

Channelling Consumer Voices to Transform Person-Centred Care (Consumer PCC): A qualitative systematic review on patient’s perspectives and experiences of living with Rheumatoid Arthritis.

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Objectives

Despite widespread acceptance of the importance of person-centred care (PCC), it is unclear whether patients’ perspectives and needs are incorporated into current healthcare delivery. We aimed to describe patients’ perspectives and experiences of living with rheumatoid arthritis (RA) to inform the design of pathways for PCC.

Methods

Databases (MEDLINE, Embase, PsycINFO, CINAHL) were searched for qualitative studies including adults (age ≥ 18 years) with RA in any language until January 2022. Inductive thematic analysis was performed. Consumers with lived experience of a variety of rheumatic conditions have been integral in co-reviewing all aspects of this study.



Results

“It could give me two heads and I’d still try it!”¹ :anti-TNF treatment and associated side-effects.

From 103 studies with 2,680 adults with RA, four themes (with subthemes) were identified:

- Debilitating symptoms affecting quality of life (profound illness burden, suffering from adverse outcomes of therapy, burdened by dependency on others, rationing limited energy resources)
- Redefining and regaining “normality” (hiding disability and deformity, support to maintain family roles, desperate for relief from treatment, being robbed of one’s identity)
- Desire for consistent and personalised care (tailoring care to address life priorities, security with nursing support, eroded trust from fragmented care, seeking timely knowledge for decision making)
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- Anxiety associated with unpredictability (uncertainty of future prognosis, reluctance to alter treatment regimens)

Conclusions

People with RA can experience severe, unpredictable symptoms that compromise their independence and impact their social, professional and personal identity to varying degrees. Community/family support and timely, consistent and personalised healthcare can promote feelings of control and security during adjustments to a new “normal”. PCC pathways for people with RA need to address these key elements. Further studies in collaboration with people living with rheumatic conditions are planned to identify essential components of PCC pathways to optimise the physical, social and mental wellbeing of people living with RA.

References

¹ Arkell P, Ryan S, Brownfield A, Cadwgan A and Packham J. Patient experiences, attitudes and expectations towards receiving information about anti-TNF medication– “It could give me two heads and I’d still try it!”. BMC Musculoskeletal Disorders. 2013, 14:165.

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