

116 | Patients' perceptions of unmet medical need in rheumatoid arthritis

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Background: Despite many available treatments for rheumatoid arthritis (RA), a considerable proportion of patients do not achieve their treatment goals. Some RA patients continue to experience symptoms, such as pain and diminished function that may affect their psychosocial outcomes and activities of daily living.

Objectives: To identify, characterize, and quantify the unmet needs of patients with RA in the United States currently taking a disease-modifying antirheumatic drug (DMARD).

Methods: A cross-sectional, web-based survey was conducted with RA patients who were identified and recruited through CreakyJoints, an online patient support community, and ArthritisPower, an online patient research registry, from 12/2017 to 1/2018. Eligible patients were aged ≥ 21 years, reported a diagnosis of RA, and failed ≥ 1 DMARDs and were receiving their current DMARD medication(s) for ≥ 6 months. Patients answered 50 questions about treatment history, RA symptoms, disease-related impacts using the Rheumatoid Arthritis Impact of Disease (RAID), flares, and treatment satisfaction using the Treatment Satisfaction Questionnaire for Medication (TSQM). Descriptive analyses were used to summarize the responses.

Results: Of 415 patients screened, 258 (62%) were eligible and completed the survey. Patients were predominantly female (87%) and Caucasian (87%), with a mean (SD) age of 54.5 (11.4) years. In total, 232 (90%) had current or past experience with a biologic, with 67% currently on a biologic, 71% on at least one conventional synthetic DMARD, and 40% on methotrexate. While almost half (46%) of patients were satisfied-to-extremely satisfied with the way their medication relieves their symptoms, the study sample reported a mean (SD) RAID score of 5.06 (2.0) on a scale from 0 to 10, with higher scores indicating worse status. Overall, 67% of patients reported moderate-to-severe pain, 61% reported difficulty with daily physical activities, and 74% reported moderate to severe fatigue because of their RA in the prior 7 days. 43% of patients reported daily or almost daily use of prescription treatments for pain relief and 44% of patients reported a current flare in their RA.

Conclusions: Results from this real-world sample of RA patients indicate that although patients tend to report satisfaction with their treatment, many continue to experience bothersome symptoms (eg, pain and impaired physical function). Despite many available RA therapies, these results suggest that there remains significant unmet need for RA patients on current approved treatments.

117 | Using social media to collect patient perspectives on quality of life: A feasibility study

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Background: Development of innovative drugs for melanoma is occurring rapidly. These drugs are often associated with marginal prolongation of overall survival, as well as increased toxicity profiles. Therefore, HTA agencies increasingly require information on health related quality of life (HRQoL) for the assessment of such drugs.

Objectives: This study explored the potential of using social media to assess patient perspectives on HRQoL in melanoma, and whether current cancer- and melanoma-specific HRQoL questionnaires represent these patient perspectives.

Methods: A web-based survey with open-ended questions to assess melanoma patients' perspectives regarding HRQoL was distributed on social media channels of Melanoma Patient Network Europe (Facebook, Twitter, and LinkedIn). Two researchers independently assessed completed surveys and conducted content analysis to identify key themes. Themes identified were subsequently compared with questions used in three current HRQoL questionnaires (EORTC QLQ-C30, EORTC QLQ-MEL38, FACT-M).

Results: In total, 72 patients and 17 carers completed the survey. Patients indicated that family, having a normal life, and enjoying life were the three most important aspects of HRQoL. Carers indicated that being capable, having manageable adverse events, and being pain-free were the three most important aspects of HRQoL for patients. Respondents seem to find some questions from HRQoL questionnaires relevant (eg, "Have you felt able to carry on with things as normal?") and others less relevant (eg, "Have you had swelling near your melanoma site?"). Additionally, wording may differ between patients and HRQoL questionnaires, whereby patients generally use a more positive tone. For example, FACT-M states "I have a lack of energy," while patients rather focus on "having enough energy."

Conclusions: Social media may provide a valuable tool in assessing patient perspectives regarding HRQoL. However, differences emerge between patient and carer perspectives. Additionally, cancer- and melanoma-specific HRQoL questionnaires do not seem to correlate fully with patient perspectives.