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Readability and Non-English Language Resources of Heart Transplant Center Websites

in the United States

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Abstract

Introduction: Health literacy is associated with heart failure (HF) care and outcomes. Online resources offer important educational materials for patients seeking access to heart transplantation but tend to be complex and potentially ineffective for non-English speakers and those with low reading levels. The purpose of this study was to evaluate both the readability of patient-level information posted on United States (U.S.) heart transplant center websites and the availability of non-English resources.

Methods and Results: We performed a review of patient-facing information on websites of U.S. heart transplant centers identified through the United Network for Organ Sharing (UNOS) in August 2022. Written English text was extracted and assessed for readability using the Fry Readability score. Websites were additionally evaluated for non-English language text and translator tools. Standard ANOVA analysis was used to compare readability levels across transplant regions. The median Fry readability level to understand a piece of text for all regions was 15, which is equivalent to a college junior reading level (range: 7-17, 7th grade to postgraduate level). There was no statistical difference in median Fry readability levels between regions ($p = 0.16$). Of the 139 eligible heart transplant center websites, only 56.1% (78/139) had non-English resources available for patients. Regions 5 (75% (15/20)) and 6 (75% (3/4)) had the highest percentage of non-English resources and region 2 had the lowest (38% (6/16)).

Conclusions: Heart transplant center online resources are inadequate, and many do not provide translations beyond the English language. Additional work is needed to standardize heart transplant patient information for a diverse U.S. patient population.

Classifications

Heart transplant, Health literacy, Readability, Websites, Non-English

Introduction

Individuals and populations affected by structural racism and discrimination, such as racial and ethnic minorities and those with limited English proficiency, are disproportionately impacted by the disease burden of heart failure (HF)¹. Centers for Medicare and Medicaid Services and the United States Department of Health and Human Services have shifted focus to redirect resources to better achieve equitable care through addressing inequities in social determinants of health (SDOH)^{2,3}. Of the five SDOH, health literacy is a key component of healthcare access and quality that describes the degree to which individuals can find, understand, and use information and services within the healthcare system⁴. Recent research has shown low health literacy to be prevalent within marginalized communities and is associated with poor heart failure outcomes. For instance, poor health literacy is found in over 39% of patients with heart failure and is associated with lower medication adherence and higher rates of mortality and readmission⁵.

Historically, health literacy has focused on the ability of patients to understand health information. However, there has been an evolving focus on evaluating the role of organizational contributions to health literacy. Organizational health literacy describes the degree to which organizations equitably enable individuals to find, understand, and use information and services⁴. This emphasizes the responsibility of organizations to understand and take a role in improving health literacy in the populations they serve. Over 74% of all US adults use the internet and 61% use it to research medical-related information⁶. Additionally, over 67 million people in the United States speak a foreign language at home⁷. Heart transplantation is the gold standard for advanced heart failure therapy, and timely access

and referral are key to patient outcomes. Transplant center websites are a widely available resource to patients and could encourage underserved populations to seek timely care. However, whether current transplant center websites have adequate readability and availability of additional language resources to meet the information needs of patients with heart failure is unknown.

In that context, we conducted a review of United States heart transplant center websites, identified through the United Network for Organ Sharing (UNOS), to (1) evaluate the readability of website material and (2) evaluate the availability of non-English resources for patients. We hypothesized that a large proportion of heart transplant centers would have website readability significantly higher than the 8th grade average U.S. reading level and limited availability of non-English resources.

Methods

This study reviewed all United States heart transplant center websites identified through the United Network for Organ Sharing (UNOS) in August 2022⁸. Geographic regions were identified by the appropriate categories according to UNOS designations. Of the 143 transplant centers, 4 were excluded for having an inactive status or not having enough content to be evaluated for readability. This study was approved by the Institutional Review Board at the University of Michigan and deemed exempt due to the use of publicly available data and following Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guidelines.

The Fry readability score was our primary scoring metric to assess the readability of websites. Fry readability is used to calculate the U.S. grade level required to understand a piece of text and is designed for most technical documents. The readability score is calculated by the average number of sentences and syllables per hundred words. In addition, three validated secondary reading scores were used to further evaluate websites (i.e., Flesch-Kincaid Grade Level, Gunning-Fog Score, and Simple Measure of Gobbledygook (SMOG)). The Flesch-Kincaid Grade Level readability score is appropriate for secondary and adult-level text and is a common readability score used by many U.S. government agencies. Scores range from 0 to 100, with higher scores correlating to easier readability. Average documents range within

scores of 60-70. The Gunning-Fog Score uses the sentence length and the number of words with three or more syllables to determine a grade level. The ideal score for Gunning-Fog is 7-8. The SMOG Index assesses grade-level readability based on the number of sentences and polysyllabic words to estimate the years of education needed to understand a piece of writing. All readability score scales have been established for assessing written patient-facing content. Websites were additionally evaluated for heart transplant-specific content in non-English languages, including the home page, subpages, and dropdown menus. The non-English resources evaluated included translation services and assistance, Google Translate, and dropdown menus to translate the entire webpage into a given language.

The median readability scores were calculated for all the websites within each region. Standard ANOVA was used to compare readability levels across transplant regions. All statistical tests were performed at the 5% level of significance. Statistical analyses were performed using STATA/MP 17.0 (State Corp., College Station, TX). Finally, website and resource readability were assessed using the Readability Studio Professional Edition program (2020, Oleander Software).

Results

The median Fry readability level to understand websites for all regions was 15, which is equivalent to the level of a college junior (range: 7-17, 7th grade to postgraduate level) (Table 1, Figure 1). There was no statistical difference in median Fry readability levels between regions ($p = 0.16$). The results of the Flesch-Kincaid Grade Level, Gunning-Fog Score, and Simple Measure of Gobbledygook (SMOG) readability scores are shown in Table 1. Of the 139 eligible heart transplant center websites, only 56.1% (78/139) had non-English resources available for patients. Regions 5 (75% (15/20)) and 6 (75% (3/4)) had the highest percentage of non-English resources and region 2 had the lowest (38% (6/16)) (Figure 2). Of the centers that offered non-English resources, 100% offered additional language options other than Spanish.

Discussion

Our study has two key findings that add to health literacy literature in advanced heart failure therapy. First, we found that most of the transplant website information was at the reading level equivalent to a college junior, which is grossly over the U.S. average 8th-grade reading level and the 6th-grade National Institutes of Health (NIH) recommended reading level for medical information. Next, we found that only 56.1% of heart transplant centers offer non-English resources, with variation by region. As a large proportion of patients receive health information online and an increasing number of patients speak foreign languages in the U.S., these findings underscore a significant, modifiable organizational contributor to poor health literacy in the access to advanced heart failure therapy in marginalized populations.

Addressing the SDOH that potentially contributes to inequities in access to life-saving advanced heart failure therapy must be addressed with urgency. To date, there has been no widespread assessment of online educational reading material of heart transplant center websites. While 60% of patients use the internet to research medical information, 98% of transplant centers did not have the appropriate reading level. Ideally, transplant center websites should provide education about transplants and empower patients to seek care. Currently, it appears that websites are not meeting the educational needs of patients with heart failure, who are likely even more impacted by the lack of readability as a result of the cognitive impairment that occurs from HF^{9,10}. Thus, there is an opportunity to develop quality digital resources that support patients' efforts to improve their health and advance equitable care. Websites can improve readability by simplifying word choice and structure as well as avoiding medical jargon. Beyond readability, websites can additionally enhance comprehension by adding visual aids and making websites easy to navigate.

For the 67 million people in the United States who speak a foreign language at home⁷, the currently available patient-facing websites for heart transplant are inadequate, in line with what has been observed for kidney transplant¹¹. Professional medical translation software is readily available and can provide educational material in many languages. Additionally, centers should ensure in-person translation services are available for patients who do not speak English.

Our findings have critical implications for UNOS policymakers and the heart transplant community. The United Network for Organ Sharing and professional transplant societies should consider creating a patient-focused, centralized information source that can be categorized by a person's location and the availability of hospitals able to perform transplants. Establishing a focal place where patients can receive reliable and professionally translated information for heart transplant will improve the transplant communities' contributions to organizational health literacy for patients with heart failure. In the meantime, centers should immediately reevaluate the appropriateness of their online resources for optimal readability and availability of non-English resources. Centers should also review non-patient-facing material to ensure adequate readability and resources to support patients. There is also the potential to increase awareness of heart transplant and facilitate access to transplant centers in a manner that could improve equity.

Our study must be considered considering some important limitations. First, readability scores are highly variable between formulas and do not fully capture the comprehension ability of patients. However, these are established scoring systems and the best currently available. Lastly, many centers have non-public-facing resources that are provided to patients once evaluated for HF. However, because most patients still refer online for medical information, and doing an internet search of transplant centers near them is likely a first step in seeking out care, improving the readability and availability of non-English resources is critical.

Conclusion

Most heart transplant centers have grossly inadequate readability and availability of non-English online resources for patients. Online resources are a critical component in how patients receive and understand medical information. Organizations have a responsibility to provide accessible health-related information that accommodates those with low reading ability and non-English languages. Urgent attention is needed to revamp online educational materials for heart transplant patients, to achieve more equitable access to care.

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Author Photo

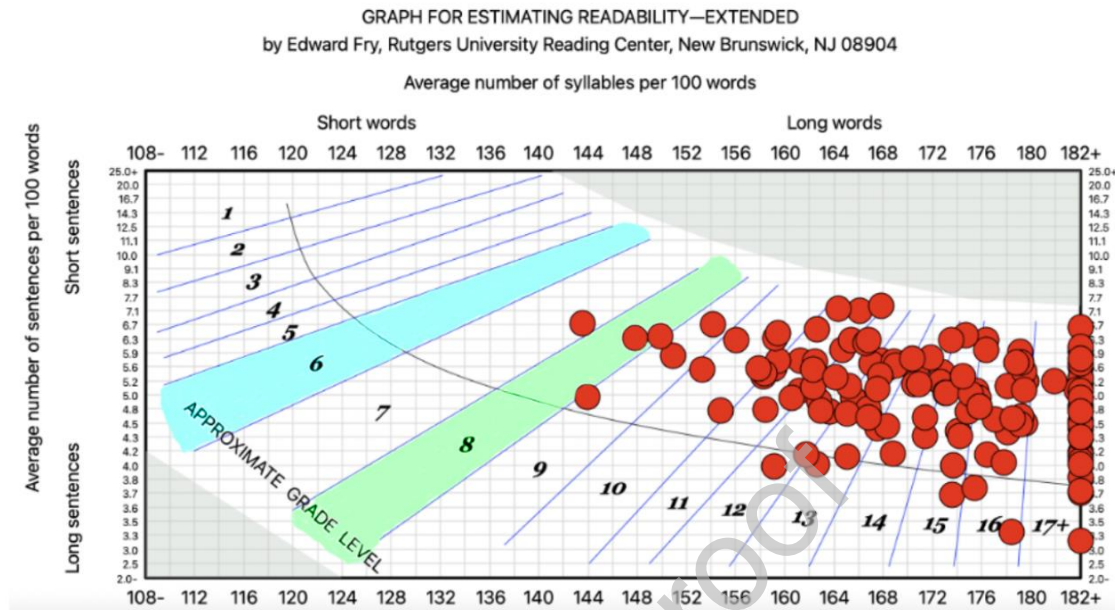


Figure 1: Fry Readability of United States Heart Transplant Center Websites
Most websites had Fry readability scores significantly higher than the average U.S. readability level and the recommended reading level of medical material by the NIH. The median Fry readability score for all websites was 15, which is equivalent to the reading level of a college junior.

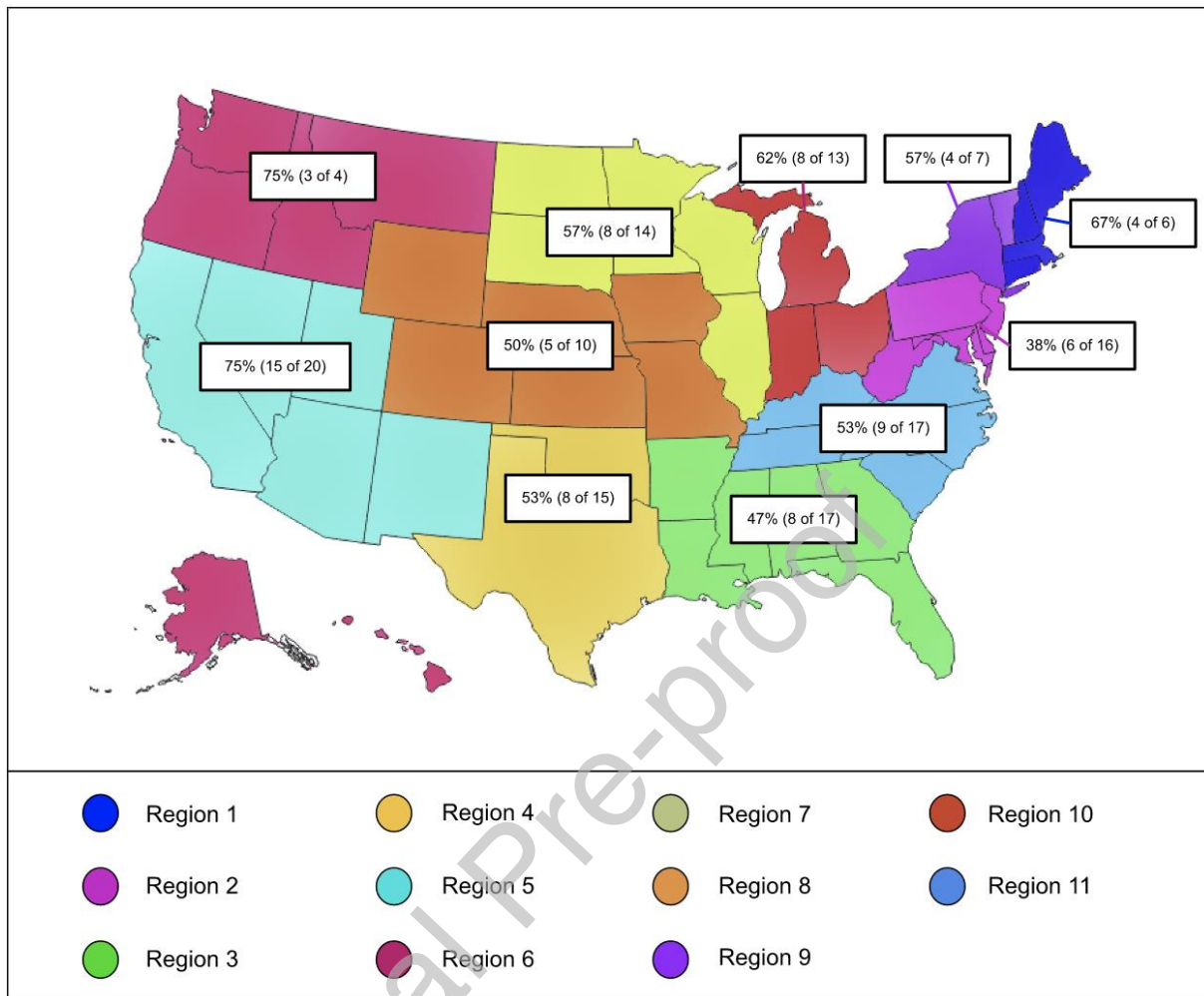


Figure 2. Non-English Resources of United States Heart Transplant Center Websites by Region
 Regions 5 (75% (15/20)) and 6 (75% (3/4)) had the highest percentage of non-English resources and region 2 had the lowest (38% (6/16)).

Table 1. Readability Scores

Test	Descriptor	Median	25th Percentile	75th Percentile
Fry Readability Score	College Junior Level	15	12	17
Gunning Fog	College Freshman Level	13.6	12.3	15
Flesh Readability	Difficult	42	33	50
SMOG Index	14 years of education	14	12.9	15.3

The median Fry readability score was 15, which is equivalent to a college junior reading level. The median Gunning Fog score was 13.6, which is equivalent to a college freshman reading level. The median Flesch readability score was 42, which equates to a difficult text to understand. The SMOG index estimated the median number years of education needed to understand transplant website content to be 14 years.