Improving Health Literacy

The New American Thoracic Society Guidelines for Patient Education Materials

Christopher G. Slatore^{1,2,3}, Hrishikesh S. Kulkarni⁵, Judy Corn⁴, and Marianna Sockrider⁶

¹Center to Improve Veteran Involvement in Care, and ²Section of Pulmonary and Critical Care Medicine, Veterans Affairs Portland Health Care System, Portland, Oregon; ³Division of Pulmonary and Critical Care Medicine, Department of Medicine, Oregon Health & Science University, Portland, Oregon; ⁴American Thoracic Society, New York, New York; ⁵Division of Pulmonary and Critical Care Medicine, Department of Medicine, Washington University in Saint Louis, Saint Louis, Missouri; and ⁶Pediatric Pulmonary Section, Department of Pediatrics, Baylor College of Medicine, Houston, Texas

This editorial introduces the newly released American Thoracic Society (ATS) guidelines for preparation of ATS-sponsored patient education materials and provides the background for this initiative, with emphasis on the broader objective of the organization to promote health literacy for patients who suffer from a chronic lung disease.

Health literacy is the “capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (1). Unfortunately, many people lack basic health literacy skills (2), and this deficit is associated with a host of poor outcomes (3). Low health literacy disproportionately impacts people with disadvantaged socioeconomic characteristics and likely underlies many aspects of health care inequity (4, 5). It is also costly, as it is associated with increased health care use (6) and decreased adherence (7). Among patients with respiratory diseases, low health literacy is associated with multiple adverse health behaviors and outcomes (8–18).

Many organizations and institutions have recognized the critical role health literacy plays in facilitating and improving patient-centered outcomes. For instance, the

U.S. Department of Health and Human Services released a National Action Plan to Improve Health Literacy, with a primary goal of providing patients with easy access to accurate health information (19). Similarly, the Institute of Medicine has called for comprehensive strategies to improve health literacy (20), and the Joint Commission emphasizes patient-centered communication as a means to improve health equity (21).

Despite this widespread recognition of the importance of health literacy, the quality of educational materials available for patients and families is variable (22, 23). Regarding respiratory illnesses, reviews of online patient education materials regarding smoking cessation, asthma, idiopathic pulmonary fibrosis, and cystic fibrosis have found the quality of the materials was often low and sometimes misleading (24–29). A similar review of chronic obstructive pulmonary disease materials on YouTube showed substantial variation in quality as well (30).

To improve health literacy and subsequent patient-centered outcomes, tailored communication regarding the risks and benefits of tests and treatments may be helpful. For instance, a systematic review found that patient education interventions

may improve overall health outcomes for patients with asthma (31). Self-management programs, a core component of pulmonary rehabilitation and other behavioral interventions, often incorporate methods to increase patients’ knowledge (32–35). Although more research is necessary to determine how best to design and implement educational materials and interventions (36), they are likely an important way to improve health outcomes.

The ATS has a long history of producing patient and family educational materials that are accessible to people across a broad range of health literacy. Indeed, developing high-quality educational materials is a core component of the mission of the ATS to disseminate and apply research findings directly to patients. The current portfolio of ATS patient education materials includes more than 100 Patient Information Fact Sheets on specific clinical topics and other materials (37).

Patient education topics are chosen through a variety of means, including those supported by ATS Public Advisory Roundtable organizations, identified by committees, assemblies, or individual members or related to ATS guidelines and statements. The development and editing of materials is done by a

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Correspondence and requests for reprints should be addressed to Christopher G. Slatore, M.D., M.S., 3710 SW U.S. Veterans Hospital Road, R&D 66, Portland, OR 97239. E-mail: christopher.slatore@va.gov

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multidisciplinary team, including nurses, physicians, scientists, and health educators.

Although all of our materials can be directly accessed by patients, we emphasize their use in the context of clinical care to facilitate and enhance communication between clinicians and patients. Clinicians are increasingly expected to be competent in multiple areas of communication with their patients (38). By using our materials, clinicians can more easily meet core communication competencies and measures (such as the Meaningful Use criteria the Centers for Medicare and Medicaid Services [39]).

Success of the Patient Information Series and widespread interest in developing more such patient materials has generated calls for guidelines to standardize the development process and the style and readability of the materials developed by ATS. In response, the ATS has developed the Patient Education Materials: Guidelines for the American Thoracic Society (P-GATS) (37).

The P-GATS include a step-by-step guide for creating new educational materials (Figure 1). We hope this improved clarity and transparency will increase the ability of members, especially those early in their career, to create new materials. By emphasizing the “bottom-up” approach, all members can be empowered to create new materials. Importantly, a core step in the process is to conduct a needs assessment. Many other organizations provide patient education materials addressing respiratory topics, and we do not want to duplicate existing

high-quality materials (40). Instead, the ATS prioritizes the creation of new educational materials where gaps exist in either content or patient accessibility. By delineating this process, the P-GATS will help us better fill these gaps.

We want to emphasize the rigor with which our educational materials are developed to provide patients and health care providers with confidence that the materials are evidence based and of the highest quality. ATS materials are written by content experts and then peer reviewed for accuracy. Next, health education and behavioral science experts collaboratively review and edit the materials, using explicit criteria to maximize patient accessibility, including assessment of reading level, language, cultural sensitivity, medical jargon, and formatting. Instruments to assess these variables are included in the appendix of the P-GATS. Throughout the process, Public Advisory Roundtable members are actively engaged to ensure that patients’ and families’ concerns are included in the materials. All content is carefully vetted to avoid commercial bias and other conflicts of interest. Finally, materials are reviewed at least every 3 years for currency. This formula helps ensure our materials can be used as communication tools to improve knowledge for patients and to better enable them to participate in their medical care and decision making with their clinicians (19).

The ATS recognizes the need to create new types of materials and to use a variety of formats, such as audio, video, and mobile apps. For example, shared decision making has been shown to improve asthma inhaler

adherence and quality of life (41), decisional conflict for patients with cystic fibrosis considering a lung transplant (42), and improved knowledge of common critical care treatments and concerns (43). Decision aids that foster shared decision making may be particularly useful tools for patients with low health literacy (44). We recently developed our first decision aid in response to the Centers for Medicare and Medicaid Services mandate for patients considering lung cancer screening (45). Our decision aid is evidence based and meets the standards of the International Patient Decision Aid Standards (46). We hope to use the framework established by the P-GATS to produce more decision aids in the future.

In addition to new types of written materials, we recognize that many patients want access to health education materials in nonwritten formats. For example, presenting information in a video format may be associated with improved knowledge (47). However, the quality and accessibility of these media are inconsistent (30), and although there has been an explosion in the number of apps for patients with asthma, their quality is variable, and the ability to improve outcomes is unknown (48, 49). The P-GATS will be a “living document” with periodic updates and serve as a platform on which these new materials can be built while still meeting our high standards regarding both content and patient accessibility.

The new ATS Guidelines for Patient Education Materials signals the commitment of the ATS to make a

Figure 1. Overview of process for creating and developing patient education materials. AJRCCM = American Journal of Respiratory and Critical Care Medicine; LOI = Letter of Intent. Reproduced by permission from Reference 50.

wide-ranging and direct impact on improving health literacy and health outcomes for patients with respiratory, sleep, and critical illnesses. All ATS and Patient Advisory Roundtable members are

invited to participate in the development of new materials. We are hopeful that the guidelines will pave the way for continuous improvements in the provision of the highest-quality materials that patients and

families need, want, and can easily access and use. ■

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