

Patient Priorities in RA Research – An Exploration of Patient Perspectives from those Enrolled in the Ontario Best Practices Research Initiative (OBRI) Clinical Registry

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Objectives: Patient experiences with rheumatoid arthritis (RA) symptoms, treatments, and rheumatology care are critically important in the assessment of treatment-effectiveness and quality of care for RA. Despite recommendations for more patient-centered research, measures to evaluate the effectiveness of RA therapies often fail to reflect patient priorities.[1] The Ontario Best Practices Research Initiative (OBRI) is a clinical registry focused on improving the quality of care and health outcomes of patients with RA through long-term data collection on therapies, clinical practices, and health-care utilization. Patient self-reported data is collected using structured interviews and validated questionnaires. These provide valuable data but may fail to reflect patient priorities and experiences. The objectives of this study were to explore patient priorities in RA research, identify gaps in OBRI data collection, and explore options for communication with patients.

Methods: RA patients enrolled in the OBRI clinical registry were invited to participate in one of three patient sessions in 2014 to provide feedback on how OBRI data collection could be improved to better capture patient needs/priorities. In small groups facilitated by a moderator, patients were asked to identify gaps in OBRI data collection and share experiences with RA and rheumatology care. Approximately 48 RA patients participated. After each discussion, patients completed a questionnaire on their use of social media.

Results: Four overarching themes were identified: 1) A need for research focused on patient experiences with RA including journeys to diagnosis, symptoms, treatments, side effects, and challenges/concerns; 2) A need for research into patient satisfaction with rheumatology care including rheumatologist accessibility, communication, and disease management; 3) A need for OBRI research addressing patient social support networks, strategies for coping with flares, diet and exercise, and the use of alternative therapies; and 4) A need for more information from rheumatologists on medication risks. Additionally, of those who completed the social media questionnaire, all (n=26) reported using email and some (n=15) reported using Facebook, however only (n=14) indicated a preference to communicate through email.

Conclusion: Patients expressed that some of their most important experiences are not captured through structured questionnaires, suggesting a need for mixed-methods RA research to capture qualitative and quantitative patient-reported outcomes. This study identifies patient research priorities and opportunities for improved care and communication.