PASSING THE LITMUS TEST: ARE WE PREPARING YOUTH TO MANAGE BASIC HEALTH CARE NEEDS? A PRELIMINARY INVESTIGATION

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Abstract

Although there has been growing awareness regarding the importance of health literacy on the social, emotional, and health related outcomes of adults, little is known about the preparedness of high school adolescents to access, navigate, and use health related information and services as they begin to enter into independence. This study evaluates the health literacy skills of 199 youth enrolled in high school health classes in a Midwestern region in the United States. Results revealed that nearly one out of three youth demonstrated some level of risk on applied measures of health literacy, and approximately half were unaware of how to access health insurance, regularly thought about what they eat and how it influences their health, knew how to make medical and dental appointments, and were aware of their family medical history. Implications, study limitations, and recommendations for practice and future research are discussed.

Key words*: health care needs, health literacy skills, health literacy, youth health-related status*

Passing the litmus test: Are we preparing youth to manage basic health care needs? A preliminary investigation

Health literacy, or the ability to understand basic health information and make sound decisions regarding health is comprised of a complex set of skills including broad reading, writing, basic math, speaking, listening, and knowledge (Nielsen-Bohlman, Panzer, & Kindig, 2004; US Department of Health and Human Services [US DHHS] 2000). Although it is well understood that poor mastery of these skills significantly impacts one's ability to manage

health related decisions, there is a growing body of literature that indicates the impact of limited health literacy extends well beyond an individuals' health related decision making(e.g., Bartley, 1994; Berkman et al., 2011; Jusot, Khlat, Rochereau, & Sermet, 2008; Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). For example, over the past two decades, studies have found that low health literacy is linked with a myriad of poor health outcomes including increased rates of chronic health conditions (e.g., high blood pressure, diabetes, asthma); less knowledge regarding management of chronic illness; more frequent hospitalizations; less frequent use of preventative care; lower reports of overall health status; lower rates of health insurance coverage; and increased overall healthcare costs (Baker et al., 2002; Baker, Parker, Williams, & Clark, 1997, 1998; Friedland, 1998; Howard, Gazmararian, & Parker, 2005; Kalichman & Rompa, 2000; Scott, Gazmararian, Williams, & Baker, 2002). Associations have also been found between poor health literacy and non-health related outcomes such as increased feelings of stigma and shame and higher levels of unemployment and economic instability (Baker et al., 2002; Baker et al., 1997; Howard, Gazmararian, & Parker, 2005; Parikh, Parker, Nurss, Baker, & Williams, 1996).

While often considered in terms of the negative health and economic impact on the individual with poor health literacy, the Institute of Medicine (2004) has proposed that health literacy is not solely a patient deficit; rather the consequences affect medical care quality, costs, and health disparities across the population (Parker & Ratzan, 2010). This is perhaps most apparent in studies evaluating the national economic impact of low health literacy. For example, in their report, *Low Health Literacy: Implications for National Health Policy*, Vernon et al., (2007) estimate annual costs of low health literacy to range between $106 and $238 billion, or between 7 and 17 percent of all personal health care expenditures in the United States. To understand the magnitude of these costs, Vernon and colleagues note that these costs are equal to the cost of insuring all of the more than 47 million people who lacked health care coverage in the United States (Almader-Douglas, 2013). Further, they estimated that when one considers the future costs of low health literacy and the lack of education directed at addressing these key skills, the real societal costs of low health literacy are more likely to be in the annual range of 1.6 to 3.6 trillion dollars (Almader-Douglas, 2013).

Given the tremendous personal and societal costs of low health literacy, it is imperative that national efforts be made to address poor health literacy through intervention as well as prevention. However, while the health literacy status of adults in the United States has received much attention over the past two decades (US DHHS Office of Disease Prevention and Health Promotion [US DHHS ODPHP], 2000), little attention has been given to the health literacy of adolescents (Brown, Teufel, & Birch, 2007; Chisolm & Buchanan, 2007; Davis et al., 2006; Manganello, 2008).Research and intervention with the adolescent population is a necessary component in combatting poor health literacy as healthy behaviors developed during adolescents have a lasting and preventative impact on future health related outcomes and decisions (Manganello, 2008). Further, more than ever, adolescents are independently managing chronic health conditions such as asthma and diabetes and are accessing health-related management information through web based resources and social media (Brown et al., 2007; Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005; Manganello, 2008). These advancements have increased the mechanisms for accessing health information, however, little is known about youths' abilities to understand this health information; access preventative care, treatment, and insurance; and make sound decisions regarding personal health care needs.

Given the dearth of research on the health literacy status of school aged youth, the primary **purpose of this study** was *to begin to evaluate and describe the health literacy of adolescents*. Specifically we sought *to evaluate youth health literacy skills, perceptions of preparedness to address health related care, and youth health-related status*. Although limited

in sample size, exploratory analyses were also conducted to examine potential differences between male and female youth.

Method

All project procedures were approved by the University's Institutional Review Board. Youth were recruited from 31 health education classrooms across 6 area high schools in the Midwest of the United States. Recruitment consisted of the following procedures. First, each health teacher was provided with (a) a brief study overview to read in class and (b) consent packets for youth to take home to their parents. Seven-hundred and thirty-three packets were distributed, each including a parental consent form and a youth information sheet. Second, for youth returning completed parental consent forms (n = 221), youth assent was obtained prior to participation. The final sample consisted of 199 youth, with 3 youth declining participation, and 19 absent the day of assessment.

Student participants ranged in age from 15 to 19 years with a mean of 15.96 years (sd = 0.76). A majority of participants were female (60%; n = 120) and reported that their primary language was English (91%, n = 181). The sample was relatively diverse in terms of their ethnic and racial background with 131 White/non-Hispanic (65.8%), 14 Black/non-Hispanic (7.0%), 15 mixed race/non-Hispanic (7.5%), 25 Hispanic (12.6%), and 14 children of other backgrounds (e.g., Native American and Asian). Slightly over 12% (n = 24) were receiving special education support at the time of data collection.

Measures

As there are no comprehensive instruments designed to assess the broad construct of adolescent health literacy (Davis et al., 2006; Jordan, Osborne, & Buchbinder, 2011), a battery of measures was included to assess youth's ability to access, process, understand, and use health related information. Measures included the Newest Vital Sign (NVS; Weiss et al., 2005), select items from the Casey Life Skills Assessment (CLSA; Casey Family Programs, 2011), and the Child Health and Illness Profile: Adolescent Edition (CHIP-AE; Starfield et al., 1994).

NVS. The NVS assesses health related reading comprehension and numeracy by providing individuals with a specially designed ice cream nutrition label which is used to answer six applied items (e.g., If you eat the entire container, how many calories will you eat?). Each of the 6 items are administered orally and individually, and on average, take less than 5 minutes to complete. The NVS has been widely used and validated to adequately assess health literacy in broad populations from young children to older adults and across racial/ethnic minority populations (Pfizer, 2011). Participant score sare calculated by adding the total number of correct responses. Scores are interpreted using three categories: high likelihood of limited health literacy (0-1 correct responses); possibility of limited health literacy (2-3 correct responses); and adequate health literacy (4-6 correct responses; Weiss et al., 2005).

CLSA. Eight items relevant to the research aims of this study were selected from the 2013 CLSA. The CLSA is a widely used measure developed to address youth's preparedness for transition into adulthood. Originally developed for vulnerable populations in foster care (Bressani & Downs, 2002), the CLSA has been widely adapted for use in the development of transition planning for at-risk youth with and without disabilities across broad settings (Nollan, Horn, Downs, & Pecora, 2002). Each of the eight questions were designed to capture current mastery of independent health related skills and include five response options (No; Mostly No; Somewhat; Mostly Yes; Yes; Casey Family Programs, 2011).For interpretation purposes, response options were categorized into three groups: No/Mostly No; Somewhat; and Mostly Yes/Yes.

CHIP-AE. The CHIP-AE is a self-administered comprehensive adolescent health status and health-related quality of life questionnaire (initial version developed by Starfield et al., 1993, revised by Starfield et al., 2000). Five domains (Satisfaction, Discomfort, Resilience, Disorder, and Achievement) consisting of 153 items were completed by youth. Items in *Satisfaction* (n = 12) include questions regarding youth self-esteem, satisfaction with self, and overall perceptions and beliefs about one's health. Items in *Discomfort* (n = 45) include questions regarding youth physical and emotional discomfort, and limitations of age-appropriate activity due to mobility or other barriers. *Resilience* (n = 37 items) evaluates youth perceptions of family involvement (support/activities), social problem solving, physical activity, and home safety. Items in *Disorders* (n = 43) include questions regarding specific health conditions, injuries, or impairments that may be related to long term, recurrent, or present health symptoms. Finally, items in *Achievement (*n = 16) are divided into two sub sections, *Academic* (n = 10) and *Work* (n =6). *Academic Achievement* includes questions related to specific youth educational performance, while *Work Achievement* includes questions related to work performance. Across domains, higher scores indicate better health related quality of life. The *Discomfort* domain is scored in such a way that higher scores denote an "absence of" negative symptoms (Starfield et al., 2000).

Procedure

Youth surveys were completed in health classes during the regular school day. On average, it took students 24 minutes to complete the demographic, CLSA, and CHIP-AE items and 5 minutes to complete the NVS. Prior to survey completion, youth were given an overview of the project by research staff and were reminded of their rights to assent or decline participation. Assenting youth individually completed a packet containing the demographic, CLSA, and CHIP-AE items in the classroom. Youth were individually removed from the class to complete the NVS in separate areas of the school (e.g., library, conference room) by one of 9 trained data collectors.

Data collectors were trained by the principal investigator and University staff. Training activities included an overview of the study's purpose, an introduction to the assessment instruments, detailed instructions on working with participants, and role plays of administering the assessments. After completing training, data collectors were tested on key data collection protocol and were required to pass the test with a score of 95% or higher.

Data Analysis

Descriptive statistics were computed for the NVS, each subscale of the CHIP-AE, and the CLSA items. Independent t-tests (t), Wilcoxon sum-rank tests (W), and chi-square (χ^2) analyses were used to assess differences between male and female students. Cohen's d effect size estimates were computed for each t-test and common language effect sizes (CL; McGraw & Wong, 1992) were computed for the significant Wilcoxon sum-rank tests using group medians rather than means. CL effect sizes represent the probability that a randomly selected member of the focal group (e.g., males) would have a higher score than a randomly selected member of the reference group (e.g., females). For both Cohen's d and CL, larger absolute values indicate larger effects. A CL of .50 is equal to a Cohen's d of 0.0 both indicating that there is no difference between groups. Cohen's d values of .2 (CL = .56), .5 (CL = .64), and .8 (CL = .71) are generically used to represent small, medium, and large effects (Cohen, 1988).

Results

Results of the NVS health literacy measure revealed that nearly 30% of youth demonstrated some degree of risk, with 8% scoring within the high-likelihood of limited

health literacy range (see Table 1). In response to the CLSA, when asked items regarding youth perceptions of their preparedness to address important health-related management skills, overall self-report ratings revealed risk (i.e., rating of Somewhat or No/Mostly No) across items related to consideration of diet on health (item #2, 45%), ability to access medical and dental appointments (item #5, 47%), knowledge of family medical history (item #7, 54%), and accessing health insurance (item #8, 82%; see Table 2). Finally, results of the CHIP-AE indicate that almost one third of youth were dissatisfied with their health status and general feelings of self-esteem, and nearly one out of four youth shared that they presently experience symptoms of physical discomfort (emotional, physical, or a limitation in activity; see Table 3). However, most youth indicated average to above average confidence in Resilience; specifically, the ability to problem-solve, engagement in physical activity, and adequate family involvement (88%). The majority of students (79%) also self-reported average to above average ranges for Achievement in School (e.g., homework performance, on honor roll, failed a class) and in the Work Achievement domain (e.g., work attendance, compliance, quantity of work).

Table 1. Youth NVS Scores by Risk Category

NVS Score Category	*n*	%
High Likelihood of limited HL	16	8.0
Possibly limited HL	45	22.6
Adequate HL	138	69.4

Table 2. Ansell-Casey Life Skills Assessment (selected items)

	No/ Mostly No	**Somewhat**	**Mostly Yes/ Yes**
1. I think about what I eat & how it impacts my health.	24 (12.12%)	66 (33.3%)	108 (54.5%)
2. I understand how to read food product labels to see how much fat, sugar, salt, and calories the food has.	13 (6.6%)	45 (22.7%)	140 (70.7%)
3. I can take care of my own minor injuries and illnesses.	9 (4.5%)	32 (16.2%)	157 (79.3%)
4. I can get medical & dental care when I need it.	6 (3.0%)	16 (8.1%)	176 (88.9%)
5. I know how to make my own medical/dental appointments.	53 (26.8%)	40 (20.2%)	105 (53.0%)
6. I know when it is better to go to a doctor's office instead of an emergency room.	32 (16.2%)	160 (80.8%)	
7. I know my family medical history.	70 (35.4%)	92 (46.4%)	
8. I know how to get health insurance when I am older than 18.	48 (24.2%)	36 (18.2%)	

[a] Total respondent differs from overall total of 199 due to one uncompleted survey.

Table 3. Child Health and Illness Profile- Adolescent Edition

	Below (<17)	Average (17-23)	Above (>23)
Satisfaction	56 (28.1%)	100 (50.3%)	43 (21.6%)
Physical Discomfort	49 (24.6%)	105 (52.8%)	45 (22.6%)
Resilience	23 (11.8%)	64 (32.8%)	108 (55.4%)
Disorders	41 (20.8%)	58 (29.4%)	98 (49.8%)
Achievement: School	41 (20.7%)	82 (41.4%)	75 (37.9%)
Achievement: Work	11 (21.5%)	21 (41.2%)	19 (37.3%)

Gender Differences

Male and female students had statistically equivalent NVS total scores (W = 11493.0, p = .247) and categorical scores ($\chi^2(2)$= 0.36, p = .835). Males and females did, however, differ significantly on ratings of overall general health on the CHIP-AE (W = 5779.0, p< .01, CL = 0.62), with males reporting better overall health; total physical discomfort ($t(196)$ = -5.50, p< .001, d = -0.80 [-1.10, -0.50]) with males reporting lower levels of discomfort; and total health satisfaction ($t(196)$ = 3.45, p< .001, d = 0.50 [0.21, 0.79]) with males reporting higher satisfaction. Males also reported that they are better informed about how to get health insurance (W = 11098.0, p< .05, CL = 0.75) while females reported that they are more mindful about what they eat (W = 6525.5, p< .01, CL = 0.71).

Discussion

A person's ability to navigate the healthcare system, manage chronic disease, care for personal health needs, and make decisions regarding health care plans, insurance, and providers affects health and economic outcomes of the individual as well as the economic system and provision of health care across the country (Almader-Douglas, 2013; Baker et al., 2002; Baker et al., 1997, 1998; Friedland, 1998; Howard et al., 2005; Kalichman & Rompa, 2000; Scott et al., 2002; Vernon et al., 2007). While efforts to better understand the health literacy and health-related needs of the adult population have continued to increase over the past two decades, much remains unknown about the health literacy and health literacy related needs of adolescents beginning the transition to adulthood.

As a necessary prerequisite to developing health-literacy curricula to better prepare youth to navigate the health-care system, this study examined the health literacy and health related preparedness of high-school youth. Two of the three measures included self-report which allowed youth to rate their health and health-literacy on a continuum, and one measure assessed specific applied math and comprehension health related skills (i.e., NVS). Overall, findings were mixed in regards to youth health literacy. As a group, the majority (66%) viewed their health as either "excellent" or "very good" and none reported their health as "poor". However, this leaves nearly one-out-of-three youth reporting some concern regarding their health. Findings on the measures of overall health literacy and specific health related problems reveal similar patterns. Specifically, results of the NVS were fairly encouraging showing that the majority of students possessed adequate health literacy in terms of being able to read, understand, and act upon health related information. There were, however, a considerable number of youth (31%) who scored in the "possible limited health literacy" and "high likelihood of limited health literacy" ranges. When evaluated separately, for the most

part, males and females scored more alike than different. However, across a few key variables, males and females differed in regards to ratings of overall general health, physical discomfort, and health satisfaction where males felt as though they had slightly better general health, reported far less physical discomfort, and had higher health satisfaction. Males also reported that they are better prepared to obtain health insurance.

Implications

These findings offer insights into the health literacy, self-reported health, and health-related quality of life amongst a sample of school aged adolescents in the Midwest of the United States. In general, the results reveal that while youth feel very prepared in some areas of health care management, continued education and support towards mastery of their personal health needs may be needed for youth to more fully prepare them for independence and self-management of health upon graduation. While additional research is needed, these findings suggest important implications for curriculum developers and health educators in secondary school settings.

For example, youth may benefit from a targeted curriculum that addresses health care management skills such as accessing health related information and insurance, identifying and preparing for doctor visits, setting medical appointments, reading and interpreting medical information, interpreting food labels, family planning, identifying community assistance and resources, and basic injury care. A structured curriculum designed to address these and other personal health-care needs may help to better prepare youth to successfully navigate the health-care system and make sound health-related decisions upon independence.

As individual youth health risks and information may not be appropriate to discuss in the classroom setting, parental involvement may also play an important role in helping the schools prepare youth for independent management of their health care needs post-graduation. Specifically, parents can assist youth with developing and completing a personal health portfolio that documents important family risk factors, prior health care providers, immunization and other health records, and insurance information. This portfolio can be updated as the adolescent reaches independence and can be beneficial as youth begin to independently access health-care providers and make important decisions that impact their short and long-term health and general well-being.

Limitations and Future Studies

Several study limitations are important to note. First, all participants attended high schools across the same school district in the Midwest. Replication of this study is needed with samples across the US and should include youth who are representative of rural and urban populations as curriculum, access, and exposure to health related information may vary across geographic areas and settings. Second, replication of this study with a larger sample would also allow for more sophisticated analysis including the examination of subgroups of students. For example, previous studies have found that persons with disabilities demonstrate elevated health and mental health related needs and are more likely to require life-long medical supports than their peers without disabilities (Office of Disability Employment Policy, 2013; Smith, 2009). Future research with specific subgroups such as with youth with learning disabilities, behavioral disorders, developmental disabilities, or mental health disorders would allow for more specific, targeted interventions to better prepare youth to manage health related needs after transitioning into independence. Third, given the limitations with existing measures of health literacy for the adolescent population (Davis et al., 2006; Jordan et al., 2011), these findings are limited to youth self-report and do not address all areas of health literacy. Continued research is needed for scale development and validation to better assess the broad domain of

youth health literacy and to allow for ratings across multiple respondents (e.g., parent, teacher, medical staff provider).

Conclusions

Health well-being has been identified as an important factor in youth independence, participation in continued education, stable employment, and community engagement (Berry, 2000; Hall, Kurth, & Hunt, 2013; Kruse, 1997; Ries & Brown, 1993). When adolescents enter young adulthood ill-prepared to manage their personal health related needs, all other areas of success are significantly and negatively impacted. Moreover, the consequences of poor-health literacy extend well beyond the individual, and affect health care and economic systems across the nation. Results from this exploratory pilot study demonstrate that although some youth feel prepared to manage their personal health care needs, anywhere from one third to one half of the sample demonstrated risk for poor health literacy limitations with their ability to access and manage health related needs. Continued research is needed to replicate these findings and identify areas of need not currently addressed in high-school health curricula to better prepare youth as they transition into independence and are required to navigate the health care system, access insurance and supports, and advocate for their own health care needs.

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Summary

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This study evaluates the health literacy skills of 199 youth enrolled in high school health classes in a Midwestern region in the United States. Given the tremendous personal and societal costs of low health literacy, it is imperative that national efforts be made to address poor health literacy through intervention as well as prevention. However, while the health literacy status of adults in the United States has received much attention over the past two decades, little attention has been given to the health literacy of adolescents.

All project procedures were approved by the University's Institutional Review Board. Youth were recruited from 31 health education classrooms across 6 area high schools in the Midwest of the United States. Student participants ranged in age from 15 to 19 years with a mean of 15.96 years ($sd = 0.76$).

As there are no comprehensive instruments designed to assess the broad construct of adolescent health literacy (Davis et al., 2006; Jordan, Osborne, & Buchbinder, 2011), a battery of measures was included to assess youth's ability to access, process, understand, and use health related information. Measures included the Newest Vital Sign (NVS; Weiss et al., 2005), select items from the Casey Life Skills Assessment (CLSA; Casey Family Programs, 2011), and the Child Health and Illness Profile: Adolescent Edition (CHIP-AE; Starfield et al., 1994).

Results of the NVS health literacy measure revealed that nearly 30% of youth demonstrated some degree of risk, with 8% scoring within the high-likelihood of limited health literacy range. In response to the CLSA, when asked items regarding youth perceptions of their preparedness to address important health-related management skills, overall self-report ratings revealed risk across items related

to consideration of diet on health, ability to access medical and dental appointments, knowledge of family medical history, and accessing health insurance. Results of the CHIP-AE indicate that almost one third of youth were dissatisfied with their health status and general feelings of self-esteem, and nearly one out of four youth shared that they presently experience symptoms of physical discomfort. However, most youth indicated average to above average confidence in Resilience; specifically, the ability to problem-solve, engagement in physical activity, and adequate family involvement. The majority of students also self-reported average to above average ranges for Achievement in School and in the Work Achievement domain.

As a necessary prerequisite to developing health-literacy curricula to better prepare youth to navigate the health-care system, this study examined the health literacy and health related preparedness of high-school youth. When evaluated separately, for the most part, males and females scored more alike than different. However, across a few key variables, males and females differed in regards to ratings of overall general health, physical discomfort, and health satisfaction where males felt as though they had slightly better general health, reported far less physical discomfort, and had higher health satisfaction. Males also reported that they are better prepared to obtain health insurance.

Results from this exploratory pilot study demonstrate that although some youth feel prepared to manage their personal health care needs, anywhere from one third to one half of the sample demonstrated risk for poor health literacy limitations with their ability to access and manage health related needs. Continued research is needed to replicate these findings and identify areas of need not currently addressed in high-school health curricula to better prepare youth as they transition into independence and are required to navigate the health care system, access insurance and supports, and advocate for their own health care needs.