

Mismatch Between Skills of Patients and Tools in Use: Might Literacy Affect Diagnoses and Research?



Findings from US Department of Education surveys of adult literacy skills conducted in 1992 and again in 2003 indicate that a majority of adults, although able to read, are constrained in their ability to use print materials and, as a result, are limited in their participation in today's society and economy^{1,2}. These findings caught the attention of researchers in the health sector and inspired research into the possible links between literacy skills of individuals and health outcomes. Over the past 2 decades, health literacy research has grown exponentially, with over 1000 peer-reviewed articles published in public health and medical journals this decade alone. Simultaneously and throughout the industrialized world, health systems and protocols for disease prevention, management, and care were becoming increasingly complex and were requiring sophisticated literacy skills from the public.

At the turn of this century, many researchers in this new field were focusing attention on and measuring the skills of patients, often implying that the findings of untoward health outcomes could be attributed to limited skills of the patients³. Research to date does provide clear evidence that patients with limited literacy skills are less likely to engage in preventive activities, participate in screening, manage a chronic disease, or know about their illness or medicine⁴. Further, studies have examined mortality as well as morbidity differentials based on literacy skills of patients, indicating a profound effect^{5,6}. However, one's appreciation of and facility with prose, poetry, or documents may have little to do with health, and no theory leads to such a conclusion. On the other hand, a mismatch between the literacy skills of patients and the demands and assumptions of health systems, including the communication skills of health professionals, may well affect one's ability to take action for health promotion and protection, for disease prevention and efficacious management, and for access and followup to care.

Highlighted across multiple literature reviews and annotated bibliographies are 2 predominate strands of research in this new field⁷. The first focuses on skills of individuals —

primarily of patients. First, as represented with a few hundred publications, are studies examining differences in health behaviors and physical markers of health status between those patients with strong reading skills and those patients with limited reading skills. Research findings have established clear links between patients' skills and health outcomes⁸. Current inquiries are expanding the scope of study with attention to a broader range of literacy skills that include oral expression, listening skills, and mathematical skills as well. Findings from newer studies further substantiate differences in outcomes between those with stronger skills and those with more limited skills⁹. At the same time, there are few publications related to efficacious action to address these stark differences, and evaluation studies focused on improving skills are scant. Further, few if any studies have examined the skills of practitioners — in public health, in medicine, or in other health fields. Certainly one's reading ability and listening skills are dependent on the clarity of the text and usability of the tools, as well as on the clarity of the writer and the skills of the speaker.

A second strand is focused on the demand side of the equation. Publications in this area number over 800 and primarily focus on assessments of printed and posted health materials designed for patients and the public. New research in this area is expanding through examinations of materials displayed on computer screens as well as of website characteristics that support or inhibit easy access to information. New publications indicate an interest in the literacy-related expectations and demands of health institutions with examinations of the health literacy environment of healthcare facilities. In general, study findings indicate a mismatch between documented literacy skills of the public and health system-level demands as expressed in print, in oral exchanges, online, and in the physical environment^{10,11}.

Research undertaken and insights gleaned in this new field of health literacy have implications for rheumatology practice and research. Patients managing arthritis, like those

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managing other chronic diseases, need sophisticated literacy skills. Patients with autoimmune diseases are expected to read prose to understand their diagnosis and treatment options, comprehend documents such as prescription labels, consider and then be on the alert for side effects, use tools such as clocks and calendars to manage medicines taken at unusual intervals, find words to describe symptoms and changes, and follow the rheumatologist's words and explanations in discussions. Along the way, they navigate the hallways and paperwork of institutions to gain access, to be on time for appointments, to consent to undergo procedures, to maintain coverage, or to take part in research. At the same time, the materials and the words offered to patients may not be suitable and may not serve as the tools they were meant to be.

The field of health literacy studies is substantive, and researchers and practitioners in rheumatology have long contributed to the growing body of literature. For example, researchers in rheumatology have been studying literacy level of patients¹², examining the materials they develop and use¹³, studying the match between the reading level of materials and the skills of the intended audiences¹⁴, exploring the influence of literacy on recruitment processes¹⁵, and evaluating efforts to improve care through attention to literacy¹⁶.

At the same time, many questions have yet to be posed and studied. Attention to Hirsh and colleagues' contribution¹⁷ in this issue of *The Journal* is clearly warranted. This study opens an area of inquiry not yet explored. The authors challenge us to examine the match or mismatch between reading skills and the demands/assumptions of our materials in order to consider the effect on our research inquiries, our diagnostic processes, and ultimately, our efforts to mobilize and sustain efficacious action for health. This interesting study by Hirsh and colleagues examines a possible link between patients' literacy skills and tools in common use — those important measures used in research and in clinical practice that influence the researchers' analyses and the clinician's decisions and actions. Thus, the focus of the study moves beyond attention to patient-oriented print information and instead draws our attention to tools used in diagnostic processes and the implications of a mismatch. Further, it provokes additional attention to the broad range of literacy skills beyond reading alone to include numeric skills and concepts. This insightful study sets a foundation for further explorations that should strengthen patient-centered practice by further exploring and then eliminating literacy-related barriers to efficacious patient/provider communication.

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