

AN ASSESSMENT OF ALLOPATHIC AND COMPLEMENTARY AND
ALTERNATIVE MEDICINE (CAM) PROVIDER'S PERCEPTIONS OF THEIR
PATIENTS HEALTH LITERACY

by

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ABSTRACT

The purpose of this study was to explore how allopathic and Complementary and Alternative Medicine (CAM) clinicians address health literacy in their practices. The research questions guiding this study were 1.) How do clinicians convey complex health information to their patients? 2.) Do clinicians believe health literacy is the responsibility of the health care provider, the patient, or the health care system? 3.) Do allopathic and CAM clinicians think differently about where the responsibility rests? The research regarding the impact of low health literacy in the U.S. is prolific but the literature is less rich regarding what clinicians are doing to improve the literacy levels of their patients in their practices.

The Institute of Medicine's Health Literacy model provided the underlying conceptual framework for this study. The data collection procedure was two focus group interviews of health care providers, one group of allopathic providers and the other group (CAM) providers.

The results indicated that all clinicians used an educational strategy during their patient visits with the intent to improve their patients' health literacy. Common themes regarding the way clinicians present health information were identified based on discussions and comments during the focus groups. These themes are direct questioning, health contexts, trust development, educational materials, and analogies.

The practice implications for this study include a) consider incorporating simple health literacy screening or measurement practices during every patient contact, b) openly support public health efforts to increase awareness of the prevalence and depth of limited health literacy at state and local levels c) conduct health literacy lectures in both professional and public forums to help decrease the roadblock of shame for individuals with limited literacy.

The research implications of this study include a need for further research determining what clinicians and health care organizations are doing to embrace a health literacy agenda among private practitioners and the health care system. Further research exploring practical and effective ways to measure health literacy could improve clinician strategies to promote health literacy, numeracy, and language skills necessary for patients to become empowered as they navigate the health care system.

CHAPTER 1

INTRODUCTION

The phenomenon of health literacy is one of the most pressing issues facing our health care system today. In 2003, the United States (U.S.) Surgeon General, Dr. Richard Carmona stated “low literacy is a threat to the health and well-being of Americans and to the health and well-being of the American medical system” (National Institute of Health, 2006). Studies of health literacy have shown that many Americans with the greatest health care needs have the least ability to comprehend information required to navigate and function in the U.S. health care system (Berkman, et al., 2004). Low health literacy has long been identified as a barrier to educating patients potentially putting people at increased risk for poorer health outcomes. Low health literacy affects people of all ages, ethnicities, incomes and education levels, but is primarily linked to those individuals who are elderly, have low incomes, are poorly educated, and have low functional literacy (National Institutes of Health, 2011).

The impact of low literacy on the health care system is well recognized and documented. The National Assessment of Adult Literacy Study (NAALS) (2003) reported that nearly nine out of ten adults might lack the skills needed to manage their health and prevent disease. Williams and colleagues (1995) found in a large hospital study that 41% of patients were unable to comprehend directions for taking medications on an empty stomach and 26% were unable to understand information regarding when their next appointment was scheduled. The data from the study identified the lack of

basic reading and numeracy skills impacted patients' understanding of their health conditions that in turn affected their quality of care and higher rates of hospitalizations. Over the last decade health literacy has become a vibrant area of research (Baker, 2006). Healthy People 2010 acknowledged the growing recognition of literacy and its role in health by including objectives in the action plan to improve the health literacy of all persons with marginal literacy skills. The Institute of Medicine (2004) challenged health care providers to take the lead in tackling the barriers of health literacy.

Given that health care systems in the U.S. are complex and often confusing, inadequate health literacy can result in difficulty accessing health care, following a provider's instructions, and taking medications properly (Safeer, 2005). Research supports the evidence that complex demands of modern health systems do not match up with people's health knowledge and skills.

Concerns about health literacy in the U.S. are relatively recent. The term "health literacy" was first used in 1974 during a health education conference where guidelines were determined for minimum requirements for a health education curriculum in elementary public schools (Simonds, 1974). It was not until 25 years later that the definition of health literacy began to appear in the healthcare literature. In 1999 the American Medical Association (AMA) published a report that recommended educating the medical community and increasing public awareness about health literacy. The AMA used the term health literacy in an attempt to explore and define the relationship between patients' literacy levels and their ability to adhere to various prescribed therapeutic regimes (Nutbeam, 2006). The AMA's approach implied adequate health literacy is the

ability to apply literacy skills to health related materials, such as prescriptions, medication labels, and directions for home care (Nutbeam, 2000; Parker, 2000).

Ratzman and Parker (2000) provided a commonly used definition of health literacy which is: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. 278). The definitions of health literacy have changed over time, but common perquisites in most definitions include the ability to read, understand, and act on health information.

The gap is widening between the required skills necessary to function in today’s health care system and the actual skills Americans possess to understand health care and health information (Gazmararian, Parker, Bernhardt, Curra & DeBuono, 2005). Health literacy has many dimensions, including the ability to read, understand, and communicate medical and health information during different phases of life (Parker, 2003). Health literacy empowers people to act successfully in new and changing health-related circumstances through the use of cognitive and social skills (Nutbeam, 2006).

Adequate literacy is necessary for patients to fully benefit from health education but assessing their health literacy level is challenging. Accurately measuring health literacy is important so that patient education can be tailored to better fit a patient’s learning needs and abilities. In response to patient’s limited reading abilities some health care practitioners attempt to gear their patient education materials toward sixth to eighth grade reading levels (Francis, 2008). If everyone read and could comprehend health information at the sixth and eighth grade level, this would solve the problem. Several

health literacy instruments are available to measure individuals' reading and numeracy skills in health care situations (Baker, 2006). Knowing an individual's reading and numeracy skills as determined with currently available health literacy instruments, does not sufficiently evaluate one's ability to make informed self-management decisions in today's health care environment (Shreffler-Grant, Weinert, Nichols, & Ide, 2011).

Health literacy is more complex than the transmission of information or being able to read a pamphlet (Nutbeam, 2006). Health literacy includes the cognitive ability to understand health related information, both orally and verbally in a way that allows patients to participate in an interactive relationship with their health care providers and enhance self-management abilities. For patients to reach this level, however, they must first build a strong foundation of functional literacy that is strengthened by having supportive health care providers who take health literacy into consideration (Nutbeam, 2006). The practicality of integrating formal health literacy measurements during clinic visits, however, can be problematic in a patient-provider relationship. Some patients have reported embarrassment and shame when revealing their limited understanding of basic math or reading skills (Gazmararian et al., 2005).

The challenges of understanding and recognizing health literacy extend to all health care providers in the arena of the health care system, including allopathic (conventional) and Complementary and Alternative Medicine (CAM) practitioners. Research is limited, however, regarding what all clinicians are doing to address low health literacy in their practices. Both allopathic and CAM practitioners provide treatment and self-management plans for individuals with acute and chronic conditions.

Few studies have assessed the relationship between health literacy and CAM, but, like allopathic medicines and treatments, there is potential for both benefit and harm with CAM therapies. Complementary and alternative medicine is frequently used for chronic conditions for which conventional medicine does not offer straightforward answers or cures (Bains & Egede, 2011). Patients are increasingly using herbal products for preventive and therapeutic purposes. The use of herbal supplements is prevalent among patients who are taking prescription medications, particularly senior citizens (Cherniack, 2001). Tachjian (2010) found that many people who use CAM were not aware of the limited regulations for monitoring efficacy and safety of CAM.

Allopathic and CAM providers can present health information in various ways, emphasizing different aspects of diagnosis and treatment. Confusion and doubt may result in patients with low health literacy, especially if they are seeing CAM and allopathic practitioners simultaneously. Little is known about how allopathic and CAM practitioners assess their patients' health literacy. If practitioners assessed the literacy level in their practices they may impact the overall quality of patient care, patient adherence for self-management regimes, and health care costs.

Purpose of Study

The purpose of this study was to explore how allopathic and Complementary and Alternative Medicine clinicians address health literacy in their practices. To achieve this purpose, a convenience sample of allopathic and Complementary and Alternative Medicine (CAM) providers from one Montana community was interviewed in focus

group format. The research questions guiding this study were: 1.) How do clinicians convey complex health information to their patients? 2.) Do clinicians believe health literacy is the responsibility of the health care provider, the patient, or the health care system? 3.) Do allopathic and CAM clinicians think differently about where the responsibility for health literacy rests?

The information gained from this research study may contribute to an improved understanding of the way allopathic and CAM providers relate to health literacy, and how this information is applied within their clinic settings. The results of the study may contribute to a better understanding and practical ways to improve care of low literacy patients.

Theoretical Framework

The conceptual model chosen for this study presents a visual framework taken from the Institute of Medicine's (IOM), *A Prescription to End Confusion* (2004). Figure 1 provides an illustration of the IOM's model. The conceptual model identifies the context for health literacy in society and its relationship between functional literacy and health outcomes and costs. (Refer to figure 1). Culture and society, the health system and the education system influence an individual's health contexts. This model illustrates health literacy as a function of the interaction of individuals and their exposure to various health contexts (Nielson-Bohlman, Panzer & Kindig, 2004).

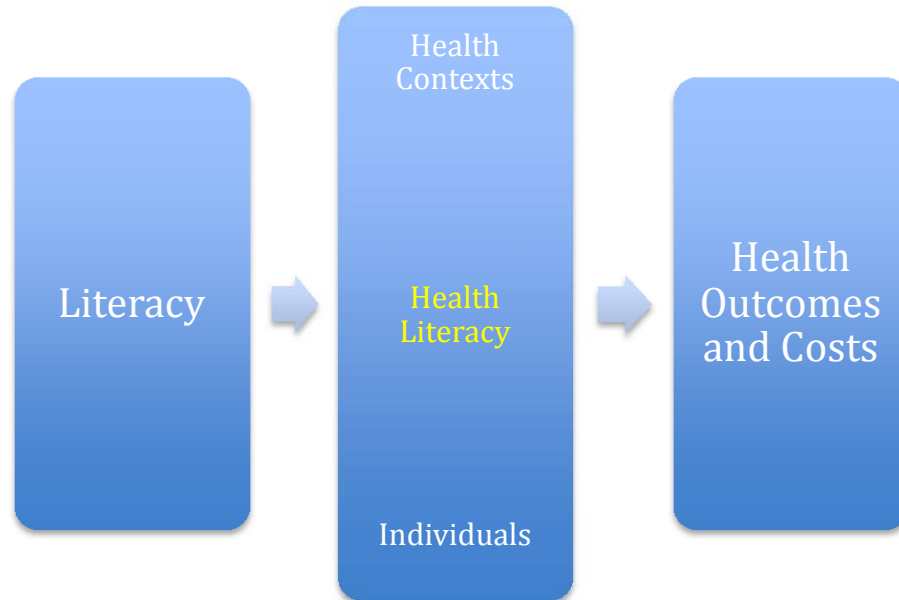


Figure 1. Health literacy framework and conceptual model.

Source: Adapted from Institute of Medicine. (2004). *Health Literacy: A Prescription to End Confusion*. Institute of Medicine. The National Academies Press

The framework places literacy as the foundation for health literacy. Literacy, as defined in the IOM (2004) report, is a set of reading, writing, basic mathematics, speech, and comprehension skills imperative to function in the health care system. Any individual, no matter what literacy skills they possess, may have limited health literacy once he or she enters complex health care contexts (Nielson-Bohlman et al., 2004). More than just the ability to read and write, health literacy includes the ability to listen, follow directions, fill out forms, calculate basic math, interact with health professionals and navigate through health care settings. Reading and numeracy skills are fundamental components of literacy. These skills enable the individual to comprehend health information, communicate concerns, and ask questions about their disease or medications.

A profound example of the implications of an individual's limited ability to comprehend health information is captured in the following scenario: "A two-year old is diagnosed with an inner ear infection and is prescribed an antibiotic. Her mother understands that her daughter should take the prescribed medication twice daily. After carefully studying the label on the bottle and deciding that it doesn't tell how to take the medicine, she fills a teaspoon and pours the antibiotic into her daughter's painful ear" (Nielson-Bohlman et al., 2004, p.19).

This model illustrates health literacy as the bridge between an individual's literacy skills and their abilities to function in various health contexts. Health contexts refer to dynamic situations and activities connected to health such as written information, media, marketplace, and government (Nielsen-Bohlman et al., 2004). Health literacy may enhance or restrict one's participation in health contexts and activities. Using the (IOM) framework, this research focused on the barriers individuals with limited literacy experience as they enter and navigate the health care system and the challenges they bring to their health care providers.

Definitions

The following definitions were used in this study:

Health literacy: The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions (Healthy People 2010, Washington, DC).

Allopathic clinician: A person who is trained and licensed to give health care in the practice of conventional western medicine. (MacIntosh, 1999).

Complementary and Alternative Medicine (CAM): A group of diverse medical and health care systems, practices, and products that are not presently considered part of conventional medicine (National Center for Complementary and Alternative Medicine [NCCAM], 2006).

Assumptions

Three assumptions underlie this work. First, it was assumed that all study participants in the focus groups would provide honest opinions, thoughts, and information. Secondly, it was assumed that information gathered in the focus groups would be comparable to other health care providers in similar specialties. Lastly, it was assumed that focus group participants have comparable challenges with health literacy as other providers in similar disciplines.

CHAPTER 2

LITERATURE REVIEW

The purpose of this chapter is to provide a summary of the research literature relating to health literacy. The literature review is organized into the following sections: Literacy and Health Literacy, Measuring Health Literacy, Complementary and Alternative Medicine Providers and Health Literacy, Health Literacy and Allopathic Providers, and Health Literacy and Outcomes.

Literacy and Health Literacy

Health literacy experts have examined the impact of patients' health and health care as influenced by literacy levels. Rudd (2009) examined adults' literacy proficiencies in multiple health contexts. She found that adults without high school diplomas and members of minority groups have lower health literacy skills. Those individuals with more general literacy skills will be more likely to have stronger health literacy skills. (Rudd, 2009). Literacy as defined by the U.S. National Literacy Act is "an individual's ability to read, write, speak English, compute and solve problems at levels of proficiency necessary to function on the job to achieve one's goals and to develop one's knowledge and potential" (National Literacy Act, 1991 p.2)).

In 1992 the National Adult Literacy Survey (NALS), was conducted to provide information about literacy as well as health literacy among the U.S. population as a whole, which was useful for population-based surveillance of trends over time (Shreffler-

Grant, Hudgins & Williams, 2009). Literacy skills assessed in the NALS included reading various levels of materials such as newspaper articles, employment forms and bus schedules. The National Adult Literacy Survey results indicated that 47 percent of the adult population had difficulty locating, matching, and integrating information in written texts with accuracy and consistency. Approximately one half of the 47 percent could not perform simple and routine tasks using uncomplicated materials. The remaining adults could locate information in moderately complicated texts, make inferences using print material, and integrate easily identifiable pieces of information, as long as things did not get complicated with distracting information and complex texts (IOM, 2004; Kirsch, 2001; Kirsch et al, 1993).

Low literacy skills were seen in all demographic groups surveyed by the NALS, but those most likely to have limited literacy included individuals older than 65 years of age, those with less than 8 years of formal education, those living in poverty, unemployed and recent immigrants to the United States (Kirsch, 2001). Based on data from NALS, Wallace & Lennon (2004) surmised that health care providers should have expected almost 25% of their patients to have limited literacy skills. Despite findings of limited literacy, most people did not recognize or admit they had trouble reading. Many surveyed participants stated they believed they could read and write English very well and would not seek help with reading from others (Kirsch et al, 1993). One decade after the NALS, the National Assessment of Adult Literacy (NAAL, 2003) included literacy assessments on a variety of health-related materials including drugs and alcohol, disease prevention and medication dosing instructions. The NAAL report elucidated the

relationship between literacy and health among the general population over a period of time. Results from the NAAL report captured the attention of many national health organizations resulting in establishing priorities in health policy, research, practice and education arenas (Healthy People, 2010).

Paasche-Orlow and Oates (2009) found in their review of the predominance of health literacy in the U.S. that low health literacy is prevalent and is consistently associated with education, age, and ethnicity. The combination of these characteristics can explain and predict one's ability to access, understand and use the information to make decisions (Saunders, 2009; Zarcadoolas, 2005). Paasche-Orlow and Oates (2009) used the NALS report to further their research and found that most hospital and clinic forms such as discharge instructions, consent forms, and health education materials are written at levels that are above patients' reading and comprehension skills.

Individuals' inability to understand words that describe health issues, medication instructions, test results, or recommendations for health maintenance can be traumatic when their literacy is limited. These same individuals are likely to be significantly handicapped when attempting tasks of self-care and experience confusion when negotiating the health care system (Bourne et al., 2010). Speros (2005) discussed the importance of distinguishing health literacy from literacy in general. She studied the mismatch between literacy skills of Americans and the literacy demands of health care instruction. Speros stated that even if a person is considered literate, he or she may be illiterate in regards to health care information due to his or her inability to comprehend unfamiliar health care vocabulary and health related concepts. A patient's health literacy

may be adequate when diagnosed with mild hypertension, but plummets when presented with a more complex or stress producing diagnosis. Baker (2006) echoed Speros, as he discussed the challenge in identifying health literacy. Baker (2006) found health literacy to be dynamic meaning one's literacy is likely to vary depending on the medical problem being treated, the health care provider, and the health care system.

The disparities between patients' skills necessary to navigate the various arenas of health care system and the demands placed on patients' to take on more responsibility for self-management has increased (McCray, 2005). Thirty years ago newly diagnosed asthmatics were typically treated with theophylline, instructed to take the medication regularly, and encouraged to be diligent about adherence to their medication. Today providers ask asthmatics to monitor and treat their disease using a complex regime of peak flow meters and titrated medications as well as avoidance of environmental triggers (Parker, 2000). Limited understanding of information can make it difficult for patients and their families to properly manage their health. Without clear information and an understanding of disease prevention and self-management of health conditions, people are more likely to skip necessary health related events from routine clinic visits to diagnostic medical tests (Nielson-Bohlman et al., 2004).

The IOM (2004) conducted a meta-analysis describing the enormity and complexities of limited literacy and the need for public health interventions to better assess the way Americans understand and comprehend health information. The IOM recommended the development, testing, and use of culturally appropriate measures of

health literacy and to use them as part of large ongoing population surveys (Nielson-Bohlman et al., 2004).

Measuring Health Literacy

In the years surrounding the NALS and NAAL reports, several instruments were developed to measure patients' literacy. The need to measure patients' ability to perform health-related tasks requiring reading and numeracy skills prompted the development of the Test of Functional Health literacy in Adults (TOFHLA). The TOFHLA was developed using actual hospital materials and measures patients' ability to complete basic reading and numeracy tasks required to function in the health care setting. . The TOFHLA consists of a 50-item reading comprehension and 17-item numerical ability test, taking up to 22 minutes to administer (Parker, Baker, Williams & Nurss, 1995).

Williams and colleagues (1995) used the Test of Functional Health Literacy in Adults (TOFHLA) to measure patient's health literacy when studying the relationship of health literacy to patients' knowledge of their chronic disease. Parker, Baker, Williams & Nurss 1995) found the TOFHLA to be a valid, reliable indicator of patients' ability to read health-related materials. Primarily used in research, Parker et al. (1999) found that TOFHLA predicts patients' health status, knowledge of chronic disease and self-management skills, and the use of health care services. The TOFHLA is considered the "gold standard" of health literacy testing, but the time required for administration may preclude its use in a busy primary care setting (Weiss et al., 2008).

The Rapid Estimate of Adult Literacy in Medicine (REALM) is a five-minute, health literacy-screening instrument consisting of 66 health-related words arranged in increased order of difficulty. It was first developed in the 1990s and was intended for easy and quick use in the health care setting. It assesses patients' abilities to read common medical words. The more words patients could pronounce, the higher the health literacy score (Davis, Michielutte, Askov, Williams & Weiss, 1998). The REALM does not test a patient's word comprehension but has been found to be a valid and reliable instrument measuring patients' vocabulary and ability to pronounce words in isolation (Davis et al., 1993; Bass, Wilson, & Griffith, 2001). Both TOFHLA and REALM have been abbreviated and modified and remain useful in identifying patients with very limited reading ability rather than health literacy.

Weiss and his colleagues (2005) developed the Newest Vital Sign (NVS), a literacy-screening tool specifically designed for the primary care setting. Patients are asked to read a nutrition label, and then demonstrate their ability to use the information from the label by answering six questions. Weiss chose this method because nutrition labels are often used for health promotion to achieve healthy eating habits in patients who suffer from chronic diseases such as heart disease, diabetes, and hypertension. Welch, VanGest & Caskey (2011) studied the time, cost, and utilization of NVS. Cost and time constraints were minimal; however, provider use was somewhat problematic. Although providers agreed that NVS increased their awareness of health literacy they believed extra training was required to improve their communication techniques to specifically tailor the literacy needs of their patients based on their NVS score.

Obstacles for routine literacy screening continue to exist. It is well known that patients underreport their abilities to read, do not recognize their limited understanding of health information, and are often embarrassed about their limited literacy. Paasche-Orlow and Rotar (2003) stated that a health literacy score pales compared to whether or not a patient understands his or her medical condition. Baker and Manusco agreed that existing health literacy measures and screenings do not fully address the concept of health literacy in terms of language, context, culture, communication, or technology (Manusco 2009). Culture and language adds to the complexity of health literacy. Chew, Bradley & Boyko (2004) understood these challenges as they developed interview-administered questions as a tool for identifying preoperative patients in a VA clinic with limited health literacy. Literacy screening questions included response options like “how often” and “how confident” regarding a particular health problem or health related activity. Chew and her colleagues demonstrated that three screening question could identify 80% of adult patients with inadequate health literacy. The questions were: 1. “How often do you have difficulty understanding written information your health care provider gives you?” 2. “How confident are you filling out medical forms by yourself?” 3. “How confident do you feel you are to follow instructions on the label of a medication bottle?” (Chew et al., 2004, p.591). Other researchers replicated Chew’s approach. Wallace, Rogers, Roskos, Holiday & Weiss (2006) found in their study that the question about filling out medical forms to be the most effective in identifying patients with limited literacy.

In addition to screening for health literacy health care providers need to be willing to tailor communication and health education to the needs of their patients. Clear communication practices can improve care for all patients regardless of their level of health literacy. Parker and colleagues (1999) agree that providers need to make their communication “fit” their patient’s actual health literacy during clinical encounters.

Universal precautions, as discussed by Macabasco-O’Connell and Fry-Bowers (2011) are an approach that assumes that everyone can have difficulty understanding medical information. Treating all patients as if they have limited literacy would preclude risking embarrassment or shame to patients with limited reading or comprehension abilities. Implementing this approach would require health care providers to structure their services and patient interactions to minimize the risk that any one of their patients will not understand the information they are given.

Complementary and Alternative Medicine Practitioners and Health Literacy

Complementary and Alternative Medicine (CAM) is defined as a group of diverse medical and health care interventions, practices, products or disciplines that are not generally a part of conventional medicine (NCCAM, 2011). Bains and Egede (2011) noted that approximately 83 million adults are using CAM in the U.S. Common in all age groups, economic strata, and educational levels, CAM is increasing in popularity. According to Eisenberg, VanRompay, Kaptchuk, Wilkey, & Appel (2001), patients had the same perceptions of confidence in both allopathic and CAM providers. People are turning to CAM as primary remedies for diseases, adjuncts to conventional medicine, and

substitution for conventional therapies. Complementary and Alternative Medicine has become an important component of the U.S. health care system and is common among patients who have chronic conditions such as diabetes, multiple sclerosis, breast cancer, osteoporosis and HIV, The 2007 National Health Statistics Report stated adults spent \$34 billion out of pocket on visits to CAM practitioners and purchases of CAM products, classes, and materials. These expenditures are comparable to the out-of-pocket costs for allopathic physician services and prescription drug use (Nahin, Barnes & Bloom, 2009). Research analyzing the relationship between health literacy status and CAM use is limited (Bains & Egede 2011). There is also little research regarding how and why individuals initiate self-administration of CAM therapies and what their understanding is of potential risks and benefits (IOM, 2005).

As noted by Eisenberg (2001), patients tended to be more concerned about their allopathic provider's inability to understand or incorporate CAM therapy within the context of their medical treatment than about their providers disapproval of CAM (Eisenberg, 2001). The IOM (2005) addressed this issue when they stated:

The integration of CAM therapies with conventional medicine requires that practitioners and researchers be open to diverse interpretations of health and healing, to finding innovative ways of obtaining the medical knowledge base. Essential to conventional and CAM practitioners alike is education about the other's field. Conventional professionals in particular need enough CAM-related training, the committee believes, so that they can counsel patients in a manner consistent with high-quality comprehensive care (Complementary and Alternative Medicine in the United States 2005 p.8).

Arcury (2011) studied techniques clinicians might use to enhance a patients' understanding of their therapies. He recommended asking specific and direct questions

about both CAM and conventional therapies so that patients can give direct answers regarding home remedies or prescribed therapies.

Health Literacy and Allopathic Providers

Many allopathic providers use the patient's educational level to indicate health literacy level. Research, as discussed previously has found that this is not a meaningful literacy or health literacy assessment. Not only can high school graduates be illiterate, but also the elderly can experience declining cognitive function and decreased sensory abilities since their final grade of education (Keenan and Shafeer, 2005). Some clinicians, as reported by Barrett, Puryear & Westpheling (2008) simply relied on their gut feelings in response to their patients' characteristics, attitudes, and questions asked, to determine individual's levels of health literacy. This approach would rely primarily on the clinician's interpersonal skills to build relationships with their patients that are trusting, communicative, and open.

Rudd believed the locus of responsibility should not fall on the shoulders of the patient, alone, but health care communities must acknowledge their role in the disparities between patient literacy skills and demands placed on them. Rudd also suggested more studies should be conducted on the affects of training health care professionals specific to behaviors that support health literacy to see if they do a better job with patients than other professionals.

Several studies revealed that providers were often unable to correctly identify patients with low health literacy levels. Bass and associates (2002) studied how

accurately resident physicians could identify patients with poor health literacy skills based on clinical interactions during a clinic visit. Patients' health literacy levels were measured based on REALM scoring. Of the 90% of patients the residents perceived as having adequate health literacy, 36% failed the screen. Three patients who passed the screening were incorrectly identified as at risk for low literacy (Bass, 2002). According to a survey of allied health providers, conducted by Brown (2004), one third of the respondents were unaware of the impact of health literacy on patient care and had no knowledge of health literacy resources.

Because research demonstrates that health care providers experience difficulty in identifying patients with low health literacy, experts have recommended routinely screening patients for health literacy in clinical settings. Seligman, Wang, Wilson, Daher, Piette, & Schillinger, 2005 conducted a study with 63 primary care physicians and 182 diabetic patients with limited health literacy. The trial evaluated the effects of notifying primary care physicians of their patients' health literacy limitations. Physicians were responsive to receiving information about their diabetes patient's health literacy but health outcomes for these patients did not improve. It was surmised by the researchers that physicians lacked appropriate training when managing patients with limited health literacy (Seligman et al, 2005).

Paasche-Orlow (2011) showed the effects of health literacy through narratives with a physician and his elderly patient who has multiple medical problems and limited health literacy. The study demonstrated the challenges the patient encountered because of limited comprehension abilities required to understand medications and self-

management instructions. The provider experienced frustrations because his patient was non-compliant resulting in exacerbation of symptoms, frequent clinic visits, and unnecessary hospitalizations. Paasche-Orlow suggested that clinicians can help their patients with limited health literacy by removing unnecessary confusion in their treatment regimes, conduct teach-back methods when introducing self-management skills, and exercise a higher index of suspicion of limited literacy when patients appear noncompliant.

Health Literacy Outcomes

There is agreement among health literacy experts that patients who have limited literacy have difficulty understanding verbal communication and written information. Research has consistently shown a clear association between low health literacy and less than adequate health-related knowledge and comprehension. Patient health literacy capabilities are linked to health outcomes, however, current research focusing on the causal relationship between health literacy and outcomes is less clear. Williams and his colleagues (2002) found that patients' health literacy is increasingly recognized as a critical factor affecting patient-physician communication and health outcomes. They found that more than 33% of patients 65 years and older have inadequate or marginal health literacy as do approximately 80% of patients in public hospital settings (Williams et al., 2002). Patients with poor health literacy have a complex array of communication difficulties, which may affect health outcomes. Berkman and her colleagues (2011) found

there is an association between low health literacy and less than optimal health outcomes and ineffective use of health care services.

Nielson-Bohlman et al. (2004) reported that it is not yet possible to establish a reliable cost figure for the impact of limited health literacy because there is not enough evidence to indicate a causal relationship between low health literacy and costs. There are few studies focusing on the costs of health literacy. Eichler, Weiser & Brugger (2009) looked at costs specifically related to patients with diabetes and hyperlipidemia. They found additional costs of limited health literacy ranged from 3% to 5% per year, at the health care system level. At the patient level it was estimated that expenditures of patients with limited health literacy, as compared to persons with adequate health literacy, ranged from \$143 to \$7,798 per year.

Summary

The review of the literature outlines the prevalence and challenges of limited health literacy limited within the U.S. health care system. Limited health literacy impacts vulnerable segments of the population. While some populations are at increased risk, all individuals at one time or another may be affected by limited health literacy. The stress of a new diagnosis and information overload can contribute to limitations in health literacy and lead to poor health outcomes. The consequences of limited health literacy contribute to the decline of health in the United States. At the population level, effective approaches for improving health literacy need to be interdisciplinary and occur in many settings. Health literacy is critical to empowerment. By improving people's access to

health information and their capacity to use it effectively the U.S. health care system including, health care providers can make a positive impact towards the realization of a health literate culture.

CHAPTER 3

METHODS

This chapter includes a description of the methods used to address the purpose and research questions in this study. The design, sample selection, and data analysis procedures used in this study to explore how two different clinician groups, allopathic and CAM, address health literacy in their practices are summarized. A description of the procedures used to protect the rights of study participants is also provided.

Study Design

This study employed a descriptive cross-sectional design with a convenience sample of participants. The data collection procedures were two focus group interviews with health care providers, one group of allopathic providers and the other group CAM providers. The focus groups were used to discuss and explore subjective opinions, attitudes, and experiences regarding health literacy in clinical practice. The focus group interviews were part of an ongoing research study developing a new instrument regarding health literacy about CAM. The first segment of the focus group was dedicated to a discussion about the new instrument, the MSU CAM Health Literacy Scale. The second segment of the focus group was dedicated to addressing the research questions in this study, 1) How do clinicians convey complex health information to their patients? 2) Do clinicians believe health literacy is the responsibility of the health care provider, the

patient, or the health care system? 3) Do allopathic and CAM clinicians think differently about where the responsibility for health literacy rests?

Sessions were recorded and field notes were kept. The focus group process was based on Krueger and Casey's framework for focus groups defined as a "carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (Krueger & Casey, 2005 p.4). For the purposes of this study focus groups were used as a self-contained data collection method. Focus group results are qualitative and not perfectly representative of the general population.

Population and Sample

In this study, a great deal of effort was dedicated to the selection process for participants of the focus groups. All practitioners were required to be currently working with patients in a health care setting. Although the goal of each group was to have a sense of homogeneity it was not required that the participants know each other. Commonalities for participation included interest in health literacy and ability to contribute to a conversation and share opinions and insight. Other important criteria were the participants' availability and willingness to take an hour out of their schedules within a timeframe amenable to study deadlines. Once the dates, times, and location for the focus groups were decided, six allopathic providers agreed to participate with one cancelling at the last minute. Six CAM providers agreed to participate and participated.

The focus group participants for this study were in two groups, depending on their practice and whether they were primarily allopathic or CAM providers. Each group involved five to seven participants who were certified and/or licensed in their respected specialty of practice and were willing to participate in the study for approximately one hour. Each participant practiced in the state of Montana and was currently practicing in private group practices in Missoula County, MT.

Allopathic and CAM participants were invited to participate by the researchers based on their interest in health literacy and willingness to participate in a focus group. Participants were contacted in person, by phone or e-mail and were asked to participate in a one-hour focus group. A centrally located meeting area, mutually agreed dates and times were determined. Nine allopathic and seven CAM clinicians were originally contacted. Due to date conflicts, five allopathic and six CAM providers participated. Reminder calls were made prior to meeting dates. The allopathic and CAM providers were divided into two groups, and met on consecutive days at the same time each day.

Instrument and Data Collection Procedures

Focus group interviews are becoming increasingly popular in health research for exploring what individuals believe or feel as well as why they behave in the way they do. The interaction among participants elicits rich and experiential data. According to Krueger & Casey (2003) the uniqueness of the focus group is its ability to generate data based on the synergy of the group. Led by a facilitator, the goal of focus groups is not to reach a consensus, solve a problem, or make a decision, (Allen, Grundes-Schuck &

Larson, 2004) but to produce qualitative data based on attitudes, perceptions, beliefs, and feelings of participants.

The focus groups were held in a reserved hospital conference room. Tables were arranged in a “U” shape with enough chairs to accommodate participants and two facilitators in a comfortable environment. The facilitators strategically placed their chairs opposite one another to better view body language, nonverbal cues, and eye contact. Each focus group session began with a 10-minute welcome and introductory period presented by the facilitator conducting the on-going study. The introduction proceeded approximately thirty minutes of focused discussions regarding the MSU CAM Literacy Scale. Participants were reminded that sessions would not exceed one hour, sessions would be recorded, and anonymity protected. During the second half of the session this researcher assumed the facilitator role by introducing the objectives for this study. Participants were asked to share their insights regarding how they perceived their patient’s health literacy and how they provide information to their patients based on their perceptions (How do clinicians convey complex health information to their patients?). Occasionally the facilitator would ask a participant for a specific detail or clarification of a comment in order to keep the discussion focused. After all participants had an opportunity to express and exchange their perceptions, opinions, and experiences regarding their patient’s literacy levels, the facilitator steered discussions towards the responsibility for improving health literacy (Do clinicians believe health literacy is the responsibility of the health care provider, the patient, or the health care system? Do

allopathic and CAM clinicians think differently about where the responsibility for health literacy rests?)

As the sessions approached the one-hour time frame, the facilitator acknowledged the closure of the sessions as promised. The facilitator briefly summarized the sessions and thanked the participants for their time and candid discussions. Reflections of each focus group including body language, and the general flow of information were captured in field notes after each focus group session. Thank you notes were sent to all participants.

Rights of Human Subject and Consent

To ensure the rights of the study participants were protected, an information packet was sent to each participant with a cover letter explaining who was sponsoring the study, the study goals, what to expect during the sessions, a copy of the MSU CAM Literacy Scale, a basic demographic information form, contact information, and Subject Consent Form. Consent was obtained from each participant prior to each session to allow the prospective participants to make an informed decision. Participants were assured that no information would be revealed that could identify them, and the comments they made would not be reported in such a way that specific individuals could be identified.

There were no foreseeable risks other than the loss of the participants' valuable time. There was no direct benefit to the participants. The Institutional Review Board of Montana State University approved this study on September 28, 2011.

Data Analysis

The focus group discussions were recorded and transcribed for analysis. A continuum of analysis suggested by Krueger (1994) was used to organize the accumulation of raw data, descriptive statements, and interpretation. The process of data analysis included several stages. The first stage began during the data collection by facilitating the discussion and generating rich data from the interview complimented with field notes. The recorded information was transcribed. This stage was followed by familiarization with the data which was achieved by reading the transcriptions several times, reading the observational notes taken during the interview, and reading the field notes written immediately after the sessions. The goal was to immerse the investigator in the details and get a sense of each session. The next stage comprised of sifting the data highlights, sorting out the quotes, and making comparisons both within and between the CAM and allopathic groups. The final stage was data reduction. Field notes included a description of participant's characteristics, descriptive phrases used by participants as they discussed the research questions, potential themes in responses to research questions, a description of participant enthusiasm or group characteristics, inconsistencies among participant comments, and a summary of the overall mood.

CHAPTER 4

RESULTS

The purpose of the study was to explore how two different groups of clinicians, allopathic and CAM, address health literacy in their practices. Focus groups were used as the data collection method. Focus group participants generated in-depth discussions of their opinions, practices, and insights regarding the way they addressed their patient's health literacy. Audiotape and field notes were used to record data. Answers to the following questions were sought from the focus group participants: 1.) How do clinicians convey complex health information to their patients? 2.) Do clinicians believe health literacy is the responsibility of the health care provider, the patient or the health care system? 3.) Do allopathic and CAM clinicians think differently about where the responsibility for health literacy rests? This chapter includes a description of the demographics of participants, interpretation of the data, and a brief summary of the answers to the research questions.

Demographics

The focus groups were divided into two practice groups, allopathic and CAM. The demographics for both groups are noted in Table 1. All participants practice in the same community in private practices or clinics. Most participants knew each in their respective groups either by reputation or referral or as colleagues. All participants were engaging, respectful and professional. All providers engage in clinician-patient

relationships, work with patients in clinical settings, provide written and verbal health information, and treat patients with medicine, supplements, conduct diagnostic assessments and provide or recommend treatment modalities.

	ALLOPATHIC	CAM
# of Participants	5	6
Age Category	41-60 years	21-60 years
Highest Level of Education	Graduate School	Graduate School
Gender	2 Males 3 Females	1 Male 5 Females
Health Provider Type	3 Medical Doctors 1 PhD 1 Nurse Practitioner	1 Physician Assistant 1 Nurse Practitioner 1 Naturopathic Physician 2 Body Talk Practitioner/Instructor 2 Massage Therapist/ Body Talk Practitioner
Specialty	1 Infectious Disease 1 Pharmacy 1 Psychiatry 1 Allergy/ Immunology 1 Family Practice	2 Ayurvedic 1 Family Practice 1 Chronic Disease 1 Life Transition 2 Various Massage Techniques

Table 1. Demographics of allopathic and CAM providers.

Interpretation

The over-arching results indicate that all clinicians applied an educational strategy during their patient visits with the intent to improve their patients' health literacy. Based on extensiveness, intensity, and frequency of comments, both groups conveyed a high priority towards patient information delivery. The following common themes surfaced during discussions in both the focus groups. These themes were direct questioning, health context, trust development, education material, and analogies.

Direct Questioning

Clinicians from both groups used direct questioning such as “what, if anything, do you know about your disease?” “What are your concerns?” “What is your understanding of when to use your medicine?” These direct questions are asked to gauge patient literacy in a clear, straightforward manner. This direct questioning encouraged patients to make a direct response. This method was used as an avenue for a mutual discussion between clinician and patient.

Health Context

Clinicians in both groups were aware that context affected patient acquisition of health information. Context can change each time a patient searches for new information regarding their disease or treatment options. Health contexts include friends, family, television advertisements, and the Web. It appeared that most allopathic clinicians determined what their patients knew about their disease through intake forms completed prior to their first visit or after 1 year from previous visit. From the intake forms, clinicians initiated discussions about what patients knew and where they got their information. When patients stated “I saw this on the internet.” or, “a friend suggest I take this medicine, ” one or two clinicians in both groups took the time to investigate the sources of information, would clarify misinformation, and encourage patients’ to use approved Internet sites.

Trust Development

The third common theme in the two focus groups was developing a trusting patient/provider relationship. “It is important that my patients feel comfortable asking me or challenging me about something.” “You hope that you’ve established a rapport where they can come back and get themselves more educated.” Clinicians apparently wanted to create a non-judgmental environment by having open discussions that empowered their patients to make their own decision regarding health issues.

Education Materials

Focus group participants reported using two types of education materials, visual aids and printed patient information to educate their patients. Depending on the practice, visual aids were the preferred method because it allowed the patient to actually see the specific organ or system related to their disease. “Some diseases do lend themselves to some kind of a visual aide that is engaged in a whole different approach to learning as compared to just a set of terms.” In some practices, such as Psychiatry, the clinician indicated that the only option for education materials was printed information. “Printed materials are so helpful [when starting a new drug] because no one can metabolize the amount of information that you really need”. “The reality is handing them something that I feel has the essential things to know about, to watch for and that reiterates what you just covered.”

Analogies

Focus group participants used examples of familiar situations in an analogous manner to help patients understand their health problems. One clinician described using a chairlift on a ski hill to explain the pharmacokinetics of a medicine requiring a loading method. “You have to load the chairlift just like you have to load the medicine. You cannot bring up a whole bunch of skiers on one chair at once; you have to load them on the chairlift one at a time.” Participants said that using simple and universal concepts allowed patients to grasp their health situation without the use of complex medical terms. Both allopathic and CAM clinicians mentioned their sensitivities regarding the potential for embarrassing patients about their health literacy level. One allopathic clinician stated “I don’t want to offend anybody as far as their intelligence, so I try to find out where they sit and then analogies are a big part of it.”

Who is Responsible for Health Literacy?

Most participants spoke about the importance of patient and provider responsibility. It was apparent, however, that participants from both groups believed increasing their patient’s health literacy was very important.

Two CAM providers specifically mentioned that many of their patients came to them after allopathic treatments stating they were ready to take on whatever they could regarding their care and wanted to increase their responsibility regarding their illness. One CAM provider commented

It seems like with health care the patients are needing to be more responsible for their care so they have to take more responsibility and that means they need to know a bit more and have more information. By the time people get to me they are ready to take a lot on.

Another CAM provider said, “By the time they get to me they are open to doing more. I don’t see people that are really interested in having somebody take care of them”.

These comments from CAM providers were slightly different from the participants in the allopathic group who appeared to take the lead in encouraging their patients to become more responsible with their care. One provider commented on the importance of a collaborative model for patient provider responsibility, “Patients must take some personal responsibility in the relationship”. Another participant stated, “I think most of my real life burden is trying to get them to educate themselves”. “At some point my patients need me to make a decision or recommendation, so they have to feel comfortable asking questions”.

The first research question in this study was how do clinicians convey complex health information to their patients. Based on the focus group interactions, clinicians convey complex health information in ways that best suits their individual specialty and practice style. Common themes of information delivery are used such as direct questioning, developing trust, analogies, and printed information such as pictures and pamphlets.

The second research question was do clinicians believe health literacy is the responsibility of the health care provider, the patient or the health care system? The comments regarding this question were limited to time restraints and to the flow of discussion; therefore answer to this question could not be determined. Answers to this

question could only be surmised. However some clinicians in both groups alluded that the responsibility of health literacy is collaborative between patient and provider. There was no discussion regarding the role of the health care system.

The third research question in this study was do allopathic and CAM clinicians think differently about where the responsibility rests. It appears that clinicians from both groups believe the responsibility of health literacy rests with both provider and patient, but the way the responsibilities are achieved appear to be subtly different. Allopathic clinicians indicated patients must take on more responsibilities for their health care and decision making, but the allopathic clinicians determine what information is necessary for the patient to know based on what the clinicians determines to be important for treatment adherence and decision making. The CAM providers expressed more of an interest in letting the patient guide the provider into determining what information the patient wants or needs. Complementary and alternative medicine providers appear to adjust their patient interactions around their patient's interests and needs. Allopathic providers appear to spend time telling patients what they need to do to be responsible for their health literacy.

CHAPTER 5

DISCUSSION

Introduction

The purpose of this study was to explore how allopathic and Complementary and alternative medicine clinicians address health literacy in their practices. To achieve this purpose two focus groups were organized for interviews. Five allopathic clinicians were in one group; the other, six CAM clinicians. The research was designed to answer the following questions: 1) How do clinicians convey complex health information to their patients? 2) Do clinicians believe health literacy is the responsibility of the health care provider, the patient, or the health care system? 3) Do allopathic and CAM clinicians think differently about where the responsibility rests? This chapter includes a summary of results, limitations of study, the implications for practice and future research.

Summary of Results

The findings of this study indicate allopathic clinicians conveyed information to their patients in various ways depending on what they believed best suited patients' needs. Most allopathic clinicians used a formal questionnaire asking patients what they knew about their health conditions, medications, medical history, and reason for their visit. Patient data from the questionnaire served as a foundation for the allopathic clinician to enhance or clarify medical information. Allopathic clinicians used various patient education modalities to convey information including analogies, pictures, and

teach-back methods. They determined which modality was used based on their specialty, comfort level, and availability of materials. For example, a psychiatrist preferred the spoken word. The internal medicine clinician used pictures or drawings. Some allopathic clinicians enhanced face-to-face information practices by providing patient with information to read at home in a less stressful environment

Complementary and alternative medicine clinicians conveyed information as determined by what their patients wanted to know. Most CAM clinicians believed a majority of their patients were armed with information about treatment modalities they had heard or read about that might best suit their healthcare needs. Many patients wanted to build on the information they had and CAM providers enhanced or clarified patients' knowledge through conversation or printed information. Complementary and alternative medicine clinicians believed patients set the stage for the information they wanted and CAM clinicians attempted to meet patient information needs. Complimentary and alternative medicine believed their patients wanted to develop partnerships to learn as much as they could to achieve health and wellness. In some instances patients preferred treatment modalities prior to the exchange of much information. If therapies were ineffective or not meeting patient expectations, CAM clinicians attempted to educate their patient to enhance successful therapies.

One clinician from each focus group referred to health literacy as information patients know or need to know regarding their health conditions, medications, treatments, and self-management impacting health outcomes. Both allopathic and CAM clinicians believed the responsibility for health information rests on the provider and the patient.

There was no discussion regarding the responsibility of the health care system and role it plays on health literacy. Some allopathic providers believed patients needed to take on more responsibility for their care and health care decision-making than previously required.

Limitations

Interviews in both focus groups were provocative and lively; however there were several limitations to this research study. Time restraints for the interviews and the small number of focus group participants limited the depth and breadth of discussions. For example, there was no discussion regarding the determinants of health literacy such as age, culture, socioeconomic status functional status or religious beliefs and whether clinicians considered these determinants from a health literacy perspective. A different set of questions may have enhanced the exploration of health literacy among clinicians in their practices. Such questions could have been added, for example: as “As a clinician what do you know about health literacy?” “How does health literacy affect your practice?” “Are there any demographic characteristics you believe shape patients health literacy?” Another limitation was the sample of participants was from only one location that may limit the ability to generalize results to clinicians practicing in other locations.

Implications for Practice

Limited health literacy taxes the health care system, providers within the system, and patients navigating the system. Parker (2000) pointed out that the social stigma

associated with low literacy creates feelings of shame and poor self-esteem. The stigma of low literacy is probably one of the main reasons so many individuals hide their inability to read. In order to better understand patients' abilities to obtain and process information Baker (2006) and Chew (2004) both believed screening and measuring health literacy would help providers to better understand their patients literacy levels potentially tailoring their approach to health education and overall communication.

In this study clinicians focused on health education as a means to improve their patients' health literacy rather than addressing patients ability to comprehend health information. Once health information is presented there is still a risk that it is not being processed or understood as intended. Thirty-five years ago research suggested that health education was thought to be the means to improved health literacy. Simmond (1974) stated that with good health education, individuals could understand medical information needed to operate in the health care system. Today, research supports that it is not health education alone that improves health literacy. Providers should use a brief standardized assessment tool to adequately determine their patient's comprehension level in order to determine the effectiveness of the health education provided. The goal is to create patient empowerment and confidence needed to make decisions about treatment and self-management. Clinicians typically use a standardized approach when assessing and examining their patients for medical problems. A similar systematic and routine approach should be implemented when assessing patients' literacy levels. Based on this research allopathic and CAM clinicians are not formally, systematically or routinely screening their patients' literacy levels, nor are they following up for comprehension. The

conundrum for healthcare providers is that many do not understand how to effectively incorporate the challenges of their patients' health literacy into their clinical practice. There are several possibilities explaining clinicians' limited approach to health literacy. Allopathic or CAM students were not taught how to evaluate patient learning because health literacy training was not part of their curriculum. Learning new ways of practicing healthcare is difficult after many years of practice. Strategies for improving communication with patients having low literacy have only recently been recommended and provided to clinicians in the form of toolkits. Learning new communication techniques and the potential benefits for health literacy screening has surfaced at the heels of the health care model requiring shorter clinic visits and increased patient volume.

Health literacy is more than reading a pamphlet or learning how to administer a particular medication or understanding specific instructions for a diagnostic test. Health literacy is a way of life, it's dynamic, and is not limited to a single health care encounter. Implications for practice are lofty and must begin with education and training for physicians, nurses, and all health care practitioners whether they are allopathic or CAM. Nurse Practitioners are likely to be more aware of their patients' health literacy given the focus of their holistic training, but all providers must learn to incorporate health literacy into their evidence-based practices. Hospitals, pharmacists, and insurance companies must also do a better job identifying their roles in health literacy. How can organizations and individual practitioners within the health care system expect patients to take on more responsibility for their healthcare management if, what is taught, is not learned?

Nurse Practitioners and other health care providers must become stakeholders in achieving a health literate society and take on leadership roles within the communities in which they practice. Ways to achieve this goal are by developing reputations among health care consumers as good listeners, good communicators, and advocates for patient empowerment. One of the biggest challenges healthcare providers may need to overcome when speaking with persons having low literacy is gaining their trust (Schillinger et al., 2004). Allopathic and CAM professionals must openly support public health efforts to increase awareness of the prevalence of health literacy at state and local levels. An example of raising awareness among health consumers is contributing to the weekly health section in local newspapers or community magazines. Presenting health literacy lectures in both professional and public forums may decrease the roadblock of shame for individuals with limited health literacy. It also demystifies the context of health literacy and strategizes ways to empower patients to take increased responsibility for their health.

Efforts to improve patients' health literacy are ongoing processes requiring professional commitment with every patient at every encounter. Evidence-based practices of diagnosis, treatment, and prevention of disease are the foundation of health care. Health care practices however, not black and white, nor is health literacy. The goal of Nurse Practitioners is to integrate health literacy into evidence based practices as a new foundation for health care.

Research Implications

Health literacy research has focused on the challenges associated with populations in the U.S. that are coping with limited literacy and the correlation of such determinants as age, culture, socioeconomic, and functional literacy levels. The disconnect remains between the proliferation of health literacy and the challenges associated with various population and what clinicians and health care organizations are doing to embrace a health literacy agenda (Egbert & Nanna, 2009). Future research is needed to investigate the relationship between patient and provider characteristics and health literacy. Based on this study, clinicians appear to know very little about screening for limited literacy in their clinical practices. Further research on practical and effective ways to measure health literacy would improve clinician strategies to promote health literacy, numeracy, and language skills necessary for patients to become empowered as they navigate the health care system.

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