THE PSS-QOL: DEVELOPMENT AND FIRST PSYCHOMETRIC TESTING OF A NEW PATIENT-REPORTED OUTCOME MEASURE FOR PSS PATIENTS

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Background: Patients with primary Sjögren Syndrome (PSS) are affected by glandular and extraglandular manifestations leading to physical and psychological impairment. To what extent these factors affect the health related quality of life (HRQL) of these patients is largely unexplored. Disease activity scores for PSS have been developed but there is no disease-specific HRQL questionnaire available so far.

Objectives: To develop a questionnaire for the assessment of HRQL in PSS.

Methods: In a previous qualitative study, concepts related to HRQL in PSS were identified by focus-group interviews with PSS patients. Based on these concepts, a questionnaire (PSS-QoL) was developed focusing on two main topics: physical (pain and dryness) and psychosocial dimension. The first draft of this questionnaire was evaluated by semi-structured interviews with PSS patients (n=6) and rheumatologists (n=4). Based on their feedback, a revised questionnaire was constructed and re-evaluated by the patients and physicians. Subsequently, psychometric testing of PSS-QoL was performed in 75 PSS patients of the outpatient clinic of the Medical University Graz. For testing of internal consistency Crohnbach’s α was used. Convergent construct validity was tested by correlating the scores with the ESSPRI and the EQ-5D. Reliability was examined by asking patients who considered themselves to be in a stable disease to complete the questionnaire 1-2 weeks apart. In addition, an English version of PSS-QoL was was developed using a standard methodology for translation.

Results: Out of the 75 PSS patients, 91% were female, disease duration was 4.8±4.08 years and age of patients was 58.5±12.5 years. The internal consistency of the PSS-QoL showed a Crohnbach’s α of 0.892 and we found a moderate correlation of the PSS-QoL with the ESSPRI (Corr coeff =0.625) and the EQ-5D (EQ5D-pain/discomfort; corr coeff =0.531). A second assessment was performed after 1-2 weeks in 21 patients with stable disease. The ICC for PSS-QoL was 0.958 (95% CI 0.926 to 0.981). In comparison, the ICC for EQ-5D in this population was 0.854 (95% CI 0.735 to 0.933). Subsequently, the final German version of PSS-QoL was translated forward and back into English by native speakers.

Conclusions: A questionnaire to assess the HRQL in PSS patients has been developed and tested for its psychometric properties. The PSS-QoL should allow for a better and more comprehensive assessment on patients' HRQL in PSS. Multicentre studies for further validation are needed.

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