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Challenges to Optimal Rheumatology Care: A focus Group study.

Objectives: To assess challenges to optimal rheumatology care, from the perspective of patients attending tertiary care clinics at our centre.

Methods: A focus group study was conducted. We used a thematic analysis, generating initial codes, searching for themes, reviewing themes, defining and naming themes. We proceeded group by group, with iterative comparisons of issues, experiences, and examples, in terms of similarities and differences as expressed by participants. Open coding was used to explore, name, and categorize topics found in the text. Axial coding was used to relate and contrast emerging topics to each other. Selective coding was used to facilitate identification of core themes emerging from the text. To ensure the trustworthiness of the data analysis, two individual independently analyzed the data. Discrepancies were resolved through discussion and consensus.

Results: A total of 18 patients participated in three focus groups (group 1=8; group 2=5; group 3=5). Eleven patients had systemic lupus erythematosus (SLE), 6 patients had rheumatoid arthritis (RA), and 1 patient had psoriatic arthritis (PsA). The average age (standard deviation) was 51.2(14) years, all participants were female with average disease duration of 23.5 (14.5) years, 72.2% were Caucasian and the average education was 14.2(2.6) years.

Three main themes emerged from the focus groups: Theme 1 identified information and support needs of patients at diagnosis and throughout the disease trajectory; Theme 2 identified barriers to accessing health care; Theme 3 identified recommendations that would improve patient experiences in seeking health care at diagnosis and throughout the disease course.

Conclusions: Our focus group analyses identified three main themes related to challenges to optimal rheumatology care from the patient perspective. These included information and support needs, barriers to accessing health care, and recommendations that would improve patient experiences in seeking health care.