A Phenomenological Study of the Lived Experience of Patients Admitted at Selected Arthritis Centres in Ernakulam District, Kerala, India

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Abstract

Background: Rheumatoid arthritis (RA) is a chronic, systemic autoimmune disease that produces progressive joint destruction, pain and disability. Beyond its measurable clinical markers, RA reshapes the everyday lives, identities and relationships of those who live with it. Understanding this lived experience is essential for delivering person-centred nursing care, yet qualitative evidence from the South Indian context remains limited.

Aim: To explore and interpret the lived experience of patients with rheumatoid arthritis admitted at selected arthritis centres in Ernakulam district, Kerala, India.

Methods: A descriptive phenomenological design informed by the Husserlian tradition and Colaizzi's method of data analysis was adopted. Twelve adults with a confirmed diagnosis of RA (disease duration ≥ 1 year) were selected through purposive sampling until data saturation. Data were generated through in-depth, semi-structured, face-to-face interviews, audio-recorded and transcribed verbatim. Trustworthiness was ensured using Lincoln and Guba's criteria, and reporting followed the COREQ checklist.

Results: Five essential themes emerged: (1) living in a body of relentless pain and stiffness; (2) erosion of self and disrupted social identity; (3) emotional turbulence of fear, frustration and uncertainty; (4) perceived burden on family and financial strain; and (5) redefining life through coping, spirituality and hope. Participants described the unpredictability of flares, the loss of valued roles, and the central role of family and faith in adaptation.

Conclusion: RA is experienced as a pervasive biographical disruption that extends well beyond the joints. Nursing care should integrate structured pain management with psychosocial support, family-centred counselling and culturally sensitive attention to spirituality. The findings offer a foundation for developing holistic, context-specific nursing interventions.

Keywords: rheumatoid arthritis; lived experience; phenomenology; qualitative research; chronic illness; nursing; Kerala; India

How to cite this article: Mole N, Dhakar ML. A phenomenological study of the lived experience of patients admitted at selected arthritis centres in Ernakulam district, Kerala, India. Int J Drug Deliv Technol. 2026;16(73s): 918-923. DOI: 10.25258/ijddt.16.73s.100

1. Introduction

Rheumatoid arthritis (RA) is a chronic, progressive, systemic autoimmune disorder characterised by symmetrical inflammatory polyarthritis that principally affects the small joints of the hands and feet. Persistent synovial inflammation leads to cartilage and bone erosion, joint deformity and, ultimately, functional disability. Global estimates place the prevalence of RA at approximately 0.5–1% of the adult population, with a marked female preponderance and a peak onset between the fourth and sixth decades of life. In India, community-based surveys have reported a prevalence of roughly 0.28–0.75%, translating into a substantial and often under-recognised disease burden.

Although the biomedical characterisation of RA—its serology, radiographic progression and pharmacological management—is well established, these clinical parameters capture only a fraction of what it means to live with the disease. RA is not merely a disease of joints; it is a condition that permeates the whole of a person's existence, reshaping daily routines, occupational roles, family relationships, self-image and future expectations. The

unpredictability of flare-ups, the invisibility of pain and fatigue, and the cumulative encroachment of disability generate a distinctive form of chronic-illness suffering that quantitative indices cannot fully convey. Phenomenology, as both a philosophy and a research method, offers a powerful lens through which to access this subjective, first-person world. By seeking to describe the essence of a phenomenon as it is lived and perceived, phenomenological inquiry moves beyond symptom checklists to illuminate meaning, embodiment and the texture of everyday experience. For nursing—a discipline explicitly concerned with holistic, person-centred care—such understanding is indispensable. Nurses who grasp how patients themselves interpret and negotiate their illness are better positioned to deliver empathetic, individualised and effective care.

In the South Indian state of Kerala, where RA is commonly encountered in specialised arthritis and rheumatology centres, there is a paucity of qualitative literature exploring how patients experience the condition within their particular sociocultural milieu—one shaped by close-knit family structures, distinctive gender roles, and strong religious and spiritual traditions. Addressing this gap, the present study sought to explore and interpret the lived experience of patients with RA admitted at selected arthritis centres in Ernakulam district, Kerala.

1.1 Aim and Research Question

The aim of this study was to explore and describe the lived experience of patients with rheumatoid arthritis. The central research question guiding the inquiry was: "What is the lived experience of patients with rheumatoid arthritis admitted at selected arthritis centres in Ernakulam district, Kerala?"

2. Materials and Methods

2.1 Study Design

A qualitative research approach employing a descriptive phenomenological design was adopted. Grounded in the Husserlian philosophical tradition, descriptive phenomenology aims to uncover and describe the essential structures of a lived experience while the researcher deliberately brackets (epoché) his or her preconceptions. This design was considered most appropriate because the study sought rich, first-person accounts of what it is like to live with RA, rather than to test a predetermined hypothesis. Reporting adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

2.2 Setting and Participants

The study was conducted at selected arthritis and rheumatology centres in Ernakulam district, Kerala, India, over a four-month period. Participants were recruited through purposive sampling to ensure the inclusion of individuals with rich, relevant experience of the phenomenon under study. Sampling continued until data saturation—the point at which no new codes or themes emerged from successive interviews—was achieved, which occurred after the twelfth interview.

Inclusion criteria: adults aged 18 years and above; a physician-confirmed diagnosis of RA (2010 ACR/EULAR criteria) of at least one year's duration; able to communicate in Malayalam or English; and willing to provide informed consent.

Exclusion criteria: patients with severe cognitive impairment or acute psychiatric illness; those who were critically ill or unable to sustain an interview; and patients with other major disabling comorbidities that could confound accounts of the RA experience.

2.3 Data Collection

Data were generated through in-depth, semi-structured, face-to-face interviews conducted in a private room at each centre by a trained researcher. An interview guide, developed from the literature and refined through two pilot interviews (not included in the final analysis), opened with a broad grand-tour question—"Can you tell me what your everyday life has been like since you were diagnosed with rheumatoid arthritis?"—followed by probes exploring physical, emotional, social, familial and spiritual dimensions. Each interview lasted between 40 and 65 minutes, was audio-recorded with consent, and was supplemented by field notes documenting non-verbal cues. Interviews were transcribed verbatim and, where conducted in Malayalam, translated into English with back-translation to preserve meaning.

2.4 Data Analysis

Transcripts were analysed using Colaizzi's seven-step method of descriptive phenomenological analysis: (1) reading and re-reading each transcript to acquire a sense of the whole; (2) extracting significant statements pertaining to the phenomenon; (3) formulating meanings from these significant statements; (4) organising formulated meanings into clusters of themes; (5) integrating results into an exhaustive description of the phenomenon; (6) reducing the exhaustive description to a fundamental structure; and (7) returning to participants for validation of the findings (member checking). Analysis was conducted manually with the support of a coding framework, and two researchers coded independently before reconciling discrepancies through discussion.

2.5 Trustworthiness

Rigour was established using Lincoln and Guba's four criteria. Credibility was enhanced through prolonged engagement, member checking and investigator triangulation. Dependability and confirmability were supported by maintaining a detailed audit trail and a reflexive journal in which the researcher bracketed personal assumptions. Transferability was facilitated by providing thick descriptions of the context and

participants, enabling readers to judge the applicability of findings to other settings.

2.6 Ethical Considerations

Ethical approval was obtained from the Institutional Ethics Committee prior to commencement [approval reference to be inserted]. Written informed consent was secured from every participant after a full explanation of the study's purpose, procedures and their right to withdraw at any time without prejudice to their care. Confidentiality and anonymity were protected by assigning pseudonymous participant codes (P1–P12), and all data were stored securely.

3. Results

3.1 Participant Characteristics

Twelve patients with RA participated in the study. The sample comprised nine women and three men, reflecting the recognised female preponderance of the disease, with ages ranging from 34 to 67 years. Disease duration ranged from 2 to 19 years. Table 1 summarises the sociodemographic and clinical profile of the participants, and Figure 1 depicts the distribution of age, disease duration and gender across the sample.

Table 1. *Sociodemographic and clinical profile of study participants*

Code	Age (yrs)	Sex	Duration (yrs)	Occupation	Education	Marital status
P1	34	F	3	Home maker	Higher secondary	Married
P2	58	F	12	Retired teacher	Graduate	Widowed
P3	45	M	7	Shop owner	Higher secondary	Married
P4	62	F	19	Home maker	Primary	Married
P5	51	F	9	Tailor	Higher secondary	Married
P6	39	F	4	Nurse (on leave)	Graduate	Married
P7	67	M	15	Retired clerk	Graduate	Married
P8	48	F	6	Home maker	Secondary	Married
P9	55	F	11	Farm labourer	Primary	Widowed
P10	42	M	2	Auto driver	Secondary	Married
P11	60	F	14	Home maker	Primary	Married
P12	36	F	5	IT professional	Postgraduate	Single

(N = 12). F = female; M = male; yrs = years.

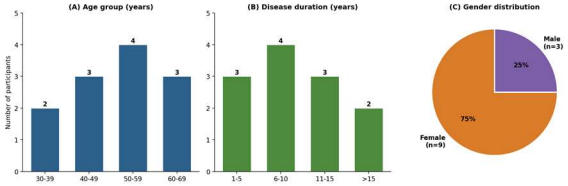

Figure 1. *Distribution of participants by (A) age group, (B) disease duration and (C) gender (N = 12).*

3.2 Overview of Themes

Analysis of the transcripts yielded 214 significant statements, which were condensed into formulated meanings and organised into 14 subthemes and five essential themes that together constitute the fundamental structure of the lived experience of RA. Table 2 presents the thematic framework with representative significant statements. Figure 2 offers a visual map of the relationship between the central phenomenon and its constituent themes, while Figure 3 illustrates the frequency with which each subtheme was endorsed across the twelve participants.

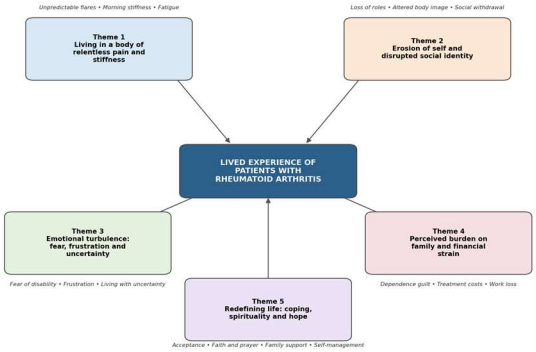

Figure 2. *Thematic map of the lived experience of patients with rheumatoid arthritis, showing the five essential themes and their associated subthemes converging on the central phenomenon.*

Theme	Subthemes	Representative significant statement
1. Living in a body of relentless pain and stiffness	• Unpredictable pain and flares • Morning stiffness limiting routines • Overwhelming fatigue	"Some mornings my fingers feel like they are locked; I cannot even hold my tea cup for the first hour." (P4)

2. Erosion of self and disrupted social identity	• Loss of occupational and household roles • Altered body image • Social withdrawal and stigma	"I was the one who ran the whole house. Now I sit and watch others do my work. I feel I am no longer the same person." (P11)
3. Emotional turbulence: fear, frustration and uncertainty	• Fear of deformity and disability • Frustration and irritability • Living with uncertainty	"I look at my hands and I am afraid—will they become bent like my mother's? I don't know what tomorrow holds." (P1)
4. Perceived burden on family and financial strain	• Guilt over dependence on family • Financial strain of long-term treatment	"The medicines are costly and never-ending. I feel guilty that my son spends his salary on me." (P9)
5. Redefining life: coping, spirituality and hope	• Acceptance and adaptation • Spirituality and faith as an anchor • Family support and hope	"I have learned to plan my day around the pain. My prayers and my family give me the strength to carry on." (P2)

Table 2. *Thematic framework of the lived experience of rheumatoid arthritis, with subthemes and representative significant statements from participants (P1–P12).*

3.3 Theme 1: Living in a Body of Relentless Pain and Stiffness

The most immediate and universal dimension of the experience was that of the suffering body. Every participant described pain and stiffness as constant companions that dictated the rhythm of their days. The pain was frequently portrayed as unpredictable, escalating without warning into flares that could confine participants to bed.

> *"You never know when it will strike. One day I am fine, the next day my knees and wrists are on fire and I cannot even walk to the bathroom."* — P7, male, 67 years

Morning stiffness emerged as a particularly disabling feature, robbing participants of the early hours and delaying essential activities of daily living. Overlaying both pain and stiffness was a profound, often invisible fatigue that participants struggled to make others understand.

> *"It is not ordinary tiredness. It is as if all my energy has been drained out. People think I am just being lazy, but they cannot see how heavy my body feels."* — P6, female, 39 years

3.4 Theme 2: Erosion of Self and Disrupted Social Identity

As the disease encroached on physical capacity, participants described a corresponding erosion of the roles and identities that had defined them. Homemakers grieved the loss of their capacity to run the household; wage earners mourned reduced or abandoned work. This loss of role was experienced as a loss of self.

> *"I was a tailor for twenty years. My hands were my livelihood. Now these same hands betray me and I had to close my work. Who am I now?"* — P5, female, 51 years

Visible joint deformities and swelling altered participants' body image and, for several, provoked social withdrawal and a sense of stigma. Some avoided social gatherings to escape questions or perceived pity.

> *"I stopped going for functions. People stare at my hands, and I feel ashamed. It is easier to stay at home."* — P11, female, 60 years

3.5 Theme 3: Emotional Turbulence — Fear, Frustration and Uncertainty

The chronic and progressive nature of RA generated a turbulent emotional landscape. A pervasive fear of future deformity and disability—often crystallised by having witnessed the condition in relatives—haunted younger participants in particular. Day-to-day limitation bred frustration and irritability, sometimes directed at loved ones and followed by remorse. Underlying all was the corrosive experience of living with uncertainty about the disease trajectory.

> *"The not-knowing is the worst part. Will the next flare cripple me? Will the medicines keep working? I try not to think about it, but the fear is always there."* — P1, female, 34 years

3.6 Theme 4: Perceived Burden on Family and Financial Strain

Deeply embedded in the collectivist family culture of Kerala, participants repeatedly framed their illness in terms of its impact on others. Many expressed guilt at becoming dependent on spouses and children for care and for financial support. The recurring cost of long-term medication, consultations and investigations imposed a tangible economic strain, especially for those from lower-income backgrounds.

> *"Every month there is a bill for medicines, tests, and travel to the hospital. I feel I have become a weight on my family instead of a support."* — P9, female, 55 years

3.7 Theme 5: Redefining Life — Coping, Spirituality and Hope

Despite the pervasive hardship, participants were not passive sufferers. Over time, many moved toward acceptance and actively adapted their routines—pacing activities, modifying their homes and prioritising tasks around their symptoms. Spirituality and religious faith emerged as a powerful anchor, offering meaning, comfort and endurance. The support of close family and a resilient hope for better days sustained participants through difficult periods.

> *"I have made peace with it in some way. I do what I can, I rest when I must, and I leave the rest to God. My grandchildren give me a reason to keep going."* — P2, female, 58 years

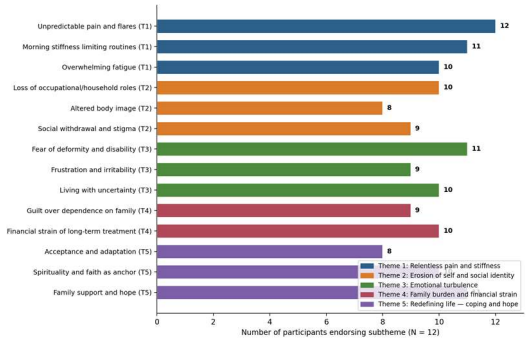

Figure 3. *Frequency of endorsement of each subtheme across the twelve participants, grouped by essential theme. Bars indicate the number of participants (of 12) whose accounts reflected each subtheme.*

4. Discussion

This phenomenological study illuminates the profoundly biographical nature of living with rheumatoid arthritis among patients in Ernakulam district, Kerala. The five essential themes collectively demonstrate that RA is experienced not as a localised joint disease but as a pervasive disruption of body, self, emotion, family and worldview—a finding that resonates strongly with Bury's classic concept of chronic illness as "biographical disruption."

The centrality of relentless pain, stiffness and invisible fatigue (Theme 1) echoes a large body of qualitative RA research in which the unpredictability of symptoms and the invisibility of suffering are recurrent motifs. The tension between an inner experience of debilitating fatigue and an outward appearance of wellness—leaving patients feeling misunderstood—has important clinical implications for validation and communication in nursing practice.

The erosion of valued roles and identity (Theme 2) reflects the loss of self described in the seminal work of Charmaz, whereby chronic illness progressively strips away the activities and relationships through which identity is constituted. In the present study this loss was culturally inflected: for women, the inability to fulfil the homemaker role, and for men, the loss of the provider role, were experienced as especially threatening to self-worth, mirroring the gendered organisation of family life in Kerala.

The emotional turbulence of fear, frustration and uncertainty (Theme 3) is consistent with the elevated rates of anxiety and depression documented among people with RA. Notably, the fear of deformity was frequently anchored in having observed the disease in older female relatives, underscoring the role of intergenerational and observational knowledge in shaping illness expectations.

A distinctive contribution of this study lies in the salience of family burden and financial strain (Theme 4) and of spirituality within coping (Theme 5). In the collectivist and religiously observant context of Kerala, participants interpreted their illness relationally—through its effect on family—and drew heavily on faith as a source of meaning and endurance. These culturally specific findings caution against the uncritical transfer of individualistic, Western coping frameworks and support the integration of family-centred and spiritually sensitive approaches into nursing care.

4.1 Implications for Nursing Practice

The findings carry several implications. First, nursing assessment of RA should extend beyond joint counts and pain scores to encompass fatigue, emotional distress, role loss and financial burden. Second, structured patient and family education—addressing the disease course, the rationale for adherence and realistic expectations—may mitigate fear and uncertainty. Third, because family members are both the principal source of support and the focus of patients' guilt, family-centred counselling is warranted. Fourth, respectful acknowledgement of patients' spiritual resources can strengthen coping. Finally, linking patients to social-support and financial-assistance schemes may relieve a burden that materially affects wellbeing and adherence.

4.2 Strengths and Limitations

Strengths of the study include its rigorous phenomenological methodology, adherence to COREQ reporting, investigator triangulation, member checking and the achievement of data saturation. Several limitations should nevertheless be acknowledged. The study was conducted at selected arthritis centres in a single district, and the sample, though information-rich, was small and predominantly female; findings should therefore be transferred to other contexts with appropriate caution. As with all qualitative work, the researchers' own perspectives may have influenced interpretation, although reflexive bracketing was employed to minimise this. Finally, translation of Malayalam accounts into English, despite back-translation, may have attenuated some nuances of meaning.

5. Conclusion

For the patients in this study, rheumatoid arthritis was far more than a disease of the joints; it was a lived reality that reshaped their bodies, identities, emotions, family relationships and spiritual outlook. The five essential themes—relentless pain and stiffness, erosion of self, emotional turbulence, family burden and financial strain, and the redefinition of life through coping, spirituality and hope—together portray RA as a profound biographical disruption negotiated within a distinctive sociocultural context. These insights call for holistic, person- and family-centred, culturally sensitive nursing care that addresses the physical, psychological, social, economic and spiritual dimensions of the illness. Future research should extend this inquiry through larger and more diverse samples, longitudinal designs, and the development and testing of tailored nursing interventions grounded in these lived realities.

Declarations

Ethics approval and consent to participate: The study was approved by the Institutional Ethics Committee [reference to be inserted]. Written informed consent was obtained from all participants.

Consent for publication: Participants consented to the publication of anonymised quotations.

Availability of data: The de-identified transcripts generated during the study are available from the corresponding author on reasonable request, subject to ethical restrictions protecting participant confidentiality.

Competing interests: The authors declare that they have no competing interests.

Funding: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Authors' contributions: All authors contributed to study conception and design; data collection and analysis were performed by the first and third authors; the first author drafted the manuscript, and all authors read and approved the final version.

Acknowledgements: The authors sincerely thank the participants who generously shared their experiences, and the management and staff of the participating arthritis centres for their support.

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