to manage my emotions well. Therefore, I started doing Yoga to learn to regulate my emotions. Effective management of emotions has been helping me to deal with symptoms." (Shalini)

Especially the patients in late 50's confessed that they never gave importance to spending time with self and have ignored their fitness, own aspirations in order to fulfill their duties as wife, daughter-in-law and mother. They realized the impact of spending time with oneself on their mental and physical health.

"I have always given importance to maintain family relations which in turn stressed me out badly. I have observed that whenever my stress level increases, my pain level also increases. So, I have stopped giving too much importance to maintain relationships with my relatives and rather started focusing on myself. Now I make efforts to look presentable. I am focusing on my career aspirations also. I can sense my stress level has gone down and I can observe it's benefit on my health too." (Shubha)

3.4.5 Spiritual practices and philosophical teachings

Diagnosis of RA and its symptoms causes significant amount of emotional distress. Majority of the patients in this study have resorted to some form spiritual practice and philosophical teachings. According to patient's experiences, the spiritual practices and philosophical teachings have facilitated the process of acceptance of disease and helped them to gain mental strength to deal with emotional distress. Two women in this study have specifically mentioned the role of Yoga and philosophical teachings in achieving acceptance.

"I have never thought Yoga can play such a crucial role in managing this disease. Yoga asanas have helped me to gain muscle flexibility and have reduced my pain substantially. In my life, Yoga has greatly impacted my mental health. Meditation helped me to realize that my emotional distress did not seem out of this disease rather because of non-acceptance of disease. Meditation and Yoga have played key role to achieve acceptance of the disease and did not allow me to get into depression. Yoga taught me to get in touch with my inner-self." (Shubha)

One participant reported that reading the philosophical teachings helped her to accept the disease and to change the perspective to look at the disease and world. This participant perceived 'suffering' as a part of the destiny.

"When I got diagnosed with RA, the question of "why me" used to haunt me. I used to feel jealous of people who could walk properly. Miraculously I have got the book by J. Krishnamurti (Philosopher). Reading his book and listening to his lectures changed my perspective towards world and my disease. Through teachings of J Krishnamurti I could attain the acceptance towards RA., I have realized the role of destiny. I have understood I was destined to get this disease. My emotional turmoil due to "why me" reduced." (Sakshi Jog)

Some women patients also prayed regularly to God and found comfort from religious beliefs and religious practices.

"I pray God regularly. God did not let happen anything worst in my case. I prayed and God took me out of this. I thanked God that my disease just affected my joints only not other areas. I believe that because of God I met good doctor" (Divya)

"I visit religious places regularly which give me lot of mental strength." (Shubha).

3.4.6 Finding the meaning in work and rewarding family responsibilities

For some patients, their work and family responsibilities did not result in strain rather they found meaning in their work and family demands. Rewarding career goals and taking care of loved ones worked as a driving force behind regaining their physical health. These patients found sense of purpose in their family responsibility and work which motivated them to bounce back from painful symptoms.

"My son is my motivation. I get strength from my son to become fit. For him I will be fit because I want to do everything for him. It is my strong belief that I want to stand for him." (Divya)

For one patient her career goal and work motivated her to resume to her work and to reduce emotional distress. The patient believed that her career aspirations gave her strength and energy to cope with the disease.

"My passion of working for students and my dream to build institute for students from rural area helped me to forget my disease. Because of my passion I did not get into depression. My passion gave me immense energy to forget my disease. My goal as well as my responsibilities as a principal gave me energy to come out" (Sakshi Jog)

IV. DISCUSSION

This qualitative study was conducted on 9 women diagnosed with Rheumatoid Arthritis (RA) with the broader purpose of understanding the subjective experience of living with RA. In India, there are very few studies conducted on RA patients which explored how patients live with this painful disease and the factors which facilitate their effective pain management. The following themes were emerged from this study: 1) Delay in diagnosis and treatment 2) Impact of RA on day-to-day life 3) Negative emotional reactions 4) Impact of taking medications 5) Role of acceptance of pain 6) Role of social support 7) Role of spiritual practices and philosophical teachings 8) Finding the meaning in work and rewarding family responsibilities.

In this study, majority of the women started their treatment from Rheumatologist late. The causes for delay in diagnosis and treatment were lack of awareness about the specialized treatment from Rheumatologist, fear of side-effects of steroids and preference to avail treatment from alternative medicine health-care services. As a result of lack of effectiveness of other treatments and the progression of disease, the patients ultimately sought treatment from Rheumatologist. However, the delay in treatment worsened their joint pain and restricted their movements. This similar tendency has been observed in many studies conducted in India on RA. According to Chopra (2002), in one of the studies conducted in rural area of Maharashtra, the patients showed resistance to seek treatment from Rheumatologist and rather preferred to visit other health-care practitioners before visiting Rheumatologist which ultimately resulted in progression of disease. Fraenkel et. al (2002) also found that patients showed least willingness to take arthritis medications due to fear of drug toxicity. Consistent with previous findings, RA impacted the lives of patients significantly. (Malm, et.al, 2017) In the initial phase, severe pain and joint stiffness deprived patients from basic needs like sleep and created difficulty to perform simple daily living activities like going to wash-room, dressing, bathing etc. without the assistance. Many patients expressed that the limitations created due to disease have hindered them from pursuing their valued activities in lives and career goals. (Barrett, et.al, 2000). Major rupture in freedom and independence to perform social and professional roles triggered range of negative emotions. (LaChapelle, et. al, 2008). Restricted mobility made patients to doubt their ability to manage their things on their own and the fear of becoming dependent on others led to anxiety, guilt and uncertainty of future. (Covic, 2000). They experienced the feelings of shock, injustice and often asked "why me" question (Kostava, et.al, 2014). Kostava, et.al (2014) found in the qualitative research on RA patients in Switzerland that, patients perceived receiving the diagnosis of RA as a punishment and injustice as they could not find any logical explanation for the cause of disease. Patients also voiced of feelings of grief when they have to let go of their old patterns of lifestyle and adopt new one. (LaChapelle, et. al, 2008). Patients waited for brief period for complete recovery by imposing restrictions and isolation on themselves. However, over a period, patients realized that there is no cure and they need to live with this disease.

Second research question of this study was how patients live with this debilitating disease. All the patients noted the key role of pharmacological treatment from Rheumatologist to alleviate their severe pain immediately and to gain mobility to perform their activities of daily living. However, all the patients echoed the sentiment that the adjusting with this disease and living the life with this disease is not possible only with the help of medicines, rather psychological and social factors play an important role to manage this disease. Narratives of most of the patients in this study reflected the acceptance as a facilitator to adjust with this disease. Once the patients accepted the chronicity of the disease, they bounced back to normal life with positive spirit by taking part enthusiastically in meaningful activities, redefining career goals, reevaluating their priorities and by developing strategies to pursue valued activities considering new restrictions. In this way, the patients embrace this disease as a part of their life with all efforts to integrate it along with its characteristics.

Self-management of pain, disease education and balancing between activity and rest give patients sense of control on their lives. Patients restructure their expectations realistically by achieving the balance between their constraints and values. These narratives of the patients reflect the components of acceptance proposed by McCracken (1998): Activity Engagement, Pain-willingness and accepting the chronicity. Large body of literature has demonstrated the effectiveness of pain acceptance in health-outcomes in chronic pain diseases like low-back pain, cervical pain, head-ache etc. (McCracken, 1998). Patients with greater pain acceptance tend to perform daily living activities with better efficacy, committed to achieve their valued goals, showed less pain-related anxiety and improved quality of life (Viene, et.al 2003, McCracken, 2006, Cho et.al, 2013). In the qualitative researches exploring the pain acceptance in patients with Rheumatoid Arthritis as well as other chronic pain conditions demonstrated that realizing the chronicity of pain and redefining the life goals was the turning point in lives of patients of Rheumatoid arthritis which led to the improvement in self-efficacy and give them sense of hope. (LaChapelle, 2008, Kostava, 2014). This crucial step of acceptance was not easy task for some patients. According to some patients, spiritual practices like Yoga and reading spiritual teachings of philosophers and saints helped them to restructure their perspectives and facilitated the acceptance. Effect of Yoga is not just limited to the physical aspects like muscle flexibility, patterns of breathing rather Yoga is way of living which affects person's all aspects of life physical, psychological, social and spiritual (Vallath,2010). Yoga based interventions are associated with reduction in pain, increase in acceptance and mindfulness (Curtis, et.al 2011).

Apart from acceptance, one of the major factors which helped them to manage pain is Social support. Emotional support obtained from family members and friends was crucial in dealing with restrictions and painful symptoms as well as in maintaining positive environment in their home and also gave them sense of hope. Patients who are satisfied with the quality of support found to be satisfied despite suffering from chronic pain and also employed adaptive coping strategies. (Holtzman, et.al 2004). Satisfaction with social support found to be related with frequent use of active coping and lesser use of passive coping strategies (Martinez et.al 2008). One of the interesting finding about the social support has emerged from this study was importance of positive communication from Rheumatologist. Positive communication included conveying the unpleasant reality of chronic nature of the disease in positive way, motivating patients to maintain normal life despite of restrictions, conversing in empathetic way and shared decision making (Gupta, 2015). Many patients noted that positive interaction with Rheumatologist helped them to reduce their fear of disease and to give them sense of hope. In this study, the narratives of the patients reflected that one of the reasons for changing the Rheumatologist was perceived negative communication from Rheumatologist. Though the impact of doctor-patients relationship on pain management is less explored, the available researches on patient-primary care (PPC) indicate that patients tend to be more satisfied, change their physicians less frequently and show better emotional health when physicians communicated in patient-centered way (Matthias, et.al ,2010, Gibofsky, et.al, 2018).

Apart from these psychosocial factors, this study has also thrown light on the role of spiritual factors in coping with this disease. Small size of sample has emphasized on obtaining emotional strength to cope with illness by visiting religious places, praying reading religious scriptures. Several researches have shown that patients with deep religious faith and spiritual experiences show less vulnerability to depression, attend positive elements of disease, show higher psychological flexibility about life goals and adapt better to chronic illness (Bartlett, et.al 2003). Another interesting dimension facilitating positive health outcomes in these patients was determination to pursue one's career goals and providing care to family. Large number of studies have linked stress with family and work demands. However, in this study, some women expressed that their career goals and family responsibilities motivated them for speedy recovery and to bounce back to normal life (Dich, et.al, 2019). In the study conducted on Indian sample of patients, Jain et. al (2019) found that patients perceived work as driving force and helped them to distract them from symptoms of disease. Motivating career goals and work commitments function as a source of gratification and higher self-esteem.

Therefore, findings of this qualitative research demonstrate that living with chronic disease and maintaining good quality of life is not a result of one-dimensional process rather it is multidimensional processes consists of biological, psychological, social and spiritual components. In majority of clinical settings, the treatment of Rheumatoid arthritis is highly influenced by biological components overemphasizing the pharmacological interventions. However, the potential of psychological, social and spiritual components is still not tapped as the powerful resources in treatment. This diversity in pain management is one of the important features of biopsychosocial model which emphasizes on implementing interdisciplinary approach for complete functional restoration of person as a "whole" rather than treating the symptoms. (Gatchel et.al,2004)

V. IMPLICATIONS OF THE RESEARCH

In India, the psychosocial spiritual components like acceptance, collective family systems and spiritual practices are an inevitable part of Indian culture. However, very few studies are being conducted to explore their effect on patient's health outcomes in clinical settings. In Indian settings, there is lack of literature exploring the effect of psychosocial approaches on pain in Rheumatoid arthritis. Therefore, the findings of this study throw light on the subjective experiences of Indian women with RA and indicates the need for developing psychosocial interventions for the disease management. In this study, causes for delay in diagnosis and treatment were lack of awareness about the difference between orthopedics and Rheumatologist and delay in referral to Rheumatologist. In India, there is need of creating awareness about Rheumatoid arthritis and effective referral system to avoid delay in treatment. Some patients have indicated the discussion with fellow patients facilitated the coping process, but very few patients were aware about the patients support group. Effective measures should be taken to create awareness about support groups and wide network of support groups.

VI. LIMITATIONS OF THE STUDY

However, this study is not without limitations. A convenience sample of 9 patients was recruited from Rheumatology consulting clinics in urban area like Pune. Recruitment of large sample of patients from rural area and various types of medical centres can provide different perspectives about experience of living with RA and coping strategies employed by patients. As RA is characterized by 'good days' and 'bad days' of functioning due to unpredictable nature of RA flare-ups. Results of the present study are based on the patients who were functioning better on the day of sampling and showed lesser disease activity. Therefore, longitudinal studies can provide insights about changes in psychological aspects like pain acceptance, active coping across the various stages of functioning.

VII. CONCLUSION

Overall, this study focuses on two major aspects of living Rheumatoid arthritis. First, Rheumatoid arthritis impacts patient's life in all aspects – physical, psychological, social. Patient's diminished ability to continue daily living activities, work and leisure triggers significant amount emotional distress. Narratives of the patients in this study reflect the pressing need of creating awareness about Rheumatoid arthritis among patients and sophisticated infrastructure of referral system for timely diagnosis and treatment. Though the pharmacological treatment has reduced pain intensity, the patient needs to play an active role to improve one's quality of life by changing one's perspective to look at the disease, employing practical strategies to face challenges posed by disease symptoms. This study demonstrates that psychological, social and spiritual factors contribute significantly to cope with this chronic disease effectively. Findings of this study highlight the need for clinicians to consider the psychological, spiritual and social coping mechanisms and to develop the interventions to enhance these coping mechanisms for positive health outcomes. This study provides important directions for future research work to tap the potential of psychosocial interventions.

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