Health Literacy, Mental Health, and Adolescents

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Introduction

Health literacy is a growing field with a continuously expanding body of research and a growing number of practice and policy guidelines (Wolf et al., 2009).¹ Given the increasing attention to this topic, it is surprising that there has been little research focused on adolescents (Manganello, 2008). There is also limited research in the USA about health literacy and mental health. This chapter will address the intersection of health literacy, with a focus on adolescents. We will give a summary of definitions of health literacy and mental health literacy, and provide a brief overview of research that has

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focused on both health literacy, including its relationship to mental health outcomes, and mental health literacy. We will highlight research in these areas that has been conducted with adolescents, and propose ideas for future work.

Health Literacy

Definitions

Health literacy is commonly 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" (Ratzan & Parker, 2000). More recently, there has been a shift to also focus on the demands of health information and services. A newer definition states that health literacy is when "the skills and ability of those requiring health information and services are aligned with the demand and complexity of information and services" (p. 28) (Parker & Ratzan, 2010).² This approach emphasizes that information and services provided by various sources should be easily understandable, "accurate, and actionable" (p. 1) (U.S. Department of Health and Human Services, 2010). This is especially important given that the National Action Plan states that "nearly 9 out of 10 adults have difficulty

¹A detailed overview of the history of research and policy related to health literacy can be found in Parker and Ratzan (2010) (Parker & Ratzan, 2010).

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²Two papers provide a useful discussion of health literacy definitions (Berkman, Davis, & McCormack, 2010; Peerson & Saunders, 2009).

using the everyday health information that is routinely available in our health care facilities, retail outlets, media, and communities" (p. 1) (U.S. Department of Health and Human Services, 2010).

Summary of Knowledge

Health literacy research has assessed health literacy skills, studied the relationship of health literacy with service use and health outcomes, investigated measurement options, and evaluated services, programs, and health information materials. Regarding research related to prevalence, many adults in the USA lack the health literacy skills needed to function in a complex health care system. Assessment of health literacy skills varies based on the population studied and instruments used to measure health literacy, but in general, "limited health literacy affects people of all ages, races, incomes, and education levels" (p. 1) (U.S. Department of Health and Human Services, 2010). A useful estimate comes from the 2003 National Assessment of Health Literacy, which found that 36 % of adults have limited health literacy (basic or below basic health literacy levels) (Kutner, Greenberg, Jin, & Paulsen, 2006). Rates of low health literacy are higher for minorities, people over 65, those with less than a GED or high school diploma, and individuals living below the poverty level (Kutner et al., 2006). Studies specific to mental health settings have found a high prevalence of low literacy among patients in a "psychiatric emergency service" (Currier, Sitzman, & Trenton, 2001) and in an "indigent psychiatric population" (Christensen & Grace, 1999).

For adolescents, the prevalence of low health literacy is not as well understood as that of adults. In one study, 46% of adolescents ages 10–19 from clinics, schools, and summer programs in North Carolina and Louisiana were reading below grade level (Davis et al., 2006). Although little research has quantified health literacy levels for adolescents, education research suggests high rates of low literacy in general among US school children. For instance, the 2009 National Assessment of Educational Progress (NAEP) found that only 38 % of twelfth graders and 32 % of eighth graders read proficiently at grade level (National Center for Education Statistics, 2009). Black and Hispanic students had an increased likelihood of poor reading skills compared to other groups including Whites and Asians, as did students from city, town, or rural environments compared to those from suburban environments (National Center for Education Statistics, 2009).

Apart from studying prevalence, there has been an increasing focus on the impact of low health literacy on outcomes. Studies have found health literacy is associated with a variety of negative health outcomes, with a recent review of the literature (95 articles) stating that "differences in health literacy level were consistently associated with increased hospitalizations, greater emergency care use, lower use of mammography, lower receipt of influenza vaccine, poorer ability to demonstrate taking medications appropriately, poorer ability to interpret labels and health messages, and, among seniors, poorer overall health status and higher mortality" (p.v.) (Berkman et al., 2011).

While there has been wide agreement that low health literacy has a negative impact on health outcomes for adults, there is limited research concerning health literacy and youth outcomes, both for adolescents and children (Manganello, 2008; Sanders et al., 2009). A growing body of literature has focused on the health literacy of parents, especially those with small children, with findings suggesting that "low caregiver literacy is common and is associated with poor preventive care behaviors and poor child health outcomes" (p. 131) (Sanders et al., 2009). While parents play a significant role in the health care of adolescents, this age group differs from children in that they are beginning to make their own choices about health behaviors and can be more involved with treatment, communicate directly with providers, and administer their own medication.

Regardless of age group, less research has considered the impact of health literacy on mental health outcomes compared to physical health outcomes in the USA (Lincoln et al., 2006). Only ten journal articles were identified in a recent review of health literacy research (Berkman et al., 2011), and findings to date are mixed. Some studies have found that low literacy is associated with greater depression symptoms (Berkman et al., 2011; Lincoln et al., 2006), while others have not observed an association (Berkman et al., 2011). For example, In a sample of Medicare enrollees, Gazmararian found the association of low health literacy and depression went away when controlling for health status (Gazmarian, Baker, Parker, & Blazer, 2000). Other research suggests there is a link between low health literacy and psychiatric disorders (Lincoln, 2008) and poor mental health (Wolf, Gazmararian, & Baker, 2005). Sentell and Shumway (2003) showed that literacy was independently associated with mental health status in a national sample (Sentell & Shumway, 2003). One report using education level as a predictor found that people with more education were more likely to use behavioral health services (Smith, Armstrong, & Davis, 2006), and were less likely to have acute care visits.

Another area of health literacy research includes the study of measurement. Multiple tools can assess literacy skills specific to medical settings, including the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993), the Test of Functional Health Literacy in Adults (TOFHLA) (Parker, Baker, Williams, & Nurss, 1995), and the Newest Vital Sign (NVS) (Weiss et al., 2005). Tools that have been validated with adolescents include the REALM-Teen (Davis et al., 2006), TOFHLA (Chisolm & Buchanan, 2007), and one based on comprehension of health information provided in passages (Wu et al., 2010). The measurement of health literacy is a particularly active area of research in this field with a number of tools currently in development.3

Research related to interventions has also been conducted, although there is a need for more work in this area (U.S. Department of Health and Human Services, 2010), especially with adolescents. The interventions to date have mainly focused on designing and testing materials and ways to make information easier to understand for those with low health literacy. Findings have been mixed, but some recommendations have resulted from the work, including the use of picture-based instructions (Berkman et al., 2011; U.S. Department of Health and Human Services, 2010). Additional interventions include the development and evaluation of programs designed to enhance health literacy skills for those with low health literacy (Berkman et al., 2011), redesigning materials for those with low literacy (Berkman et al., 2011; Pignone, DeWalt, Sheridan, Berkman, & Lohr, 2005), raising awareness of health literacy issues among providers (Kripalani & Weiss, 2006), improving provider communication (Connelly, 2007; Ferreira et al., 2005; Kripalani & Weiss, 2006), and making organizational changes (U.S. Department of Health and Human Services, 2010). However, little information about interventions for adolescent populations exists, with the exception of discussion of health education classes and school programs (Brey et al., 2007; St Leger, 2001).

Mental Health Literacy

Definitions

The term health literacy takes a general approach to understanding health information, and has been applied to a variety of health topics. However, in recent years, professionals have also developed terms that reflect specific skills related to subareas of health including nutrition (Zoellner, Connell, Bounds, Crook, & Yadrick, 2009) and oral health (Jones, Lee, & Rozier, 2007).

A specific definition for mental health literacy was published in 1997 by Anthony Jorm, who stated that mental health literacy is "the knowledge and beliefs about mental disorders which aid their recognition, management, or prevention" (p. 2) (Jorm et al., 1997). Jorm considered mental health literacy to include the ability to identify disorders, understand risk factors and causes of disorders, be familiar with both self and professional help that is available to treat disorders, to

³For more information on measurement, see a recent report from the Institute of Medicine (Hernandez, 2009).

know how to obtain information about mental health, and to have attitudes that lead a person to seek help if needed. Since then, a majority of the work related to mental health literacy has relied upon this definition.

Summary of Knowledge

Limited work has been done concerning mental health literacy in the USA for either adults or youth. A recent review identified only 12 studies of adults between the years of 1987 and 2007 (Cabassa, 2009). Studies related to youth are even less common. Coles and Coleman (2010), using Jorm's definition, studied undergraduate students in a psychology course. After reviewing a series of vignettes, fewer than half correctly identified panic disorder and generalized anxiety disorder, and there seemed to be a relationship between perception of cause of the disorder and whether help should be sought for that disorder (Coles & Coleman, 2010). Olsson and Kennedy (2010), using Jorm's definition, found students in Virginia in grades 6 through 12 (n=281) had difficulty identifying mental disorders, and those who reported they would seek help for treatment were more likely to be those who had an easier time identifying disorders (Olsson & Kennedy, 2010).

While little research on this topic has taken place in the USA, there has been considerable action around this work outside the USA, with research occurring most often in Australia (Jorm et al., 2006). However, mental health literacy research specifically focusing on adolescents even internationally is rare (Burns & Rapee, 2006). The handful of adolescent studies suggest that adolescents have mixed abilities to identify depression when reading vignettes (N=202, ages 15-17, Australia) (Burns & Rapee, 2006) and are unlikely to respond to a friend experiencing problems in a way that would assist them with getting treatment (n = 1,137, school years 8–10, Australia) (Kelly, Jorm, & Rodgers, 2006). Some research has also found that girls have higher mental health literacy than boys (Burns & Rapee, 2006; Cotton, Wright, Harris, Jorm, & McGorry, 2006). For instance, a study of youth (n=1,207, ages 12-25,

Australia) discovered that girls were more likely to recognize symptoms of depression when reading a vignette (although no differences were noted for the psychosis vignette) (Cotton et al., 2006). Much of the work done has focused on assessing rates and characteristics of mental health literacy, with a focus on recognition of symptoms and knowledge about treatment options, as opposed to studying the relationship between mental health literacy skills and outcomes.

Some work has established methods to measure mental health literacy. A majority of published studies have relied on providing vignettes with follow-up questions (Bapat, Jorm, & Lawrence, 2009; Coles & Coleman, 2010; Cotton et al., 2006; Lauber, Nordt, Falcato, & Rossler, 2003; Marie, Forsyth, & Miles, 2004), including the Mental Health Literacy Questionnaire (Jorm et al., 1997) and the Friend in Need Questionnaire (Burns & Rapee, 2006), while some have used self-report questions about attitudes, beliefs, and knowledge (Farrer, Leach, Griffiths, Christensen, & Jorm, 2008; Lauber et al., 2003). There do not appear to be any word recognition tests similar to those seen in the health literacy field, but work has been done to develop a 28-item scale to assess mental health literacy for caregivers of children with mental health problems (Smith et al., 2007).

Researchers have also examined interventions designed to enhance mental health literacy, with mass media campaigns being one of the main strategies studied that appear to be effective (Francis, Pirkis, Dunt, Blood, & Davis, 2002). School-based programs for adolescents have had some limited success, and programs for caregivers of people with mental illness have had some positive results (Francis et al., 2002). A literature review specific to adolescents and young adults provides an overview of intervention programs that have enhanced mental health literacy and recommends campaigns targeting entire communities as well as specific campaigns for adolescents, and school-based educational programs, as useful intervention options (Kelly, Jorm, & Wright, 2007). For example, an Australian depression program called beyondblue has a youth component called Ybblue. An evaluation of that program found that youth who were familiar with it were better able to identify depression symptoms and were more likely to rate professional treatment options as helpful (Morgan & Jorm, 2007). Also in Australia, a media campaign The Compass Strategy called targeting 12-25-year-olds was successful in increasing self-identified depression and addressing barriers related to seeking help (Wright, McGorry, Harris, Jorm, & Pennell, 2006). In another study of 472 secondary school students in England, researchers found that attitudes toward people with mental health problems became more positive after an education intervention involving educational workshops (Pinfold et al., 2003). They also found that female students and those students who knew someone with a mental illness were more likely to experience an attitude change (Pinfold et al., 2003). One USA study suggested that a program called In Our Own Voice did not increase mental health literacy for adolescents 1 week after the intervention, but did show an improvement at 4 and 8 weeks after the intervention (Pinto-Foltz, Logsdon, & Myers, 2011).

Implications for Adolescents

The existing literature suggests that both health literacy and mental health literacy have implications for the diagnosis and treatment of mental health issues for youth. First, low health literacy and low mental health literacy could impact the ability of adolescents and their parents to obtain reliable information about mental health. Knowing how to search for information, understanding information obtained, and assessing reliability and credibility of information are all critical to recognizing symptoms of mental health problems, when treatment should be sought, and what treatment options are available.

Less than a third of adolescents seek help for mental health issues (Gulliver, Griffiths, & Christensen, 2010). "The ability to correctly recognize mental disorders has been found to be associated with better help-seeking preferences in young people aged 12–25 years" (p. 359) (Scott & Chur-Hansen, 2008), suggesting that that mental health literacy, especially the ability to identify symptoms, can play an important role in whether youth seek treatment or not (Cotton et al., 2006). Low health literacy could also impact an individual's ability to access and navigate the mental health system, understand treatment options, and know whether or not one has insurance coverage and how it works. Recent studies suggest that enhancing mental health literacy can help youth seek treatment early (Kelly et al., 2007) and know how and where to access treatment (Burns & Rapee, 2006). Several barriers to seeking mental health treatment for adolescents were identified in a recent literature review of 22 studies from various countries including youth ages 12-25 (Gulliver et al., 2010). Stigma was the most significant barrier adolescents faced in seeking mental health care, a barrier that has been identified in much of the literature on adults as well (Barney, Griffiths, Jorm, & Christensen, 2006; Gorman, Blow, Ames, & Reed, 2011; Ward, Clark, & Heidrich, 2009). Other barriers for youth included concerns about confidentiality and preference to rely on self, limited knowledge about services, and a failure to recognize symptoms, which the authors considered to be related to low mental health literacy (Gulliver et al., 2010). Given these barriers, programs to improve the mental health literacy of adolescents would likely be useful in ensuring that adolescents are aware of symptoms of mental health problems and know how to seek treatment.

For those adolescents who do make it into treatment, low health literacy may limit adherence to treatment. Many therapies may include a complex schedule of medications and/or psychotherapy that could demand high health literacy skills, including math skills. Low health literacy may also influence the ability to communicate with mental health providers and clearly understand information given by providers. Among adult patients with low health literacy, poor oral communication with providers has been noted, including problems understanding the explanation of conditions and process of care or treatment plans (Schillinger, Bindman, Wang, Stewart, & Piette, 2004; Williams, Davis, Parker, & Weiss, 2002), which can have an effect on compliance

(Williams et al., 2002). Some therapies might demand homework activities, which would be challenging for an adolescent with limited health literacy. In addition to helping with compliance, improved mental health literacy might also help adolescents be able to make informed decisions about which treatments are the safest, most effective, and appropriate ones for their condition.

For adolescents, obtaining treatment for a mental health problem is not just important from a medical perspective. Identifying and treating mental health issues among adolescents can have an impact on their success in school, and the ability to succeed in school is critically important for adolescents given the significant role education plays in predicting one's future life trajectory for health and other factors (Cutler & Lleras-Muney, 2006). Depression and anxiety, for instance, can impact school performance (Charvat, 2008), and "poor academic functioning and inconsistent school attendance were identified as early signs of emerging or existing mental health problems during childhood and adolescence" (p. 1) (DeSocio & Hootman, 2004).

Finally, as adolescents are at a gateway between receiving parental supervision for medical care and achieving independence, they are likely taking on new responsibilities related to health care management. They may be responsible for making their own health decisions, including being responsible for taking their own medications and choosing which medications to take (Manganello, 2008; Sanders et al., 2009), as well as getting to and from treatment. At the same time, parents/guardians typically still play a role in health care. Thus, the health literacy and mental health literacy of parents is also important to consider.

Conclusions

We believe there is much work to be done concerning health literacy, adolescents, and mental health, especially in the United States. Given the potential implications that health literacy may have on the mental health of adolescents, more research on adolescent health literacy, especially as it relates to mental health, is needed, and issues unique to adolescents' mental health care needs and concerns will need to be better understood and addressed specifically.

Research should address predictors of mental health literacy for adolescents as well as outcomes for adolescents with low mental health literacy. Investigation into how health providers should best communicate about mental health issues to adolescents with low mental health literacy is also warranted. In addition, further study of the measurement of health literacy and mental health literacy for adolescents is important, and studies should continue to evaluate programs to enhance health literacy and mental health literacy for adolescents. Can interventions for adolescents improve their mental health literacy, and what are the most optimal interventions to do so? Information about mental health should be easy to understand for adolescents and should be provided in a way that is both appealing to and captures the attention of this age group. Thus, future work should evaluate what information should be given and how to best provide that information to adolescents. Other issues to address include the role of media in influencing adolescent mental health literacy, as well as interpersonal influences, such as family and friends.

Adolescence is a critical period in a life course in which the cumulative experiences of childhood can not only contribute to current health status but can also lead to choices about pathways and behaviors that may last through adulthood. Poor health literacy and mental health literacy, and poor mental health, can be particularly disruptive to this path. These two factors together may be worse in a nonadditive way, particularly among adolescents experiencing distress who, due to poor mental health literacy, may not know what they are experiencing, how to describe it, or where and how to get help for it. Further, if their caregivers also have low health literacy and/or low mental health literacy, this may exacerbate the problem by creating additional barriers to diagnosis and treatment. There is a need to better understand the role of health literacy and mental health literacy for the mental health of adolescents, and how these relationships may be distinct from patterns seen in adults and children. We hope this overview will inspire future work and consideration of this important topic.

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