## Do Patient Education Materials in Sleep Apnea Hit the Target?

## Shazia M. Jamil, M.D.

Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, Scripps Clinic, La Jolla, California; and Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, University of California San Diego School of Medicine, La Jolla, California

ORCID ID: 0000-0001-7627-7346 (S.M.J.)

The past decades have seen an enormous emphasis on developing patient education resources. The aim of patient education, at a general level, is simple: by improving patients' understanding of their medical diagnosis and treatment options, practitioners might be able to improve their patients' compliance and healthcare outcomes. A variety of patient education materials (PEMs) have been developed by professional societies, medical institutions, and healthcare systems, with similar resources also being created by pharmaceutical and medical device companies. Yet, research has shown that PEMs only produce modest improvements in health-related behaviors (1). As a physician involved in developing medical education materials myself, two factors appear paramount: a low health literacy across the general public and very limited training in designing effective PEMs. The unfortunate facts are that U.S. adults score below the international average for literacy, numeracy, and problem solving in technology-rich environments when

compared with their counterparts across 23 industrialized nations (2). Only 12% of adults possess health literacy proficiency, defined as the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions (3). Furthermore, low health literacy is reported to be associated with billions of dollars in additional healthcare costs and poor health outcomes (4).

How can we better design educational materials for patients to actually help improve their health outcomes? Research shows that authors of health education materials often present information in ways that the general public cannot fully understand. Emphasis has not been placed on fostering textual comprehension for readers, and many presentation approaches that are proven to increase understanding have not been used (5–7). A troubling gap between U.S. adult health literacy rates and the complex health materials created for them is thus hard to miss.

ATS Scholar Vol 3, Iss 1, pp 1–4, 2022 Copyright © 2022 by the American Thoracic Society DOI: 10.34197/ats-scholar.2021-0134ED

This article is open access and distributed under the terms of the Creative Commons Attribution Non-Commercial No Derivatives License 4.0. For commercial usage and reprints, please contact Diane Gern.

The context of obstructive sleep apnea (OSA) presents an excellent research study for the stakes involved in well-designed PEMs. Benjafield and colleagues estimate the prevalence of OSA at about 1 billion people worldwide (8). OSA is accompanied by major neurocognitive and cardiovascular sequelae (9), and therefore optimal management is not just cost effective but potentially cost saving as a result of the prevention of major complications (10, 11). The Institute of Medicine and the National Institutes of Health have recognized OSA as a chronic disease that requires novel adherence strategies to promote enhanced quality of life and to diminish social and economic costs (12).

OSA management, however, is challenging, as the most effective therapies are devices such as positive pressure devices and oral appliances, which require a fair amount of patient understanding and involvement. Patients need to learn how to operate and when to replace various components of a device to fully comply with medical and insurance usage guidelines.

In this issue of ATS Scholar, Robbins and colleagues sought to evaluate the understandability, accessibility, actionability, and readability of widely available web-based PEMs designed for patients with OSA, their families, and the general public (13). A multidisciplinary team of sleep medicine physicians, OSA and positive pressure device adherence researchers, patients, and patient advocates was used to identify 20 web-based OSA PEMs that were most likely to be used, including those developed by academic and medical organizations and by medical device companies. The authors then sought to use five validated health communication assessment tools to evaluate and compare these PEMS, like the U. S. Centers for Disease Control and Prevention's Clear Communication Index, the Patient Education Materials Assessment Tool with different scorecard for print and audiovisual resources, the Simple Measure of Gobbledygook, and the Flesch-Kincaid Reading Level Index.

Their results are alarming. Unfortunately, none of the commonly accessed, webbased sleep apnea PEMs that have been developed by major professional societies, healthcare organizations, and medical device companies had an acceptable score on the Clear Communication Index for clear and effective communication. Only three (15%) met the cutoff score for both understandability and actionability on the Patient Education Materials Assessment Tool dimensions, and only one PEM (5%) had an acceptable score on reading level at sixth grade or lower, noting that the American Medical Association and Department of Health and Human Services recommend that PEMs be written at around the sixth- to seventh-grade reading level or lower (14). Furthermore, none of the 20 PEMs had a passing score on more than one dimension, such as clarity and readability.

Robbins and colleagues are to be congratulated on taking interest in this often-overlooked but critical research area. We now have a glimpse of how understandable patient materials developed by experts in the field of OSA really are. Their study is also among the first available in the literature to apply validated health communication tools to evaluate OSA educational materials.

Their study has limitations. The education level of the patients or patient advocates on their team was at the college level or higher. Only web-based PEMs were evaluated, and the study did not analyze PEMs available within electronic medical record systems, which could be more widely used by clinicians and sleep centers directly caring for patients with OSA and perhaps more widely distributed to them during the process of diagnosis, treatment, and health provider visits. The study may have benefitted from also using a comprehensive suitability score like the Suitability Assessment of Materials instrument, which takes into account a material's learning stimulation, reader motivation, and cultural appropriateness (15). Nonetheless, their study has provided a major contribution to the field of health education.

As clinicians, we want to help patients improve their ability to use a given therapy and their ability to comply with an intervention through the long term. OSA management is challenging, and this study has brought to light gaps in health communication in patient materials that have serious implications for the efficacy of current PEMs produced in this field. The gap is expected to be wider for those with low English-language proficiency, who may have more limited health literacy than is already reported. The increasing ethnic, racial, and cultural diversity of the United States therefore further underscores that improved patient understanding of medical information, led by professional societies, healthcare institutions, and clinicians, is critical to achieving health equity.

Once developed, PEMs should be evaluated with validated health education assessment tools to evaluate their

suitability, alongside effective recommendations that outline steps in writing, designing, and revising PEMs (16, 17). They should also undergo feedback from the patient population before becoming widely available. With respect to OSA, professional societies committed to sleep medicine, such as the American Academy of Sleep Medicine, American Thoracic Society, and American College of Chest Medicine, could develop a task force of clinical educators. They could combine their efforts to develop OSA-related PEMs, similar to the consensus clinical guidelines published by multiple professional societies. This joint task force could learn from and respond to the significant variability found in this study between various PEMs on understandability and actionability scores. This would also reduce duplicate efforts from these organizations. Developing validated PEMs could make a clinician's task easier when it comes to referring a patient to educational materials. It could reduce the burden for patients and the general public in attempting to search for the most effective PEMs for OSA. One thing is for certain: professional societies, clinicians, and institutions have a shared responsibility in the "arc of health literacy" for population health to provide critical take-home messages that patients can easily understand and use (18).

<u>Author disclosures</u> are available with the text of this article at www.atsjournals.org.

## REFERENCES

- 1. Giguère A, Légaré F, Grimshaw J, Turcotte S, Fiander M, Grudniewicz A, *et al.* Printed educational materials: effects on professional practice and healthcare outcomes. *Cochrane Database Syst Rev* 2012;10:CD004398.
- 2. Organisation for Economic Cooperation and Development (OECD). OECD skills outlook 2013: first results from the survey of adult skills. OECD [accessed 2022 Mar 16] Available from: https://

www.oecd-ilibrary.org/education/oecd-skills-outlook-2013/summary/english\_9789264204256sum-en?parentId=http%3A%2F%2Finstance.metastore.ingenta. com%2Fcontent%2Fpublication%2F9789264204256-en.

- US Department of Education, National Center for Education Statistics (NCES). The Health literacy of America's adults: results from the 2003 National Assessment of Adult Literacy. NCES [accessed 2022 Mar 16]. Available from: https://nces.ed.gov/pubs2006/2006483.pdf.
- Baker DW, Parker RM, Williams MV, Clark WS. Health literacy and the risk of hospital admission. *J Gen Intern Med* 1998;13:791–798.
- 5. Kools M, Ruiter RA, van de Wiel MW, Kok G. Increasing readers' comprehension of health education brochures: a qualitative study into how professional writers make texts coherent. *Health Educ Behav* 2004;31:720–740.
- Whittingham JRD, Ruiter RAC, Castermans D, Huiberts A, Kok G. Designing effective health education materials: experimental pre-testing of a theory-based brochure to increase knowledge. *Health Educ Res* 2008;23:414–426.
- Lambert K. Art and science of designing patient education material for the 21st century. *Nutr Diet* 2019;76:493–495.
- Benjafield AV, Ayas NT, Eastwood PR, Heinzer R, Ip MSM, Morrell MJ, et al. Estimation of the global prevalence and burden of obstructive sleep apnoea: a literature-based analysis. Lancet Respir Med 2019;7:687–698.
- Redline S, Young T. Epidemiology and natural history of obstructive sleep apnea. Ear Nose Throat J 1993;72:20–21, 24–26.
- Ayas NT, FitzGerald JM, Fleetham JA, White DP, Schulzer M, Ryan CF, et al. Cost-effectiveness of continuous positive airway pressure therapy for moderate to severe obstructive sleep apnea/ hypopnea. Arch Intern Med 2006;166:977–984.
- Frost & Sullivan. Hidden health crisis costing America billions: underdiagnosing and undertreating sleep apnea draining health care system. American Academy of Sleep Medicine; 2016 [accessed 2021 Dec 4]. Available from: https://aasm.org/resources/pdf/sleep-apnea-economic-crisis.pdf.
- Riley RW, Powell NB, Guilleminault C, Clerk A, Troell R. Obstructive sleep apnea: trends in therapy. West *J Med* 1995;162:143–148.
- Robbins R, Dudley KA, Monten KN, Le C, Hanes S, Patel SR, et al. A health communication assessment of web-based OSA patient education materials. ATS Scholar 2022;3:48–63.
- 14. Weiss BD. Health literacy: a manual for clinicians. Chicago: American Medical Association; 2003.
- Doak CC, Doak LG, Root JH. Teaching patients with low literacy skills, 2nd ed. Philadelphia, PA: J.B. Lippincott; 1996.
- Aldridge MD. Writing and designing readable patient education materials. *Nephrol Nurs J* 2004;31: 373–377.
- Vahabi M, Ferris L. Improving written patient education materials: a review of the evidence. *Health Educ J* 1995;54:99–106.
- 18. Koh HK, Rudd RE. The arc of health literacy. JAMA 2015;314:1225-1226.