

THE GERMAN PBC* REGISTRY (GPR) ANALYSIS OF COMPLEXITY OF SYMPTOMS

*PBC = primary biliary cholangitis

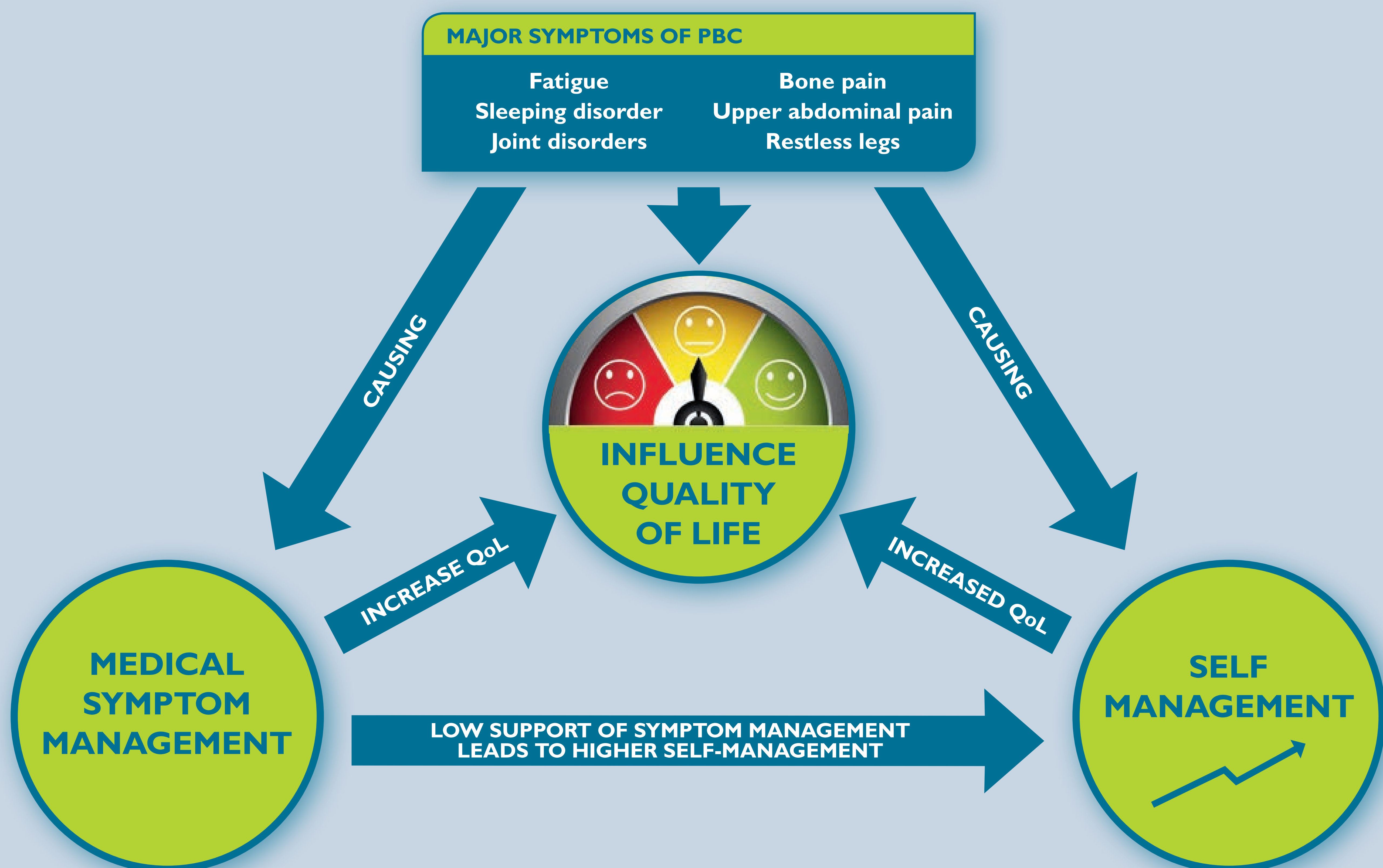
BACKGROUND & AIMS

Patients with PBC suffer from a complex and multifactorial symptomatology. Some symptoms are induced by PBC, others by comorbidities. Symptomatic patients have an inferior quality of life and employ self-management.



METHODS

A registry was established by the Leberhilfe Projekt gUG to collect symptoms and their cause. For this purpose, a questionnaire containing 89 questions was designed and validated. Affected patients completed the questionnaire online. The patients were contacted by means of a homepage and social media. The collected data were analysed descriptively and correlation analyses were performed.



RESULTS

Data of 629 PBC patients were available for this analysis. The median age was 52 years with a range from 20 to 82 years. The median disease duration was 4 years (range 0 to 37 years). The majority of participants (93%) were female.

92% of patients reported on symptoms of the disease and most of them resorted to self-management. The need for self-management increased with the severity of symptoms. The quality of life was strongly impacted by several symptoms such as fatigue and pruritus but

similar effects were observed for less well established items such as personal diet and sleep. For example, 91% of patients who were unable to eat everything as desired during the last 4 weeks preceding the completion of the questionnaire considered their quality of life as impaired by PBC, as opposed to only 60% of patients who observed no impairment of their personal diet. Of those patients who were unable to eat as desired, 59% reported a worsening in quality of life during the last 12 months, in contrast to only 31% of patients who did not need to change their diet. 79% of

patients who were unable to sleep through the night reported that PBC impaired their quality of life, in comparison to 67% of patients without sleep disturbance. The quality of life in the last 12 months was considered as having decreased by 49% of patients who were unable to sleep through the night, but only by 32% of patients without sleep disturbance. PBC patients challenge to relieve their symptoms by various methods of self-management. Among the patients who were not able to eat as desired, 73% used self-management to cope with fatigue, in contrast to 57% who were able to

eat everything. A similar, but weaker effect was found in relation to sleep: 64% of the patients who were unable to sleep through the night used self-management for fatigue, in contrast to 58% of patients without sleep disturbance.

In a currently undertaken workshop series (participants=200) it became apparent that patients depend on strategies of self-management. Most patients reported that they are offered insufficient medical symptom management.

CONCLUSION

The GPR results illustrate the complexity of symptoms of PBC patients. In addition to the most frequent symptoms of pruritus and fatigue, also cognitive impairment and joint dis-

orders play an important role for the perceived measure of the Quality of Life (QoL). Insufficient medical symptom management caused self-management, in particular if the domains

of diet and sleep were affected. Therefore it is important, that these patients are offered a better symptom management and on the other hand – following the EASL PBC guideline –

that patients are connected to support groups to exchange experiences with other patients. A recent study from UK shows that this has a positive impact on the patients' QoL^[1].