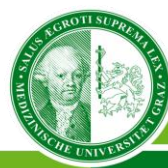


# PAIN, DRYNESS AND THEIR RESULTING COMPLAINTS AFFECT THE HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH PRIMARY SJÖGREN'S SYNDROME- A QUALITATIVE STUDY



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## PURPOSE

This qualitative study was conducted to explore perspectives and needs of patients with PSS influencing health related quality of life (HRQL).

## METHODS

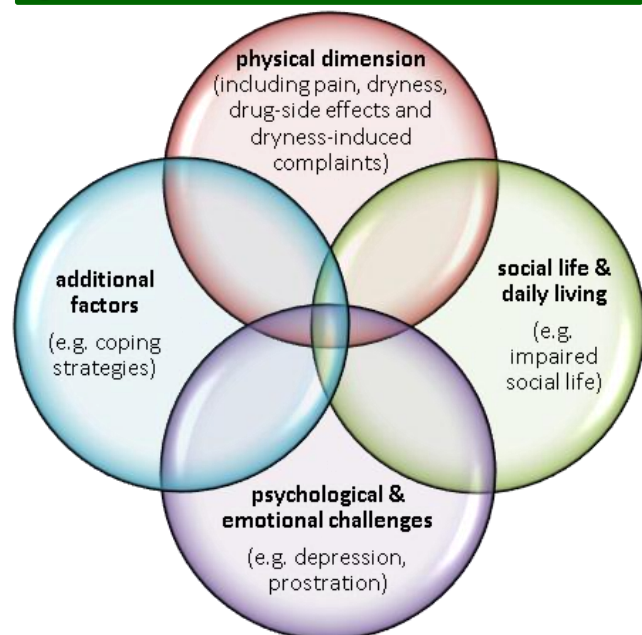
We recruited 20 PSS patients fulfilling the American-European consensus classification criteria out of the PSS cohort of the Medical University Graz, Austria. A total of 6 focus group sessions were performed. A discussion guide with four open-ended questions was developed based on a literature review. The questions contained the components of the definition of HRQoL (physical, mental, social, daily life). All interviews were audio-recorded and transcribed verbatim. A modified meaning condensation procedure was used to analyse the data.

## RESULTS

All patients were female, the mean age ( $\pm$  SD) was  $61 \pm 8$  years. Disease duration average was  $5 \pm 2$  years. The average duration of the focus group sessions was  $58 \pm 13$  minutes. The meaning condensation procedure resulted in 484 meaning units, 254 subconcepts and 82 concepts. The concepts could be summarized into four main dimensions: physical dimension, psychological & emotional challenges, social life & daily living and additional factors. As shown in figure 1, the four dimensions had an impact among each other.

Most concepts were found in the physical dimension which consisted of 4 concepts: pain, dryness, drug side effects and additional physical complaints. "Dryness" was further subdivided into different groups according to conditions resulting from dryness like e.g. burning of the skin, loss of sense of taste and smell, weight loss because of impossibility to eat and chew food, as well as the impossibility to cry. Crying was an important concept related to psychological and emotional challenges, as well. Among "additional physical complaints", stomach pain, obstipation and fatigue were most frequently mentioned. Social life and daily living contained aspects like dependency on relatives, impaired social contacts and household activities. The additional factors contained concepts like coping strategies and additives for daily life.

Figure 1: The four main dimensions



## DISCUSSION

PSS patients suffered most from consequences of dryness such as burning, loss of the sense of taste and smell, as well as the impossibility to cry. These factors should be included in patient related outcome measures that are being developed for trials and clinical practice.