

Health Literacy *and* Adolescents

AN AGENDA FOR THE FUTURE

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TYPICALLY DEFINED AS “THE DEGREE TO WHICH INDIVIDUALS have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Selden, Zorn, Ratzan, & Parker, 2000), health literacy has become an important public health issue. While various professional groups and individuals have different ideas concerning what health literacy includes and how it should be addressed (Logan, 2007; Baker, 2006), most would agree that health literacy involves the acquisition of skills that allow people to make informed choices about their health care and behavior.

Don Nutbeam provides a useful and often cited model of health literacy, describing functional, interactive, and critical literacy, which together contribute to a more complete perspective of health literacy (Nutbeam, 2000). The first, functional literacy, refers to the basic ability to read and write. Interactive literacy concerns one’s ability to coordinate functional literacy and social skills to fully participate in daily activities and communication, while critical literacy addresses a person’s potential to evaluate information. Media literacy, the ability to critically evaluate media messages, has been widely studied among youth, and also is relevant to health literacy as it relates to adolescents (Kaiser Family Foundation, 2003). Studies of adolescent health literacy may focus on one or more of these literacy types or may be grounded in other frameworks of health literacy.

Why Study Adolescents?

A recent survey of health literacy and adults found that 14% had below basic health literacy, with females, Whites and Asians, and those with more education or in the 25 to 39 age group having higher health literacy levels (Kutner, Greenberg, Jin, Paulsen, & White, 2006). Prior research with adult patients with low levels of literacy has found problems completing medical forms, an inability to understand instructions for prescription medications, and difficulty comprehending provider instructions (Ad Hoc Committee, 1999; Baker et al., 1996). Literacy problems limit the ability to provide medical histories and accurate responses to scales or other questionnaires (Lee, 1999; Weiss & Palmer, 2004), and are associated with higher use of health services and greater health care costs (Agency for Healthcare Research and Quality, 2004; Baker, Parker, Williams, Clark, & Nurss, 1997; Baker, Parker, Williams, & Clark, 1998; Baker et al., 2004; Weiss & Palmer, 1994). Literacy problems also may result in limited participation in or benefit from health education programs (Williams,

Baker, Parker, & Nurss, 1998) and can influence communication between patients and providers (Schillinger, Bindman, Wang, Stewart, & Piette, 2004; Williams, Davis, Parker, & Weiss, 2002). People with low literacy may not fully benefit from media interventions, campaigns, or educational programs due to an inability to read, understand or access the messages (Lindau et al., 2002; Rudd, Comings, & Hyde, 2003).

While much research has examined literacy in health settings and the association of literacy levels with health outcomes for adults (DeWalt, Berkman, Sheridan, Lohr, & Pignone, 2004), little is known about how health literacy impacts health behavior and outcomes for adolescents. Some might argue that adolescents have less interaction with the health care system than adults (Newacheck, Wong, Galbraith, & Hung, 2003) and fewer health problems, suggesting that studying health literacy and youth should not be a priority. However, given that adolescents represent a group who will soon be navigating the health care system on their own for the first time, it is crucial to gain a better understanding of their health literacy skills and to understand the implication of low health literacy skills on adolescent health outcomes and behavior. It is unclear whether the trends found above for adults are also issues affecting adolescents.

Extensive literature exists in the education field regarding adolescents and literacy. Studies have shown that literacy is a significant problem for adolescents, as many adolescents are unable to read at the appropriate grade level (Biancarosa & Snow, 2004). The Nation’s Report Card reported that in 2007, for a national sample of eighth graders, 26% of students scored below the basic reading level score (National Center for Education Statistics, 2008). In 2005, 41% of eighth graders scored below the basic level of understanding for science information (NCES, 2008).

While information concerning literacy skills of adolescents is useful, a specific focus on health literacy is becoming more relevant as adolescents are increasingly involved with their health care (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005), regularly interact with the health system, and access health information which informs their actions and behaviors. In addition, a person with high literacy does not always have high health literacy (Yin, Forbis, & Dreyer, 2007). Given the low literacy levels among adolescents, it is unclear how well this age group is able to understand, process, and evaluate health information, and while prior research has demonstrated that adolescents are

interested in understanding health information, they may find it difficult. A recent survey of young adolescents by the Nemours Foundation reported about 80% of respondents said they were very or sort of interested in learning more about health, but almost a quarter of them (22%) said health information was very or sort of hard to understand (Kidshealth, n.d.). Another study found about 25% of students said it was hard to understand health information (Brown, Teufel, & Birch, 2007), and a recent study of literacy related to health terms found that 46% of adolescent participants were reading below grade level (Davis et al., 2006). Health literacy for adolescents also requires attention given the large amount of educational and other materials distributed to youth by health providers, schools, and intervention programs. The readability of materials is highly relevant to this issue, as adolescents cannot use information to guide their choices about health behavior or develop health literacy skills if they fail to understand information provided to them.

Health literacy has the potential to affect all adolescents, but it is especially relevant for those who have a chronic illness. There is a growing prevalence of chronic illness such as asthma, diabetes, cystic fibrosis, and mental illness among youth age 0 to 17 (Agency for Healthcare Research and Quality, 2005; Boice, 1998; Millstein & Litt, 1990). Adolescents with chronic illness are likely to have more interaction with the health system, as well as greater responsibility for participating in their care and treatment (Boice, 1998). Studies have found that teens with a chronic illness such as diabetes go online to seek information about managing their illness (Ravert, Hancock, & Ingersoll, 2004), and that medical providers believe it is important for adolescents with chronic illness to have adequate health literacy skills (Fleming & Madamala, 2005).

Finally, adolescents are at a crucial stage of development characterized by many physical, emotional, and cognitive changes (Feldman & Elliott, 1990). Adolescents experience changes in cognitive abilities, developing an improved capacity for processing information, thinking more about abstract ideas, and using reasoning skills (Keating, 1990; Steinberg, 2005). They also are achieving greater autonomy (Steinberg, 2005). These changes make adolescence an appropriate time to begin thinking about health literacy interventions, and improving health literacy at an early age has a direct impact on health literacy later in life as adolescents are acquiring knowledge and setting behavior patterns they will carry with them as they transition into adulthood (Modell & Goodman, 1990).

What about children?

While this paper focuses on adolescents, it should not be assumed that health literacy skill development is not appropriate for children. For instance, the Institute of Medicine (IOM) report suggests incorporating health materials into current educational programs, specifically mentioning literacy instruction for children and adults (Nielsen-Bohlman, Panzer, & Kindig, 2004). However, almost no research has been conducted in the health field to explore issues of health literacy with children themselves. Typically, studies focusing on health literacy and children measure health literacy of caregivers and assess the impact of caregiver health literacy on children's service use and outcomes (Bennett, Robbins, & Haecker, 2003; Davis & Mayeaux, 1994; Moon, Cheng, Patel, Baumhaft, & Scheidt, 1998; Sanders, Thompson, & Wilkinson, 2007; Yin et al., 2007; Yin, Dreyer, van Schaick, & Mendelsohn, 2007). For example, one study of Latino parents found that people with a higher literacy level were more likely to use medications for their children correctly (Leyva, Sharif, & Ozuah, 2004), while another study of children with asthma found that lower literacy of parents was correlated with children's incorrect inhaler use and more visits to the emergency department (Wilks-Gallo, Sharif, & Ozuah, 2004). During childhood, parents or guardians are coordinating health care and often making decisions about health behavior, such as what is served for dinner. Adolescents, on the other hand, are becoming more independent, as mentioned above, and adolescents are closer to the time when they will begin to oversee their own health care.

It is important to consider the development of health literacy skills for both children and adolescents, but focusing on adolescents will ensure that those who are in more immediate need of the information and skills will have them. It will also allow for the development and evaluation of approaches that can then be used with children.

Influences on Adolescent Health Literacy

In order to think about what future work is needed concerning health literacy and adolescents, it is important to consider the multiple factors that can influence adolescent health literacy skill development. Frameworks proposed by both the IOM report and the Ecological Model (EM) suggest that different levels of influence contribute to individual development and health behavior (Nielsen-Bohlman et al., 2004; Sallis & Owen, 2002). While schools play a crucial role in teaching health literacy skills, the Ecological Model suggests that factors at multi-

ple levels influence health knowledge and behavior. Governali and colleagues point to this model in their article, suggesting that it is relevant to the social change philosophy as it encourages health educators to focus on the environment of youth in addition to individual skills (Governali, Hodges, & Videto, 2005).

Individual Characteristics

Individual traits, such as age, race, gender, cultural background, cognitive and physical abilities, and social skills predict one's health literacy, which then determines health outcomes (Nielsen-Bohlman et al., 2004). In addition, media use is a crucial component for adolescent health literacy given that adolescents are frequent users of the mass media. Youth ages 8 to 18 spend almost six and a half hours per day with some type of media, and media have been shown to influence physical and social development, health behavior, and are often cited as a source of health information for adolescents (Borzekowski & Rickert, 2001; Brown & Witherspoon, 2002; Jordan, 2004; Millstein, 1993; Rideout, 2001; Skinner, Biscope, Poland, & Goldberg, 2003). Educational television has been linked with advances in literacy, reading comprehension, and math skills for children (Fisch, 2002). Given that media has been linked to development, health behavior, and literacy, it is reasonable to conclude there may be an association of media use with health literacy (Zarcadoolas, Pleasant, & Greer, 2006).

Peer and Parent Influences

In addition to individual characteristics, peer and parent influences are especially relevant for youth (Feldman & Elliott, 1990; Nielsen-Bohlman et al., 2004; Steinberg, 2005). Prior research has shown a relationship between family factors and school achievement (Sikorski, 1996). For instance, reading aloud in the home setting can enhance vocabulary skills (Blachowicz & Fisher, 2007), and encouraging reading at home is linked with an interest in learning (Strommen & Mates, 2004). Peers also have been shown to have a direct influence on literacy as well as health behavior, given their growing prominent role in the lives of youth as they transition into adolescence (Brown, 1990; Cheung, 1997; McCabe & Ricciardelli, 2001; Prinstein, Meade, & Cohen, 2003).

Systems

A framework in the IOM report shows how culture and society, the health system, and the education system all

serve as potential contributors to the development of health literacy skills, and thus, act as possible areas for interventions (Nielsen-Bohlman et al., 2004, p.34). Systems are an area especially important for adolescents as they are still engaged with organizations that can facilitate education programs and other interventions to enhance health literacy skills. The health system clearly is important to include in a framework of health literacy, given its direct impact on how accessible health care is and how well information is communicated to patients (Nielsen-Bohlman et al., 2004). Readability of materials in health centers, clarity of provider communication with adolescent patients, and interventions in health settings all are crucial to the development of health literacy skills for adolescents. However, to date, little information exists concerning interventions in health settings to build adolescent health literacy skills.

The IOM report and other publications also highlight the need for schools to play an important role in improving health literacy for adolescents, as schools have a direct influence on the education and development of adolescents (Entwisle, 1990; Nielsen-Bohlman et al., 2004). One of the main goals of the education system is to develop literacy skills, and routine literacy instruction offers opportunities to enhance health literacy by building reading and writing skills. In fact, merging literacy instruction with health literacy is possible, with a recent resource providing a list of books along with ideas to connect health concepts into regular assignments (Benham-Deal & Hudson, 2006; ToucanEd, 2008). In addition to developing general literacy skills, school-based health education classes provide an excellent opportunity to facilitate the development of skills specific to health literacy, such as how to evaluate credible information on the Internet. In fact, in 1995, a report titled "The National Health Education Standards: Achieving Health Literacy", provided guidelines to assist education program with enhancing the health literacy of students (Joint Committee on Health Education Standards, 1995). The standards were slightly revised in 2007 (Joint Committee on Health Education Standards, 2007).

Lesson plans exist and information is available to inform teaching skills to improve health literacy. Lawrence St. Leger (2001) provides suggestions regarding how schools can teach health literacy, including regular professional development for teachers and the sharing of information with other schools about programs that schools may develop which are proven to be successful. Peterson and

colleagues (2001) discuss ways teachers can be more involved with teaching health literacy to youth, such as assisting students with comprehension and evaluation of health information. A recently published article offers a lesson plan to use for developing skills to access health information and learn about health advocacy for youth in grades 6 through 12 (Brey, Clark, & Wantz, 2007). One article studied the use of two textbooks approved by the state of Arkansas for middle and high school classes, and found an increase in knowledge and skills when using assessment items to measure changes for both concept and skill acquisition (Hubbard & Rainey, 2007). Others have emphasized the importance of training for educational professionals and ensuring that teachers have adequate levels of health literacy (Benham-Deal & Hudson, 2006; Peterson et al., 2001).

There has been debate in the education literature concerning the philosophy and focus of school health education. Some argue that health education must account for behavior change and focus on teaching information designed to bring about positive health behaviors (Governali et al., 2005). Others have argued that it would be difficult to hold schools accountable for health behavior, and thus, a focus on teaching knowledge and skills should be the priority (Benham-Deal & Hudson, 2006). However, it seems that people agree that skills designed to enable youth to access and utilize health information should be an integral part of health education programs (Benham-Deal & Hudson, 2006; Governali et al., 2005; Kolbe, 2005), with some saying it is the “primary goal” and the “skills development philosophy,” which is most closely tied to health literacy, is considered to be emphasized in health education today (Governali et al., 2005; Hubbard & Rainey, 2007).

Measurement of Health Literacy

Although it is important to identify factors that can impact health literacy skills, it is equally important to understand how to measure health literacy. Assessment is crucial to gain a better understanding of a population's current skill levels and to evaluate change occurring through interventions.

People often use education as a proxy measure for literacy in health research. However, studies have shown that health literacy can act as a unique measure even when accounting for other factors such as race, education, culture, and income (Ad Hoc Committee, 1999; Davis, Byrd, Arnold, Auinger, Bocchini, 1999). Multiple tools have

been developed to measure health literacy (Andrus, 2002; Baker, 2006; Yin et al., 2007), but tests such as The Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) are focused on word recognition or reading comprehension, and as the IOM report points out, they do not test other aspects of health literacy, such as verbal communication skills or critical thinking skills (Nielsen-Bohlman et al., 2004). A recently published study by Davis and colleagues tested the REALM-Teen, based on the REALM, and found it to be a valid and reliable tool (Davis et al., 2006), and another study found the TOFHLA to be valid when used with adolescents (Chisolm & Buchanan, 2007). However, no adequate tool currently exists to assess the full concept of health literacy, according to the recent report by the Institute of Medicine (Nielsen-Bohlman et al., 2004).

In the education field, the Council of Chief State School Officers' State Collaborative on Assessment and Student Standards Health Education Assessment Project (SCASS-HEAP) has been working on developing tools for the assessment of health education programs since 1993 (Marx, Hudson, Deal, Pateman, & Middleton, 2007). Specific measures were created to align with NHES, and many supporting items, such as professional development materials and rubric cards, have been developed as well. Now there is an existing database of items which can be accessed to measure unique components of content and skill aspects of health education programs (Tompkins, Kamal, & Chapman, 2005), and a specific health literacy competency assessment currently is being tested which includes 60 items designed to improve standardization and speed of scoring (Garman, Hayduk, Posey, Teske, & Crider, 2004).

Future Agenda

The above discussion outlines why health literacy is an important issue to address for adolescents, what factors are likely to influence health literacy, and how health literacy is typically measured. Given current knowledge, the items discussed below provide suggestions for future work in the area of health literacy and adolescents to gain an understanding of how prepared the current generation of youth will be as they begin navigating the health care system.

1.) Continue to develop and validate tools to measure health literacy in adolescent populations. Developing a tool to specifically measure health literacy skills for adolescents is crucial as a building block for future research. Scales and

questionnaires should allow for self-administration when possible to allow for inclusion in large scale surveys. They should include measures for different types of health literacy skills, such as functional and critical literacy. Measures used for school assessment should continue to be developed and be designed in accordance with NHES standards. Research evaluating whether or not such measures provide appropriate assessment of both the success of school health education programs and health literacy skills will provide valuable information to the field. For example, further work to construct and validate specific instruments using HEAP items could offer more complete measures of health literacy at different grade levels in accordance with the IOM report (Nielsen-Bohlman et al., 2004).

2.) Examine predictors of health literacy levels for adolescents. Studies to understand the association of individual traits with health literacy skills and to compare academic achievement measures with scores on assessments of health literacy are two possibilities. A study of variations by systemic and environmental factors, such as schools and communities, also may provide needed insight into which adolescents are more or less likely to have high health literacy skills.

3.) Examine the relationship between adolescent health literacy and health outcomes, including behavior, health care service use, and costs. Once measures are further developed to assess health literacy for adolescents, resulting scores can be used to help show how health literacy skills may influence behaviors or other health outcomes of interest, including decision-making around health behavior and the ability to access the health care system. Although similar research has been conducted for adults, it is necessary to understand these relationships for adolescents to inform interventions.

4.) Further develop and evaluate health education programs and other interventions that can promote a greater understanding of health information for

adolescents. Interventions to enhance health literacy skills may include programs that can be conducted in schools or health care settings, and could potentially use mass media (TV programs such as ER or health Web sites) to teach health literacy skills to adolescents. Detailed discussions of health education programs are provided elsewhere (Benham-Deal & Hudson, 2006; Governali et al., 2005; Hubbard & Rainey, 2007; Kolbe, 2005), and a comprehensive discussion of potential interventions in medical settings can be found in a recent paper published by Yin and colleagues (Yin et al., 2007). Creating, implementing and evaluating interventions that are varied according to content, target group, and setting will enhance adolescent health literacy skills, and interventions specific to professional groups also may be warranted (i.e., specific to nursing providers; Betz, Ruccione, Meeske, Smith, & Chang, 2008).

5.) Consider needs of specific groups and populations. In addressing each of the above priorities, studies should consider focusing on specific populations to account for cultural, societal, technological and systemic differences. A report by the RAND Corporation concluded that adolescent literacy varies by race and socioeconomic status (McCombs, Kirby, Barney, Darilek, & Magee, 2004), and a recent study using REALM-Teen found gender and race differences (Davis et al., 2006), emphasizing the need to study specific groups of adolescents in an effort to reduce health disparities (Brown et al., 2007).

6.) Foster collaboration across multiple disciplines. Experts in multiple disciplines are working on this issue. However, each specific field has unique conferences and journals, and people may have little opportunity for discussion and exposure to ideas across disciplines. As Benham-Deal and Hudson mention (2006), education and public health can “reinforce” one another. Encouraging a multidisciplinary approach will bring about a useful integration of ideas to advance the field and improve health literacy skills for all adolescents.

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