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# Assessment of Written Patient Information Pertaining to Cirrhosis and Its Complications: A Pilot Study

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**Abstract**

**Background:** Written patient information may play an important role in the compliance of the cirrhosis disease, but little is known on the quality and patients' understanding of them. **Objectives:** To assess the written patient information leaflet pertaining to cirrhosis and its complications. **Methods:** The Baker Able Leaflet Design (BALD) criteria and the Ensuring Quality Information for Patients (EQIP) questionnaire were applied to assess design, layout characteristics, and information quality. Readability was calculated using the Læsbarhedsindex (LIX) and the Simple Measure of Gobbledygook (SMOG). A cross-sectional study with a mixed methods design was carried out, using a questionnaire consisting of closed- and open-ended questions. **Results:** The BALD score was 24 and the EQIP score 70%. The LIX score was 46 and the SMOG score 15.8. Sixteen phrases from the leaflet were selected to explore patients' understanding. Four phrases were understood by 100% of the patients, 6 phrases by more than 50% of the patients, and 6 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 leaflet. **Conclusion:** The leaflet had a good design, layout, and information quality but was difficult to read. Patients appeared to relate poorly to the leaflet and demonstrated limited health literacy. These results suggest that an assessment of written patient information ought to be made in an effort to improve readability. Further studies on intervention to improve patients' health literacy are recommended.

**Keywords**

BALD, cirrhosis, EQIP, health literacy, LIX, patient information leaflet, readability, SMOG

## Introduction

Cirrhosis is the final pathway for several chronic liver diseases and is an advanced stage of liver fibrosis. It results in portal hypertension and hepatic dysfunction which may cause severe complications that contribute to increased mortality (1). The leading causes of cirrhosis are alcoholic liver disease, viral hepatitis B and C, and nonalcoholic fatty liver disease (2,3). The management of cirrhosis partly depends on the underlying etiology, but the goal is prevention and treatment of complications of cirrhosis to stabilize progression and to avoid or delay clinical decompensation (1,2). This requires patients to be compliant to the management of the cirrhosis disease. However, many patients consider cirrhosis management as challenging due to difficulties with life-style restrictions, medical adherence, and nutritional prescription (4). This is further compounded by the nature of cirrhosis because the management becomes more complex as the disease progresses. To help patients stay compliant, written patient information on cirrhosis and its complications has been developed by many gastroenterology and hepatology departments including ours (5). Unfortunately, the quality of the written patient information is rarely assessed, and studies have indicated that patients may have difficulties understanding the information (6). This is not a trivial problem as studies have shown that patients with limited health literacy are more likely to experience increased

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hospitalization, poor health status, and poor management of chronic diseases (7,8), such as cirrhosis. This may play a significant role as it may prevent patients from making healthful choices and staying compliant.

Therefore, the aim of this study was to assess the quality of the written patient information leaflet pertaining to cirrhosis and its complications and to explore the patients' understanding of the leaflet.

## Methods

The quality of the leaflet was assessed using different validated criteria and readability indexes. To explore patients' understanding of the leaflet, a cross-sectional questionnaire-based pilot study with an embedded mixed methods design was conducted. This design enabled the collection and analysis of both qualitative and quantitative data within, in this case, a quantitative design (9).

### *Quality Assessment of the Leaflet*

The leaflet, which underwent assessment, consisted of 2 pages of patient information on cirrhosis and advices and/or instructions on how to observe and prevent disease complications, such as ascites, hepatic encephalopathy, undernutrition, and varices (5). It was developed in 2009 by a clinical nurse specialist and nurses from the Department of Hepatology and Gastroenterology, Aarhus University Hospital and revised in 2015. It is handed out to patients with cirrhosis during hospitalization or in the outpatient clinic.

The design and layout characteristics of the patient information leaflet were assessed using the Baker Able Leaflet Design (BALD) criteria. Baker Able Leaflet Design is validated and consists of 16 criteria used to rate the design and layout on a rating scale with a total maximum score of 32 (10). The validated 20-item Ensuring Quality Information for Patients (EQIP) questionnaire was used to assess the quality of the leaflet according to published quality criteria (11). Scoring of EQIP was done by means of the formula specified in Table 1.

The readability of the leaflet was calculated using 2 readability indexes: The "Læsbarhedsindex" (LIX) and the Simple Measure of Gobbledygook (SMOG) (12,13). Læsbarhedsindex is validated for assessment of the readability of written information in Danish, which is the language of the leaflet while SMOG is recommended for use in healthcare information (14). Table 1 describes the formulas for the readability index used. Before calculating the readability, dashes, headings, and images were deleted from the leaflet, and all magnitudes, unit symbols, and numbers were spelled out. The LIX has 5 ranges that relate to the obtained score: very easy (24<), easy (25–34), standard (35-44), difficult (45-54), and very difficult (55>), while the obtained SMOG score indicates the education grade level, that is, number of years of education needed to understand the leaflet (12,13).

**Table 1.** Quality Assessment of the Leaflet.

| | Leaflet pertaining to cirrhosis and its complications[a,b,c] |
|---|---|
| Design and layout | |
| Baker Able Leaflet Design (BALD) score | 24 |
| Ensuring Quality Information for Patients (EQIP) score | 70% |
| Readability | |
| "Læsbarhedsindex" (LIX) score | 46 |
| Simple Measure of Gobbledygook (SMOG) score | 15.8 |

[a]Calculation of EQIP: ((Yes × 1) + (Partly × 0.5) + (No × 0)/20 − Not applicable) × 100
[b]Calculation of LIX: Number of words/number of periods + (number of long words [more than 6 letters] × 100)/number of words
[c]Calculation of SMOG: $1.0430\sqrt{\text{number of polysyllables} \times 30/\text{number of sentences}} + 3.1291$

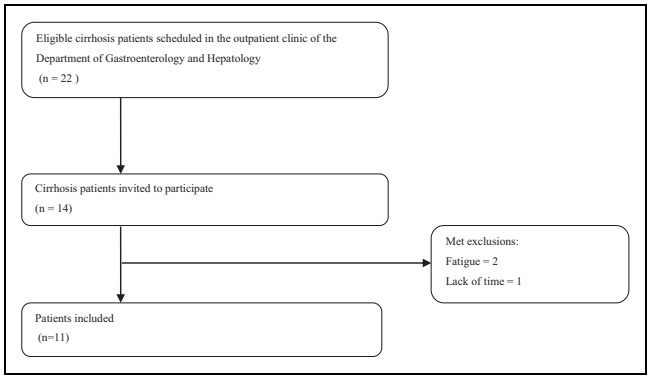


**Figure 1.** Patient flowchart.

### *Participating Patients*

The participating patients were consecutively recruited from the Department of Hepatology and Gastroenterology at Aarhus University Hospital. Inclusion criteria included adult (+18 years) patients with an established diagnosis of cirrhosis. Furthermore, the patients needed to be native Danish speakers. The diagnosis of cirrhosis was ascertained by specialized hepatologists. Exclusion criteria were dementia or other cognitive impairment. The inclusion period was 2 weeks during spring of 2017. Twenty-three patients were assessed for eligibility and 14 patients were invited to participate. Eleven patients accepted, while 2 declined due to fatigue and one due to lack of time. The patient flowchart is illustrated in Figure 1.

### *Instrument Development*

A questionnaire was developed based upon a review of relevant research literature (15). Some questions regarding the patients' understanding of the leaflet were relying on previously validated questionnaires with modifications (16,17),

while other questions were composed by the authors. The questionnaire consisted of 28 questions that were divided into 3 parts: (a) background (age, gender), (b) general questions regarding the leaflet (received, read, and compliance with the advice and/or instructions), and (c) questions regarding the understanding of the leaflet (understanding of phrases).

The response format to the closed-ended questions consisted of a rating scale, and the patients were instructed to choose only one response. The third part of the questionnaire was supplemented with open-ended questions. If the patients indicated that they understood the given phrases, they were asked to explain them verbally to ensure that their understanding was correct. In addition, the patients were encouraged to share their experience with the written patient information leaflet in order to get a deeper understanding of their perception. Examples of interview questions were "How did the leaflet help you to understand your disease?" "After reading the leaflet, what new knowledge have you reviewed?" "Have you sought other sources of information to better manage you disease?" and "How do you prefer getting information on you disease?" Responses from the open-ended questions were taped and transcribed verbatim by 2 of the authors (K.B. and R.S.). The transcription resulted in 22 pages in total.

Information on marital status, occupational status, present alcohol use, cirrhosis etiology, cirrhosis severity, present or past episodes of cirrhosis-related complications, and comorbidities was collected from the patients' medical charts.

### *Data Collection*

The questionnaires were distributed when patients had appointments at the outpatient clinic. Before completion of the questionnaire, the patients were informed about the aim of the study. The completion of the questionnaire took at least 30 minutes and was performed in a secluded room together with one author (K.B. or R.S.) who had no previous relationship with the patients.

### *Testing of the Questionnaire*

In order to eliminate misunderstandings in the questionnaire and to ensure that important details would not be missed, the questionnaire was tested by means of 3 patients who were randomly selected. In addition, the questionnaire was assessed by 2 clinical nurse specialists with experience in questionnaire development. The testing participants found the language and questions to be understandable. One minor correction was made to the questionnaire. Data from the testing were not included in the final results.

## Data Analysis

Descriptive statistics were used to assess the quality of the leaflet and for the closed-ended responses in the questionnaire. Data were expressed as numbers and percentages, and the statistical analyses were performed by the computer software program, Microsoft Office Excel 2010.

**Table 2.** The 5 Steps in the Analytical Process. (13)

| Step | Description |
|---|---|
| 1 | Reading the transcribed text in order to achieve an overall understanding |
| 2 | Breaking the text into meaning units, as expressed in the participating patients' own words |
| 3 | Searching for essential aspects of the phenomenon and categorizing the essential themes from the participating patients' point of view |
| 4 | Investigating the meaning units in the light of the study aim |
| 5 | Condensing the transformed meaning units into descriptive statements |

Data from the open-ended responses were analyzed according to the meaning condensation, in accordance with Kvale and Brinkmann (18). The meaning condensation involves a systematic process of reducing the transcribed text into shorter formulations (18). The analysis contains of 5 steps and is described in Table 2. The analysis was performed by one of the authors (L.L.G.), who is experienced within the field of qualitative analysis and method. Thereafter, the formulations and analysis were checked and discussed by all authors to ensure consistency.

## Ethical Considerations

All participating patients were given oral and written information regarding the aim of the study and its voluntary nature. The Central Denmark Region Committees on Health Research Ethics were informed about the study. The study was performed according to the Declaration of Helsinki.

## Results

### *Assessment of the Quality*

The BALD score of the leaflet was 24, which indicated good design and layout. The quality information score from the EQIP questionnaire was 70%. The LIX score was calculated at 46 and the SMOG score at 15.8, both indicating a high readability level and an education on college or university level to understand the information, that is, the leaflet was difficult to read.

### *Demographics*

The majority of the participating patients were men (64%), and the mean age was 61 years, ranging from 41 to 70 years. Around half of the patients lived alone and was retired. The mean number of year of school completed was 11 years. All of the patients had cirrhosis due to alcohol, and over half of the patients had experienced cirrhosis-related complication.

**Table 3.** Demographic and Clinical Characteristics of Patients.

| Variable | Patients (n = 11) |
|---|---|
| Clinical features | |
| Age (mean and range, years) | 61 (41-70) |
| Men | 64% |
| Marital status | |
| Single/divorced/widower | 55% |
| Married/cohabiting | 45% |
| Occupational status | |
| Disability pensioner | 27% |
| Retired | 45% |
| Unemployed | 28% |
| Education (mean and range, years attending school) | 11 (7-14) |
| Present alcohol use | |
| Yes | 36% |
| Etiology of cirrhosis | |
| Alcoholic | 100% |
| Severity of cirrhosis | |
| Child Pugh score (mean and range) | 7 (5-11) |
| Model for End-Stage Liver Disease (MELD) (mean and range) | 10 (7-19) |
| Present or past episodes of cirrhosis-related complications | |
| Yes | 64% |
| Comorbidities (measured by the Charlson comorbidity index) | |
| 3+ | 4% |
| 2 | 13% |
| 1 | 24% |
| 0 | 59% |

Their clinical and demographic characteristics are presented in Table 3.

## General Questions Regarding the Leaflet

Fifty-five percent of the patients stated that they had received the leaflet, while 27% could not recall if they had received it. Eighteen percent reported that they never had received the leaflet.

Fifty percent of the patients who had received the leaflet had read it, and all reported that they had followed the advice and/or instructions from the leaflet. However, only 1 patient was able to recall the specific advice and/or instructions.

## Questions Regarding the Understanding of the Leaflet

Sixteen phrases from the leaflet were selected in order to explore patients' understanding (Table 4). All patients stated that they understood several of the phrases. However, 10% of the "understood" answers had to be changed to "not understood" when the patients had to verbally explain the meaning of the phrases. The result was that 4 of the phrases were understood by all the patients, 1 phrase was understood by 91%, while another 5 phrases were understood by more than 50%. Six phrases were understood by 18% to 45% of the patients (Table 4).

**Table 4.** Understanding of the Phrases From the Leaflet.

| | Phrases | Understood |
|---|---|---|
| 1. | Weigh yourself daily | 100% |
| 2. | Be aware of increased abdominal size and weight gain | 64% |
| 3. | Call 112 in case of bloody vomiting | 100% |
| 4. | You should have 2-3 bowel movements daily | 100% |
| 5. | In cirrhosis, the brain function may be impaired because of toxins in the blood | 45% |
| 6. | Cirrhosis—prevention of complications at home | 18% |
| 7. | Often lactulose is used to reduce the absorption of toxins from the gut | 55% |
| 8. | Dehydration occurs when you get too little fluid | 100% |
| 9. | You can prevent infections by having good hygiene | 91% |
| 10. | Avoid sleep medicine, because the medicine can harm the liver and cause brain dysfunction | 27% |
| 11. | Cirrhosis is characterized by the replacement of normal liver tissue by scar tissue which makes it lumpy and stiff | 18% |
| 12. | Esophageal varices | 55% |
| 13. | Fluid in the belly (ascites) | 64% |
| 14. | Brain dysfunction caused by cirrhosis (hepatic encephalopathy) | 36% |
| 15. | The protein requirement in cirrhosis patients is almost twice as high as in healthy people | 55% |
| 16. | Department of Hepatology and Gastroenterology. Contact with questions regarding disease/medicine, change of appointment, need for ascites drainage | 36% |

## Open-Ended Responses

The meaning condensation showed that patients had difficulties understanding cirrhosis and its complications. Nine patients revealed a low level of insight and understanding into the pathophysiology and management of cirrhosis and its complications.

> I know I got cirrhosis due to alcohol. But I can't explain why I have these complications, because I just don't understand it.

Moreover, even when written patient information was available to the patients, they could be quite passive, not really relating to the available information.

> I receive so much information all the time which is why I did not read the leaflet.

Even patients who had read the leaflet had trouble translating the knowledge into action.

> I have read the leaflet and all its advice and instructions, but I still think it is difficult to manage it all. It is like the leaflet is not written for me. Some of the complications I have never heard about. Others I am struggling with by myself.

None of the patients indicated that they had actively sought other sources of information. Likewise, they did not express any desire or ideas to be informed in a different way.

However, 8 of the patients did state that it was important to them that health-care professionals were able to explain about cirrhosis and how to manage them in a way that the patient could understand and relate to.

> For example, this doctor, he drew a liver on a piece of paper and told me about the normal liver functions, cirrhosis, and complications of cirrhosis. It made it much easier for me to understand. Now I see this picture for me every time I talk about cirrhosis.

## Discussion

This study assessed the quality of a written patient information leaflet pertaining to cirrhosis and its complications and explored the patients' understanding of the leaflet. The study found that the leaflet was difficult to read, and patients appeared to relate poorly to the leaflet and demonstrated limited health literacy. These results provide new valuable insight into how patient with cirrhosis may be supported to make healthful choices regarding their disease and stay compliant.

There are no commonly accepted scales for assessing the quality of written patient information. In this study, the quality of the leaflet was assessed by means of BALD and EQIP, which are both frequently used and validated for assessment of written patient information (10,11). The leaflet had a BALD score of 24. According to the criteria, a leaflet scoring between 20 and 25 is considered as having good layout and design characteristics. The EQIP score was 70% which likewise indicates that the leaflet met a majority of the quality criteria. However, the leaflet failed to include pictures or pictograms which along with the written advice and/or instructions may enhance patients' understanding (10,11,19).

The readability was assessed using the LIX and the SMOG indexes (12,13). Both indexes revealed that the leaflet was difficult to read and required a higher education grade level than the recommended sixth to seventh grade level (20). The score may be due to the fact that the leaflet is developed by highly educated health-care professionals and that the information given on the cirrhosis disease and its complications is complex. This study encourages authors of written patient information to pay more attention to the readability of the information they produce. However, the use of readability indexes in the development of written patient information is sometimes criticized, claiming that improving readability by simplifying text may make it difficult to convey accurate information and that studies have shown that improving reading ease failed to improve patients' comprehension of health information (21).

This study showed that only 50% of the patients had read the leaflet. This is surprising, but in accordance with other studies, although it has been shown that leaflets have the potential to influence patients to make healthful choices and stay compliant (22,23).

In this study, patients who had read the leaflet reported that they had followed the advice and/or instructions from the leaflet, but they had difficulties recalling the information. This is consistent with other studies that indicate that patients recall less than 50% of what they read or are told by health-care professionals (24). Several studies have investigated interventions, such as audio recordings, cognitive approaches, and visual aids in order to improve the memory of patients. However, the effects of these methods are still not fully understood (25). In addition, a study found that the benefit of receiving patient information by use of leaflets is highly depending on the patients' motivation and that it is unlikely to be sufficient for patients with cirrhosis (26). Thus, the handing out of leaflets should always be accompanied by oral information from the health-care professionals (27,28).

In this study, 16 phrases from the leaflet were selected to explore patients' understanding. All patients understood 4 phrases, and one phrase was understood by 91% of the patients. Three of these 4 phrases were addressing the patient personally, with a short instruction and without the use of medical jargon. The use of short sentences using everyday language increases the readability and understanding (29). Five phrases were understood by more than 50% of the patients. These phrases contained medical jargon about complications such as "ascites" and "varices" and verbal nouns which may reduce the comprehension of the leaflet and make it difficult to read (16,29). The meaning condensation showed that patients who had experience with some of the complications mentioned in the leaflet could recognize and understand the medical jargon. This indicates that patients may become familiar with such expressions and overcome language barriers (30). Six phrases from the leaflet were understood by less than 50% of the patients. Complex pathophysiological explanations, long sentences, medical jargon, and verbal nouns characterized these phrases.

Patients' difficulties in understanding the leaflet may result in limited knowledge about their cirrhosis disease and its complications. Limited knowledge has been identified as a significant barrier to disease management and patient compliance (31). An emerging area of research in the field of improving patient knowledge is health literacy, that is, the capacity to find, understand, and act on health information (32). Studies on cirrhosis and health literacy are sparse (33), and ours is the first to use a mixed method design to explore patient interaction and understanding of written patient information. Our study showed that patients' knowledge and understanding of cirrhosis and its complications were not enhanced by the availability of the leaflet. Thus, patients had limited understanding of the complexity and management of cirrhosis and its complications despite having access to the leaflet. This, together with patients' difficulties in understanding several of the phrases in the leaflet, may indicate limited health literacy. The mismatch between the patients'

limited health literacy and the poor comprehension and readability of written patient information have not before been studied in patients with cirrhosis but is documented in studies with other patient groups and confirms that many patients may not be able to adequately comprehend much of the written information provided to them (34).

American and European studies on the general population have shown that around 50% of the adults have limited health literacy (35,36). In addition, other studies have shown that health literacy is further limited by older age, male gender, low education and income, and having one or more diseases (37,38). In this study, the participating patients were characterized as being diagnosed with cirrhosis and 40% of them also had other diseases. They were older, around half of them were men and with limited education. Thus, these clinical and demographic characteristics may further have impaired the patients' health literacy and the ability to comprehend the written patient information.

Oral and written patient information from health-care professionals can facilitate information exchange and enable disease management. However, given the newness of the field approaches to improve health literacy is limited and much needs to be done to provide evidence-based guidance to health-care professionals on effective interventions. One approach could be to educate health-care professionals to communicate health information that develops patients understanding of their disease and how to manage it. Interventions for improving patients understanding includes clear, patient-centered communication using plain language, supplementing oral communication with pictures/pictograms and written information that is nuanced, distributed thoughtfully, and personalized by the health-care professionals during the meeting with the patient (38).

Another approach could be the implementation of digital and social media use in the health-care system to improve patients' health literacy and ability to understand written patient information. Studies have shown that the use of these media may be beneficial for disease knowledge and management (39). However, further studies are needed to fully understand the potential along with education of health-care professional in the use of digital and social media in patient information.

Patients with cirrhosis often have an ongoing interaction with health-care professionals and the health-care system due to the complexity of their disease. Therefore, focusing on health literacy in the interaction with the cirrhosis patients, health-care professionals can obtain knowledge and understanding of patients' capacity and limitations and use it to remove barriers to disease compliance and thus improve disease management and enable a stronger patient engagement with the health-care system.

### *Study Limitation*

The cross-sectional questionnaire-based pilot study with an embedded mixed methods design was a cost-efficient and ideal way to assess the quality of our written patient information leaflet pertaining to cirrhosis and its complications. However, there are limitations to this study. The readability of the leaflet was assessed using the LIX index and the SMOG index. The SMOG index was developed to score texts written in English which along with Danish belongs to the Germanic language family. The 2 languages have common characteristics and we thus assume that the index may be used although it is not yet validated in Danish. However, we cannot ignore the fact that the score may be influenced by the language factor.

All of the participating patients were diagnosed with alcoholic cirrhosis, which is not surprising since in Denmark, the main cause of cirrhosis is alcoholic liver disease. Thus, some of the results may be explained by the fact that patients with alcoholic cirrhosis tend to be less health-conscious than patients with nonalcoholic cirrhosis (40). The present sample size is small, and although a wide age range was represented, the participating patients might not be representative for the entire population of cirrhosis patients and a study with a bigger sample size is necessary to confirm the results.

Despite the exploratory nature of our study, it provides a previously unexplored combination of interviews with patients and an analysis of the leaflet they have been provided, which not before have been performed. We believe that these results will add useful information to the sparse knowledge of health literacy and written patient information in the field of hepatology, and we hope that the results of the study may motivate further studies within this field.

## Conclusion

The leaflet had a good design, layout, and information quality but was difficult to read. Patients appeared to relate poorly to the leaflet and demonstrated limited health literacy. These results suggest that an assessment of written patient information ought to be made in an effort to improve readability and that awareness among health-care professionals on matching oral and written patient information to the patients' level of health literacy in order to ensure effective patient understanding and disease management needs to be raised. This may improve patients' understanding of cirrhosis and improve their active role in cirrhosis management.

## Future Directions

The results of this study provide a background on which assessment of patient information on chronic diseases can be carried out at the clinic. This study also highlights a number of future chores in the area of health literacy and written patient information. First, planning patient information on disease management necessitates more focus on content accuracy and improved readability in order to match the patient group. Second, more work is needed to enhance the use of illustrations, pictures, and pictograms and thus improve the usefulness of the information and make patients

more engaged. Written patient information should aim at explaining difficult concepts and enhancing the understanding as a supplement to patient-centered, oral information from the health-care professionals. Third, future research should aim at assessing the significance of health literacy, design intervention studies to improve patients' health literacy and provide approaches for disease management, and explore the effect of written patient information on the association with health status and disease management.

## Authors' Note

L.L.G., K.B., R.S., and M.M. contributed to study concept and design; analysis and interpretation of data; and critical revision of the manuscript. K.B. and R.S. contributed to development of questionnaire. L.L.G., K.B., and R.S. contributed to acquisition of data. L.L.G. contributed to drafting of manuscript.

## Declaration of Conflicting Interests

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