Conclusion: Compared with RA without ILD, HRQL of patients with RA-ILD was significantly impaired. Disease activity, fatigue, depression and rural residence were independent predictors of HRQL in Chinese RA-ILD.

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AB1331-HPR ACTIVE DISEASE ACTIVITY IN ANKYLOSIS SPONDYLITIS: WORSE OUTCOMES AND POORER HR-QOL

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Background: Ankylosing spondylitis (AS) is a chronic inflammatory disease that mainly affects the sacroiliac joints and the spine, resulting in decline in quality of life[1,2]. Poor QoL is significantly related to high disease activity[3]. However, there is no systematic report on which prognosis indicators are affected by disease activity in AS patients.

Objectives: This study aimed to evaluate the patient-reported outcome measures and health-related quality of life (HR-QoL) in AS patients defined on the basis of the Bath Spondylitis Ankylosing Disease Activity Index (BASDAI).

Methods: 204 AS patients were involved in this study. A series of questionnaires were used to overall assess AS patients, which include: Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), Bath Ankylosing Spondylitis Metrology Index (BASMI), Bath Ankylosing Spondylitis Functional Index (BASFI), the 10cm Visual Analog Scale (VAS), the Self-Rating Anxiety Scale (SAS), the Self-Rating Depression Scale (SDS), the Pittsburgh Sleep Quality Index (PSQI), the Health Assessment Questionnaire-Disability Index (HAQ-DI), the Fatigue Severity Scale(FSS) and the Short Form 36 Health Survey (SF-36). Independent samples t-test, Mann-Whitney U-test, Chi-square analysis and Pearson /Spearman correlation were used to analyze the data.

Results: The results demonstrated 31.4% AS patients were in active disease activity stage. Active AS patients were older, unemployed, and had less exercise therapy than stable AS patients. Besides, AS patients with active disease activity presented more severe pain($P<0.001$), poor physical function($P<0.001$) and spinal mobility($P<0.001$). They were more anxious($P<0.001$), depressed($P<0.001$) and had more sleep disturbance($P=0.001$). Compared with active AS patients, stable AS patients had more leukocytes($P=0.040$), lymphocytes($P=0.002$), erythrocytes($P=0.001$) and hemoglobin($P<0.001$). Active disease activity had a significant impact on all dimensions of quality of life in AS patients($P<0.001$).

Conclusion: These findings suggested that medical personnel should pay more attention to active AS patients and make effective interventions to improve quality of life.

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AB1332-HPR ASSESSING THE PATIENT EXPERIENCE OF LUPUS NEPHRITIS: DEVELOPMENT OF A CONCEPTUAL MODEL AND REVIEW OF EXISTING PATIENT-REPORTED OUTCOME (PRO) MEASURES

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Background: Lupus nephritis (LN) is an autoimmune disease characterized by inflammation of the kidneys as a result of systemic lupus erythematosus (SLE). Approximately 50% of SLE patients will develop LN, which is considered to be one of the most severe manifestations of SLE and the leading cause of morbidity and mortality in SLE. While there is ample existing evidence on disease experience and PROs used in extra-renal SLE, little research has been done in LN. Qualitative interviews with patients can help identify concepts that are both important and relevant to the patient. In order to effectively evaluate treatment benefit, it is critical that PRO measures used to assess such concepts and define clinical trial endpoints are fit for purpose and have strong evidence of content validity in the specific context of use.

Objectives: The objective of this study was to understand the patient experience of LN and to identify and characterize the signs and symptoms of LN and their impact on health-related quality of life (HRQoL) through the development of a disease-specific conceptual model. This model was then used to evaluate the content validity of existing PRO measures available for use in LN.

Methods: A structured literature search was conducted in Medline, Embase and PsycINFO to identify qualitative research articles documenting the patient experience of LN. PRO measures developed or commonly used to assess patient experiences of LN were also identified. Semi-structured concept elicitation interviews were conducted with 15 adult patients in the US with a clinician-confirmed diagnosis of LN (defined in accordance with established clinical guidelines). Supplementary qualitative data were also collected from a review of publicly available online blogs/forums. Findings were used to inform the development of a conceptual model detailing the impact of LN signs, symptoms and HRQoL and evaluate the validity of existing measures used within LN.

Results: Searches revealed a paucity of qualitative research conducted with LN patients, supporting the need for prospective research in LN. Consistent with existing literature in SLE, the core signs and symptoms identified from the qualitative literature review, interviews and blog/forum review included joint pain, fatigue, joint stiffness, swelling (particularly in the extremities) and skin rashes. LN patients also reported urinary frequency, urgency, foamy urine and blood in their urine. Disease impact on physical functioning, activities of daily living, emotions, social life, work/finances and sleep were reported. PRO measures commonly used to evaluate patient experiences in LN included the SF-36, LupusQOL, LupusPRO, SLE Symptom Checklist, KDQoL and KSQ. Conceptual mapping of instruments against the newly developed conceptual model (Figure 1) highlighted that no single measure provides a comprehensive assessment of all symptoms/impact important to LN patients. Furthermore, items are largely focused on impact of symptoms with few items on symptom severity.

Figure 1. Conceptual model of lupus nephritis symptoms and associated impacts

Conclusion: The presentation of signs and symptoms in LN patients appears similar to those reported in extra-renal SLE populations, with the addition of swelling and urinary symptoms. Qualitative research with LN patients guided the development of a comprehensive LN conceptual model outlining the disease experience from the patients' perspective. These insights can be useful to inform PRO measurement strategies for clinical trials in LN.

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