

ADRENAL GLAND

Health-related quality-of-life questionnaires for patients with Addison disease

Disease-specific questionnaires have proven a useful tool to evaluate the effects of interventions on health-related quality of life in clinical trials. "Previous cross-sectional studies using general questionnaires reproducibly indicated deficiencies in health-related quality of life in patients with Addison disease," say investigators Kristian Løvås from Haukeland University Hospital, Bergen, Norway and Krishna Chatterjee from the University of Cambridge, UK. "The aim was to develop a questionnaire that addresses health-related quality-of-life issues that are particularly relevant for patients with Addison disease and to select items that were likely to be sensitive to treatment effects."

The investigators first performed a search of the available literature, along with interviews of patients with Addison disease and their partners, to identify health-related quality-of-life issues particularly relevant for these patients. Second, a list of 70 items was

generated that covered these issues with both positive and negative phrasings. A group of experts assessed each item for frequency, importance and clarity of expression. This evaluation reduced the number of items to 60. Third, the list was presented to, and scored by, 100 patients with Addison disease. On the basis of statistical analysis and clinical considerations, the number of items was further reduced to 36. The final 36-item questionnaire was presented to the same 100 patients and their responses analyzed to determine the internal consistency of the questionnaire.

The literature search and interviews clearly indicated that fatigue is a central health-related quality-of-life issue in patients with Addison disease and that coping with emotional stress can be particularly challenging.

The questionnaire has been translated into several European languages, and further validation studies are ongoing. These studies will attempt to determine



whether the questionnaire yields similar results in different countries.

The ultimate aim will be to evaluate effects on health-related quality of life of new treatments in Addison disease with high precision, in order to establish which interventions do or do not work.

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