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Readability of Patient-Reported Outcome Measures for Head and Neck Oncology

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Objectives/Hypothesis: Patient-reported outcome measures (PROMs) are communication tools to help patients convey their disease experience to medical providers and guide management decisions. However, the utility of healthcare outcome measures is dependent on patient literacy and readability of PROMs. If written for a more advanced literacy level, they can misestimate symptoms and add significant barriers to care, especially in the underserved. However, readability of head and neck (H&N) oncology PROMs has not been assessed. The aim of this study was to evaluate the readability of H&N oncology PROMs to assess whether they meet recommended readability levels.

Study Design: Bibliometric review.

Methods: Three readability measures: Gunning Fog, Simple Measure of Gobbledygook, and FORCAST were used to evaluate the readability level of commonly used H&N PROMs. PROMs with sixth grade readability level or lower were considered to meet the recommendations of health literacy experts.

Results: Eight H&N oncology PROMs were reviewed. None of H&N PROMs met health literacy experts’ and National Institutes of Health recommended reading levels. Gunning Fog consistently estimated easiest readability and FORCAST the most difficult.

Conclusions: PROMs are important clinical tools that drive patient-centric care in H&N oncology. All H&N PROMs are written above recommended reading levels and do not meet suggested standards. Future PROMs should be written with easier readability to accurately convey patients’ H&N oncology disease experiences.

Key Words: Patient-reported outcome measure, readability, head and neck oncology.

Level of Evidence: 4

INTRODUCTION

Both head and neck (H&N) cancer and their treatments can lead to substantial symptoms and subsequent quality of life concerns for patients. Their management requires clear communication between the patient and the multidisciplinary cancer care team. A tool used in management of H&N cancers are patient-reported outcome measures (PROMs), which are described by the Food and Drug Administration as “any report of the status of a patient’s health condition that comes directly from the patient, without interpretation of the patient’s response by a clinician or anyone else.”¹,² Use of PROMs has demonstrated improved symptom control, supportive care measures, and overall patient satisfaction. Subsequently, this leads to better patient-centered care and patient safety. However, the utility of PROMs exists only when patients are able to adequately read and understand them, which has led to increased focus on patient health literacy, defined by the Centers for Disease Control and Prevention as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions in the healthcare system.³ Although the average American adult reads at the eighth-grade level, only 12% of Americans have proficient health literacy based on a 2008 study, which is insufficient to understand complex medical jargon.⁴–⁶ Furthermore, underserved patients have even lower literacy.⁷ Thus, the National Institutes of Health and other health organizations recommend publishing healthcare-related information at or below sixth-grade readability levels.⁸–¹³

Literacy experts have developed objective measures to assess readability, defined as the comprehension level a person must have to understand written material, to objectively measure the difficulty of written material, and correlate to a grade level of education of written material correlating these to a grade level of education.¹⁴ These measures are calculated with algorithms based on syllability or word to sentence ratios of texts.¹⁵,¹⁶ Recent studies in other healthcare fields, including medical oncology and orthopedics, have measured readability scores with widely ranging results.¹⁷,¹⁸ Within otolaryngology, prior readability studies of PROMs have analyzed those used for audiology and dysphagia only.¹,¹⁹,²⁰ No prior studies have evaluated H&N PROMs.

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Symptoms drive aspects of patient-centered decision making in H&N oncology care, making readability of these PROMs critical.21 The goal of this study is to analyze PROMs used in H&N oncology using various readability algorithms to evaluate whether they meet recommended readability criteria.22 Based on trends based on literature review of other healthcare fields, we hypothesize that these PROMs have more difficult readability levels than recommended.

MATERIALS AND METHODS

Identification and Inclusion

We performed an institutional review board–exempt bibliometric review of H&N oncology PROMs in the literature. Inclusion criteria for H&N oncology PROMs was based on a systematic review by Boyes et al. that identified thirteen PROMs commonly used specifically for the evaluation of H&N oncology.22 Most recent iterations of PROMs publicly available in full-text form were included. Those not accessible through literature search were excluded including the Head and Neck Cancer Inventory and the H&N Radiotherapy Questionnaire. Modified or condensed versions of PROMs were excluded including the Radiation Therapy Oncology Group Modified University of Washington QoL and functional assessment of cancer therapy-head and neck symptom index (FHNSI-10). The performance status scale (PSS) H&N is intended as a verbally administered PROM and was also excluded. In total, eight PROMs were included in our study (Fig. 1).

Each PROM was obtained by an online PubMed (www.ncbi.nlm.nih.gov/pubmed) database search, manually converted to a text-based document, then reviewed for accuracy by two coauthors. Likert scale answer choices and answer choices with monosyllabic words were excluded from the readability assessment, as these were deemed to have minimal cognitive burden on patients.

Readability Measurement and Analysis

The readability of each PROM was evaluated using three well-known readability scores commonly used in analysis of healthcare materials: Gunning Fog, a Simple Measure of Gobbledegook (SMOG), and FORCAST formulas.15,16 There are no specific criteria for choosing readability algorithms for analysis. Therefore, those used in our analysis were chosen based on frequency of use in the literature, suitability for healthcare material, and applicability for a questionnaire format. Calculations were performed using Readable software (Added Bytes, East Sussex, United Kingdom). Data analysis was performed using Microsoft Excel (Microsoft, Redmond, WA).

The Gunning Fog score is obtained with the equation:

\[
\text{grade level} = 0.4 \times \left( \frac{\text{average sentence length}}{\text{polysyllable words}} \right).
\]

The SMOG score is obtained with the equation:

\[
\text{grade level} = 3 + \sqrt{\frac{\text{polysyllable count}}{30}},
\]

where polysyllable count is measured from 30-sentence sampling. If the narrative is less than 30 sentences, the algorithm is adjusted to take this into account.

The FORCAST score is obtained with the equation:

\[
\text{grade level} = 20 - \left( \frac{N}{10} \right),
\]

where \(N\) = number of monosyllable words in a 150-word sample. If a PROM did not meet the 150-word threshold, FORCAST results were excluded from calculations to maintain validity.

Fig. 1. Patient-reported outcome measures (PROMs) selection process for study.

Fig. 2. Average readability for head and neck oncology patient-reported outcome measure (PROM) by questionnaire. Bars represent mean readability scores for each PROM. EORTC QLQ-H&N = European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Head and Neck Module 43; FACT-HN = Functional Assessment of Cancer Therapy–Head and Neck; HN-QOL = Head and Neck Quality of Life; MDADI = M.D. Anderson Dysphagia Inventory; NDI = Neck Dissection Impairment Index; QoL-RTI/HN = Quality of Life–Radiation Therapy Instrument Head and Neck; UMXQ = University of Michigan Xerostomia Questionnaire; UW-QoL = University of Washington–Quality of Life. [Color figure can be viewed in the online issue, which is available at www.laryngoscope.com.]
TABLE I.
Readability of Head and Neck Oncology Patient-Reported Outcome Measures.

<table>
<thead>
<tr>
<th>European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Head and Neck Module [43]</th>
<th>Gunning Fog</th>
<th>SMOG</th>
<th>FORCAST</th>
</tr>
</thead>
<tbody>
<tr>
<td>University of Washington—Quality of Life [25]</td>
<td>7.9</td>
<td>8.7</td>
<td>10.3</td>
</tr>
<tr>
<td>Quality of Life–Radiation Therapy Instrument Head and Neck Module [26]</td>
<td>6.2</td>
<td>7.6</td>
<td>N/A</td>
</tr>
<tr>
<td>Neck Dissection Impairment Index [27]</td>
<td>11.9</td>
<td>11.6</td>
<td>10.1</td>
</tr>
<tr>
<td>Head and Neck Quality of Life [28]</td>
<td>8.5</td>
<td>9.9</td>
<td>10.2</td>
</tr>
<tr>
<td>Functional Assessment of Cancer Therapy–Head and Neck [29]</td>
<td>7.3</td>
<td>8.4</td>
<td>9.5</td>
</tr>
<tr>
<td>M.D. Anderson Dysphagia Inventory [30]</td>
<td>8.5</td>
<td>9.4</td>
<td>10.3</td>
</tr>
<tr>
<td>University of Michigan Xerostomia Questionnaire [31]</td>
<td>8</td>
<td>8.8</td>
<td>N/A</td>
</tr>
<tr>
<td>Average</td>
<td>8.0</td>
<td>8.9</td>
<td>10.0</td>
</tr>
</tbody>
</table>

N/A = not applicable.

With variations across readability indices, our study weighed all three readability algorithms as equal predictors of readability.

RESULTS

All eight PROMs included in our study had readabilities above the recommended sixth-grade level; thus, none met recommended standards for readability (Fig. 2). The overall readability was 8.8, nearly equivalent to readability at the ninth-grade level. See Table I for comprehensive readability data of analyzed PROMs. Average readability levels for Gunning Fog, SMOG, and included FORCAST scores were 8.0, 8.9, and 10.0 respectively (Table I, Fig. 3). Concordance coefficients between algorithms were calculated using Lin’s concordance correlation coefficient and were as follows: Gunning Fog to SMOG, 0.98; Gunning Fog to FORCAST, 0.61; SMOG to FORCAST, 0.66.

DISCUSSION

Based on our analysis, PROMs used widely in H&N oncology have been written at levels beyond those recommended by health literacy experts. As PROMs demonstrate patients’ unique personal experiences with their disease and help guide medical decision-making, they should be comprehensible. Otherwise, potential misinterpretation between patients and provider may occur. Furthermore, this helps patients advocate for themselves and be a part of their own treatment team. This may be especially useful when patients experience treatment-related toxicity.

The underserved have historically had struggles accessing healthcare; PROMs that are difficult to understand may add an additional barrier to adequate care. This is particularly concerning with the association of socioeconomic status with H&N cancer outcomes. In a prior study, patients with median household incomes of <$38,000 were noted to have 1.5 times the mortality risk compared to patients with an income of >$63,000. Besides increased mortality, there is increased prevalence and later stage of presentation of H&N cancers in the underserved. This striking difference based on socioeconomic status, and by proxy educational status, may further bias PROM data given the high readability requirement for understanding.

Although PROMs indicate symptoms related to H&N cancer, they may also reflect patients’ overall health status. At diagnosis, up to 57% of these patients present with malnutrition and over 10% with weight loss. They often endure difficulty eating and maintaining appropriate nutrition due to cachexia from the cancer itself, tumor burden in the upper aerodigestive tract, or from the arduous treatment modalities. Because malnutrition has an impact on overall survival in H&N cancers, otolaryngologists may be able to identify and address these concerns or safety risks through use of PROMs. They may also involve other members of the healthcare team such as cancer care coordinators, dieticians, speech–language pathologists, or social workers to improve outcomes. With more readable PROMs and thus clearer communication, there could be better symptom control, as well as potential for improved comprehensive patient-centric care. Recent healthcare initiatives have increased focus and cognizance of nationwide health literacy initiatives since the 2000s, most prominently exemplified by the formation of the Patient-Reported Outcomes Measurement Information System network. This has driven the establishment of guidelines to develop, delineate, and verify PROMs utilized in healthcare settings. Despite this, more recently developed H&N PROMs do not demonstrate easier readability.

There are several limitations to our study. Two of the readability formulas, Gunning Fog and SMOG, were intended for running narrative, rather than a questionaire format, which includes informal sentence structures. This format likely skews toward easier readability levels than the traditional narrative form, given abbreviated questions and answer choices. However, SMOG has still been validated as the best suited for healthcare-related materials due to its “consistent results, higher
level of expected comprehension, as well as use of more recent validation criteria to determine reading grade estimates.\textsuperscript{47} FORCAST is the algorithm most appropriate for questionnaire formats; however, it requires 150 words for analysis, which a few PROMs did not meet. Lastly, with medical jargon in PROMs, the comprehensibility is likely higher than measured, as medical terms add complexity unmeasured purely by syllabicity.\textsuperscript{48,49} Thus, readability levels may be even higher than demonstrated by the three measures utilized.

CONCLUSION

Our study demonstrates that H&N oncology PROMs have readability levels that do not meet recommended standards. With higher readability in PROMs, barriers to clear communication between patients and providers are raised, particularly for the underserved patient population, which is disproportionately affected by H&N cancer. This precludes patients from receiving the comprehensive care they need and deserve. To provide patient-centered care, PROMs with appropriate readability should be utilized for the assessment of H&N cancer symptom burden. Readability should be strongly considered with development of future PROMs in the field.

BIBLIOGRAPHY


![Laryngoscope 130: December 2020 Lee et al.: Readability of H&N Oncology PROMs](https://example.com/fig1.png)