

# Health Literacy Gaps in Online Resources for Cirrhotic Patients

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## Abstract

**Background:** The average readability level in the USA is a sixth grade level and for patients with chronic disease it is lower. Cirrhosis is a prevalent chronic disease that requires complex knowledge and instructions to manage. No research has been done about the understandability of online educational content for cirrhotic patients. Patients can find online materials curated by both general health platforms and high-volume liver transplant centers, and thus these materials were analyzed.

**Methods:** After determining exclusion criteria, the websites of the top 20 general health platform results and the websites of the top 20 high-volume hepatology centers were analyzed. Readability was assessed using the Patient Education Materials Assessment Tool (Audiovisual Materials) (PEMAT-A/V), Flesch-Kincaid Grade Level tests, word counts, sentence counts, words per sentence, and time for an average sixth grader to read.

**Results:** The mean grade level readabilities were 12.3 and 11.3 for the general resources and the transplant center resources, respectively. The online resources ranged from 9 to 389 sentences requiring an average of 9.8 min to read. The mean PEMAT-A/V scores were 70.05% for the general resources and 72.45% for the transplant center resources. There was a statistically significant difference in the Flesch-Kincaid grade level, sentence number, words per sentence, word count, and time for an average sixth grader to read the general

resources and transplant center resources ( $P < 0.05$ ).

**Conclusions:** The online resources both from health platforms and hepatology centers available to patients with cirrhosis are too long and complex and underscore the need for simpler and shorter resources.

**Keywords:** Patient education; Cirrhosis; Media and social media; Quality of life

## Introduction

An estimated five million people suffer from liver cirrhosis, a chronic disease that requires extensive health care resources and intricate understanding to obtain and follow optimal treatment, such as regular care through gastroenterologists, liver cancer screening through ultrasounds, and endoscopies to assess portal hypertension [1]. However, disease understanding in this population is generally lacking. In Denmark, cirrhotic patients were found to have low levels of understanding about their conditions [2]. Another study in Melbourne identified that hepatitis B patients had significant gaps in their knowledge of the disease, transmission routes, and treatment [3]. In a US query of patients with liver cirrhosis, 15% listed that their most important disease-related need is accessible and understandable educational material [4].

Patient education materials can promote understanding [5]. Most patients of all socioeconomic and age strata seek information about their disease online, either through general internet resources or attached to large medical centers [6]. But online resources often tower above patients' reading levels, which average at sixth grade [7]. Educational material can also be filled with medical jargon [8]. One US study reported that online reading materials on hepatitis B, hepatitis C, hepatocellular carcinoma, and cirrhosis had a mean reading level over 10th grade [9]. Similar challenges in patient reading materials have been described for kidney transplantation and other chronic conditions such as diabetes [10, 11].

Little is known about the comprehensibility of the highest visibility online resources on liver cirrhosis. Over 95% of traffic from an online search comes from the first page of results, so the first few web links have the greatest chance of being read by patients [12]. In this study, we therefore aimed to assess the understandability of the top patient education materials about

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liver cirrhosis available online through general search terms as well as the websites of large hepatology centers.

## Materials and Methods

This research did not require human subjects, and Institutional Review Board (IRB) review was not required. Two online searches were performed. One online search for “liver cirrhosis” was performed using the “Google” search engine (“Google”). The second search targeted the highest volume liver transplant centers (“hepatology centers”). For the “Google” search, the websites of medical centers, news articles, magazine articles, and videos were excluded as medical center websites were analyzed in the second search, and patients would have to listen to videos or download issues of magazines to get information (they were not quick readable sources). The results from the remaining top 20 websites were analyzed. For the “hepatology centers” search, the highest volume liver transplant centers were determined through the United Network for Organ Sharing (UNOS). The top 20 centers with websites on liver cirrhosis were analyzed. For both searches, the grade level, word count, number of sentences, and number of words per sentence were calculated. Grade level readability was determined using the Flesch-Kincaid grade level analyzer, which takes into account word length and sentence length. Averages and standard deviations were calculated. The time needed to read each passage was calculated based on an average sixth grade reading speed of 140 words/min as in Hasbrouck and Tindal’s norms [13]. In addition to a grade level metric of readability, the Patient Education Materials Assessment Tool (Audiovisual Materials) (PEMAT-A/V) test on understandability was used by two raters to evaluate all 40 samples. This test included subsections on “Content”, “Word Choice and Style”, “Organization”, “Layout and Design”, and “Visual Aids” [14]. The search was performed on February 1, 2019. A two-tailed paired *t*-test for means was used with  $\alpha = 0.05$  level of significance to compare the metrics of Flesch-Kincaid grade level, sentence number, words per sentence, word count, time for an average sixth grader to read, and PEMAT-A/V score for the “Google” search and “hepatology centers” search.

## Results

### Google

After exclusion of search results from medical centers (12) (see second analysis), videos (1), and newspaper and magazine articles (4), the top 20 search results were analyzed. The mean grade level readability was 12.3 (6.8 - 20.8), the mean word count was 1,841 (200 - 7,767), the mean number of sentences was 105 (9 - 389), and the mean number of words per sentence was 19.6 (10.6 - 29.4) (Table 1). Sixteen (80%) websites’ resources had subsections on etiology, symptoms, and treatments, which were included in the analysis, while four (20%) websites had no information on these subsections. The Medline Plus web resource had the lowest reading grade level at 6.8,

with the lowest words per sentence (10.6) and fifth lowest PEMAT score (61). The most complicated web resource was the National Center for Biotechnology Information (NCBI) with a readability at 20.8 grade and a PEMAT score of 64, which was the second lowest score. The average time for a sixth grader to read these web resources was 13.15 min (1.4 - 21.9). The average PEMAT score for this sample was 70.05 (50 - 93).

### Hepatology centers

To find information on 20 websites of high-volume hepatology centers, 35 were queried. Of the 20 centers with online information on cirrhosis, five were in the Northeastern USA, four on the West Coast, six in the Midwest, and five in the South; 19 out of 20 (95%) were academic institutions. The 20 centers performed an annual average of 122.9 (93 - 170) liver transplants from 2017 to 2018. Among the 20 online texts, the mean grade level readability was 11.3 (6.7 - 17.2), the mean word count was 904 (276 - 2,677), the mean number of sentences was 64.15 (12 - 194), and the mean number of words per sentence was 18 (11 - 32) (Table 2). Subsections related to etiology, symptoms, and treatments were found on 18 (90%) websites. University of Wisconsin’s patient materials had the lowest reading grade level at 6.7, and Georgetown Medical Hospital’s patient materials had the highest reading level at 17.2. However, Georgetown’s materials had a higher PEMAT score (80) than University of Wisconsin (64). Ohio State University’s patient materials had the lowest number of words (175) and would take a sixth grade reader the shortest number of minutes to read (1.3), while the readability was at a 10.3 grade level and the PEMAT score was 73. The average time for a sixth grader to read these passages was 6.5 min (1.3 - 19.1). The average PEMAT score for this sample was 72.45% (40-90%).

### Comparison between centers

The readability of the top 20 sources found through both a general web search and a high-volume hepatology center search was over an 11th grade level, with transplant centers providing materials an average of one grade lower than general resources (11.3 vs. 12.3, respectively). In addition to Flesch-Kincaid grade level, the average number of sentences, words per sentence, word count, and time for an average sixth grader were higher for the general resources than the transplant center resources (105 vs. 64.15, 19.63 vs. 18.02, 1,841 vs. 904, 13.15 vs. 6.46, respectively). A two-tailed paired *t*-test for means showed a statistically significant difference in the average Flesch-Kincaid grade level, sentence number, words per sentence, word count, and time for an average sixth grader to read the general resources and transplant center resources ( $P < 0.05$ ) (Fig. 1).

## Discussion

The web sources readily available to patients with liver cirrhosis required an average reading level over 11th grade and the

**Table 1.** Readability and Understandability of Top “Google” Searches

| Website (in order of grade level readability) | Flesh-Kincaid Grade Level | Number of sentences | Words per sentence | Word count | Time to read for sixth grade level (min) | PEMAT-A/V score (%) |
|---|---------------------------|---------------------|--------------------|------------|--|---------------------|
| Medline Plus (branched to Family Doctor Link) | 6.8                       | 97                  | 10.56              | 1,014      | 7.24                                     | 64                  |
| British Liver Trust                           | 9.9                       | 84                  | 19.80              | 1,604      | 11.46                                    | 93                  |
| NIDDK   | 10.2                      | 151                 | 15.38              | 2,246      | 16.04                                    | 75                  |
| Griswold Homecare                             | 10.4                      | 36                  | 17.09              | 581        | 4.15                                     | 73                  |
| WebMD   | 10.8                      | 83                  | 17.61              | 1,444      | 10.31                                    | 80                  |
| eMedicineHealth                               | 10.8                      | 109                 | 17.99              | 1,637      | 11.69                                    | 73                  |
| NATAP   | 11.0                      | 155                 | 16.48              | 2,076      | 14.83                                    | 70                  |
| Medical News Today                            | 11.3                      | 150                 | 18.24              | 1,988      | 14.20                                    | 61                  |
| Wikipedia                                     | 12.3                      | 172                 | 13.87              | 2,330      | 16.64                                    | 50                  |
| Healthline Alcoholic Liver Cirrhosis          | 12.5                      | 62                  | 17.94              | 969        | 6.92                                     | 70                  |
| ACG Patient Center                            | 12.5                      | 135                 | 19.13              | 2,391      | 17.08                                    | 73                  |
| NHS   | 12.7                      | 36                  | 24.50              | 735        | 5.25                                     | 80                  |
| MyDr  | 13.1                      | 101                 | 24.52              | 2,256      | 16.11                                    | 80                  |
| Merck Manuals                                 | 13.1                      | 169                 | 21.86              | 3,367      | 24.05                                    | 55                  |
| Medicine Net                                  | 13.7                      | 389                 | 21.76              | 7,767      | 55.48                                    | 73                  |
| Healthline Cirrhosis                          | 13.9                      | 71                  | 23.18              | 1,298      | 9.27                                     | 70                  |
| Otsuka Pharmaceutical                         | 14.3                      | 19                  | 21.44              | 386        | 2.76                                     | 75                  |
| SciTechnol                                    | 15.1                      | 9                   | 22.22              | 200        | 1.43                                     | 58                  |
| Verywell Health                               | 15.9                      | 37                  | 25.69              | 899        | 6.42                                     | 73                  |
| NCBI  | 20.8                      | 127                 | 29.43              | 3,061      | 21.86                                    | 55                  |
| Average                                       | 12.3                      | 105                 | 19.63              | 1,841      | 13.15                                    | 70.05               |
| Standard deviation                            | 3.13                      | 85.77               | 4.77               | 1,670.8    | 11.93                                    | 10.35               |

Mean and standard deviation of the Flesch-Kincaid Grade Level, number of sentences, number of words per sentence, word count, time for an average sixth grader to read, and PEMAT score of the top 20 web results from the “Google” search. PEMAT-A/V: Patient Education Material Assessment Tool (Audiovisual Materials); NIDDK: National Institute of Diabetes and Digestive and Kidney Diseases; NATAP: National AIDS Treatment Advocacy Project; ACG: American College of Gastroenterology; NHS: National Health Service; NCBI: National Center for Biotechnology Information.

ability for a sixth grader to focus for more than 9.8 min. In the USA the average adult reading proficiency is at eighth grade, but over 20% of patients read below a fifth grade level [7, 15]. Hence, the reading level required to read about cirrhosis far exceeds the national average reading level and far more exceeds the reading level of chronically ill patients. In a study of asthma patients, over 40% read at or below a sixth grade level despite being high school graduates [16].

In addition to high reading grade levels, the average PEMAT understandability score was 71.25, with transplant centers providing slightly more understandable materials than general web resources (72.45 vs. 70.05, respectively) (Fig. 1). Only four websites had a score above 90 in understandability and one was as low as 40. A patient with liver cirrhosis will likely struggle to comprehend any significant amount of online information provided when it is, on average, 70% understandable. While there is not an average educational website score to reference for the PEMAT, trends were observed that lowered scores of the analyzed web results. More than half of websites in both searches did not receive points in the PEMAT subsec-

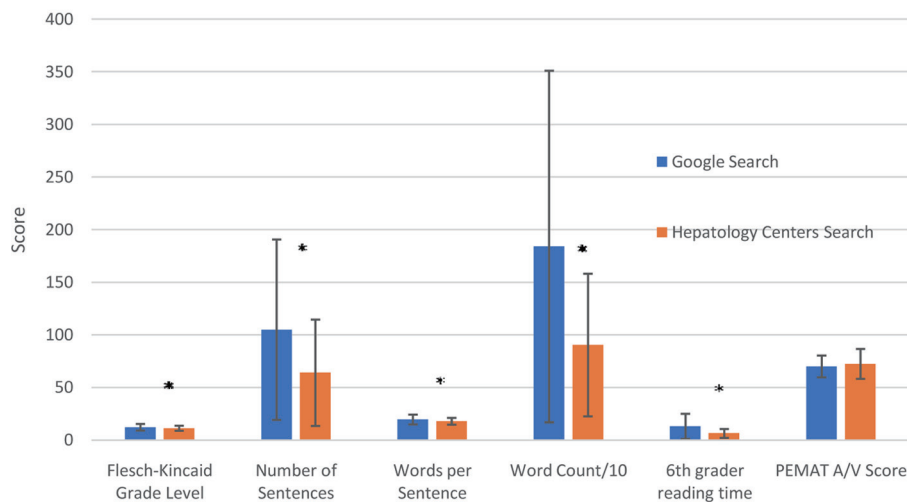
tions titled “Word Choice and Style” and “Layout and Design”, because they used passive voice and did not use a readable text size. Both of these factors have been independently linked to the capacity to remember words and comprehend text [17, 18]. Over 75% of all websites did not use any images, which have been shown to facilitate recall of main ideas of text [19]. Websites with lower grade level readabilities did not have greater understandability scores than websites with higher grade level readabilities, which has also been observed in an analysis of diabetes-related education materials [20].

As of 2019, the duration of an average web user’s Google search session was under 9 min [21]. While some cirrhosis websites might take under 9 min to read, they are unlikely to be understood because cirrhotic patients are not average web users. Many suffer from hepatic encephalopathy, which causes neurocognitive impairment, issues with executive function, slower problem solving, and attention deficits. Hence, they need more time to read long passages on websites with small fonts and few images [22]. They also have a decreased ability to sustain focus while reading which limits their capacity and

**Table 2.** Readability and Understandability of Top “Hepatology Centers” Searches

| Website   | Flesch-Kincaid Grade Level | Number of sentences | Words per sentence | Word count | Time to read for sixth grade level (min) | PEMAT-A/V score (%) |
|---|----------------------------|---------------------|--------------------|------------|--|---------------------|
| University of Wisconsin Hospital and Clinics          | 6.7                        | 79                  | 11.03              | 827        | 5.91                                     | 64                  |
| University of Pittsburgh Medical Center               | 6.8                        | 79                  | 11.07              | 830        | 5.93                                     | 50                  |
| Johns Hopkins Medical Center                          | 7.9                        | 104                 | 14.03              | 1,319      | 9.42                                     | 90                  |
| Northwestern Medicine                                 | 8.0                        | 104                 | 14.06              | 1,322      | 9.44                                     | 90                  |
| University of California Los Angeles Medical Center   | 8.0                        | 104                 | 14.06              | 1,322      | 9.44                                     | 90                  |
| Emory Healthcare                                      | 9.8                        | 19                  | 14.53              | 276        | 1.97                                     | 40                  |
| Mayo Clinic   | 10.1                       | 194                 | 14.63              | 2,677      | 19.12                                    | 64                  |
| Ohio State University Medical Center                  | 10.3                       | 12                  | 15.91              | 175        | 1.25                                     | 73                  |
| Baylor Medical Center                                 | 10.5                       | 113                 | 15.59              | 1,653      | 11.81                                    | 75                  |
| Barnes Jewish Hospital                                | 11.3                       | 20                  | 19.19              | 307        | 2.19                                     | 70                  |
| Cleveland Clinic                                      | 11.4                       | 89                  | 18.65              | 1,399      | 9.99                                     | 82                  |
| Stanford Medicine                                     | 12.1                       | 64                  | 15.65              | 767        | 5.48                                     | 70                  |
| Vanderbilt University Medical Center                  | 12.1                       | 18                  | 21.41              | 364        | 2.6                                      | 60                  |
| Piedmont Hospital                                     | 12.2                       | 47                  | 16.05              | 674        | 4.81                                     | 80                  |
| University of California San Francisco Medical Center | 12.8                       | 35                  | 21.12              | 679        | 4.85                                     | 80                  |
| Lahey Clinic  | 14.1                       | 60                  | 22.60              | 904        | 6.46                                     | 82                  |
| Henry Ford Health System                              | 14.4                       | 41                  | 22.87              | 686        | 4.9                                      | 90                  |
| Cedars-Sinai Medical Center                           | 15.2                       | 29                  | 28.46              | 683        | 4.88                                     | 55                  |
| Mt. Sinai Healthcare                                  | 15.4                       | 55                  | 17.58              | 798        | 5.7                                      | 64                  |
| Georgetown Medical Hospital                           | 17.2                       | 17                  | 31.85              | 414        | 2.96                                     | 80                  |
| Average   | 11.3                       | 64.15               | 18.02              | 904        | 6.46                                     | 72.45               |
| Standard deviation                                    | 2.44                       | 50.53               | 3.23               | 677.61     | 4.19                                     | 14.21               |

Mean and standard deviation of the Flesch-Kincaid Grade Level, number of sentences, number of words per sentence, word count, time for an average sixth grader to read, and PEMAT score of the top 20 web results from the “Hepatology Centers” search. PEMAT-A/V: Patient Education Material Assessment Tool (Audiovisual Materials).



**Figure 1.** Comparison between “Google” search and “Hepatology Centers” search. Comparison of mean (± SD) scores between “Google” search results and results from “Hepatology Centers” online searches. \*P < 0.05. PEMAT-A/V: Patient Education Material Assessment Tool (Audiovisual Materials); SD: standard deviation.

motivation to learn about cirrhosis [23].

Improving the readability and comprehensibility of patient education materials has proven to be successful at improving patient understanding in other contexts [24, 25]. Cirrhotic patients face fatigue, a lower quality of life, and helplessness and could potentially gain a better sense of control by understanding their disease [26]. Lower levels of disease understanding in cirrhotic patients have shown to negatively influence self-management behaviors, while well-informed cirrhotic patients are more likely to be adherent to their complex and exhausting treatment regimens, which leads to greater well-being and less fatigue [27-30].

This study was limited to reading resources and excluded other sources such as locally available paper pamphlets provided by centers or videos. The analyses were performed using the Flesh-Kincaid Grade Level tool to measure readability and PEMAT to measure understandability. There are other tools (e.g. Gunning Fog Index, SMOG score) available, but cursory application did not change the reported results.

Educational material is too long and complex for the target population. Involving patients with cirrhosis in creating appropriate educational material that is available online through simple searches might significantly improve understanding of this chronic disease and may increase guideline adherence and satisfaction [31].

## Conclusions

Our findings corroborate the claim of liver cirrhosis patients in a national online query indicating that information about the disease is elusive, as most general websites and especially those from hepatology centers are too high in grade level readability, very long (13 min for the Google search and 6.5 min for hepatology centers) and low in understandability (70.05% for the Google search and 72.45% for the hepatology centers) (Fig. 1) [4]. No websites contained information that was a sixth grade level and had a 90% PEMAT score. This obvious educational resource gap can easily be mitigated through targeted information made available and is likely to positively affect treatment adherence of patients with liver cirrhosis [32].

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## Conflict of Interest

None to declare.

## Informed Consent

Not applicable.

## Author Contributions

TK contributed to data analysis/interpretation, drafting article, critical revision of article, statistics analysis; NM, KA and LMC contributed to the critical revision of article; AS contributed to data analysis/interpretation; AD contributed to data analysis/interpretation, and critical revision of article; DPL contributed to concept/design, and critical revision of article. All authors approved the article.

## Data Availability

The authors declare that data supporting the findings of this study are available within the article.

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