

December 2015

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Recommended Citation

Hollar, David W. Jr. and Rowland, Jennifer (2015) "Promoting Health Literacy for People With Disabilities and Clinicians Through a Teamwork Model," *Journal of Family Strengths*: Vol. 15 : Iss. 2 , Article 5.
Available at: <https://digitalcommons.library.tmc.edu/jfs/vol15/iss2/5>

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Promoting Health Literacy for People With Disabilities and Clinicians Through a Teamwork Model

Introduction

Applied health literacy programs are plagued by three fundamental, interconnected problems: (1) lack of a clear, operational definition (Golbeck, Ahlers-Schmidt, Paschal, & Dismuke, 2005; Nielsen-Bohlman, Panzer, & Kindig, 2004; Nutbeam, 2008; Rothman et al., 2006); (2) inconsistent and likely hyperinflation of statistics on the measurement and prevalence of health illiteracy (Yin et al., 2009); and (3) a medical model approach that often fallaciously assumes a low level of health literacy for people with disabilities (Aulagnier et al., 2005; Gill, Stenfert Kroese, & Rose, 2002; Ostapczuk & Musch, 2011; Safer & Keenan, 2005).

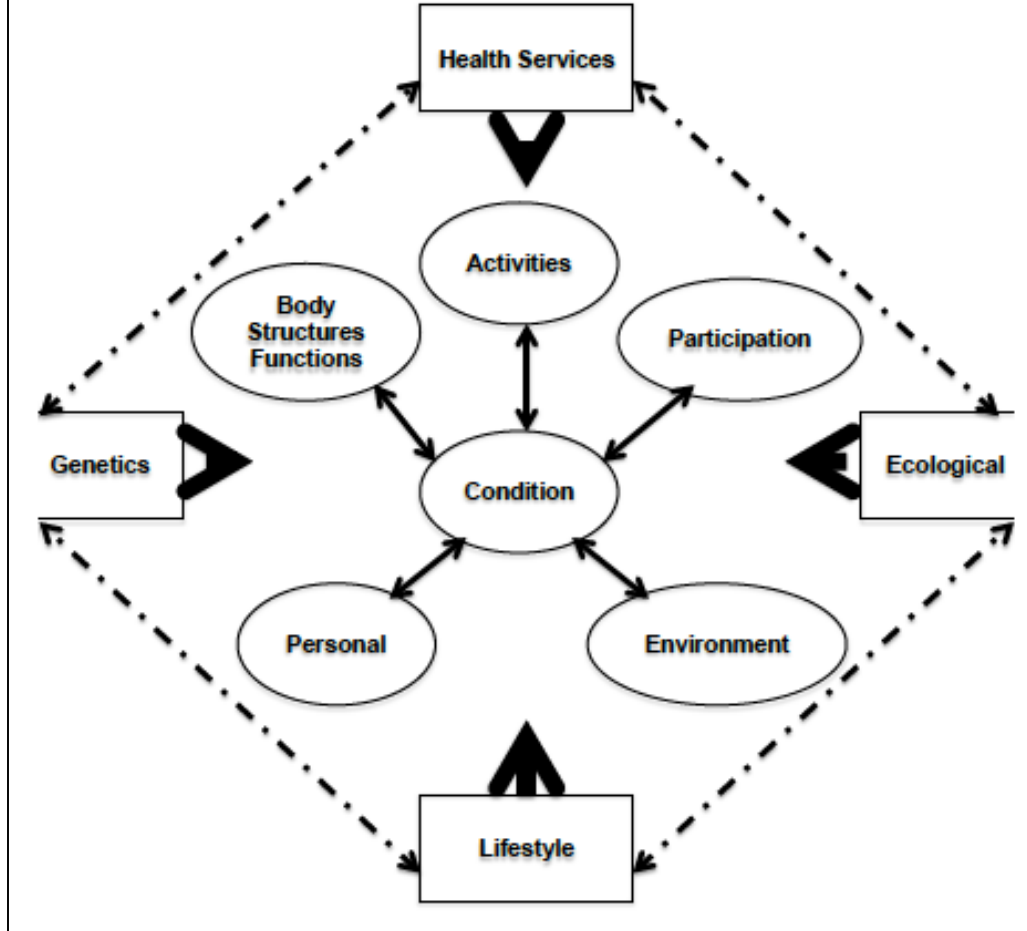
The objective of this review and proposed model is to address common communication barriers associated with the medical model approach; this is done by introducing an applied biopsychosocial model of health literacy for people with disabilities that places the patient as a member and leader of the healthcare team. Using an inclusive approach, this model addresses literacy as a communication issue among the individual, health care providers, family, other supports, and accessible health care teamwork environment.

The biopsychosocial model presented in this paper is adapted from the International Classification of Functioning, Disability, and Health (ICF; World Health Organization, 2001; Figure 1). The ICF model is unique in that it moves beyond traditional medical models that focus on patient body structures to overall level of functioning and the social, personal, and environmental factors that serve as facilitators or barriers to improved health (Figure 1). This model places the patient at the center of the health model and identifies external factors that prevent the patient from achieving full participation in activities and society.

At least one definition of health literacy 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” (Hernandez, Roundtable on Health Literacy, Board on Population Health and Public Health Practice, & Institute of Medicine, 2009, p. 1; Ratzan & Parker, 2000). This definition can vary considerably based upon the complexity of the patient’s health condition, his or her educational level and attitudes, and environmental support factors. Furthermore, family, peers, educational providers, and health care providers need to communicate health care information in a clear, concise fashion. With respect to the latter, the Institute of Medicine (Kohn,

Corrigan, & Donaldson, 2000) and the Joint Commission on the Accreditation of Healthcare Organizations (O'Daniel & Rosenstein, 2008) have identified poor communication, staff training, and information systems as major contributors to medical errors that potentially result in 50,000 to 100,000 preventable patient deaths each year. Coupled with the estimated low levels of health literacy among American adults (U.S. Department of Health & Human Services, 2008; Yin et al., 2009), it is poor communication, not individual lack of knowledge, that may be the primary problem between the vertices of the patient-provider system.

Figure 1. International Classification of Functioning, Disability and Health, a biopsychosocial model of facilitators and barriers impacting persons with disabilities (adapted from World Health Organization, 2001, p. 26; Blum, 1983, p. 37; Longest & Darr, 2014, p. 5).



Prevalence of Health Illiteracy

The U.S. Department of Health & Human Services (2008) has estimated that of the 240 million American adults older than 18 years of age, 77 million (32%) have basic or below-basic health literacy, which is generally defined as the ability to read instructions and explain why a person should be tested for a disease/condition. Others (Yin et al., 2009) have estimated that an even higher number of adults (90 million) are thus affected. In another study, only 12% of adults were rated as proficient at health

literacy, meaning having the skills to use a table to estimate their employee/employer percentage of annual health care costs (U.S. Department of Health & Human Services, 2008). An intermediate health literacy level (53%) indicated that an individual could read and follow prescription directions (U.S. Department of Health & Human Services, 2008).

These studies provide very general, selective criteria for measuring health literacy. Such basic criteria do not begin to address the knowledge of health conditions, screening, prevention, and treatments that typically is part of mandated middle and secondary school health curricula, secondary school biology courses, and college/university curricula (Connell, Turner, & Mason, 1985; Summerfield, 1995). Given that most Americans are exposed to this relatively continuous sequence of health education for at least a decade, accompanied by periodic physical and dental examinations, it would seem reasonable to expect that a typical patient would be conversant with health care providers on various aspects of anatomy and basic physiology, nutrition, and exercise beyond the mere ability to follow prescription directions. Unfortunately, almost no studies have addressed the paradox of a high level of health illiteracy despite school health curricula. Furthermore, health intervention programs generally produce negligible behavioral health changes once interventional supports are withdrawn (Jepson, Harris, Platt, & Tannahill, 2010). Health care teamwork, especially teamwork involving patients in the decision-making process, is a potential solution to this paradox (Kuziemyky, Astaraky, Wilk, Michalowski, & Andreev, 2014; Leggat, 2007). Nevertheless, comprehensive studies of health literacy in conjunction with other health interventions have been limited, especially for people with disabilities.

Health Literacy Levels of People With Disabilities

The complexities involved in the treatment of many conditions further complicate assessments of health literacy among people with disabilities. Specifically, the vast continuum of types of disability, as well as the lack of adequate disability indicators in longitudinal, nationally representative databases, are factors that often impede these assessments (Field & Jette, 2007; Hollar, 2005; Hollar & Moore, 2004; Hollar, McAweeney, & Moore, 2008). For example, people with sensory limitations (e.g., poor vision or hearing) generally experience positive health outcomes (Harrison, Mackert, & Watkins, 2010; Munoz-Baell, Ruiz-Cantero, Alvarez-Dardet, Ferreiro-Lago, & Aroca-Fernandez, 2011; Pereira & Fortes, 2010). However, people with mobility limitations often report poorer health outcomes that

are due to a lack of access to physical activity/exercise accommodations, pain, and secondary conditions (Iezzoni, Park, & Kilbridge, 2011; World Health Organization, 2011). Access to many health and exercise facilities for people with mobility disabilities is limited, and people with various disabilities report inadequate health information and autonomy in health decisions (National Council on Disability, 2009). People with mental illness or intellectual and developmental disabilities may have the greatest need for health literacy and health communication transmission/translation (Chew, Iacono, & Tracy, 2009). For example, Lincoln et al. (2006) found that a poor quality of life and low level of health literacy were significantly associated with people receiving treatment for depression.

Goodman, Finnegan, Mohadjer, Krenke, and Hogan (2013) used the Program for the International Assessment of Adult Competencies (PIAAC) 2012 data to distinguish literacy and numeracy in problem solving, a distinction that also has emerged in assessments of health literacy/numeracy. On five levels of proficiency (1, low; 5, high), 29% of people with disabilities demonstrated general literacy proficiency at levels of 3 to 5, compared with 50% of persons without disabilities (Goodman et al., 2013). The study identified individuals with disabilities as representing approximately 13% of the adult population, comparable with the findings of other studies (Hollar, 2005). However, the PIAAC data are limited to an unclear disposition variable (31 individuals with learning disabilities in an overall sample of 5010), self-report of not seeking work due to extended illness ($n = 268$), and self-report of ever being diagnosed with a disability ($n = 417$). Lack of distinctiveness in level of functioning and reduced cell sizes when crossed with additional demographic variables yield inconsistent estimates on literacy and numeracy outcomes. No nationally representative databases adequately address the tremendous diversity of disability or level of health literacy in relation to level of functioning compared with the general population. Kutner, Greenberg, Jin, and Paulsen (2006) cited similar demographic factors and proficiency levels for the general population, but their study appeared mostly to exclude people with mental disabilities among nonrespondents. Exclusion of people with disabilities from research studies can result in false conclusions on the diversity in population health needs (Figure 2). Increased involvement of people with disabilities and other special populations has been stressed in institutional review board research protocols, not merely for inclusiveness but to better inform health and scientific knowledge (Public Welfare. Protection of Human Subjects. Basic HHS Policy for Protection of Human Research Subjects, 2009; National Institutes of Health, 2011; Federal Policy for the Protection of Human Subjects, 2015).

To better address the health disparities that people with disabilities experience, valid assessments of health literacy should be designed to examine a much broader range of patient knowledge and experiences. Such tools have not yet been developed, but they would be of considerable value in assessing health behaviors and providing predictive validity (Messick, 1988) to improve long-term health outcomes. To correctly evaluate health literacy, this construct must be clearly defined for each contextual situation (e.g., health condition, treatment, disability, culture) so that valid evaluation instruments can be developed. The wide disparities in estimates of people with low levels of health literacy indicate a lack of consensus on valid measures of this construct. A central theme in decision-making processes and validation is maximizing the correct identification of true positives and true negatives in the measurement of phenomena (Swets, Dawes, & Monahan, 2000; Rothman & Greenland, 1998; Figure 2).

Figure 2. Decision matrix for health literacy. In any health literacy communication interaction, it is important to match provider perceptions with actual patient literacy. The goal is to maximize true positives (i.e., we think that the patient is health-literate and he or she actually is) and true negatives (i.e., we think that the patient is not health-literate and he or she actually is not). The decision model should reduce assessment errors (i.e., false positives and false negatives).

		Health Literacy Perception or Assessment	
		True	False
Health Literacy Reality	True	True Positive	False Negative
	False	False Positive	True Negative

Health Disparities Experienced by People With Disabilities

Despite the exclusion of many people with disabilities from nationally representative databases and the lack of health literacy measures for this population of more than 50 million (Field & Jette, 2007), a substantial body of research demonstrates that people with disabilities experience substantial disparities in health outcomes, employment, social participation, and health risk behaviors compared with people who do not have disabilities (Brucker & Houtenville, 2015; Hollar & Moore, 2004; Hollar et al., 2008; Rimmer, Rowland, & Yamaki, 2007; Seekins et al., 2006). Multivariate factors are involved in these disparities, including low socioeconomic status, barriers to access to public and private

transportation, lack of social supports, lack of preventive services and devices to assist physical activity, and negative stereotypes/discriminatory attitudes. People with disabilities were significantly more likely to experience physiological allostatic load, including exceedingly high obesity rates in persons with mobility limitations, compared with people without disabilities, during the Centers for Disease Control and Prevention Healthy People 2000–2010 decade (Hollar, 2013). Healthy People 2010 (http://www.cdc.gov/nchs/healthy_people/hp2010.htm) and Healthy People 2020 (http://www.cdc.gov/nchs/healthy_people/hp2020.htm) represent national objectives for healthy outcomes across the entire population, with specific measures supplied from national databases. Allostatic load is the “cumulative biological risk” caused by acute and chronic stress and by wear and tear on the body (Hollar, 2013; Seeman et al., 2001; Selye, 1950).

Multiple factors, including a low level of health literacy, lack of access to exercise, and secondary conditions, contribute to these negative health outcomes related to allostatic load. Furthermore, Hollar and Lewis (2015) demonstrated negative heart age differentials (i.e., hearts older than bodies) in people with mobility limitations, significantly higher than those in people with other types of disabilities as well those in people without disabilities. Both studies (Hollar, 2013; Hollar & Lewis, 2015) documented these trends for Healthy People 2010. The results indicate that people with disabilities are not achieving equivalent health outcomes, possibly because of barriers to health care and alternative health/exercise venues, including health communications from providers and lack of access to exercise (Rimmer et al., 2007; Seekins et al., 2006). The causal mechanisms for these health disparities have not been established, but health communication and literacy have been promoted as community health interventions for people with disabilities and for other underserved populations (Raja et al., 2015).

Several variables aiming to improve health outcomes for people with disabilities (Gray, 2002, p. 17) include the following objectives from Healthy People 2010 (U.S. Department of Health & Human Services, 2000), Disability and Secondary Conditions:

- Objective 6.4 - “Increase the proportion of adults with disabilities who participate in social activities.”
- Objective 6.6 - “Increase the proportion of adults with disabilities reporting satisfaction with life.”

These objectives have been extended to the Healthy People 2020 national goals (U.S. Department of Health & Human Services, 2010). However, there are limitations related to the Healthy People 2010 and Healthy

People 2020 data: specifically, the restricted use of generic disability variables/indicators and a failure to crosslink disability data outside specific disability objectives to other disability categories, the latter of which can be done with national data sets such as the National Health and Nutrition Examination Survey (NHANES; Hollar, 2013; Hollar & Lewis, 2015). These weaknesses/limitations indicate that we lack a clear understanding both of facilitators that improve health and of barriers that prevent health, functioning, and participation in society by people with disabilities.

For the Healthy People 2010 Focus Area 11 - Health Communication set of objectives, health websites improved from 22.2% to 58% toward targeted goals across several categories (National Center for Health Statistics, 2012, p. 40). Additionally, patients reported improvements of 14.3% to 42.9% in physician listening, explanations, and respect for patients (National Center for Health Statistics, 2012, p. 40).

For the Healthy People 2010 Focus Area 6 - Disability and Secondary Conditions set of objectives, there was an 86.7% improvement in the inclusion of children and youth with disabilities in regular education programs (K-12), but only a 5.4% increase in health promotion programs for persons with disabilities, plus no change in health promotion programs for personal health caregivers outside clinical health providers (National Center for Health Statistics, 2012, p. 27). Therefore, there is a clear need for improved health communication programs to help people with disabilities, their families, and caregivers in relation to health providers, and vice versa. Numerous health communication and access programs for people with disabilities are provided by the following organizations: the National Association of Rehabilitation Research and Training Centers (narrtc.org); the Center on Knowledge Translation for Disability and Rehabilitation Research (ktdrr.org); the National Center on Health, Physical Activity, and Disability (www.nchpad.org); the Amputee Coalition Limb Loss Resource Center (<http://www.amputee-coalition.org/limb-loss-resource-center>); The Arc (www.thearc.org); and Special Olympics (http://www.specialolympics.org/healthy_athletes.aspx).

Healthy People 2020 Topics and Objectives (<http://www.healthypeople.gov/2020/topics-objectives>) were greatly expanded to evaluate health literacy and provider communications for the general population. Healthy People 2020 Disability and Health (DH; <http://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health>) objectives included adding prevention programs (DH 2.2-2.4), decreasing medication use (DH-7), and increasing social supports (DH-17).

A Biopsychosocial Model

Much of the health literacy literature is based on the traditional medical model, which views health conditions as centered within the individual. The ICF (World Health Organization, 2001) provides a biopsychosocial interpretation of health parallel to Blum's model of health (Blum, 1983, p. 37; Longest & Darr, 2014, p. 5), which expands the scope of health and disability to a continuum of functioning impacted by facilitators and barriers in the body, the social environment, and individual behaviors, all resulting in successful or unsuccessful activities and participation (Figure 1). For example, an individual with an acute or chronic mobility limitation could have varying levels of functioning depending upon current levels of pain, access to assistive technology and transportation, family and peer supports, attitudes of employers and people in society, and health assessments based upon full or partial access to provider facilities. All of the factors in Figure 1 consist of many variables, each of which can be assessed as a facilitator that improves a health condition or as a barrier that worsens a health condition. For example, the environmental variables include family and peer supports, technology, services, transportation, attitudes of other people, and public health policies. The ICF (World Health Organization, 2001; Figure 1) includes a Likert-type scale for rating positive (facilitator) and negative (barrier) accessible environments; attitudes of family, peers, and employers; participation in society, etc. Applying Figure 1 to an individual case, one can identify facilitators to be enhanced and barriers to be reduced so that health communication and outcomes for people with disabilities can be improved.

Hernandez et al. (2009) highlighted a biopsychosocial approach to health literacy in which patient and clinical care knowledge and attitudes coincide with supportive environments for successful health outcomes. Both Bigby, Frawley, and Ramcharan (2014) and Johnson, Minogue, and Hopkins (2014) argued that persons with intellectual disabilities should be included and should be advocates in all aspects of research and health care involving their own outcomes, a situation that rarely occurs. Bailey et al. (2014) evaluated parent ratings of the ability of their children with fragile X syndrome to consent to participation in a clinical trial of medication and found that 71% of parents indicated that their children were able to provide consent, although at varying degrees of decision-making capability. For people with severe disabilities, the involvement of family, significant authorized peers, and health care providers represents an opportunity for teamwork, communication, and support to provide optimal health care.

Human Decision Making in Health Literacy

Tversky and Kahneman (1974) and Kahneman (2002) demonstrated that most people, regardless of educational level, use poor heuristics and fallacies in making decisions. Such fallacies include stereotyping patients, anchoring medical decisions based upon initial information while discounting later information, and basing diagnoses on similar patients previously examined (Croskerry, 2003). Croskerry presented 32 types of fallacious clinical reasoning that can result in incorrect patient diagnoses/medical errors, and he suggested 11 debiasing strategies (e.g., awareness, feedback, cognitive forcing strategies) to reduce these errors. Teamwork strategies in health care (Leggat, 2007) include these strategies to improve communication and information clarity among health team members for improved patient outcomes and safety.

Furthermore, Newton et al. (2008) studied successive waves of medical school classes that exhibited declining empathy toward patients in general. Consequently, the health literacy construct may require not just patient literacy but also the attitudes and decision-making processes of clinicians as a provider literacy component, thus making health literacy an interactive issue among patients, family, and the providers who represent the health care team. Health literacy is not a patient issue from a medical model perspective, but it is an interactive issue in the ICF biopsychosocial model (Figure 1), thus involving communication, understanding, and empathy between patient and provider. To facilitate this biopsychosocial decision-making model, it should be noted that Kahneman (2002) argued for System 2 (reasoning) over System 1 (intuition) problem solving, both of which are important, although the former requires higher-level thinking skills. Unfortunately, the level of measured System 2 reasoning remains low across professions regardless of educational achievement (Kahneman, 2002). A communication model of health literacy involving all parties will involve addressing reasoning for clear communications to promote patient understanding along with respect for patient autonomy and knowledge.

Certainly, differences in literacy will exist based upon specific types of disability (e.g., intellectual and developmental disabilities) and levels of education. Providers will need to tailor health communications toward these differences while addressing their own decision-making and judgmental biases. In other words, providers and patients alike will be responsible for clear communication of health needs, consent for procedures, understanding of each person's role in the process, mutual respect, and the right of any person to raise concerns to which the team will respond. The latter is illustrated with the standard decision-making

matrix (Figure 2), in which the decision maker with limited information for judgment must aim to minimize false positives and false negatives in understanding patient/family concerns and what needs to be accomplished in the health care activity (Swets et al., 2000; Rothman & Greenland, 1998).

To detect true health literacy and illiteracy, or shades thereof, our judgments, perceptions, and measurement tools must maximally match the truthfulness and falseness of reality (Figure 2). If a person with a disability is health-literate on a specific topic, then the provider's assessment tool for health literacy should indicate that fact (i.e., true positive). If a person with a disability is health-illiterate on a specific topic, then the assessment tool likewise should indicate that fact (i.e., true negative). Given that tools and judgments can be inaccurate to some degree, even for diagnostic tests, Swets et al. (2000) strongly recommended the use of multiple assessments to triangulate assessment decisions (Figure 2). Unfortunately, clinicians and caregivers have limited access to assessment measures that have been rigorously tested for psychometric reliability and predictive validity (Messick, 1988). Many educational and psychological questionnaires have been briefly tested for reliability (i.e., precision or repeatability of the questions) but have not been validated (i.e., accuracy in measuring the true, specific psychological concept rather than something else). A valid measurement will measure what it claims to measure (construct validity) and strongly predict (predictive validity) its measured behavior (e.g., adherence to medication use, abstinence from substance abuse). With reference to Figure 2, plotting true positives versus false positives will yield a curve; the steeper the curve, the greater the area under the curve (optimally 80% or more) and predictive validity (Swets et al., 2000; Wray, Yang, Goddard, & Visscher, 2010).

Communication and Teamwork

The impact of lower literacy levels and the capacity of providers to communicate health information for understanding can be implemented within existing patient safety teamwork models. Although not representing a biopsychosocial model, the Agency for Healthcare Research and Quality TeamSTEPPS (Team Strategies as Tools to Enhance Performance and Patient Safety) program (Sheppard, Williams, & Klein, 2013) is a human interaction and behavior approach that aims to create a cohesive patient-centered health care team and that uses improved communication approaches while promoting each provider, regardless of specialty, as a leader who can identify areas for improvement and concern. The program

has been widely implemented in hospitals nationwide. The Duke University Health System Patient Safety Center was one of the first TeamSTEPPS training centers and has adopted a patient-centered organizational mission (<http://dukepatientsafetycenter.com/index.asp>). Practitioners of TeamSTEPPS use a variety of strategies (e.g., check-back verifications of statements made by sender to receiver; huddles of team members to evaluate problems, make consensus decisions, and then implement solutions) to improve the timely and accurate communication of information among everyone involved with a patient's care (Agency for Healthcare Research and Quality, 2006).

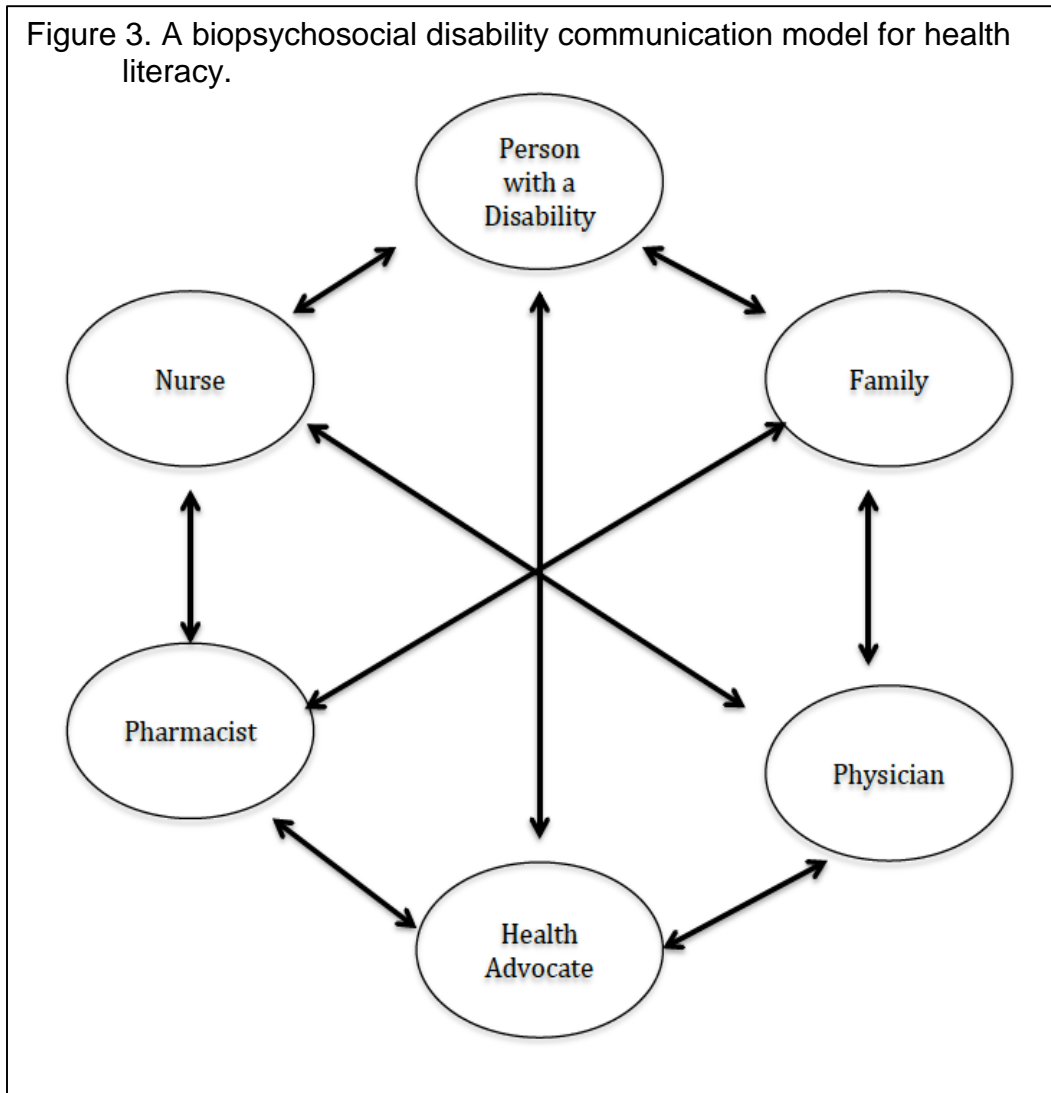
However, one of the central failings of the nationwide rollout of the TeamSTEPPS and similar programs at many hospitals and clinics is not adhering to the concept that the patient is part of the team; this concept has rarely been implemented in practice, indicating the continuing emphasis on traditional medical models that view conditions within the patient as an object, further disregarding ethical emphasis on patient autonomy. Certainly in acute illness and in some other instances, some patients will not be able to communicate effectively, so that the clinical team must exert more authority. Nevertheless, in the majority of patient-provider interactions, a holistic, biopsychosocial model of communication and teamwork can be effective at promoting positive health outcomes and reducing recidivism into unhealthy behaviors. For example, a person with a spinal cord injury may receive more immediate and focused care for an adverse health issue, such as a pressure sore, if he or she is able to communicate effectively with health care providers about the circumstances surrounding the development of the sore. By having the knowledge of how to prevent and manage future health problems, the individual can contribute to his or her overall long-term health promotion efforts.

Practitioner Awareness

The effect that caregivers can have on this process (e.g., facilitating information exchange) is to support models of behavioral change that involve all individuals in the health care process (Figure 3). This model uses a strategic planning, teamwork design (Bess, 1988, p. 25) in which channels of communication exist among all members of a closely knit team. By using TeamSTEPPS practices, such as callouts, check-backs, timely handoffs of accurate information, and team huddles/debriefings, to evaluate the process (Agency for Healthcare Research and Quality, 2006), the patient and health care providers can have clear communications and expectations of what each person needs to do to address the health

condition (Figure 1). There will be obstacles to overcome, including authority gradients, personality differences, communication styles, and personal biases. Changing the health care culture is central to the process.

Figure 3. A biopsychosocial disability communication model for health literacy.



Conclusion

Health care communication is central to health literacy and understanding among all members of the health care team, not just the patient. This approach is consistent with the decision-making psychological literature and business strategic planning literature. With the current dramatic changes in health care provision, many health care systems are exploring

changes in the culture of medical/health care, moving away from strict medical models in which the patient is an object with a condition. Instead, biopsychosocial models (Figures 1 and 3) view the patient as a central component and equal decision maker within the health care team.

Persons with disabilities experience substantial health care and other social disparities compared with the general population. Social systems have been slow to move beyond physical accommodations alone to total inclusion models with accommodations for human interactions and communication as well, in the same way that an organization would provide translators to accommodate language differences in global cooperative projects.

Health literacy remains an elusive concept that is continuing to be researched and assessed. The teamwork decision-making model (Figure 3) places health literacy as a communication/understanding issue outside individuals and their backgrounds/abilities and refocuses it as a problem to be addressed in human interactions. This approach logically stands to promote improved health outcomes for persons with and without disabilities that are consistent with current Healthy People 2020 objectives.

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