

Quality of life in patients with autoimmune and cholestatic liver diseases: ongoing agenda in ERN RARE-LIVER NETWORK

M.K.Janik¹, E.Wunsch¹, T.Gevers², J. Willemse², M.Krawczyk^{1,3}, D.Thorburn⁴, Ch.Schramm³, A. Lohse³, P.Milkiewicz*¹
on behalf of the ERN RARE LIVER, 1 - Poland, 2 - The Netherlands, 3 - Germany, 4 - United Kingdom

BACKGROUND

Issues related to Health-Related Quality of Life (HRQoL) have emerged as a critically important in the management of patients with rare liver conditions. This area has been largely neglected over the years, despite being of central importance to affected patients. Only recently have we become more aware of its relevance in the context of nonadherence to therapy, thus impacting on prognosis.

AIM

To approach the issue of HRQoL in a systematic way as a coordinated effort within ERN-RARE LIVER Network

1 HRQoL TASK FORCE

The first step was the creation of a dedicated HRQoL Task Force. A group started from an on-line survey amongst members of our Network focusing on their perception of HRQoL.

Up to 80% of 40 clinicians from 16 European countries appreciate the importance of an assessment of HRQoL.

However, clinicians measure HRQoL mostly in the context of clinical studies. As HRQoL questionnaires are generally perceived as time consuming, the majority of respondents highlighted the need for dedicated personnel, such as research nurses. There was also wide variability and no general consensus in terms of questionnaires used.

These findings have led us to design two projects in patients with autoimmune and cholestatic disease.

2 THE ON-LINE SURVEY

Constructed with an involvement of psychosomatic medicine experts and patient representatives. It contains 42 questions, some derived from well validated HRQoL questionnaires. The survey also contains a section dedicated to compliance. So far (by the 18th of April 2020) around 700 patients took part and the study is ongoing
The survey: <https://ec.europa.eu/eusurvey/runner/rareliver>

3 THE MULTICENTRE, CROSS-SECTIONAL STUDY

This project focuses more specifically on HRQoL in patients with autoimmune hepatitis (AIH). Carefully selected questionnaires, which included not only generic HRQoL ones, but also tests measuring anxiety, depression, fatigue, as well as patient's adherence, will be provided to patients during their routine appointment in the clinic.

The results were to be presented during The ECRD, however the coronavirus pandemic caused significant disruption in conduction of these project.

CORRESPONDING AUTHOR

p.milkiewicz@wp.pl