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Extending the reach of science – Talk in plain language

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ABSTRACT

There has been increasing interest by the general public to read and share mainstream medical and scientific literature. Consequently, more and more medical journals are adopting strategies to make complex literature more accessible to the lay public. One such strategy is the creation of so called "lay summaries". The benefits of lay summaries can include wider dissemination of knowledge, and is increasingly being recognized as a unique expertise by authors. While on the surface, it may seem to be an easy task to translate scientific literature into a lay summary. However, occasionally authors who are experienced in communicating complex information to a peer group, may struggle with translating their work to an audience with limited medical or scientific background. The objective of this review is to discuss strategies that scientific writers may consider to better facilitate translating scientific literature into lay summaries.

Contents

As research becomes more and more available in digital format from multiple sources, including social media, the medical literature is no longer the sole provenance of the scientific community. Over the past few years, there has been an increasing demand from the general public for concise, accurate information. Accordingly, a number of journals now request that authors adjust or add a section to medical literature to make it more accessible for non-experts (putting the gist in "layman's terms") [1]. For example, *Epilepsy & Behavior Reports* encourages authors to include lay summaries following acceptance of articles for publication. A lay summary is an additional paragraph added to a scientific manuscript that summarizes key points for the general public. Similarly, some funding sources now ask for a lay summary to be included as part a grant application. A lay summary as part of a research manuscript is different from a full article that might be wholly written

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for the general public (e.g., articles that are written for popular science publications).

The purpose of this article is to serve as a guide for authors on crafting the medical literature in a way that is more applicable to the general public. As more authorships apply this writing tool, we expect lay summaries comprising medical research to have a wider audience and better reception, especially with the accessibility of online education. As more than half of internet users look for health-related information via a search engine, online platforms like social media sites have become a popular source for health information [10,11]. Alternative metrics (also called ‘‘altmetric”) is an emerging term applied to assessing web-based literature using many sources of informatics. An altmetric score reflects how well information is shared through social media, including research blogs, and postings of information in social networks [12,13]. If a journal article includes a lay summary, patients and lay population will be more likely to understand, access, and share information. Ultimately, this might lead to a greater impact on web-based information represented by a "score".

Drafting lay summaries can be difficult, given the variability in a readers’ literacy. Health literacy was once defined as ‘‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate healthcare decisions [2].” As part of the U.S. Department of Health and Human Services’ (HHS) Healthy People 2030 Initiative, the definition of health literacy now addresses both personal and organizational health literacy. This revised definition places not only emphasizes reaching the general public, but also addresses health organizations’ responsibility to help patients understand and use health information [2]. To help accomplish this, authors in the medical field could use a style of writing that is understandable at a non-expert reading level [3], in addition to including lay summaries as part of the medical literature.

Although reading skills are not the sole determinant of health literacy, a patient’s ability to read and understand written text can have a major impact on their clinical outcomes [4]. The 2003 National Assessment of Adult Literacy found 36% of American adults do not have the skill set to understand ordinary text and simple documents, making interpretation of the medical literature particularly problematic [5]. Another determinant involves computer literacy, which similarly impacts a patient’s ability to access, interpret, and use online health information [6].

For example, in patients with type 2 diabetes, poor health literacy may predict the lack of glycemic control and be associated with a higher likelihood of microvascular complications. There is some evidence that poor health literacy is more common in people with chronic health conditions, likely because similar socioeconomic factors influence both literacy and health [7]. Despite this, most written resources for patients are still written well above the average American reading level [8]. Brigo et al. reviewed the health literacy of English-written websites and articles for patients with epilepsy [9]. The average readability was at an 11th-grade level and was “difficult.” Experts suggest educational materials should be written at a fifth- or sixth-grade reading level, and definitely not higher than that of an eighth-grader [3].

Writing for lay audiences

Lay summaries, or simplified abstracts of scholarly articles, are a way for authors to make their work more accessible to a larger readership. Lay summaries can help reach new audiences, including readers who aren’t part of the scientific community, or who work in a different field of study. This should not be confused with writing for social media platforms, which will likely necessitate a different approach. Before writing a lay summary, one should consider the audience. It’s likely that a reader outside the scientific community will have the experience to understand scientific writing [1,14]. Additionally, the focus of the lay summary might be different from the goals of the scientific paper itself. Authors should consider what they want readers to take away from the summary. Should readers simply be aware of the overall "gist"? If so, the summary might be organized similarl to the article, only with simpler explanations of the methods, objectives, and significance. Should readers take action based on their interpretation of the information, like seeking different healthcare, learning about different treatment options, or talking to their healthcare team about new symptoms? If so, the summary might look quite different from the conclusions of the article itself.

Another consideration for writers is anticipating where the lay summary will be published. It is likely that articles and summaries will be disseminated online. The way readers look at web contents has evolved over time. Readers now spend more time scanning articles, and make decisions quickly about whether the content is interesting and relevant to them. Authors should deliberately highlight the intent of the summary in the beginning and subsequently reflect on the concepts or conclusions drawn from the information. The remainder of the summary should be clear, concise, and easy to follow.

The following are selected techniques suggested for authors who wish to convey clear summaries of their research for a lay audience.

Avoid jargon

Jargon is the specialized vocabulary that is familiar to people within a field of study, but difficult for those outside the field to understand. Jargon is a major barrier for readers to understand scientific text [14]. For medical personnel, scientific jargon quickly becomes second nature when composing a written work. The more advanced we are within our field, the more difficult it is to recognize when we are using terminology unlikely to be widely interpreted [1]. In this case, it can be helpful to take a step backwards and remember words and concepts that were unfamiliar to us before we completed experience and training. Lerner and colleagues conducted a study and found that patients could only identify analogous words for medical terms about 50% of the time [15]. When writing for a lay audience, writers should use the simplest terms possible. Sometimes, that means giving additional background information that is not present in the original text, and offering brief definitions for important words that can’t be simplified. Authors should avoid using different terms that apply to the same topic, especially after scientific terms have been defined. Table 1 contains a glossary of potential word substitutions that represent scientific terms that are commonly used and appear in epilepsy research. The example below is from an article studying the effects of enzyme-inducing antiseizure medication (ASM) on vitamin D dosing in patients with epilepsy.

> *Original:* ‘This retrospective chart review aimed to characterize the pharmacokinetic interaction between ASMs and vitamin D so clinicians can better assess and monitor vitamin D supplementation in patients on these medications” [16].
> *Simplified:* The goal of this study was to see if seizure medications interferred with vitamin D. This is important because low vitamin D levels cmay lead to bone loss in people with epilepsy. Doctors can use this information to recommend the right vitamin D dose for patients who take seizure medication.

Table 1
Example substitutions for terms commonly used in epilepsy research.

Medical Term	Suggested Substitution
Adverse effects of antiseizure medications	Seizure medicine side effects
Amygdalohippocampectomy	Surgery to remove the inside portion of a temporal lobe
Antiepileptic drug/antiseizure medication	Seizure medicine
Comorbidities	Health problems that happen more often in people with epilepsy
Cortical dysplasia	An area of abnormal brain that was malformed at birth
Cortical resection for epilepsy	Surgery to remove part of the brain where seizures start
Epilepsy syndrome	Type of epilepsy
Epileptologist	Epilepsy specialist
Focal impaired awareness seizure	Staring spell or "small" seizure
Focal to bilateral tonic-clonic seizure	Convulsion or "grand mal"
Hypoxia	Lack of oxygen
Mesial temporal sclerosis	Scar on the brain in the temporal lobe
Neuromodulation	Electrical devices used to control seizures
Psychiatric problems	Emotional health problems

Simplify text

Simplifying text doesn't mean just eliminating jargon. It also refers to sentence structure and length, overall word choice, and phrasing. Limting sentences to less than 20 words improves readability and reduces unnecessary wording [1,17]. One way to test whether a sentence is too long is to read it out loud. A good rule of thumb is, if you have to take a breath while reading, the sentence is too long. Authors should simplify words whenever possible and minimize the number of words over three syllables [17,18]. For example, try "used" instead of "utilized" or "gave" instead of "administered" [19]. In the end, the simplified text might be longer than the original text and that is okay! The simplified text will be much easier for a lay person to read and understand. This is noted by the following examples.

Original: "The association of antiseizure medication (ASM) and bone density abnormalities has long been recognized, however, there remains a lack of consensus on efficacy and optimal vitamin D dosing in patients receiving enzyme inducing and non-inducing ASMs" [16].
Simplified: Patients who use seizure medications are more likely to have weaker bones than other people. Vitamin D helps the body build and keep strong bones. Giving patients more vitamin D can help prevent bone loss. Health professionals disagree on how well vitamin D supplements prevent bone loss in people with epilepsy. There is also disagreement about the dose of vitamin D that patients should take.
Original: This study was a placebo-controlled trial of two antiseizure medications to examine efficacy and safety.
Simplified: Two drugs for seizures were compared to see if they worked without causing side effects. The medicines were compared to a placebo (harmless substance a.k.a. a "sugar pill").

Use an active voice

In the passive voice, the subject of the sentence (the person or thing performing the action) is "missing." For example, in the sentence "The drug was given to the patient," the object ("the drug") is being acted upon, but it is not clear who is performing the action. Using this voice, who is giving the drug to the patient? The passive voice is often used in scientific writing to make the author or investigator neutral [1,14]. By using an active voice, the subject of the sentence comes first and more clearly illustrates "who" is doing "what". For example, "The pharmacist gave the drug to the patient." Using an active voice, the sentence is easier to read and understand.

Original: "Patients with a diagnosis of epilepsy receiving supplemental vitamin D were included in this retrospective chart review" [16].
Active voice: In this study, researchers included patients with epilepsy who took vitamin D.

Use positive phrasing

Positive phrasing makes writing more direct than negative phrasing. It also tends to be more concise. Look for sentences that include "no," "none," "never," "negative," or "not" and try to rewrite them without using "negative" wording [14]. Sentences that use negative phrases inherently impart a negative tone. This can influence how readers perceive the results and might even cause confusion about what the results imply. Think about a common example involving "a negative test." To people outside the medical community, that sounds like a bad thing. But in many cases, a "negative test" suggests an absence of disease and reflects a desirable result.

Original: "There was not an adequate sample size to conduct the adjusted analysis for the ergocalciferol subgroup [16]."
Positive phrasing: The sample size was too small to test patients taking vitamin D.
Original: There was no improvement in satisfaction between patients who had follow-up appointments every 3 months versus every 6 months.
Positive Phrasing: Patients who had doctor's appointments every 3 months were as satisfied as people seen every 6 months.

Simplify titles of lay summaries

Titles of journal articles are often long. Furthermore, the titles may use medical terminology to describe key aspects of the study type, purpose or results. Journal titles usually do not include the implications or relevance of the article. Those comments are usually presented in the Discussion sections of the manuscript. A lay summary should draw attention to the paper by describing the topic of the paper using clear language-specific wording and/or commenting on the potential relevance of the findings to the readership. Using short words and titles will also be easier to understand. The following are two examples of titles used in lay summaries that were published on epilepsy.com (the official website of the Epilepsy Foundation of

America). The titles reflect a journal article that was published in Epilepsy & Behavior.

Example 1. *Original journal article title:* Recent changes in attitudes of U.S. adults toward people with epilepsy – Results from the 2005 *SummerStyles* and 2013 *FallStyles* surveys.

This journal title provies critical information about the focus and findings from a national survey of adults living in the United States. The words are clear and easy to understand to a health care professional. However, the Flesch reading level is relatively low for the ease of interpretation and 4 online citations rate the level of necessity required for interpretation at a high grade level. There are free online tools that exist to aid authors in estimating the reading level of their text (https://www.online-utility.org/english/readability_test_and_improve.jsp_). When the title is *revised as a Lay summary;* "Changes in Attitudes of U.S. Adults toward People with Epilepsy", the shorter title was used in a lay summary that appeared on the website epilepsy.com. By shortening the title and just focusing on key findings (change in attitudes), the interpretive grade level was lowered (between 8 and 10th grade level) and therefore may be more easily understood by more people.

Example 2. Original journal article title: "How do you exercise with epilepsy? Insights into the barriers and adaptations to successfully exercise with epilepsy".

This journal title is engaging to the reader, starting with a question about the main topic. The additional content offers readers more information about what is addressed in the article. If one is revising the title as alay summary, rephrasing it to read "How do you exercise with epilepsy?" may be more engaging for the reader by including a title that is short enough to hold the reader's attention. By using the shorter title, the interpretive grade level may be reduced from 10 to 17 down to 3 to 10, depending upon the online tool used. In this case scenario, the reading ease can be increased as well.

Get feedback

Asking for feedback from colleagues without specific expertise in epilepsy can help you identify additional words or phrases that might be unclear to readers outside of the field [14]. Asking for feedback from members of the target audience can help, too. Asking for help to identify and reduce scientific jargon, and whether the message you intend is able to reach a broad range of readers will improve conveying what an author intends. Engaging individuals with expertise or experience as a writer/journalist may also be a consideration.

Assessing readability

Aside from obtaining feedback, there are many tools available that can help assess readability of the text. Three of the most common tools are the SMOG and Flesh-Kincaid readability formulas, which identify the estimated grade level of a text, and the Flesch reading ease score [20,21]. All three tests are calculated using the number of syllables per word and sentence length. The reading-ease test gives text a rating between 0 and 100 (0 is difficult to read and 100 is very easy to read). You can locate these calculators online. One downside of these tools is that they often overestimate readability, because they do not correct for jargon, sentence structure, or reading comprehension. So, in addition to these tools, authors should use the other techniques that have been outlined to simplify content and sentence structure, and improve clarity.

Conclusion

As healthcare transitions to involve patients to a greater degree, it is becoming more important to ensure that research is being adequately shared with the public [22]. It is also equally important for readers to be able to comprehend the content [21]. Doing so through lay summaries will allow patients or their caregivers to use the scientifc literature to augment the integrity of informed decisions about their care. By using the techniques found in this article, we hope that authors can improve the readability of their text and help make their research more accessible to a lay audience. Text that is easier to read and comprehend is more likely to be shared on virtual platforms to a wider audience includng social media. Lay summaries therefore have the potential to effect a positive impact on web-based informatic scores reflecting widespread interest as well as influencing patient outcomes.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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