

This is a **Sample** version of the
**Chronic Liver Disease
Questionnaire (CLDQ)**

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- CLDQ Scoring/ Administration instructions
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Assessment (29 sets of question criteria)
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Development of a disease specific questionnaire to measure health related quality of life in patients with chronic liver disease

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Abstract

Background and aims—To develop and assess a disease specific instrument for measuring health related quality of life (HRQL) in patients with chronic liver disease (CLD).

Methods—Based on responses from 60 patients with chronic liver disease, from 20 liver experts, and from a Medline search of the literature, items potentially affecting the HRQL of these patients were identified. A separate sample of 75 patients identified which items they found problematic and rated their importance. Results were explored using factor analysis; domains were chosen and items placed within domains. Redundant questions were eliminated and the final questionnaire was pretested in 10 patients. Using this instrument, HRQL was assessed in a further 133 patients with various types and stages of liver disease.

Results—Patients, experts, and the literature search identified 156 items of potential importance. Of these, 35 proved important to over 50% of 75 respondents in the item reduction sample. The factor analysis suggested six domains. After eliminating redundancies, the Chronic Liver Disease Questionnaire (CLDQ) included 29 items in the following domains: fatigue, activity, emotional function, abdominal symptoms, systemic symptoms, and worry. In pretesting, patients found the CLDQ clear and easy to complete in 10 minutes. In another 133 patients, the CLDQ showed a gradient between patients without cirrhosis, Child's A cirrhosis, and those with Child's B or C cirrhosis. CLDQ has evidence for moderate reliability at six months and seems to be responsive.

Conclusion—The CLDQ is short, easy to administer, produces both a summary score and domain scores, and correlates with the severity of liver disease.

(*Gut* 1999;45:295–300)

Keywords: quality of life; liver disease; liver specific quality of life; well being

The traditional “biomedical model” of health which is based on the basic sciences (molecular biology, genetics, physiology, biochemistry, etc.) is being integrated with the “social science model” of health, based on a psychosocial and economic foundation. This integrated ap-

proach to clinical practice and research in medicine requires not only monitoring the traditional physiological and biochemical outcomes but also health related quality of life (HRQL).^{1–3}

Chronic liver disease (CLD) results from a variety of disorders and is a major cause of morbidity and mortality worldwide. Death from liver disease or its complications is the ninth leading cause of mortality in the United States. About 5 million Americans suffer chronic infection from hepatitis B or C viruses (HBV or HCV) and millions more bear the consequences of other chronic hepatocellular or cholestatic liver disorders.⁴ Patients with chronic liver disease experience a variety of symptoms with profound negative impact on their HRQL. A systematic assessment of determinants of this impairment is currently not available. In a recent study of HCV infected individuals without cirrhosis, impairment in HRQL was not related to the degree of liver inflammation or mode of acquisition.⁵ The biology of chronic liver disease, and our clinical experience with these patients, is such that we would anticipate patients experiencing progressive symptoms and functional limitation with increasing severity of liver disease. Complications of cirrhosis (hepatic encephalopathy, ascites, spontaneous bacterial peritonitis, and recurrent variceal haemorrhages) can have further negative impact on patients' well being. On the other hand, the relation between HRQL impairment and severity of disease is unlikely to be very strong.

Many interventions in patients with CLD are geared primarily to make patients feel better and improve their HRQL. While investigators may choose from a variety of validated generic instruments for measurement of HRQL, these questionnaires may fail to detect small but important improvements in HRQL in patients with CLD. A liver specific instrument is likely to be more responsive to changes in HRQL that, while small, are nevertheless important.^{6–13} Although preliminary data on modular instruments (based mainly on generic instruments) for liver disease are available, a disease specific instrument for patients with CLD is not available. In this article we describe the development of a disease specific HRQL

Abbreviations used in this paper: CLD, chronic liver disease; CLDQ, Chronic Liver Disease Questionnaire; GRC, global rating of change; HBV, hepatitis B virus; HCV, hepatitis C virus; HRQL, health related quality of life; PBC, primary biliary cirrhosis; PSC, primary sclerosing cholangitis.

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THE CHRONIC LIVER DISEASE QUESTIONNAIRE (CLDQ)—QUALITY OF LIFE INDEX

Scoring & Administration

The CLDQ is short, easy to administer, produces both a summary score and domain scores, and correlates with the severity of liver disease.

On average, it takes about 10 minutes to complete the questionnaire.

For a domain specific score, divide each domain score by the number of items in the domain = mean average score. Higher score equates to worse quality of life.

Domains	CLDQ questions per domain
Abdominal symptoms (AB)	1, 5, 17

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THE CHRONIC LIVER DISEASE QUESTIONNAIRE (CLDQ)—QUALITY OF LIFE INDEX

FOR PATIENTS WITH CHRONIC LIVER DISEASE

TODAYS DATE _____ NAME _____ DOB _____

This questionnaire is designed to find out how you have been feeling during the last two weeks. You will be asked about your symptoms related to your liver disease, how you have been affected in doing activities, and how your mood has been.

Please complete all of the questions and select only one response for each question.

1. How much of the time during the last two weeks have you been troubled by a feeling of abdominal bloating?

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 Hardly any of the time
- 7 None of the time

2. How much of the time have you been tired or fatigued during the last two weeks?

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 Hardly any of the time
- 7 None of the time

3. How much of the time during the last two weeks have you experienced bodily pain?

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 Hardly any of the time
- 7 None of the time

**This is the end of the SAMPLE CLDQ questionnaire.
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