

Headache Literacy- A definition and theory to help improve patient outcomes of diverse populations and ameliorate headache and headache care disparities

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In this work, we will define headache literacy (HL), provide a rationale for the need for increased HL, discuss what we know and the potential shortcomings of current headache education interventions, and briefly propose how domains of HL can be leveraged to develop interventions to improve headache outcomes and improve disparities in these outcomes.

In spite of growing public and professional awareness, disparities in pain care still persist.(1) The AHRQ reported in 2012 that “disparities in quality and outcomes by income, race, and ethnicity are large and persistent, and were not...improving substantially.” (2) At about this same time, an Institute of Medicine (IOM) report on chronic pain identified the development of interventions targeting health disparities in pain as a major research priority and guided the development of the National Pain Strategy (NPS). The National Pain Strategy suggests disparities in pain care including headaches may be due to conscious and unconscious biases and negative attitudes, beliefs, perceptions, misconceptions about higher-risk populations groups (e.g. race and gender biases), lack of sufficient knowledge of behavioral and biological issues that affect pain, management and data to understand pain and its treatment in higher risk and vulnerable populations, and pain itself.(1)

There is a paucity of research regarding racial/ethnic disparities and in methods of ameliorating racial/ethnic disparities in headache medicine. A summary of the literature by Shavers et al suggests racial/ethnic disparities in

pain may be due to the following: a) limited access to health care and appropriate analgesics; b) patient access to or utilization of pain specialists; c) miscommunication and/or misperceptions about the presence and/or severity of pain; d) patients' attitudes, beliefs, and behaviors that influence the acceptance of appropriate analgesics and analgesic doses; and e) providers' attitudes. knowledge and beliefs about patient pain.(3)

Based on evidence on the etiology of racial/ethnic disparities in pain, we might categorize the sources of disparities in pain as system/environment-generated, provider-generated, and/or patient-generated. Headache is the leading pain syndrome and reason for medical consultation, especially for neurological evaluation. (4, 5) Tension type headache and migraine are ranked as the second and third most common prevalent disorders, respectively, and migraine is the seventh-highest specific cause of disability worldwide.(6)

Disparities in headache and migraine exist in the U.S. (7-13) I hypothesize that a key factor underpinning headache care disparities may lie in patients' headache literacy (HL).

In general, health literacy skills can be defined as 'the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health' ([World Health Organization, 2015](#)). Health literacy is becoming widely acknowledged to be a significant cause of health disparities. (14-17) Prior literature has not defined or well-described health literacy specifically regarding

headaches. However, adapting the WHO 2015 definition, I propose a definition of headache literacy (HL) as “the personal characteristics and social resources for individuals and communities to be empowered to access, understand, and use information and services to make informed decisions regarding headaches.”

Headache literacy may lead to awareness and use of headache-specific treatments, headache specialists, improved communications, decreased misperceptions, decreased medication overuse headache, and early and safe health intervention-seeking behaviors, thereby, reducing morbidity of headache disorders and increasing quality of life.

Rothrock et al demonstrated that patients with intensive education on headaches and appropriate care had a significantly greater reduction in mean MIDAS score, a reduction in mean headache days per month and a greater reduction in functionally incapacitating headache days per month, exhibited less analgesic overuse and need for abortive therapy, were more adherent to prophylactic therapy prescribed, and made fewer headache-related calls to the clinic or unscheduled visits. (18) These researchers then sought to expand their “headache school” program interregionally; however, this program failed for several reasons, many of which appear to be related to methodological issues and not the education itself.(19) Extrapolating from this program, one may consider other methodologies to increase participation and get a better understanding of patient demographics, cultural behaviors and influences, vernacular, etc. (e.g., qualitative, mixed-method, community based participatory

research). Indeed the authors concluded, "...we learned the bittersweet lesson that such educational initiatives should be tailored to the particular characteristics of the patient population for which they are intended." In addition, studies of headache educational programs would likely need to be well funded and given adequate time to complete and to assess longer-term outcomes after completion of the program. (19)

On the other hand, although headache literacy has an educational component, it is not just headache knowledge. Attitudes, beliefs, culture and perceptions all play a role in "personal characteristics", an integral part of HL. Social resources contribute to an adequate definition of HL. In addition, effective patient-provider communication is an integral part of HL. The ability to effectively receive and transmit information is essential to HL. In a review of 21 studies, Steward et al found that effective patient-physician communication positively affected patients' outcomes in areas such as pain, anxiety, functional status, and physiologic measures of blood pressure and blood glucose. (20) Interpersonal skills and communication have also been an Accreditation Council for Graduate Medical Education (ACGME) requirement. (21) Patient-provider communication may further improve quality of care and patient satisfaction which may result in better outcomes from headache sufferers.(22)

Instruments such as the short test of functional health literacy in adults (S-TOFHLA), the rapid adult estimate of adult literacy in medicine (REALM), and new vital sign (NVS) are commonly used to assess health literacy.(23-25) However, these generic measures of health literacy obviously lack many terms

germane to headache medicine and do not exhaustively take into account “patient characteristics” and/or “social resources” aside from education.

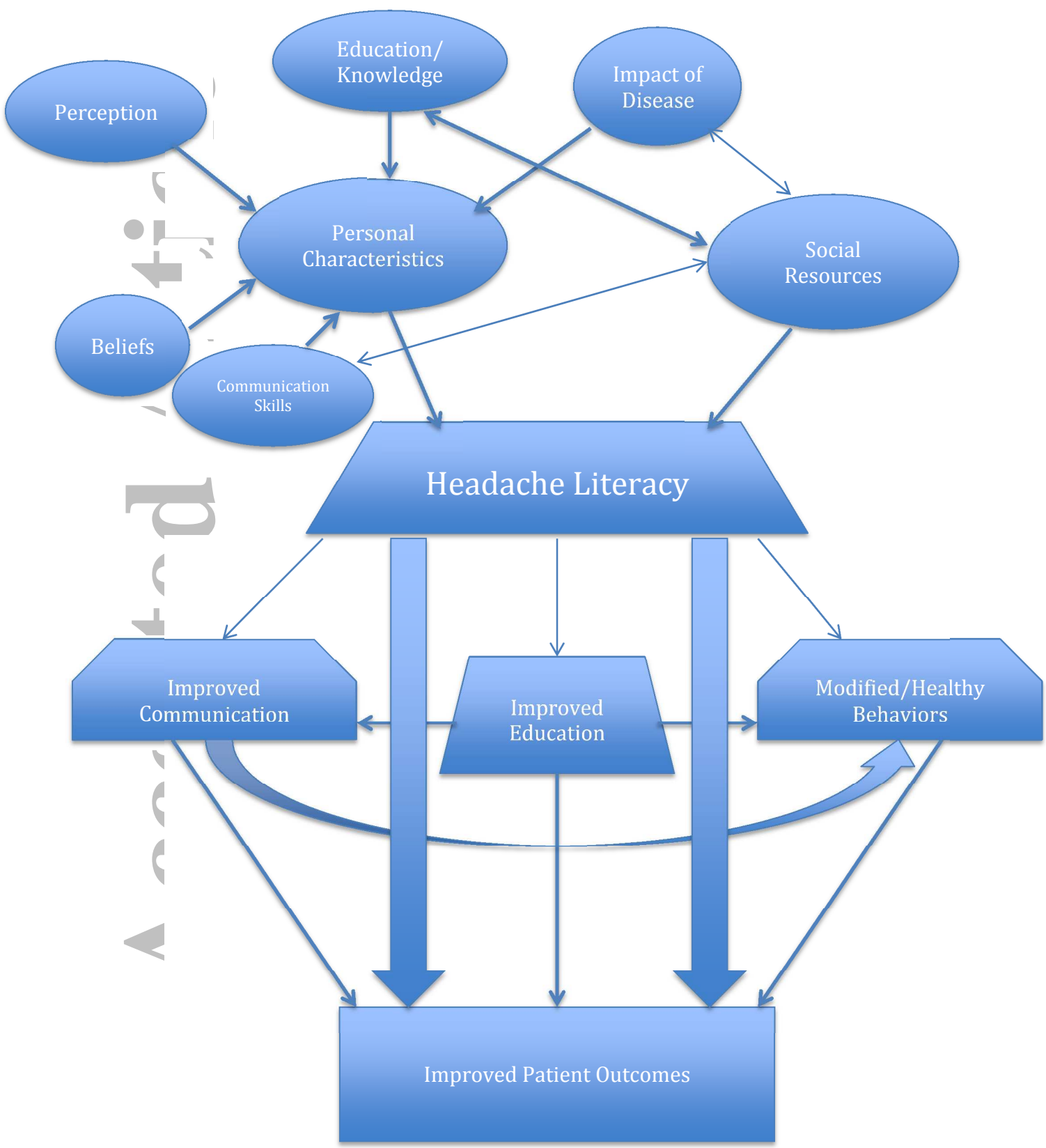
Headache literacy requires patients to not only “know” information about headaches, but they also need to be able to understand, access, and utilize the knowledge.

An adequate and comprehensive definition of the key components of headache literacy is an essential first step for the development and evaluation of effective interventions to improve headache literacy and outcomes. Key components likely include headache knowledge, perceptions, beliefs, overall literacy, and other factors influencing headache decision-making (e.g. behaviors, impact, burden, modes of communication, methods of obtaining information, etc.) in patients that may contribute to headache literacy. These elements likely vary among and possibly within different communities, cultures and/or race/ethnic backgrounds. Enhancing HL among individuals may be a critically important mechanism to improve patient outcomes of diverse populations and ameliorate headache/headache care disparities. Well-designed studies are needed to test this hypothesis of the key role of headache literacy in disparities in headache care and outcomes. These in turn will provide the foundation for the development and rigorous evaluation of health system and community-specific interventions to improve headache outcomes.

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