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Adaptation and Validation of Measures to Assess Coping with Fatigue in Scleroderma: Two Scleroderma Patient-centered Intervention Network (SPIN) Cohort Studies.

Fatigue is one of the most significant challenges faced by people with systemic sclerosis (SSc), a rare, chronic autoimmune disease. However, no measures have been validated to assess coping with fatigue in SSc. We first conducted a study to adapt and test the 27-item Coping Strategies Questionnaire Revised (CSQ-R) for fatigue in SSc. Then, we worked with patients to develop a new questionnaire that better reflected their experiences.

Both studies utilize the multinational Scleroderma Patient-centered Intervention Network (SPIN) Cohort (participants from 54 centres in 7 countries). Since the CSQ-R was originally developed for pain, we adapted the items for fatigue, and a panel of people with SSc verified content validity. We then assessed factor structure, differential item functioning (DIF) by English and French language and disease subtype, and internal consistency and test-retest reliability. To develop the new questionnaire, we combined items from the Illness Management Questionnaire (which addresses active coping in chronic fatigue syndrome), the CSQ-R-Fatigue, and items developed based on fatigue management programs for people with autoimmune rheumatic diseases. We conducted 5 nominal group technique sessions with 19 participants to refine item content by having participants identify missing strategies, unclear items, and items to remove. We are currently administering resulting items in the SPIN Cohort and will conduct an exploratory factor analysis to determine items to retain and factor structure and will examine DIF by language and disease subtype.

For the CSQ-R-Fatigue, 863 participants were included. The 6-factor structure of the questionnaire was replicated, and the questionnaire was reliable, but we found substantive DIF for language and disease subtype. We also received feedback that this questionnaire missed important active coping strategies. The new questionnaire includes 40 items resulting in 9 hypothesized factors. Items are being administered to SPIN Cohort participants with results pending.

The CSQ-R-Fatigue may not be appropriate to assess coping with fatigue in SSc due to possible biases related to language and disease severity and its exclusive focus on psychological coping and non-inclusion of active coping strategies, such as planning, taking breaks, and prioritizing tasks. The new coping questionnaire, once validated, will provide a more comprehensive measure to fully assess coping with fatigue and will be used to evaluate different coping strategies and their associations to outcomes in SSc in order to improve fatigue management.