Advisory Committee on Training in Primary Care Medicine and Dentistry

Health Literacy and Patient Engagement

Twelfth Annual Report to the Secretary of the United States Department of Health and Human Services and the Congress of the United States

September 2015
The views expressed in this document are solely those of the Advisory Committee on Training in Primary Care Medicine and Dentistry and do not necessarily represent the views of the Health Resources and Services Administration nor the U.S. Government.
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Advisory Committee on Training in Primary Care Medicine and Dentistry

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) is a Federal advisory committee under the auspices of the Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services (HHS). HRSA is the primary Federal agency for improving access to healthcare by strengthening the healthcare workforce, building healthy communities, and achieving health equity.

The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) is authorized by sections 222 and 749 of the Public Health Service Act (PHSA) (42 U.S.C. §§ 271a, 749), as amended by section 5303 of the Patient Protection and Affordable Care Act (ACA). The ACTPCMD originally was established under the authority of section 748 of the 1998 Health Professions Education Partnerships Act.

The ACTPCMD provides advice and recommendations on policy and program development to the Secretary of the U.S. Department of Health and Human Services (Secretary) and is responsible for submitting an annual report to the Secretary and to Congress concerning the activities under sections 747 and 748 of the PHSA, as amended. Reports are submitted to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives. In addition, ACTPCMD develops, publishes, and implements performance measures and longitudinal evaluations, as well as recommends appropriations levels for programs under Part C of Title VII of the PHSA, as amended.
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This report is the result of a collaborative effort by members of the ACTPCMD. The ACTPCMD provides advice and recommendations on policy and program development to the Secretary of the U.S. Department of Health and Human Services. Each year, the ACTPCMD selects a topic concerning a major issue within the healthcare delivery system that is relevant to the mission of the Bureau of Health Workforce, Public Health Service Act, Title VII, Part C, Sections 747 and 748 training in Primary Care Medicine and Dentistry programs. After the ACTPCMD analyzes the selected topic, it submits an annual report with recommendations regarding policy and program development to the Secretary and ranking members of the Senate Committee on Health, Education, Labor, and Pensions and the House of Representatives Committee on Energy and Commerce. In 2015, the ACTPCMD examined Health Literacy and Patient Engagement.

This report is the culmination of the efforts of many individuals who provided their expertise to the ACTPCMD during two required formal meetings on this topic: the first as an in-person meeting held in Rockville, Maryland on August 5-6, 2014 and the second as a scheduled conference call/webinar on February 6, 2015. Experts informed the ACTPCMD; provided their expertise; and responded to a broad array of issues concerning patient engagement, health literacy, cultural and linguistic competence, and quality improvement. The members of the ACTPCMD express appreciation to all presenters for their time and expertise.

Finally, this report has benefited from the capable assistance of federal staff from the Health Resources and Services Administration, Bureau of Health Workforce, Division of Medicine and Dentistry (DMD): Dr. Joan Weiss, Designated Federal Official and Senior Advisor, DMD; Dr. Candice Chen, Director, DMD; Dr. Nina Tumosa, Public Health Analyst, DMD; Dr. Tamara Zurakowski, Public Health Analyst, DMD; and Ms. Crystal Straughn, Technical Writer, DMD. The ACTPCMD appreciates the hard work and dedication of these individuals in producing this report.

Sincerely,

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Individuals of all ages, races, incomes, and education levels will be faced with making minor to major decisions about their health throughout their life. These decisions will require them to be engaged in their care. Patient engagement is described as the individual actions that must be taken to obtain the greatest benefit from the healthcare services available (Center for Advancing Health, 2010). It relies on a patient’s ability to obtain, process, communicate, and understand basic health information. Engagement therefore requires health literacy. Health literacy is the ability to “read, comprehend, and analyze information; decode instructions, symbols, charts, and diagrams; weigh risks and benefits; and ultimately make decisions and take action” (Schulz & Nakamoto, 2013 p. 6). When patients are engaged in their health and are health literate, they can comprehend the causes of illness, engage in preventative activities to protect their health, and make decisions about treatment at times of poor health.

More than a third of adults are in the basic or below basic health literacy groups and twenty-four million Americans (8.7 percent) are not proficient in English (Koh et al., 2012). Patients with low health literacy are at risk of adverse health outcomes such as higher systolic blood pressure, poor glycemic control, higher rates of hospitalization and longer stays, insufficient knowledge of treatment plan after discharge, and less knowledgeable about chronic disease management (Findley, 2015). In addition, patients with low health literacy or limited English proficiency find it difficult to navigate the complex healthcare system, fill out complex health and insurance forms, and communicate with healthcare professionals. It is important for healthcare professionals to recognize the signs of low health literate patients and to be provided training in communicating with diverse populations.

Healthcare professionals must also understand the social determinants of health. These constitute the factors that can affect health such as health behaviors, health literacy, physical environments, income, access to quality healthcare service, quality of schools, workplace safety and water, food, and air cleanliness. These factors can affect how well and how long we live (Healthy People 2020, 2014-b).

Culture and language also have a major impact on health literacy (Singleton & Krause, 2009). Culture and language affect how patients acquire and apply health literacy skills. It also influences patients’ health beliefs and behaviors and the way they seek treatment (O’Connell et al., 2013). Minority patients may be “more subjected to the effects of low health literacy than patients from other cultures because of interactions between literacy, cross-cultural communication barriers including language and the experience of bias” (Singleton & Krause, 2009, para. 11). Healthcare professionals must practice cultural humility and become culturally competent to communicate with their patients and provide the best care. “Cultural competency is a broad concept used to describe a variety of interventions that aim to improve the accessibility and effectiveness of healthcare services for people from racial/ethnic minorities. Cultural competence recognizes the impact social determinants of health have on a “patients’ health beliefs, behaviors, and decision making, which are important for health equity for diverse patient populations” (Dy & Purnell, 2012, p. 584). “Cultural humility” moves beyond that, to encompass the “ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [person]” (Hook, et al., 2013, p. 354)
Health literacy models and best practices can improve health literacy and patient engagement. Healthcare professionals should be trained to be culturally competent and to engage patients in their care. Social determinants of health should be addressed and improved through community interventions and policy changes to improve health outcomes for all populations. The ACTPCMD members have proposed the following recommendations to improve health literacy and patient engagement:

**Recommendation 1:** The ACTPCMD recommends that HRSA’s Title VII, Part C, Section 747 and 748 education and training programs prepare students, faculty, and practitioners to involve patients and care partners in shared decision-making for person-centered goals of care and treatment.

**Recommendation 2:** The ACTPCMD recommends that HRSA’s Title VII, Part C, Section 747 and 748 education and training programs integrate content on health communication, health literacy, and social determinants of health into health professions curricula. The goal is to improve patient understanding of their health condition(s), motivate them to action, and improve their health and health outcomes.

**Recommendation 3:** The ACTPCMD recommends that HRSA’s Title VII, Part C, Section 747 and 748 funding opportunity announcements include the development of culturally competent interprofessional clinical education and training sites that address social determinants of health and the complex medical, psychosocial, and health literacy needs of vulnerable populations.

**Recommendation 4:** The ACTPCMD recommends that skills to address health literacy be incorporated into all health professions activities whether or not these activities are a consequence of Title VII, Part C, Section 747 and 748 funding. This systemic change should take the form of including language in accreditation and licensure standards that requires health professions programs and schools to integrate content on the interprofessional team approach that address social determinants of health, patient engagement, and health literacy. Content on health literacy should be incorporated in undergraduate and graduate health professions training as well as in ongoing professional development and continued licensure.
Health Literacy and Patient Engagement

Background

Optimal healthcare outcomes are achieved when a patient is fully engaged in making decisions about their care (Koh, Brach, Harris & Parchman, 2013). Patient engagement recognizes that patients play an important role in their healthcare through health literacy (the ability to read and act on health information), shared decision making (the ability to engage multiple healthcare professions and the patient in selecting appropriate treatment and management options), and quality improvement (assessing the healthcare processes and outcomes) (Coulter, 2012). However, engaging patients in their care depends on the patient’s level of health literacy. Individuals with low health literacy have a poorer health status, decreased comprehension and use of preventative services, lower compliance rates, increased hospitalizations, less adherence to treatment recommendations, and increased health costs (Schulz & Nakamoto, 2013).

Health literacy is not simply the ability to read health information. The National Institutes of Health defines health literacy as the ability to read, comprehend, and analyze information; decode instructions, symbols, charts, and diagrams; weigh risks and benefits; and ultimately make decisions and take action. However the concept of health literacy extends to include the materials, environments, and challenges specifically associated with disease prevention and health promotion (Schulz & Nakamoto, 2013). Nearly 36 percent of America’s adult population (87 million adults) is considered functionally illiterate (Somers & Mahadevan, 2010). “Functional health literacy is the ability to apply reading skills and basic knowledge in a health context” (Bostock & Steptoe, 2012, p.1). In addition, there are those who are literate, but not health literate, that have difficulty understanding healthcare information.

Limited health literacy affects everyone. Individuals from all walks of life struggle with understanding health information. However, older adults, immigrants, minorities, and individuals with low incomes are more likely to have difficulty with health literacy (Donnelly, Lane, Winchester & Powell, C., 2011). With the advent of the Affordable Care Act (ACA), medical coverage is estimated to be extended to 32 million adults by 2019. More than half of these individuals will be racial and ethnic minorities (Morgan, et al., 2014). These individuals need assistance with enrolling in health plans, completing forms, finding providers, and receiving covered services (Koh, et al., 2012).

In the past, clinicians and researchers asserted that low health literacy was a result of a patient’s deficiency in skills understanding health issues and information. As a result, health literacy was usually addressed by using culturally sensitive information handouts and an interpreter. However, health literacy is not dependent on the individual’s skills alone, but is also related to the complexity and structure of the healthcare system (Koh et al., 2012). Healthcare organizations assume patients understand their health issues and conditions and can make appropriate decisions regarding their health. But there are many situations patients face in addition to low health literacy that affect their health. For example, a parent may be unable to determine the correct dosage of medicine for their child due to confusing directions. Similarly, older patients with multiple complex conditions may face difficulty in managing each condition effectively (Koh et al., 2013).
Most Americans and nine out of ten adults have a difficult time using health information that is available in healthcare facilities, retail outlets, in the media, and within the community (U. S. Department of Health and Human Services, 2010-a).

In 2010, three initiatives highlighted the consequences of low health literacy: the ACA, the National Action Plan to Improve Health Literacy and the Plain Writing Act of 2010. These initiatives require all new federal government publications, forms, and publicly distributed documents be written in a clear, concise, well-organized manner (Koh et al., 2012). In addition, Healthy People 2020 outlines objectives to improve health literacy. These objectives include: easy-to-understand instructions about patients caring for their illness or health condition; improving provider to patient communication; patient and family engagement and shared decision making; and improved e-health tools (Healthy People 2020, 2014-a). Health literacy is essential in involving patients in their care and improving health outcomes. Therefore, all strategies developed to strengthen patient engagement should focus on improving health literacy (Coulter, 2012). It is now evident that the healthcare system, to include medical providers, must be health literate to achieve optimal outcomes in patient care and management. Health literacy issues should be addressed through system-level changes for both health professionals and organizations.

There are many barriers to health literacy such as poor reading, writing, and numeracy skills; limited English proficiency; poor communication between the healthcare professional and patient; cultural beliefs; and social determinants of health. This report will address these barriers and discuss the challenges a patient faces in managing their health, navigating the healthcare system, and how low health literacy exacerbates these issues. In addition, it will explore how healthcare professionals can be trained at all stages of their professional education to improve health literacy in patients and engage the patient and their families in making decisions about their health to improve outcomes.

Health Literacy and the Patient

Health literacy is critical to patient empowerment, engagement, and making informed health decisions to improve health outcomes. Literacy and health literacy give patients a sense of personal control over their lives and health (Findley, 2015). Individuals with low health literacy often get lost in a complicated healthcare system filled with complex forms, medical jargon, multiple healthcare providers, and insurance premiums. Attempting to navigate the healthcare system combined with a chronic condition or other health issues further intensifies a seemingly helpless situation. Managing health requires more than functional health literacy. It requires skills developed through formal education and personal experiences. It involves understanding the condition, providing consent, communicating effectively with health professionals, and applying health information to different situations. This requires the patient to use the major components of health literacy which are print literacy (writing and reading), oral literacy (listening and speaking), and numeracy (using and understanding numbers, such as medication doses, calculating premiums, copays, and deductibles) (U.S. Department of Health and Human Services, 2010-b). Health literacy is also measured by the ability to complete clinical tasks (correctly comprehending information such as how and when to take a pain reliever or how to use portable oxygen), preventative tasks (understanding recommendations related to preventative services such as breast cancer screenings and prostate exams), and healthcare system navigation.
More than a third of adults are in the “basic” or “below basic” health literacy groups, which means they may fail to understand warnings on prescription and over-the-counter medicine labels. Adults with “intermediate” health literacy skills may have challenges understanding or defining a medical term in a complex document. In addition, twenty-four million Americans (8.7 percent) are not proficient in English (Koh et al., 2012).

Health literacy is an essential component in managing health. Research exploring the relationship between health literacy and health outcomes found that patients with low health literacy are at risk of adverse health outcomes such as: higher systolic blood pressure, poor glycemic control, higher rates of hospitalization and longer hospital stays, insufficient knowledge of treatment plan after discharge, and less knowledge about chronic disease management (Findley, 2015). Patients with low health literacy and chronic conditions find it difficult to manage their conditions effectively. There may be high levels of emotion and fear when facing an illness making it difficult to make clear decisions about one’s health (Francis, 2008). They may take multiple prescription medications and are confused about drug interactions, dosage, and instructions on how and when to take them. Table 1 (Appendix) illustrates how low health literacy increases the issues patients experience when seeking medical attention (Koh et al., 2012).

Low health literacy can also have high personal and societal financial costs. Low literate patients do not effectively use healthcare services. A study of 3000 Medicare enrollees showed that low literate patients had higher emergency room costs and total costs compared to literate patients (Schulz & Nakamoto, 2013). In addition, the annual healthcare cost for Medicare enrollees with limited health literacy is $10,688 compared to $2,891 for all enrollees. To translate this to the impact low health literacy has on United States, limited health literacy costs the United States between $50 and $73 billion per year (Misra-Hebert & Isaacson, 2012). In addition to the financial strain health literacy has on the economy, poor health literacy affects all populations in different ways. A lack of exposure to certain experiences and education can impede what one may learn about their health. To compound the problem, aging, disabilities, and learning and language capacity can augment the literacy and affect optimal health outcomes. (Donnelly, et al., 2011).

Social Determinants of Health

There are many factors that influence health. An individual’s health behaviors, health literacy, physical environments, income, access to quality healthcare service, quality of schools, workplace safety and water, food, and air cleanliness, affect how well and how long one lives. These factors are some of the social determinants of health. “Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks” (Healthy People 2020, 2014-b). There are five determinants of health that have been identified in a population. They include: genes and biology (gender and age), health behaviors (alcohol use, drug use, and smoking); social environment or social characteristics (discrimination, income, and gender), physical environment or total ecology (where a person lives and crowding
Social determinants influence an individual’s available choices and his or her ability to choose the appropriate routes to good health. Therefore, social determinants of health affect health outcomes. Factors related to health outcomes include the following (CDC, 2014):

- How a person develops during the first few years of life (early childhood development)
- How much education a person obtains
- Acquiring and keeping a job
- What kind of work a person does
- Having food or being able to get food
- Having access to health services and the quality of those services
- Housing status
- How much money a person earns
- Discrimination and social support

Some individuals find it challenging to overcome the hurdles of social determinants of health to achieve improved health outcomes. For example, children who cannot choose their environments are vulnerable to social and physical conditions that can affect their health negatively well into adulthood (Braveman, Egerter & Mockenhaupt, 2011). According to the Census Bureau, over 46 million individuals are living in poverty in the United States (David et al., 2004). Disparities in racial and ethnic minority populations and with individuals with lower socioeconomic status increase the probability of low health literacy. Because of lower socioeconomic status, which is associated with income, education, and occupation, there is a shorter life expectancy and a higher incidence of chronic disease (David et al., 2004). It is important to address limited health literacy to reduce healthcare disparities.

Therefore, addressing the social determinants of health is a primary approach to achieving health equity. “Social determinants of health such as poverty, unequal access to healthcare, lack of education, and racism are underlying, contributing factors of health inequities” (CDC, 2009). Health equity occurs when everyone has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstance. Health equity has further been defined as addressing the societal structure and the disparities in health between different social groups who have, or have not, social advantages (CDC, 2014).

Interprofessional research and health professional training on social determinants of health is needed to determine the root causes of health inequities. There must be mechanisms and resources in place to obtain data that will develop effective interventions in an effort to improve overall health outcomes and reduce health inequities (World Health Organization (WHO), 2008). Interprofessional research will aid in determining the degree of the problem, what population is most affected, whether the situation is improving or declining, and evaluating the impact of policies (WHO, 2008).
Health Literacy and Older Adults

An individual with low health literacy faces many issues in caring for their health but an older adult with low health literacy faces a unique set of challenges. Older Americans, aged 65 years or older, have difficulties with health literacy that can further complicate complex health issues (U. S. Department of Health and Human Services, n.d.). For example, over half of older adults at the age of 85 years struggle to manage their health and need help with at least one of their activities of daily living. This situation is exacerbated by low health literacy (Findley, 2015) and could have a major impact on health outcomes and care costs for older Americans (Cutilli, 2007). In addition, as many as 80 percent of older Americans have at least one chronic health condition. The more health conditions people have, the more there is a need to navigate the healthcare system and interpret complex health information (U. S. Department of Health and Human Services, n.d.). To make matters worse, advancing age is associated with a higher prevalence of cognitive, hearing, and vision impairment and dementia in older adults. This only adds to the challenge of improving healthcare outcomes in an already challenged population (Findley, 2015).

Older adults often have poor communication with their healthcare providers (CDC, 2009). Some may have anxiety and low self-esteem and are embarrassed to admit that they are unable to use a computer or the internet to access information, let alone understand what the healthcare professional is telling them. Because of the age discrepancy, older adults may have been socialized not to challenge medical authority (CDC, 2009). This results in an acceptance of information that prevents an engagement of an open and honest discussion about their health and health plan. Because of this, many older adults seek out help from their family members, friends, and caregivers, thus limiting the interaction with the healthcare professional and the provision of accurate information (CDC, 2009).

Sensory processes, such as hearing and vision, are usually age related. Research with focus groups of older adults who have limited health literacy skills demonstrate that in many situations processing of health information is associated with these sensory processes (CDC, 2009). Transcripts from these focus groups include some of the following quotes from study participants:

- “Sometimes I get nervous and I can’t read as good, but I can look at the pictures all right.”
- “One time I took an overdose of medicine . . . when I got my new prescription I saw the word Tegretol but I didn’t see 400, you see, so I took too much . . . there’s really nothing wrong with my eyes, it’s just I don’t know what.”
- “You look at something and you read it—but you just can’t comprehend—you can’t get it in your head straight—it’s like a picture that’s out of focus” (CDC, 2009, p. 12).

Healthcare professionals can implement certain strategies to help the older adult become an active participant in their health. Resources such as community advocates, community health workers, other patients, and promotoras can help to encourage health literacy and improve the quality of care (Barrett, Puryear & Westpheling, 2008). Community health workers and healthcare professionals can intervene to improve health literacy among older adults and empower them to participate in their health. These resources can encourage older adults to
participate in social activities, encourage older adults and their families to ask questions about their health, improve computer skills to access trusted health websites, create educational materials for older adults, and produce media campaigns informing older adults where they can receive assistance in caring for their health (Findley, 2015). Older adults should be encouraged to be confident in acting on their health information and in learning to navigate the healthcare system more effectively. When health literacy is improved in older adults, it enables them to take control of their health, and in turn reduce healthcare costs and improve physical and psychosocial well-being (Findley, 2015).

**Health Literacy and Children**

Many studies conclude that children with low literacy generally have worse health behaviors and children’s health literacy is usually linked to the level of their parent’s health literacy. Since parents with low literacy have less health knowledge and poor health behaviors that could harm their child’s health compared to parents with higher literacy, children whose parents with low literacy often had worse health outcomes (DeWalt & Hink, 2009). Parents and caregivers of young children and adolescents with limited literacy skills may have problems navigating complex health systems, understanding medical instructions and recommendations, performing child and self-care tasks, and understanding consent, medical authorization, and risk assessments (Rothman et al., 2009). The parent’s decision can place the child at a disadvantage that will influence the child’s health. A recent health literacy and childhood obesity study found that a school aged child’s obesity is associated with their parent’s behaviors. Adolescent obesity was strongly associated with the parent’s level of functional health literacy (Chari et al., 2013).

For example, there is an association between low functional health literacy in parents and medication dosing errors, poor asthma care, and worse glycemic control in children with type 1 diabetes. In spite of this, many children understand their health needs. Children as young as 4 years participate in self-care. Recent studies demonstrate that children 4 to 6 years old understand that they require low sugar diets and that insulin is needed to convert sugar into energy. Children 9 to 12 years old can read carbohydrate details on food labels and adjust insulin doses to match their energy needs.

Health literacy and health behaviors begin early in life. Early childhood and childcare services, schools, and community groups establish and build health literacy skills. These services aid in developing the tools and skills needed to make smart health decisions. In addition, community resources can provide residents with information, education, social support, and local health and social services, thus directly impacting the child’s health. Community organizations improve health literacy by determining community needs and incorporating health literacy strategies and activities (CDC, 2015, para. 3).

Interventions that improve communication between the healthcare system and the patient have been found to be effective. Improving written materials can increase health knowledge, and combining good written materials with brief counseling can improve behaviors including adherence (DeWalt & Hink, 2009). Pediatricians should communicate effectively with patients and their families to assist them in understanding health information, making informed decisions, and managing their child’s health. By improving health literacy of parents and children,
communication throughout the healthcare system can be more effective and reduce health disparities. (Cheng, Dreyer & Jenkins, 2009).

**Health Literacy and Veterans**

The discussion of health literacy and the veteran population centers on the healthcare provider and the medical system. A study comparing the health literacy skills of active duty military personnel to the national population suggests that military personnel had higher literacy and health literacy skills than the national population (Weld, Padden, Ricciardi, & Bibb, 2009). Therefore, it is essential that healthcare providers are trained to care for the veteran and active duty population and their families.

Of the 22 million U.S. veterans, approximately 9 million are cared for by the Department of Veterans Affairs (VA) system. It is estimated that the VA can only care for 40 percent of those veterans who are enrolled in the VA system, despite a wide array of services such as primary and specialty care, mental health, substance abuse treatment, physical therapy, pharmacy services, vision, and home care. It is estimated that over one million service members will be separating from the military over the next several years (Lee, Sanders & Cox, 2014), creating an insurmountable demand on the services the VA offers. As a result, much of the care of veterans will fall upon civilian and civilian trained healthcare providers.

In a survey by the Association of American Medical Colleges in 2012 of 104 medical schools, only 57 percent of the undergraduate medical education (UME) institutions taught Post Traumatic Stress Disorder (PTSD) and 47 percent addressed Traumatic Brain Injury (TBI) as it pertains to military service members and veterans. In addition, 93 percent of UME institutions educated medical students on cultural competency as it pertains to the civilian population, but only 21 percent included military cultural competency. The percentages improve slightly during graduate medical training but this is in part due to the utilization of Department of Defense and VA facilities for resident training (Association of American Colleges, 2012).

The Joining Forces Initiative has helped to increase an awareness of the special needs of the military, veterans, and their families. Inclusion of the military culture, PTSD and TBI as it relates to the care of the member, veteran, and family needs to routinely be incorporated in the healthcare curriculum as more non-military and non-VA healthcare providers address the needs of this vulnerable population.

**Health Literacy and Cultural Competency**

Culture and language have a major impact on health literacy (Singleton & Krause, 2009). “Culture refers to the learned, shared and transmitted knowledge of values, beliefs, and lifeways of a particular group that are generally transmitted intergenerationally and influence thinking, decisions, and actions in patterned or in a certain ways” (Singleton & Krause, 2009, para. 5). Culture and language, such as reading, writing, and numeracy in English, affect how patients acquire and apply health literacy skills. Culture also influences a patient’s health beliefs and behaviors and how they seek treatment (O’Connell, et al., 2013). Some minorities and individuals with limited English proficiency have the challenge of making health decisions based on a healthcare professional’s recommendations as they struggle with their own cultural values.
and beliefs while at the same time attempting to navigate a complex health system. Some minority patients may be affected more by low health literacy than patients from other more generally accepted cultures because of cross-cultural communication barriers, including language, and the experience of bias (Singleton & Krause, 2009).

**Language**

Limited English proficiency can have detrimental effects on healthcare and outcomes. Patients with language barriers are less likely to have consistent medical care, use preventive services at reduced rates, and have an increased risk of medication nonadherence. In addition, patients with mental health conditions along with language barriers are more likely than others to receive a diagnosis of severe psychopathology and are also more likely to leave the hospital earlier than medically advised. Children with asthma and language barriers have an increased risk of intubation. Overall, patients with limited English proficiency are less likely to return for follow-up appointments and these patients have higher rates of hospitalization and drug complications. Moreover, patients with limited English proficiency have increased healthcare costs, utilize more resources, and have lower levels of patient satisfaction than those who are proficient in English (Flores, 2006).

Many patients who need interpreters do not have access to them. In some cases, when interpreters are available, they mistranslate crucial information. This can have tragic consequences. For example, a Spanish-speaking woman told a medical resident that her two-year-old had “hit herself” when she fell off her tricycle. The resident misinterpreted the patient and concluded that the fracture was a result of abuse. The medical resident subsequently contacted the Department of Social Services (DSS). DSS sent a case-worker who, without an interpreter present, had the mother sign over custody of her two children (Flores, 2006).

However, research on limited English proficiency has established that the use of interpreters can increase rates of appropriate healthcare visits, improve treatment adherence, and improve patient satisfaction. Interventions using community health workers, health coaches, and language interpreters, are often used for limited English proficiency populations. Health literacy and limited English proficiency researchers must work together to understand how culture, language, literacy, education, and disabilities influence health disparities and health outcomes (McKee & Paasche-Orlow, 2012).

**Cultural Competency**

“Cultural competency is a broad concept used to describe a variety of interventions that aim to improve the accessibility and effectiveness of healthcare services for people from racial/ethnic minorities” (Truong, Paradies & Priest, 2014, p. 1). This concept was developed to raise the awareness that cultural and linguistic barriers between healthcare providers and patients may affect the quality of healthcare delivery. Cultural competence recognizes the impact social determinants of health have on a patient’s health beliefs, behaviors, and decision making, which are important for health equity for diverse patient populations (Dy & Purnell, 2012). Mindful practice of culturally competent care can lead to cultural humility, a state in which neither the provider’s nor the patient’s health belief system is privileged and true partnership can emerge (Tervalon & Murray-Garcia, 1998).
In the United States, culturally and ethnically diverse populations have increased significantly. As a result, healthcare professionals need to practice cultural humility and provide culturally appropriate healthcare that utilizes health literacy practices. In order to improve health literacy through cultural competency, both require knowledge of diverse social practices in order to deliver appropriate healthcare (Ingram, 2012). Healthcare professionals can prepare to care for diverse populations by increasing their own cultural competence and using appropriate resources that diverse populations can understand to prevent miscommunication and subsequent mistrust between the healthcare professional and patient. In turn, patient/provider mistrust may negatively affect patient adherence and subsequently impede the development of quality patient health outcomes (Ingram, 2012). Healthcare professionals can promote trust by sharing information that is culturally appropriate and comprehensible for patients with low health literacy. Healthcare professionals that are non-judgmental, respect a patient’s culture, health practices and health literacy, even when they are different from their own, are considered culturally competent. Culturally competent care occurs when healthcare professionals understand the patient’s illness culturally and biomedically. Cultural knowledge of an illness involves understanding the patient’s language and the way they perceive their illness (f, 2012).

In order to develop cultural humility, healthcare professionals should evaluate and understand their own beliefs and their patient’s beliefs to provide person-centered care designed to engage the patient and achieve better health outcomes. Patients want healthcare professionals who value and respect their culture and beliefs, communicate effectively, and focus on their individual needs. The patient will have greater satisfaction with healthcare professionals who want to learn about other cultures and demonstrate knowledge skills and attitudes on cultural sensitivity (O’Connell et al, 2013). Healthcare professionals can reduce disparities by evaluating their own assumptions and biases, communicating appropriately with diverse patients, and building a team of professionals and resources to recognize, diagnose, and address low health literacy and cultural differences (Désirée, Carter-Pokras, Braun, & Coleman, 2012).

**Patient Engagement**

Low health literacy, social determinants of health, and health inequalities need to be addressed by healthcare professionals and health systems leaders in order to improve population health outcomes. Some healthcare professionals believe low health literacy is a patient issue and it is the patient’s responsibility to become more literate (Frosch & Elwyn, 2014). However, healthcare professionals and the healthcare system play a role as well by improving patient understanding through information that is tailored adequately for the specific patient population (Frosch & Elwyn, 2014). The following scenario describes healthcare through the patient's view:

*Imagine waiting in an exam room for your healthcare professional. He or she enters the room with the healthcare team. They greet you and begin reading your chart to themselves. Then your healthcare professional examines you. He or she quickly discusses findings with the team in a language you don’t understand. The team discusses you and a care plan for you, and then they leave the room* (Blanton, 2015).

In this scenario, the healthcare team did not engage, educate, and partner with the patient. A transformed healthcare system that includes improved and increased health communication (provider-to-patient), team-based care, patient engagement, and increased healthcare professional
training in health literacy and social determinants of health is needed to make significant change. Better interventions, different training of health professionals, societal changes, incentives that focus on patient needs and wants, and ensuring integrated care, is also needed to motivate change (Frosch & Elwyn, 2014).

Patient engagement can be achieved if healthcare professionals, organizations, and policies provide the support that people need to engage (Suter & Hennessey, 2013). The Center for Advancing Health defines patient engagement as the “actions individuals must take to obtain the greatest benefit from the healthcare services available to them” (Center for Advancing Health, 2010, p. 2). Patient engagement relies on a patient’s ability to obtain, process, communicate, and understand basic health information. It acknowledges that patients play an important role in their healthcare. It can be characterized by how much information flows between patient and provider, how active a role the patient has in care decisions, and how involved the patient or patient organization becomes in health organization decisions and in policy making (Carman, et al., 2013). Patients want access to reliable and safe healthcare. In addition, they expect to receive compassion, dignity, and respect and be provided the necessary information and support to participate in making decisions about their health. Health literacy is essential in involving patients in their care. Therefore, all strategies developed to strengthen patient engagement should focus on improving health literacy (Coulter, 2014).

Factors that influence patient engagement include the patient, organizational perspectives, and societal beliefs (Carman et al., 2013). The American Institutes for Research developed the following framework for patient engagement on three levels (Health Policy Brief, 2013):

- **Direct Patient Care**: patients receive information about their health condition and ask questions about their preferences for treatment options. Patients and healthcare professionals make decisions together based on medical evidence and the patient’s preference.
- **Organizational design**: healthcare organizations request input from patients to ensure they are providing the best care possible.
- **Policy Making**: patients are involved in making decisions about public health, healthcare policies, laws, and regulations.

**Shared Decision Making and Motivational Interviewing**

Shared decision making is also effective in engaging patients in their care. It is a process in which providers and patients work together to select tests, treatments, management, or support packages (Coulter, 2014). This process requires providers and patients to recognize that a healthcare decision is necessary, taking into consideration the best available evidence and the patient's preferences on treatment decisions (Health Policy Brief, 2013).

Vulnerable populations may participate in a variety of behavioral supports such as one-to-one counseling with health professionals, peer support groups, and educational offerings to improve health literacy. However, additional benefit may be gained by participating in seeking additional information to improve their ability to make more informed decisions about their health. Despite these efforts, educational programs alone are not sufficient to close health outcome gaps. Most educational programs use traditional didactic methods that may not be effective for individuals who do not respond to these conventional methods. Motivational interviewing is an engaging technique that has demonstrated success with some individuals. A review of 72 students found
that motivational interviewing improved their health behaviors more than traditional advice (Coulter, 2014). This technique is focused on assisting patients in changing behavior by exploring their personal perspectives and perceived barriers. There are four steps involved in motivational interviewing: (1) engaging – building relationships, (2) focusing – discussing the change that needs to be made, (3) evoking – discussing the patient’s motivations for change and their ideas and emotions explored, and (4) planning – developing a commitment to change and an action plan (Elwyn et al., 2014).

Both shared decision making and motivational interviewing focus on engaging patients to discuss their needs, opinions, and treatment options. Healthcare professionals can achieve a patient-centered practice by applying these methods alone and together (Elwyn et al, 2014). Shared decision making and motivational interviewing are challenging to implement in routine practice especially when the patient’s needs are complex. However, these tools should be taught and integrated into daily practice, then appropriately measured and rewarded (Elwyn et al, 2014).

**Effective Communication**

Effective patient and healthcare professional communication is critical to the care of patients with low health literacy. Healthcare is complex and many patients struggle to communicate and understand health information as well as navigate the healthcare system (Health Policy Brief, 2013). However, many healthcare professionals do not regularly use the recommended techniques to communicate with low health literate patients (Howard, Jacobson & Kripalani, 2013). These techniques include avoiding the use of medical jargon, reducing the amount of information discussed at each visit, and requesting patients to repeat information in their own words (teach back method) (Howard et al., 2013). The teach-back technique is used to confirm patient understanding at the end of a visit. The healthcare professional asks the patient to explain or repeat back information that was conveyed to them to ensure understanding.

Older adults may experience visual and hearing loss that negatively impacts their understanding of health information. Consequently, it is important to present information in ways they can process and understand. Information should be focused and repeated as needed. The healthcare professional should communicate face-to-face with the patient, make information personally relevant, explain the benefits of a specific action, and provide appropriate follow-up.

Staff members in community service departments are often the main source of information for older adults. Community health workers and healthcare providers need more access to education, training, and materials to help them improve health literacy among older adults. Healthcare professionals and workers who are knowledgeable about age-related health issues will improve the lives of older adults if they work together and receive the training and support they need (CDC, 2009).

**Health Professionals Training**

Healthcare professionals should be trained to be health literate and culturally competent, engage and communicate effectively with patients, and recognize and address social determinants of health. Health information must be presented in ways that improve patient understanding. Unfortunately, studies have shown that gaps exist in the health professional’s awareness and knowledge of low health literacy in the patient and caregivers, intervention to address low health
literacy, and attitudes about patients with low health literacy among nurses, physicians, dentists, physician assistants, and other allied health professionals. In addition, many best practices for effectively communicating with low health literacy patients are not routinely used by healthcare professionals (Coleman, 2011).

Health literacy is not being adequately addressed in health professions schools. Increasing and improving health literacy education for health professionals has been identified as a priority area in National Action Plan to Improve Health Literacy. Research suggests that integrating health literacy into health professions curricula can positively influence learner knowledge, skills, and attitudes, as well as patient-centered outcomes. Educational techniques and tools used to teach communication and health literacy principles to healthcare personnel include didactic teaching methods, experiential teaching (workshops, small-group exercises, and role plays, videotaped clinical encounters with real or simulated patients), patient encounters, direct observation, modeling, and feedback (Coleman, 2011).

Medical facilities and offices should provide health literacy training for front-desk staff and other nonclinical personnel to improve quality of care. Front-desk staff are important to patient satisfaction because they see patients when they enter and leave the clinic and assist them in filling out forms, scheduling appointments, and handling health records. Health literacy training can assist staff in identifying patients that may need additional support because of low health literacy. This training allows nonclinical staff to serve as a liaison between the patient and the healthcare professional team.

Healthcare professionals, including physicians, dentists, physician assistants, nurses, auxiliary personnel, and community workers, must recognize health inequities as an important public health problem. Most medical and health curricula have minimal training on the social determinants of health. Social determinants of health must be a required competency of medical training and integrated into all health professions curricula at all levels of education. Training and education on the social determinants of health needs to be extended to all members of the healthcare team, policy makers, and stakeholders (WHO, 2008). Cultural sensitivity and cultural competency courses are beginning to be added to curriculum at several schools:

- At Southern Illinois University Edwardsville, a team-based learning approach was used in a required cultural competency and health literacy course to discuss differences in health beliefs among various religious and ethnic groups, individuals with disabilities, and individuals with HIV/AIDS.
- At Wayne State University, a course was developed that focused on race, ethnicity, religion, physical disability, sexual orientation, complementary and alternative forms of healing, and various chronic illness cultures. The course included different readings and movies, followed by small group discussions and reflections, a field trip to a Native American–integrated clinic incorporating Western medicine with Native American therapies such as herbs, sweat lodge, and medicine man care, and in-class interactive presentations by people from diverse cultures. The students also participated in role-playing as patients from different cultures and identified important cultural issues affecting healthcare decisions and outcomes. They also interviewed alternative healing practitioners and shared their findings with the class.
• At Howard University, an interprofessional course included written assignments such as self-heritage assessments and journal reflections. Students also viewed the Worlds Apart videos, role-played, practiced interviewing strategies, and had a community immersion experience.

• At the University of Cincinnati, an interprofessional course was designed using patient case discussions. Students were assigned to interprofessional teams to develop interpersonal and small group skills. The student teams discussed cases addressing various cultural topics including Puerto Rican, Lao, Appalachian, and Chinese cultures; Muslim, African-American, Native American, and Jewish faith; and use of complementary and alternative medicine. The course also included guest speakers and reflection exercises (O'Connell et al., 2013).

The Accreditation Council for Graduate Medical Education and the National Commission on Certification of Physician Assistants, American Academy of Physician Assistants, Accreditation Review Commission on Education for the Physician Assistant, and the Physician Assistant Education Association developed six competencies areas whereby all medical and physician assistant students should demonstrate proficiency by the time of graduation. The six competencies include medical knowledge, patient care, interpersonal and communication skills, professionalism, practice-based learning and improvement and system-based practice (University of Maryland Medical Center, 2013).

Best Practices and Models of Care

Interventions and care models are needed to improve health literacy and health disparities. The following models of care demonstrate how students, universities, communities, and healthcare professionals are working together to improve health literacy and improve health outcomes.

Health Scholars Program Puentes de Salud (“Bridges of Health”)
The Health Scholars Program (HSP) is a 9–month interprofessional service- learning course on the social determinants of health designed by faculty and doctoral students in medicine, public health, and education from Temple University and the University of Pennsylvania in partnership with a local community health center, Puentes de Salud (“Bridges of Health”) in Philadelphia, Pennsylvania. The goals of the HSP are to 1) improve the health of underserved populations, 2) deepen health professions students understanding of the social determinants of health, and 3) promote a commitment to community health. Students are required to participate in lectures, readings, critical reflections, and community service that focus on the social determinants that impact the health. The students also receive training on immigrant healthcare navigation, health databases, and legislative advocacy. In addition, students volunteer for at least 8 hours per month in the Puentes de Salud clinic, its after-school tutoring program, or both (O’Brien et al., 2014).

Health Literate Care Model
Patients must be fully engaged in prevention, decision making, and self-management to improve health outcomes. The Health Literate Care Model includes health literacy principles incorporated into the widely adopted Chronic Care Model (proposed by Edward Wagner) (Wagner, Austin & Von Korff, 1996). It calls for healthcare providers to approach all patients as if they are at risk of not understanding health information, employ a range of strategies for clear
communication, and confirm patients’ understanding (Koh et al., 2013). The model recommends a universal precautions approach to health literacy that includes ensuring materials and language is free of medical jargon and written at appropriate levels for various populations. In addition, healthcare professionals must consistently confirm all patients’ understanding of health information (Suter, & Hennessey, 2013).

The Health Literate Care Model encourages healthcare staff, patients, families, and caretakers to work together to support a patient’s prevention, decision-making, and self-management activities. This can improve the patient’s understanding of their condition and options; increase participation in community services that improve wellness, prevention, and chronic care management; allow patients to view their relationships with their healthcare teams positively; and make informed decisions (Koh, et al., 2013).

Yes! Youth Empowerment Model
The Yes! Youth Empowerment Model empowers youth (defined as those aged 10–24 years) to be engaged in their healthcare. The Model provides youth with opportunities to create positive outcomes in the community by understanding the role that health equity plays in healthcare systems and health disparities. It also develops advocacy and decision-making skills to assist youth to effectively address social determinants of health. Engaging youth in the healthcare system as both stakeholders and patients improves their ability to successfully navigate the healthcare system, advocate for their care, and improve their health literacy skills. The YES! Model has produced strong outcomes in the Montefiore Medical Center in the Bronx, New York. Students developed youth councils within their network of primary care clinics located on school campuses. These centers primarily serve uninsured and underserved students and provide care for youth who do not have a medical home (Klaus, 2015).

Beth Israel Deaconess Medical Center
In 2009, the 600-bed Beth Israel Deaconess Medical Center, in Boston, Massachusetts increased patient engagement by involving patients and family members in improving care. In 2013, they were awarded first prize in the Quest for Quality award organized by the American Hospital Association for its efforts at engaging patients. By creating an open and transparent patient-centered organization, the medical center was able to reduce the percentage of patients involved in harmful events, from 22.5 percent in 2006 to 11.5 percent in 2010. The center reduced surgical site infections from seventy-nine in 2010 to forty-seven in 2011 and reduced the rate of unexpected deaths by 80 percent. In 2010, the medical center created a patient care committee and patient and family advisory councils to ensure that the patient’s voice was heard. Their goal was to improve communication and develop innovations that improved the patient’s experience of care.

To increase a patient’s involvement in decisions about their care, the medical center created a web-based portal called Patientsite.org. The portal allows patients to view their test results, email their healthcare professional or practice, and request appointments and prescription refills. It also reduces medical errors by allowing patients to check their medication lists, allergies, and test results to correct inaccuracies. Patientsite.org also has an open notes system that gives patients access to their clinical records. This encourages patients to be more engaged with their care. In a study of 11,797 patients given access to their notes at three hospitals, including Beth Israel Deaconess Medical Center, approximately 82 percent of the patients reported feeling
empowered in taking control of their care and health and approximately 69% percent stated the access to their information increased medication adherence.

The medical center educated staff members when they were hired about building a patient-centered environment. They trained staff by having them work through patient-oriented scenarios to teach best practices and the medical center’s standards. Educating patients about their right to see their test results, read healthcare professionals medical notes, and communicate with their physicians is achieved through the distribution of information packs, creating support groups in the community for Spanish-speaking and Chinese-speaking patients who may need help with translation of test results and medical records, and the employment of patient advisers (Laurance et al., 2014).

Health Literacy Case Studies
The following case studies highlight the specific skills needed to evaluate health literacy and effectively communicate health information to geriatric patients:

Case 1: Geriatric patients being seen in an orthopaedic outpatient clinic are having difficulty understanding how to take their medications and are taking them incorrectly. The healthcare professional is confused as to why this is occurring because they ensure that the patient is provided with written drug information before leaving the clinic.

The geriatric patients described in the case study are experiencing low health literacy and the healthcare provider must take into consideration varied health literacy levels when providing health education. The healthcare professional can accomplish these goals by reviewing health information material before using to determine the appropriateness for a specific patient. They can also educate themselves with information on how to present health information to patients with low health literacy (Cutilli & Schaefer, 2011).

Case 2: Mr. S. is a 76-year-old retired Certified Public Accountant who was recently admitted to the emergency department for chest pain where he was found to have a prolapsed mitral valve. At a follow-up visit, Mr. S. states he believes he is going to die because of the mitral valve prolapse in his heart. The emergency department gave him information about his condition and had started him on a beta-blocker. The information he received appeared to be direct and straightforward. The healthcare professional is not sure why he is struggling with understanding the information. Upon further questioning, the patient states he does not understand much of the medical terminology on the information sheet. Mr. S. does not have adequate health literacy, despite his higher level of education.

Healthcare professionals can increase their knowledge about patients that have low health literacy by knowing the demographic and socioeconomic indicators associated with low health literacy. They can observe patient behaviors that suggest low health literacy such as not having reading glasses available, exhibiting frustrating and angry behavior when asked to complete forms, the use of improper terms, or asking to review information with a family member or other care partner in making healthcare decisions.

To help Mr. S. understand his diagnosis, the healthcare professional could present him with a heart model and show him the impact of mitral valve prolapse. Then they could review the
information given to him in the emergency department and explain any confusing sections. The healthcare professional could also write Mr. S simple instructions in plain language he can understand (Cutilli & Schaefer, 2011).
Recommendations with Rationale

**Recommendation 1:** The ACTPCMD recommends that HRSA’s Title VII, Part C, Section 747 and 748 education and training programs prepare students, faculty, and practitioners to involve patients and care partners in shared decision-making for person-centered goals of care and treatment.

**Rationale:** It has been shown that patients who are motivated and share in their healthcare decisions have better healthcare outcomes. Furthermore, those from the vulnerable populations who participate in one-to-one counseling and peer support groups and classes improve their health literacy. These tools, as well as effective communication methods within the healthcare system and as practiced by healthcare professionals, improve patient centered care. Informed patients make better healthcare decisions.

**Recommendation 2:** The ACTPCMD recommends that HRSA’s Title VII, Part C, Section 747 and 748 education and training programs integrate content on health communication, health literacy, and social determinants of health into health professions curricula. The goal is to improve patient understanding of their health condition(s), motivate them to action, and improve their health and health outcomes.

**Rationale:** Health literacy is necessary to achieve optimal health outcomes. Most Americans and nine out of ten adults have a difficult time using and understanding healthcare information. Therefore, it is incumbent upon the health care provider to be health literate and assume a responsibility in addressing the barriers many patients experience. By recognizing and addressing these barriers, patients will be motivated to be engaged in their own care, thus improving healthcare outcomes. Tools to assist the medical practitioner, such as personal awareness of cultural humility, understanding the social determinants of health, utilizing other health care professionals and non-professionals, and identifying resources should be included in health professions curricula. Faculty development should include methodologies that address these issues.

**Recommendation 3:** The ACTPCMD recommends that HRSA’s Title VII, Part C, Section 747 and 748 funding opportunity announcements include the development of culturally competent interprofessional clinical education and training sites that address social determinants of health and the complex medical, psychosocial, and health literacy needs of vulnerable populations.

**Rationale:** Healthcare professionals, including auxiliary personnel, staff, and community workers must recognize that health inequalities are a major public health problem. An interprofessional approach includes all personnel who are involved in the care of the patient, whether the intervention is medical or psychosocial, and it therefore essential in providing comprehensive care to vulnerable populations. Addressing the patient’s environment, social resources, culture, and financial resources collectively impact on the welfare of the patient and society as a whole. Therefore, interprofessional training should be a part of clinical education. In order for the training to have a lasting effect, it should be experiential and be included in all training sites.
**Recommendation 4:** The ACTPCMD recommends that skills to address health literacy be incorporated into all health professions activities whether or not these activities are a consequence of Title VII, Part C, Section 747 and 748 funding. This systemic change should take the form of including language in accreditation and licensure standards that requires health professions programs and schools to integrate content on the interprofessional team approach that address social determinants of health, patient engagement, and health literacy. This should be incorporated in undergraduate and graduate health professions training as well as in ongoing professional development and continued licensure.

**Rationale:** In order for changes in medical training, to include health literacy and the social determinants of health, to have an impact on the overall structure of the delivery of healthcare and the healthcare system, a systemic change must take place within the structure that defines the optimal quality of health care delivery. This systemic change should be reflected in the standards set forth by professional accrediting bodies as well as in state licensure requirements. An emphasis should be placed in continuing medical education to include these subjects so that a transition can be made by practicing providers in their practice.
Summary

Low health literacy causes adverse health outcomes and higher health care costs. In order for patients to be engaged in their health, they must understand their health conditions, be able to navigate the health care system and comprehend terminology and treatment options. Low health literacy levels can make it difficult for a patient to (Boehringer Ingelheim Pharmaceuticals Inc., 2011):

- Complete forms or understand the concept of “informed consent”
- Report symptoms accurately or provide a complete medical history
- Find appropriate providers and services or seek recommended preventive care
- Read directions on medicine vials or avoid making errors when taking medication
- Grasp mathematical concepts that affect healthcare decisions, such as probability and risk
- Understand how lifestyle choices such as smoking, poor dietary habits, or lack of exercise may adversely affect one’s health
- Acquire enough knowledge about chronic conditions to be able to manage them effectively

It is essential that healthcare professionals engage all patients and recognize the signs of health literacy through effective communication. Current and future healthcare professionals must be trained to be culturally competent and be aware of the impact social determinants of health have on a patient and acquire the skills needed to eliminate health disparities.
References


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Appendix

Table 1: The Cycle of Crisis Care: A Patient’s Experience

Source: Koh H K et al. Health Affairs 2012;31:434-443