

Readability of Online Patient Education Materials for Merkel Cell Carcinoma

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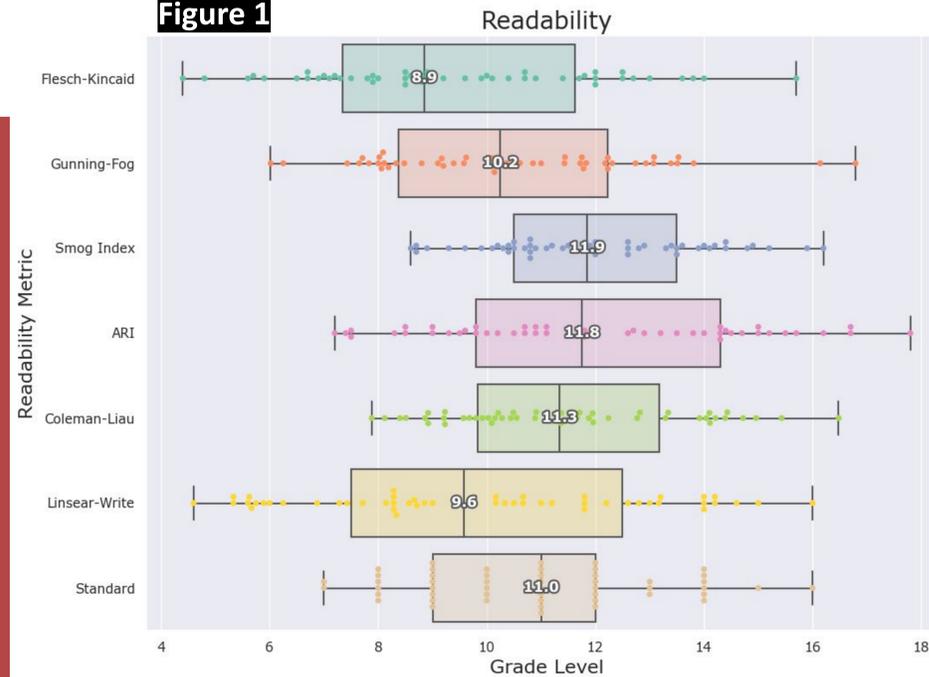
Introduction

The Internet is a significant source of information for patients learning about their health; however, the quality of resources varies widely. Many websites associated with academic institutions or care centers provide information for patients on a variety of topics, and patients rely on these sites for accurate information. These patient education materials (PEMs) must be readable by the average patient, and accessibility has been shown to increase the interface between patients and providers¹. According to The National Institutes of Health, reading materials should be at or below an eighth-grade reading level². Multiple studies have shown that the average readability of online PEMs exceed this level³; however, few investigate underlying characteristics that are associated with decreased readability.

Our Study

Our study examines Merkel cell carcinoma (MCC), a rare and highly aggressive skin cancer that mainly occurs in patients over 50 with rising incidence⁴. The management of MCC often requires a multidisciplinary team of dermatologists, surgeons, and oncologists, and the care plan follows established treatment guidelines. Many cancer care centers provide PEMs online for patients that convey information about the disease and treatment. Unfortunately, US adults aged 65 and older, the demographic most affected by MCC, have the least proficiency in health literacy of any age group^{5,6}.

Figure 1



Results

The graphs of the first 50 PEMs readability scores are in Figure 1. Overall, only eight articles had a standard reading level of 8th-grade level or below (16%). The median standard reading level was at the 11th-grade level. This demonstrates a need to continue improving the readability of online PEMs.

We also examined MCC PEMs from cancer center websites (N=20). We determined whether they contained institution-specific care team information, meaning they contained text information about the institution-specific expertise and specialist team. Websites that only explained the disease and treatments did not have this information. Websites containing this information (N=13) had a significantly higher reading level than websites that did not (N=7) in five of six readability metrics (p<0.05) (Figure 2).

References

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Discussion

MCC PEMs with institution-specific care team information led to significantly higher reading level scores. We propose that such information may increase cognitive load, as patients are learning about their disease and treatment and contending with the institution-specific information. As patients typically read pages linked from their search engine, we suggest moving the institution-specific care team information into another page, separate from the PEMs. Overall, most MCC PEMs have not reached the eighth-grade reading level or below; here, we propose a target for change to achieve this goal.

Research Design

We used the googlesearch Python library to query the search term "Merkel cell carcinoma." We retrieved a total of 111 links, yielding 50 PEM websites. The websites chosen belonged to either academic-affiliated organizations, government organizations, or foundations, and were deemed reliable. We excluded academic publications, commercial articles and blogs, and social media, as those were not considered PEMs. These websites were chosen to represent the most easily accessible online resources from using a search engine that are affiliated with a reliable source. We extracted each website's primary content, excluding headers, links, citations, and media. A python script was used to separate the body of the text into single-line sentences. A readability software package calculated six readability statistics (Flesch-Kincaid, Gunning-Fog, SMOG Index, Automated Readability Index (ARI), Coleman-Liau, and Linsear-Write) and generated a consensus standard readability using sentence characteristics⁸. Whitney-Mann U-test was used to calculate significance.

Readability and Institution-Specific Care Team Information

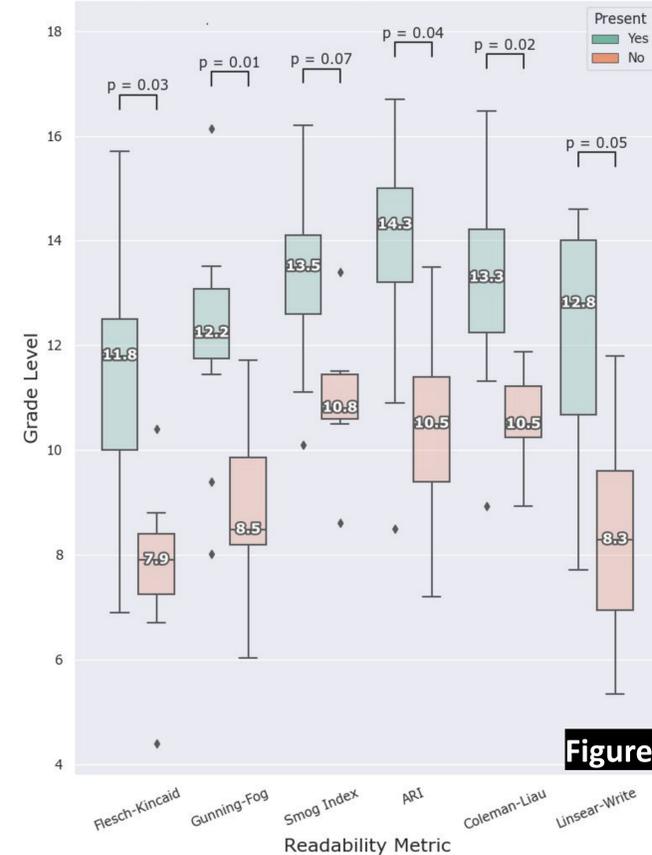


Figure 2