

Nursing Education 2016: Validity and Reliability of the Turkish Version of the Liver Disease Quality of Life (LDQOL 1.0) Instrument- Belgin Sarper Can- University Faculty of Nursing

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Chronic liver disease and cirrhosis caused by excessive alcohol consumption, viral hepatitis, or non-alcoholic fatty liver most of which are preventable lead to morbidity and mortality. The prevalence of etiologic causes is closely related to cultural and economic reasons. In Turkey, viral hepatitis is the major cause of chronic liver diseases with a prevalence rate of 50 to 90%. It is followed by alcoholic cirrhosis with a prevalence rate of 10%. According to annual statistics in Turkey, 19,120 patients were treated in hospitals because of cirrhosis. Of them 1,101 died and the others were discharged.

The studies in the literature show that physical, mental, social and economic domains of the quality of life are impaired due to chronic liver disease. There are many factors reducing health related quality of life (HRQOL) such as disease symptoms, disease severity and disease type, complications of liver disease, age, female sex, low socioeconomic status, financial burden, and poor health perception of HRQOL [4-9]. Chronic liver disease with various etiologies differs from asymptomatic chronic hepatitis to decompensated cirrhosis. That is why, symptoms, especially the ones affecting the quality of life, vary. Most patients can remain asymptomatic until decomposition occurs. In the previous studies, patients with decompensated cirrhosis reported poorest HRQOL, which is followed by patients with compensated cirrhosis.

Patients with no sign of cirrhosis are capable of performing the daily activities.

In the past decades, most research on the HRQOL of the chronic liver patients focused on the treatments inducing changes in HRQOL, the variation of HRQOL depending on the disease severity and the comparison of HRQOL between etiologies. However, HRQOL is often defined not only as the impact of disease and/or treatment on a patient's physical, emotional and

social function and well-being, but also as an individual's satisfaction from his/her life experience [6,8]. In addition, many studies investigated the HRQOL of patients with chronic liver disease by means of a generic questionnaire. A generic questionnaire is capable of assessing fatigue, pain, energy level, social activities and physical conditions. However, chronic liver disease has some specific characteristics including ascites, hepatic encephalopathy, edema, pruritus, yellow appearance of the skin etc. For this reason, generic instruments cannot reflect the quality of life of the patients thoroughly. The quality of life instrument with the specific characteristics for the liver disease has been recommended because a specific instrument addresses to a specific disease.

Nursing focuses on a number of areas including health promotion, living with chronic conditions and enhancing quality of life and caring for clients experiencing changes in their health. One way to improve the health is to strengthen the quality assurance systems employed to evaluate nurse-led interventions. In particular, the integration into practice of validated tools to monitor and evaluate

patient-reported outcomes such as the health gain and quality of life benefits of care to patients and their families. However, there is not a validated and reliable instrument to determine the quality of life of the patients with chronic liver disease in Turkey. Therefore, in Turkey, it is unlikely for nurses caring for patients with chronic liver disease to determine the patients' needs and to evaluate the results of nursing activities they apply.

Aim of the Study: The aim of this study was to establish the psychometric properties including validity, reliability and sensitivity of a Turkish version the Liver Disease Quality of Life Instrument 1.0 (LDQOL-1.0) to Turkish patients with chronic liver disease.

Methods: Participated settings

A cross-sectional and methodological design was used in the study. The research was took place at out-patient clinic of Hepatology, Department of Gastroenterology, School of Medicine at Ege University in Izmir. This hospital has 1884 bed capacity. The hospital was serviced 716,594 patients receives out-patient care and 55,592 patients receives in-patient care. The selection criteria of this hospital are to being the biggest hospital in Aegean region. In addition, Gastroenterology department has a hepatology out-patient clinic in this hospital.

The research was administered to 170 patients with chronic liver disease in a hepatology out-patient clinic. Normally there is no agreement on adequacy of sample size but one important feature is the ratio of items to the number of participants and, generally, a ratio of 1:10 is advised . LDQOL 1.0 consisted of 17 main questions related to quality of life of patients with chronic liver disease. The 170 participants met the criteria for an adequate sample.

Inclusion criteria: (1) Voluntary, ambulatory and conscious participants. (2) At least 18 years of age and literate.

Exclusion criteria: (1) Secondary chronic disease could decrease quality of life and affect the results. Therefore, patients who had a secondary chronic disease were not included in the research.

(2) The patients in the class Child A and B were out-patient clinic patients. But the patients in the class Child C were treated in hospital which did not take place in the research. The duration of interviews

was approximately 20-25 min for each patient.

Instruments: A third- part survey was used to collect the data. The survey included:

- Demographic questionnaire and disease information
- The Liver Disease Quality of Life Instrument 1.0
- The Child-Turcotte-Pugh classification

Sociodemographic data form

This form consisted of sociodemographic questions about patients' age, sex, marital status, educational status, disease etiologies.

The Liver Disease Quality of Life Instrument 1.0 (LDQOL 1.0)

The Liver Disease Quality of Life Instrument 1.0 is a comprehensive disease specific instrument. LDQOL 1.0 was developed to measure the effects of chronic liver disease on the quality of life and the daily activities by Gralnek IM et al. The instrument consists of 17 main questions, 12 subscales which include 75 questions were formed. The 12 subscales in the LDQOL 1.0 are: liver disease-related symptoms, liver disease-related effects on activities in daily life, concentration, memory, sexual function, sexual problems, sleep, loneliness, hopelessness, quality of social interaction, health distress, and self- perceived stigma of liver disease. The LDQOL 1.0 is the likert type scale. To ensure balance among questions, scores were calculated for each scale by summing the scores of their component items and converting the sum to a scale ranging from 0 to 100, higher values indicate better HRQOL.