



Cancer Pain: An Analysis of the Quality, Content and Readability of Information on the Internet

Kanser Ağrısı: İnternetteki Bilgilendirme Metinlerinin Okunabilirlik, İçerik ve Kalite Açısından Analizi

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ABSTRACT

Background: Pain develops in 39.3%–66.4% of cancer patients. Cancer pain decreases the patient's quality of life and causes mood disorders; however, the patient's access to healthcare information may improve these problems. It has been shown that 79% of cancer patients use the internet to access health information. The internet helps patients in making informed decisions concerning their treatment. This study aimed to evaluate the readability levels, content, and quality of patient information texts on Turkish websites regarding cancer pain. **Methods:** The texts were transferred to the readability calculation engine and the results were obtained according to the Ateşman and Bezirci-Yılmaz formulas. The content of the patient information texts on the websites was evaluated by the author. The texts were also evaluated in terms of quality by the DISCERN tool. **Results:** The mean value of the Ateşman formula was 47.74 ± 10.39 and compatible with being difficult to read. The result of the Bezirci-Yılmaz formula was 13.28 ± 3.53 and compatible with a license degree. The mean value of the total DISCERN score was 29.13 ± 6.26 . **Conclusion:** Turkish healthcare information articles about cancer pain on the internet were not suitable for the education level of our society. The articles were insufficient in terms of content and comply with having a poor quality. Therefore, they could not meet the needs of the patients. A better relationship between the patient and physician may be achieved by improving the readability of health information texts on the internet and ensuring that its content is sufficient and reliable. In this manner, the success of the treatment may be improved and the results of any undertreatment may be minimized.

Keywords: Health information, quality, readability, cancer pain, internet.

ÖZET

Giriş: Kanser hastalarının %39,3-66,4'ünde ağrı gelişmektedir. Kanser ağrısı yaşam kalitesini kötüleştirmekte ve duygudurum bozukluklarına neden olmaktadır. Hastanın sağlık bilgisine erişimi ile bu alanlardaki sorunların iyileştiği gösterilmiştir. Kanser hastalarının % 79'unun interneti sağlık bilgilerine erişmek için kullandıkları ve internetin hastaların tedavileri hakkında bilinçli kararlar vermelerinde yardımcı olduğu gösterilmiştir. Bu çalışmanın amacı, Türkçe internet sitelerinde kanser ağrısına ilişkin hasta bilgi metinlerinin okunabilirlik düzeylerini, içeriklerini ve kalitesini değerlendirmektir. **Yöntem:** Metinler okunabilirlik hesaplama motoruna aktarılıp sonuçları Ateşman ve Bezirci-Yılmaz formüllerine göre elde edilmiştir. Web sitelerindeki hasta bilgilendirme metinlerinin içeriği yazar tarafından değerlendirilmiştir. Ayrıca metinler DISCERN aracı ile kalite açısından değerlendirilmiştir. **Bulgular:** Ateşman formülünün ortalama değeri 47.74 ± 10.39 idi ve okunması zor ile uyumlu idi. Bezirci-Yılmaz formülü 13.28 ± 3.53 idi ve lisans derecesi ile uyumluydu. Toplam DISCERN skorunun ortalama değeri $29,13 \pm 6,26$ idi. **Sonuç:** Kanser ağrısı ile ilgili Türkçe sağlık bilgilendirme makaleleri toplumumuzun eğitim düzeyine uygun değildir. İçerik açısından ise yetersizdir ve düşük kalitede bulunmuştur. Bu haliyle kanser ağrılı hastaların ihtiyaçlarının karşılanması mümkün görünmemektedir. Hasta ve hekim arasındaki ilişki, sağlık bilgi metinlerinin internetteki okunabilirliğini geliştirerek, içeriğinin yeterli ve güvenilir olmasını sağlayarak iyileştirebilir. Bu şekilde hem tedavinin başarısı artırılabilir hem de tedavisiz kalmanın sonuçları en aza indirilebilir.

Anahtar kelimeler: Kanser ağrısı, kalite, okunabilirlik, sağlık bilgisi, internet.

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INTRODUCTION

Cancer pain is observed in 66.4% of advanced and metastatic patients, 55.0% during anticancer treatment, and 39.3% after curative treatment. Approximately 38% of the patients complain of moderate to severe pain.¹ Cancer pain causes fatigue, loss of appetite, sleep disturbances, mood changes, limitations in daily activities, and problems in one's social life and family relationships.² Cancer pain is also associated with depression and anxiety.³ Kugbey et al. showed that depression and anxiety levels decrease, and quality of life increases as a result of a patient's access to health information.⁴

People with chronic illnesses are looking for information on the internet to learn more about their health and to exchange ideas with their healthcare professionals.⁵ Of cancer patients, 79% use the internet to access healthcare information.⁶ The internet is a powerful way of obtaining health information in cancer patients. Also, the internet helps patients to communicate their concerns and questions and take a more active role in their treatment decisions, and consequently make informed decisions.⁷

Patient-physician communications have evolved from a paternal approach to mutual communications and sharing of information with each other.⁸ In this model, where the physician can act together with the patient in the treatment method, the feedback of the patient is taken into

consideration. This allows patients to have an active role in their disease management and share in the responsibilities. However, in this new patient-physician communication style, there is a need for patients to have a sufficient level of awareness and knowledge of health-related matters.⁹

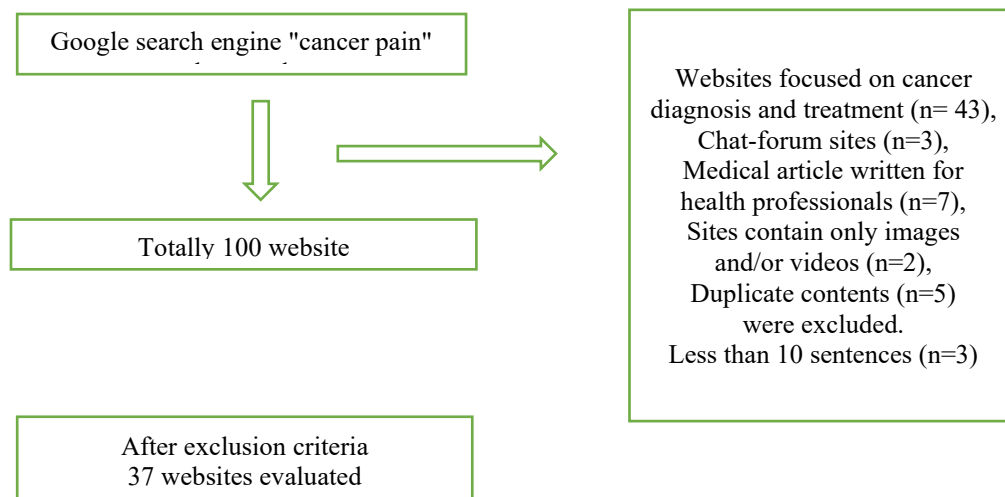
While health information materials on the internet have an important role in patient education, the informative texts should be valid and reliable, and the readability level should be suitable for the patient population.¹⁰

In the literature review, no study was found out that evaluated internet-based health information texts concerning cancer pain in terms of readability, content, and quality. Therefore, this study aimed to evaluate the readability levels, content, and quality of patient information texts on Turkish websites regarding cancer pain.

MATERIALS AND METHODS

This was an observational-descriptive study in which we evaluated 100 websites that were identified in a Google (<http://www.google.com.tr/>) search using the term "cancer pain" in October 2020. Sites containing less than ten sentences of information, articles containing only video and images, articles published in medical journals for health professionals, and chat, forum or commercial blog sites were excluded from the study (Fig. 1).

Fig. 1: Flow chart



Readability

The information texts on these sites were transferred to the Microsoft Word program and the training titles, site URL addresses, and links were deleted so as not to affect the readability results. This information was then transferred to the readability

calculation engine and the results were obtained according to the Ateşman and Bezirci-Yılmaz formulas. The "Measurement of Readability in Turkish," published by Ateşman in 1997, was the first study on the readability of Turkish texts.¹¹ Claiming the formula developed by Flesch is the most suitable for the unique structure of the Turkish

language, Ateşman stated that this formula was created for English texts and based on sentence and word length variables, should be adapted. Ateşman adopted the Flesch formula to Turkish as a result of various applications and calculations. The resulting values from this formula are classified as very difficult (1–29), difficult (30–49), medium (50–69), simple (70–89), and very simple (90–100).

Ateşman readability formula is as follows:
 $8,875 - 40,175 \times (\text{number of syllables/number of words}) - 2,610 \times (\text{number of words/number of sentences})$

Bezirci and Yılmaz created a new formula by considering the negative effect of three or more syllable words specific to Turkish texts in addition to the principle that increasing the length of sentences in all languages makes it harder to read. The result of this formula explains which grade level a text is suitable for in the education system in our country. In the Turkish education system, primary education is grades 1–8, secondary education (high school) is grades 9–12; license for classes is 13–16, and shows academic education level for grades 17 and up.

The Bezirci and Yılmaz readability formula are as follows:

$$\sqrt{\text{OKS} \times (\text{H3} \times 0.84) + (\text{H4} \times 1.5) + (\text{H5} \times 3.5) + (\text{H6} \times 26.25)}$$
The definitions of values in this equation are as follows:

- OKS: Average number of words
- H3: Average number of three-syllable words in a sentence
- H4: Average number of four-syllable words in a sentence
- H5: Average number of five-syllable words in a sentence
- H6: Average number of six- or more-syllable words in a sentence

Content

Table 1: DISCERN tool

| Section 1 IS THE PUBLICATION RELIABLE? | | | | | |
|---|---------|---|----------------|---|----------|
| Questions | 1 no | 2 | 3 partially | 4 | 5 yes |
| Q1. Are the aims clear? | | | | | |
| Q2. Does it achieve its aims? | | | | | |
| Q3. Is it relevant? | | | | | |
| Q4. Is it clear what sources of information were used to compile the publication (other than the author or producer)? | | | | | |
| Q5. Is it clear when the information used or reported in the publication was produced? | | | | | |

Articles about cancer pain were searched on the American Cancer Society website.¹² After all the articles on cancer pain were carefully examined, the criteria of contents were determined by the author. The availability of the incidences of cancer pain in cancer patients, causes of cancer pain, pain assessment tools, breakthrough pain, pain characteristics, effects of pain on quality of life, pharmacological options in cancer pain treatment, the efficacy of pharmacological agents, interventional treatment options for cancer pain, complications of interventional treatments, radiotherapy option for pain, opiophobia, wrong beliefs and attitudes of patients about cancer pain, barriers of cancer patients in pain management, treatment success in cancer pain, and psychological support needs in cancer pain were evaluated in the content of patient information texts on the websites.

Quality

The websites were evaluated in terms of quality by the DISCERN tool. DISCERN is a short tool that contains important questions on critical issues and evaluates health information concerning treatment options. This tool aims to facilitate the high quality of health information texts while providing information about the quality of the text edited for information purposes.¹³ The DISCERN tool is comprised of 15 questions plus an overall quality rating. The first eight questions address reliability, the next seven questions focus on the treatment information on the site. The last question addresses the overall quality of the site. Each question is scored on a 5-point Likert scale (5 = yes, the criteria for quality have been met; 2–4 = the criteria for quality have been partly met; and 1 = no, the criteria for quality have not been met). The instrument is scored with a maximum score of 80 and the quality of internet-based health information is categorized as low, moderate, good, or excellent, according to the total DISCERN score (Table 1).

| | | | | | |
|--|---|---|---|---|-----------------------------------|
| Q6. Is it balanced and unbiased? | | | | | |
| Q7. Does it provide details of additional sources of support and information? | | | | | |
| Q8. Does it refer to areas of uncertainty? | | | | | |
| Section 2 HOW GOOD IS THE QUALITY OF INFORMATION ON TREATMENT CHOICES ? | | | | | |
| Questions | 1 no | 2 | 3 partially | 4 | 5 yes |
| Q9. Does it describe how each treatment works? | | | | | |
| Q10. Does it describe the benefits of each treatment? | | | | | |
| Q11. Does it describe the risks of each treatment? | | | | | |
| Q12. Does it describe what would happen if no treatment is used? | | | | | |
| Q13. Does it describe how the treatment choices affect overall quality of life? | | | | | |
| Q14. Is it clear that there may be more than one possible treatment choice? | | | | | |
| Q15. Does it provide support for shared decision-making? | | | | | |
| Section 3 OVERALL RATING OF THE PUBLICATION | | | | | |
| Question | 1 Serious or extensive shortcomings Low | 2 | 3 Potentially important but not serious shortcomings Moderate | 4 | 5 Minimal shortcomings High |
| Q16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices: | | | | | |

The Statistical Package for Social Sciences 22.0 (SPSS Chicago, IL, USA) program was used for statistical evaluations of the data. There were no missing data from the variables in the study. Shapiro-Wilk tests were used to evaluate the distribution of the data. Descriptive data are presented as the frequency (*n*) and the percentage (%) for categorical variables, and the mean and standard deviation for normally distributed numerical variables.

RESULTS

Thirty-seven websites were included in this study (Fig. 1). The mean value of the Ateşman formula was 47.74 ± 10.39 and compatible with difficult to read. The mean value of the Bezirci-Yılmaz formula was 13.28 ± 3.53 and compatible with a license degree. The difficulty levels according to the Ateşman formula are given in Table 2.

Table 2: The results of difficulty level according to the Ateşman formula

| Difficulty levels | Percentages (%) | Numbers |
|-------------------|-----------------|---------|
| Very difficult | 2.7 | 1 |
| Difficult | 48.6 | 18 |
| Medium | 48.6 | 18 |
| Simple | 0 | 0 |
| Very Simple | 0 | 0 |
| Total | 100 | 37 |

Internet-based information texts on cancer pain were evaluated in terms of content. Information about the incidence of pain in cancer patients, causes of cancer pain, pain assessment tools, breakthrough pain, pain characteristics, possible effects of pain on quality of life, pharmacological options in treatment, side effects of pharmacological agents, interventional treatment options for pain, complications of interventional treatment methods, radiotherapy option for pain, opiophobia, patients' false beliefs and attitudes towards cancer pain, cancer patients' barriers to pain management, treatment success in cancer pain, and the need for psychological support in cancer pain were present in the texts 75.37% (*n* = 28), 54.1% (*n* = 20), 18.9% (*n*

= 7), 27% (n = 10), 21.6% (n = 8), 54.1% (n = 20), 100% (n = 37), 18.9% (n = 7), 83.8% (n = 31), 0% (n = 0), 24.3% (n = 9), 43.2% (n = 16), 16.2% (n = 6), 8.1% (n = 3), 32.4% (n = 12), and 29.7% (n = 11), respectively.

The quality of the informative texts was evaluated with the DISCERN tool. The mean value of the total DISCERN score was 29.13 ± 6.26 . The values of 16 items within the scope of the quality assessment of the DISCERN tool are given in Table 3. For each text, we asked the following questions. *Is it clear what sources of information were used to compile the publication (other than the author or producer)?; Is it clear when the information used or*

reported in the publication was produced?; Does it provide details of additional sources of support and information?; and Does it refer to areas of uncertainty? These questions were evaluated, and 100% of the texts did not meet these criteria. Another question was: *Does it provide support for shared decision-making?* This question was evaluated, and 91.9% of the texts did not meet this criterion. Another question was: *Does it describe the risks of each treatment?* The question was evaluated, and 75.7% of the texts did not meet this criterion. Another question was: *Does it describe what would happen if no treatment was used?* This question was evaluated, and 70.3% of the texts did not meet this criterion.

Table 3: Percentages and numbers of likert scores for 16 questions in the DISCERN tool

| Questions | Likert | | | | | Total |
|-----------|------------|-----------|----------|-----------|-----------|------------|
| | 1 | 2 | 3 | 4 | 5 | |
| Q1 | 43.2(16) | 29.7 (11) | 10.8 (4) | 2.7 (1) | 13. (5) | 100.0 (37) |
| Q2 | 56.7 (21) | 2.7 (1) | 8.1 (3) | 13.5 (5) | 18.9 (7) | 100.0 (37) |
| Q3 | 0.0 (0) | 0.0 (0) | 0.0 (0) | 18.9 (7) | 81.1 (30) | 100.0 (37) |
| Q4 | 100.0 (37) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 100.0 (37) |
| Q5 | 100.0 (37) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 100.0 (37) |
| Q6 | 0.0 (0) | 8.1 (3) | 13.5 (5) | 18.9 (7) | 59.5 (22) | 100.0 (37) |
| Q7 | 100.0 (37) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 100.0 (37) |
| Q8 | 100.0 (37) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 0.0 (0) | 100.0 (37) |
| Q9 | 56.8 (21) | 18.9 (7) | 8.1 (3) | 8.1 (3) | 8.1 (3) | 100.0 (37) |
| Q10 | 54.1 (20) | 24.3 (9) | 13.5 (5) | 8.1 (3) | 0.0 (0) | 100.0 (37) |
| Q11 | 75.7 (28) | 13.5 (5) | 5.4 (2) | 0.0 (0) | 5.4 (2) | 100.0 (37) |
| Q12 | 70.3 (26) | 16.2 (6) | 0.0 (0) | 8.1 (3) | 5.4(2) | 100.0 (37) |
| Q13 | 64.9 (24) | 162 (6) | 24.3 (9) | 32.4 (12) | 5.4 (2) | 100.0 (37) |
| Q14 | 32.4 (12) | 2.7 (1) | 2.7 (1) | 0.0 (0) | 2.7 (1) | 100.0 (37) |
| Q15 | 91.9 (34) | 2.7 (1) | 2.7 (1) | 0.0 (0) | 2.7 (1) | 100.0 (37) |
| Q16 | 2.7 (1) | 86.5 (32) | 8.1 (3) | 2.7 (1) | 0.0 (0) | 100.0 (37) |

The criteria for quality were met with 59.5% of the texts for the question, *Is it balanced and unbiased?* Furthermore, the criteria were met with 81.1% of the texts for the question, *Is it relevant?*

In all, 43.2% of the information texts could not be evaluated for the question, *Does it achieve its aims?* Because they did not answer the question, *Are the aims clear of the texts?*

DISCUSSION

This study revealed that internet-based patient information texts in Turkish on cancer pain were difficult to read and suitable for those that have 13 years of education. According to the Türkiye İstatistik Kurumu (TUIK) data, 80.7% of the population has 12 years of education or less in our country;¹⁴ thus, the internet-based health information on cancer pain was not suitable for our society. In the

literature, the readability levels of health articles on the internet were 10.9 years for general information texts about cancer,¹⁵ 11 years for information texts about colorectal cancer,¹⁶ and 9.3 years for information texts about kidney cancer.¹⁷ Passos et al. evaluated the difficulty in reading the information about oral cancer. This group found that 51.8% of oral cancer information articles were difficult, 37% were easy, 1.9% were very easy, and 9.3% were very difficult.¹⁸

In terms of content assessment, the complications of interventional treatment methods for pain and the side effects of pharmacological agents are not mentioned in the texts. Content such as pain assessment tools, breakthrough pain, pain characteristics, incorrect beliefs, patients' attitudes on cancer pain, and patients' barriers in pain management was not found on most websites. Because of the cancer patients' beliefs and attitudes about the side effects of analgesics, cancer

pain and its treatment are getting hard to manage, the belief that cancer treatment will be suspended as a result of the physician occupation with the patient's pain, and fear of being addicted to opioids are the obstacles in overcoming cancer pain.¹⁹ Internet-based information texts on cancer pain in Turkish are unsatisfactory in these important topics and therefore, they cannot help patients overcome the barriers to management of cancer pain.

In terms of quality assessment by the DISCERN tool, the questions were as follows: *Are the aims clear?*; *Is it clear what sources of information were used to compile the publication (other than the author or producer)?*; *Does it provide details of additional sources of support and information?*; and *Does it refer to areas of uncertainty?*, remained unanswered on most websites. De Boer et al. revealed that 78% of cancer patients use the internet to obtain health information, and 82% of those who use the internet aim to obtain additional information after interviewing the clinician. There were 65.3% of the patients who believed the internet is a reliable source of obtaining health information, 59.6% believed that the internet includes information from experts, and 52.8% believed the internet includes correct information.²⁰ Approximately 39% of the patients sought information on the internet for cancer pain before a clinical consultation. These trusts and expectations of the patients regarding internet-based health information can be misused by misinformation or bias. Also, the patients' confidence in their clinician may be impaired, and the patients may make a mistake in deciding on treatment.²¹ As a result of the present study, it can be said that current informative texts do not meet the needs of the patients.

Although it is a known fact that patients should consult with their physician in the management and treatment methods of the disease, this topic has not found its place in the texts.

In the present study, the overall DISCERN average score was 29.13, indicating a poor quality for the studies. The overall quality of the patient information texts on the internet sites was quite low in this study, in which 240 websites related to chronic pain were evaluated.²² On the other hand, in the literature, better results were observed regarding the quality of internet-based health information. Patient information texts about both colorectal cancer²³ and kidney cancer¹⁹ were considered at a moderate quality level, while all websites about breast cancer were in the good-to-excellent quality range.²⁴

One of the limitations of this study was that the DISCERN tool may be insufficient in evaluating the quality of the informative texts on cancer pain.

This may be because the tool emphasizes the treatment options structurally. It is important to assess pain and know the properties of pain in cancer patients. There is also a need to inform patients about pain itself and false beliefs and attitudes about opioids. The DISCERN tool does not measure these areas. In this context, it may be useful to develop a tool for measuring the quality of the health information texts that can be modified or restructured.

Turkish health information articles about cancer pain on the internet were not suitable for the education level of our society. The articles were insufficient in terms of content and comply with poor quality. Therefore, they could not meet the needs of cancer patients with pain. The relationships between patients and physicians may be achieved by improving the readability of health information texts on the internet and ensuring that the content is sufficient and reliable. In this manner, the success of the treatment may be improved and the results of undertreatment may be minimized.

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