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The Montana State University Conceptual Model of Complementary and Alternative Medicine Health Literacy

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Abstract

This article aims to present and describe a model of complementary and alternative medicine (CAM) health literacy. The model is the conceptual basis for CAM health literacy, which is operationally defined as the information about CAM needed to make informed self-management decisions regarding health. Improving health literacy is a national priority, and widespread use of CAM has added to the complexity of this task. There are no currently available models or measures of health literacy regarding CAM. The authors developed the model using an iterative process of deriving concepts, constructs, and empirical indicators from the literature and the author's prior work, review and critique by experts, and revision. The model of CAM health literacy can serve as the basis for future research on the use and efficacy of CAM and the constructs and concepts within it can be used to identify points of intervention for research or for clinical practice. It is anticipated that the model will have scientific and clinical application for assessing health literacy in other self care decision-making situations.

Health literacy is a critical problem in the United States, with nearly 9 out of 10 adults having difficulty using routine everyday health information from providers, retail outlets, and the media (U.S. Department of Health and Human Services, 2010). Inadequate health literacy has been shown to be associated with a wide variety of adverse health outcomes (Baker et al., 2002; Berkman et al., 2004; Gazmararian, Williams, Peel, & Baker, 2003; Mancuso, 2009; Weiss & Palmer, 2004). In health care situations, skills beyond functional literacy are required to sort through and comprehend the vast amount of information available and to choose the most appropriate information upon which to base actions. Adding to the complexity of health care decision making for U.S. consumers is the increased popularity of complementary and alternative medicine (CAM). Nahin, Barnes, Stussman, and Bloom (2009) found that U.S. adults spent \$33.9 billion out of pocket on CAM in 2007

and nearly two thirds of that amount was for self-care or self-administered CAM products and materials. Although there are a few models and measures of health literacy in the literature, none focuses on health literacy specific to CAM.

The overall goal of the research is to develop a sound CAM health literacy measure. An initial step in that process is the development of a conceptual model. The purpose of this article is to present and describe the model of CAM health literacy.

Background

Improving health literacy is a major priority in the nation's health care policy, research, practice, and education arenas, and is a continuing objective of Healthy People 2020 (U.S. Department of Health and Human Services, 2008). In addition, the Institute of Medicine (IOM) included health literacy as 1 of 20 priority areas that are keys to health care quality improvement (Adams & Corrigan, 2003). The current health care marketplace demands that consumers be active participants in their health care; however, many consumers do not always have the knowledge and skills to seek accurate and adequate information. Tu and Hargraves (2003) found that the majority of American health consumers of all ages did not seek information about their health conditions; and that more than half the individuals with chronic health problems sought no information about their problems.

Health literacy is critical to making complex health care decisions and may also affect the ability to successfully obtain treatment. It has been shown that people with poor health literacy have more difficulty understanding and processing written and oral instructions and navigating health care environments than do those with sufficient literacy. For example, Grubbs, Gregorich, Perez-Stable, and Hsu (2009) found that the ability of individuals to understand basic health information may have a significant effect on whether they can successfully navigate the health behavior protocols associated with receiving an organ transplant, such as a kidney.

Continually rising health care costs are also a factor in making health literacy a priority. Better informed consumers often choose more conservative and less costly treatment options for certain conditions (e.g., selecting medication and rest rather than surgery for back pain; Tu & Hargraves, 2003). It is critical that consumers have sufficient health literacy to understand the associated risks and benefits of various treatment options so that choices can be based not just on financial cost but also on health care quality and effectiveness. To make informed health care decisions, consumers must be able to identify reputable information sources as well as know their rights and responsibilities with respect to health care.

Despite the published definitions, there continues to be significant disagreement on what constitutes health literacy and how to measure it. The IOM (2004) found that none of the existing measures approach literacy demands on consumers from different health contexts, such as those needed for decision making about use of CAM.

In today's health care arena, the need for health literacy is heightened by the increased number of treatment approaches, providers, and products, including the broad array of CAM practices and products. CAM has become an important component of the U.S. health care

system as consumers increasingly turn to these therapies and practices as an adjunct to or substitute for conventional health care (McFarland, Bigelow, Zani, Newsom, & Kaplan, 2002). Because CAM therapies are often self-selected, unregulated, and untested, decisions about their use may be more complex and outcomes harder to evaluate.

Individuals have a variety of reasons for using CAM, including symptom relief, management of chronic illness, ineffectiveness of allopathic treatments, dissatisfaction with allopathic care, concerns about adverse effects of allopathic care, and desire for control. Those most likely to use CAM therapies are women, younger, with higher incomes and more education living in the western United States (Astin, Pelletier, Marie, & Haskell, 2000; Shreffler-Grant, Hill, Weinert, Nichols, & Ide, 2007). Despite the widespread use, consumers tend not to inform allopathic providers that they use CAM (Eisenberg et al., 1998; U.S. Department of Health and Human Services, 2011).

There is limited evidence about how much CAM users know about the products and treatments they use, what sources of information they use, or how they evaluate and use the information they have or acquire (IOM, 2005). King and Pettigrew (2004) found that, whereas 80% of older study participants reported using two or more CAM therapies, their self-rated knowledge about most of the therapies was very low. Evidence is also lacking about how U.S. consumers decide when and how to use CAM and whether or not they comply with instructions from CAM providers or product labels.

Dietary supplements, herbs, and other CAM products and treatments are readily available. Some CAM options have significant therapeutic value and can expand the viable treatment options available. They may also, however, present potential health safety risks to the user. For example, some biologically based products, such as herbs or dietary supplements, are known to interact with prescription medicines and the strength of the products may be inconsistent from batch to batch. In the United States, herbs and dietary supplements are regulated as “dietary ingredients” under authority provided by the Dietary Supplement Health and Education Act. The Dietary Supplement Health and Education Act does not permit supplement manufacturers to make drug claims for their products, or claims to “diagnose, treat, cure, or prevent a disease” (Bass & Young, 1996, p. 4). Many supplement labels and marketing materials, however, contain claims about relief of symptoms or health problems that are at best unsubstantiated or at worst blatantly false. The limited space generally available on supplement labels and packaging limits the manufacturers’ opportunities to educate consumers about the product. Making informed decisions about the use of these products and treatments requires increasingly sophisticated levels of health literacy on the part of the consumer.

Three primary sources of information that consumers use about CAM are word of mouth, the Internet, and health food stores, yet there is limited research evaluating the quality of information available from these sources (IOM, 2005). Although it is widely known that consumers obtain information and recommendations about CAM by word of mouth from friends and acquaintances, the IOM (2005) found no studies regarding the role of an individual’s family or social network on the use of CAM. Several investigators studied what consumers would find if they sought information on the Internet about CAM for

hypothetical health concerns or questions (Ashar, Miller, Getz, & Pichard, 2003; Bonakdar, 2002; Morris & Avorn, 2003). In general, the majority of Internet searches led to CAM retail sites, many with unsubstantiated claims to treat, prevent, diagnose, and/or cure specific diseases. Some sites reviewed contained incorrect or misleading statements about supplements that could result in serious harm to consumers. Several investigators found that health food store employees recommended a wide variety of CAM products when asked for recommendations for treating specific health problems such as cancer, depression, and Crohn's disease (Calder, Issenman, & Cawdron, 2000; Glisson et al., 2003; Mills, Ernst, Singh, Ross, & Wilson, 2003). Investigators also found that most store employees did not ask about prescription medications taken by the patient, some provided inaccurate and potentially unsafe information, few recommended seeing a health care professional, and few mentioned potential adverse effects of the CAM products.

Method

It is difficult to adequately measure health literacy, and it is even more complex to measure CAM health literacy. To construct a conceptually sound instrument to assess CAM health literacy, the authors developed the Montana State University (MSU) Conceptual Model of CAM Health Literacy (see Figure 1) using a variety of strategies. A comprehensive review of the literature, as well as review of data from the authors' prior research (Nichols, Sullivan, Ide, Shreffler-Grant, & Weinert, 2005; Shreffler-Grant, Hill, Weinert, Nichols, & Ide, 2007; Shreffler-Grant, Weinert, Nichols, & Ide, 2005) provided an initial set of model constructs and concepts and proposed relationships among the constructs and concepts. In addition, an extensive list of empirical indicators, again generated from the literature and expert sources, such as the National Center for Complementary and Alternative Medicine's website and the Office of Dietary Supplements website was developed. The indicators were carefully examined for redundancy and relevance to CAM health literacy. National and international experts in CAM, health literacy, and model development were identified. Sixteen experts participated in critique and discussion of the model through written feedback and a telephone teleconference. A list of the participating experts is included in the acknowledgement statement. Insight from these experts was carefully considered and adjustments made in the model.

The Model

The MSU Conceptual Model of CAM Health Literacy has three components: the antecedents, the structural components, and the outcome. The definition of CAM health literacy, or the information about CAM needed to make informed self management decisions regarding health, was developed by the authors and is the driving focus for the structural component of the model. It is recognized, however, that there are other factors that influence whether an individual will seek, obtain, and use the information identified as necessary to be CAM health literate. There are personal and environmental characteristics that affect information seeking and processing; these are designated the antecedents in this model. There are also outcomes that derive from adequate CAM health literacy. In this model, the desired outcome is informed self-management of health.

The constructs and empirical indicators included in the three components of the model are described in the following sections. To place the structural component of CAM health literacy into a broader and more comprehensive context, descriptions of the antecedents and the desired outcome components are presented first. A thorough presentation of the concepts and constructs that characterize CAM health literacy, the structure component of the model, follows.

The CAM Health Literacy portion of the model includes the concepts and empirical indicators that the research team considers the essential information about CAM that one must have to be CAM health literate. The working definition of CAM health literacy is the information about CAM needed to make informed self management decisions regarding health. Outside of the CAM health literacy portion of the model are two domains that represent the Antecedents and Outcome of CAM health literacy.

Antecedents

The construct *environment* is the physical and sociocultural setting of the individual. The empirical indicators are *demographics* and *health status*. Demographics include age, gender, marital status, socioeconomic status, education, and culture. Health status is defined as an individual's general level of health/illness.

The constructs *information seeking*, *health/illness trajectory*, and *general health literacy* affect the level of health literacy regarding CAM. *Information seeking* is the proclivity of the individual to actively seek out information about health and options for health care. *Health/illness trajectory* is the perceived level of health including the presence of a chronic health condition, the length of the health condition, the progression of the condition, and the impact on physical, emotional, and social functioning. *General health literacy* is the capacity to obtain, process, and understand basic health information and services in order to make appropriate health decisions.

Outcome

The construct *Informed Self Management of Health* is conceptualized as the overall outcome of CAM Health Literacy. Individuals often consider a wide variety of self care options when managing their health. Before choosing whether or not to use CAM, individuals often must confront a variety of options, sort through and interpret conflicting information, and seek additional information. Those who are more CAM health literate are more informed self-managers of their health relative to CAM use.

CAM Health Literacy

The MSU Conceptual Model of CAM Health Literacy goes beyond just the reading and computational skills that are assessed by the available health literacy measures. Many of the components in the model expand the conceptualization of health literacy and include health literacy in a context different than allopathic health care as called for by the IOM (2004). The model is a beginning explanation of the processes and characteristics that affect the decision making of an individual about whether to initially use, or continue to use, a CAM treatment.

CAM Health Literacy is the prime construct in the model. We believe that to be health literate about CAM, individuals need to have knowledge about four major concepts: *dose*, *effect*, *safety*, and *availability*.

Dose—The concept of *dose* is the amount of CAM used. The following are the empirical indicators for *dose*: (a) *frequency*—how often CAM is taken or used, (b) *strength/amount*—quantity to use, (c) *duration*—length of use, and (d) *route*—way to use.

Effect—The concept of *effect* is what the user expects the CAM to do. The following are the empirical indicators of *effect*: (a) *effect evaluation*—knowledge of what the CAM practice or product does or is intended to do, (b) *treatment replacement/addition*—whether the user substitutes or adds the CAM to other therapies, and (c) *tradeoffs*—what the user is willing to give up (or take on) in order to use CAM.

Safety—The concept of *safety* is the information needed to minimize harm when using a specific CAM. The following are the empirical indicators of *safety*: (a) *empirical validation*—awareness of whether research has demonstrated therapeutic effectiveness of the specific CAM, (b) *quality of the CAM used*—knowledge that CAM should be obtained from reputable sources, (c) *source of information*—knowledge that information about CAM should be obtained from reputable and professional sources, and (d) *risk*—knowledge of potential interactions with other allopathic or complementary therapies and knowledge of basic symptoms of an adverse reaction.

Availability—The concept of *availability* concerns whether the specific CAM would be reasonably available. The following are the empirical indicators of *availability*: (a) *accessibility*—whether the CAM can be obtained within a reasonable distance from the user and (b) *cost*—whether the CAM is affordable given the user's resources.

Discussion

The MSU Conceptual Model of CAM Health Literacy presented in this paper is the first known attempt to conceptualize the essential elements of health literacy regarding CAM. The carefully constructed CAM health literacy model is anticipated to make a significant contribution to the state of the science regarding CAM health literacy and to contribute to the measurement of CAM health literacy. The model of CAM health literacy can serve as the basis for future research on the use and efficacy of CAM and the constructs and concepts within it can be used to identify points of intervention for research or for clinical practice. The model has the potential to further the discussion and definition of the concept of CAM health literacy and of health literacy in general. It is anticipated that the model will have scientific and clinical application for assessing health literacy in other self care decision-making situations.

The IOM noted that there is very little research on how American consumers obtain, understand, and evaluate information about the various CAM therapies. The empirical indicators of the concepts identified in the structural component of the CAM health literacy model have been used as the basis for developing items for a scale to measure CAM health

literacy. The pool of items will be subjected to further review by the same panel of experts that conducted a previous review as well as focus groups of consumers and health care providers, and then revised appropriately to form a scale. The preliminary scale will undergo extensive psychometric evaluation.

A better understanding of consumers' knowledge of and health literacy about CAM is important to adequately assess the safety, efficacy, or cost effectiveness of these therapies (IOM, 2005). If consumers are not health literate about CAM, they may not know of all the appropriate choices, may fall victim to scams or unscrupulous sales practices, or ingest potentially harmful substances. Informed use of CAM, on the other hand, can increase health and illness management options and encourage well-informed decision making regarding self care.

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Figure 1.
Montana State University (MSU) conceptual model of complementary and alternative medicine (CAM) health literacy.