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Assessment of written patient information pertaining to cirrhosis and its complications: A pilot study

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Background and aims: Written patient information may play an important role in the patient compliance of the cirrhosis disease but little is known on the quality and patients understanding of them. The aim of this pilot study was to assess the quality of written patient information pertaining to cirrhosis and its complications, and to explore patients' understanding of the written information.
Method: A web-based search was performed to retrieve written patient information from different Danish Gastroenterology and Hepatology departments. Baker Able Leaflet Design (BALD) criteria´s and Ensuring Quality Information for Patients (EPIQ) questionnaire was applied to assess design, layout characteristics, and information quality of the written information. Readability was calculated using the Læsbarhedsindex (LIX) and the Simple Measure of Gobbledygook (SMOG). In addition, a cross-sectional study with a mixed-method design was carried out among eleven outpatients with cirrhosis at the Department of Hepatology and Gastroenterology, Aarhus University Hospital, Denmark, using a questionnaire consisting of 28 closed and open questions regarding written patient information. Descriptive statistics were used for assessing the quality of the written information and for the closed-ended responses. Data from the open-ended responses were analysed in accordance with Kvale and Brinkmanns meaning condensation
Results: The mean BALD score was 24 and the mean EQIP score was 70%. The mean LIX score was 46 and the mean SMOG score 15.8. Fifty percent of the patients stated that they had received written patient information, but only one patient was able to recall advices and/or instructions from the written information. Sixteen identical phrases from the written information were selected to explore patients' understanding. Four phrases were understood by 100% of the patients, six phrases by more than 50% of the patients, and six phrases were understood by less than 50% of the patients. The meaning condensation showed that knowledge and understanding of cirrhosis and its complications were not enhanced by the availability of the written information.
Conclusion: The written patient information had good design, layout, and information quality but was difficult to read. Patients appeared to relate poorly to the written information and demonstrated limited health literacy. These results suggest awareness among healthcare professionals in the importance of matching written patient information and patients' level of health literacy in order to ensure effective patient understanding and thereby disease compliance. Further studies on intervention to improve patients' health literacy are recommended.