

THE HEALTH LITERACY STATUS OF YOUTH WITH DISABILITIES IN A RESIDENTIAL TREATMENT SETTING

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Abstract

Research³ has indicated that youth eligible for special education services in residential centers are at an increased risk across many areas including overall health, medication use, academic, behavioral, and familial functioning. Yet it remains unknown how well they are able to read, understand, and use health-related information. The purpose of this study was to investigate the health literacy status of youth receiving special education ($N= 61$) services at a large residential care facility in the Midwest. Results indicate youth with disabilities are at increased risk of low health literacy in areas of reading recognition and comprehension. Specifically, well over 50% of the sample scored in the possible to likely limited health literacy level. Study limitations, future research, and implications are provided.

Keywords: health literacy, special education, residential care, youth

Introduction. The Health Literacy Status of Youth with Disabilities in a Residential Setting

In recent years, health literacy has become an international public health issue as individuals are being asked to play a greater role in managing their physical health (Manganello, 2008; Sorensen & Brand, 2011). Along these lines, establishing a healthy population and workforce is part of success for the Europe 2020 strategy (European Commission, 2010; Sorensen & Brand, 2011). Health literacy, defined as the ability to obtain, process, and understand basic health information and services needed to make sound decisions regarding health (US Department of Health and Human Services [US DHHS], 2000) has been studied extensively with adults (US DHHS Office of Disease Prevention and Health Promotion [US DHHS ODPHP], 2000). However, similar efforts are lacking for youth (Chisolm & Buchanan, 2007; Davis, Wolf, Arnold, Byrd, Long, Springer, & Bocchini, 2006). While limited, initial research efforts have included the development of health literacy measures for adolescents, the validation of measures among different populations, and preliminary studies of health related knowledge (Brown, Teufel, & Birch, 2007; Chisolm & Buchanan, 2007; Davis et al., 2006; Diamond, Saintonge, August & Azrack, 2011; Fortenberry, McFarlane, Hennessy, Bull, Gimley, St Lawrence, & Van Devanter, 2001; Hoffman, Trout, Nelson, Huscroft-D'Angelo, Sullivan,

³ The research reported here was supported by the U.S. Department of Education, through Grants R324B110001 and H325D040020 to the University of Nebraska-Lincoln. The opinions expressed are those of the authors and do not represent views of the Institute of Education Sciences or the U.S. Department of Education

Epstein, & Gibbons, 2013; Manganello, 2008; Trout, Hoffman, Epstein, Nelson, & Thompson, 2014; US DHHS, 2000; US DHHS ODPHP, 2000). While these efforts are encouraging, this topic remains a significant concern given that serious health related problems (e.g., diabetes, obesity, asthma) continue to be on the rise for youth in general (Van Cleave, Gortmaker, & Perrin, 2010). These problems are of additional concern for high-risk youth, such as those in residential care, as research suggests a link exists between individuals that demonstrate mental health challenges and risk of physical health problems. For example, it is recognized there is a relationship between stress and weaker immune functioning as well as an association between asthma and emotion, stress, or other psychological factors (Connor, Doerfler, Toscano, Volungis, & Steingard, 2004; Herbert & Cohen, 1993; Nelson, Smith, Thompson, Epstein, Griffith, Duppong-Hurley, & Tonniges 2011; Segerstrom & Miller, 2004).

Annually, approximately 200,000 youth receive behavioral and mental health services in residential centers (Child Welfare League of America [CWLA], 2007). According to Kott (2010), "...Residential treatment is a system of care or services provided outside of the home, within the child welfare system" (p. 15) and includes programs such as substance abuse centers, family-style residential group homes, residential schools, or therapeutic boarding schools. These programs may differ depending on the target population, length of stay, or level of restrictiveness and are often considered to be one of the most restrictive settings (Lee, 2008). Youth typically enter with elevated risks across many areas including academics, behavior, family, physical, and mental health (Breland-Noble, Elbogen, Farmer, Dubs, Wagner, & Burns 2004; CWLA, 2007; Connor et al., 2004; Drais-Parrillo, Baker, Fojas, Gunn, Kurland, & Schnur 2004; Griffith, Ingram, Barth, Trout, Hurley, Thompson, & Epstein, 2009; Pottick, Warner, & Yoder, 2005).

Studies reveal that as many as 33% to 40% of youth in care are diagnosed with at least one medical condition, including elevated risk for asthma, neurological conditions, and obesity and these have also been linked to poor mental health functioning (Connor et al., 2004; Nelson et al., 2011). In a separate study, Nelson et al. (2012) examined the association between psychopathology and physical health and reported high levels of youth psychopathology to be associated with elevated risk for comorbid medical problems. More specifically, internalizing problems such as anxiety were closely associated to medical status and youth with mental health comorbidity were found to have heightened medical risk (Nelson et al., 2012). Therefore, the importance of understanding personal health needs and related information is critical for youth in care.

Although the general population of youth in residential care tends to demonstrate broad risks, youth with disabilities may be at increased risk for poor health literacy due to elevated risk in areas such as academics, behavior, family stability, and co-occurring physical health challenges. For example, in a study of youth served in a residential setting, Trout et al (2009) found that youth with disabilities are at elevated risk in several academic areas including reading fluency, spelling, and reading comprehension—all essential components of health literacy. In the same study, youth with disabilities were also significantly more likely to have substance abuse, social problems, and externalizing behaviors than their peers in care without disabilities. Similar results were found by Chmelka, Trout, Mason, & Wright (2011) who noted that those receiving special education services had significantly lower IQs, were on more psychotropic medications, had more formal placements and transitions, and reported elevated social problems at entry to care. When examining differences at departure, youth with disabilities were more likely to leave care using more psychotropic medications, were more likely to have transitioned to a more restrictive level of care, and were less likely to reintegrate into a home setting or to independent living (Chmelka et al., 2011). These risks present significant continuing challenges to youth across broad areas of functioning, and likely also

reveal a negative impact on their ability to make informed health decisions, access appropriate health services and supports, and follow medical instructions.

The physical health and medical conditions of students with school-identified disabilities both in and out of residential care has become a focus for researchers in the past few years. Specifically, in two large longitudinal studies (i.e., National Longitudinal Transition Study-2[NLTS-2]; Wagner, Marder, Levine, Cameto, Cadwallader, & Blackorby, 2003; Special Education Elementary Longitudinal Study [SEELS]; Blackorby, Wagner, Cadwallader, Camento, Levine, Marder, & Giacalone, 2002) parents of elementary school (N=12,785) and secondary school (N=11,280) students receiving special education services were surveyed on the physical health status of their children. Almost 30% of these students with disabilities were in poor or fair health, which was significantly greater than students without disabilities. Also, almost 25% of these students with disabilities were taking prescription medications related to their medical conditions with the most use reported for students with reported fair or poor health status. Trout and colleagues (submitted) followed up this line of inquiry with 346 youth with disabilities in residential care. This research found that over one-third (34%) of these youth enter residential care with a diagnosable medical condition, which is almost five times greater than found in youth in the United States (e.g., Van Cleave, Gortmaker, & Perrin, 2010). Also, they found that the most prevalent medical problem was asthma with 15.6% of youth presenting with this condition, which is twice the national rate (Adam, Hendershot, & Marano, 1999).

While youth with disabilities in residential care are likely at increased risk for low health literacy due to co-occurring behavioral, academic, family, and physical health challenges, they also have a documented high prevalence of medical conditions, continued need for medication management and health care support following departure from care, making health literacy of particular importance. Yet, research has not evaluated the health literacy of this high-risk population.

Object of the research – the health literacy status of youth with disabilities in a residential treatment setting.

The purpose of this study was to examine the health literacy status of youth with disabilities in a residential setting. Health literacy status along with the relationship between health literacy and key youth demographic characteristics such as gender, race/ethnicity, and disability category were examined.

Methods of the research

Participants

All procedures were approved by the Institutional Review Boards at the authors' university institution and the participating residential program. The residential program is comprised of 61 community-based family style homes (Family Home Program) in which 6 to 8 youth, 12 to 18 years of age live with a married couple (Family Teachers) and one assistant (Assistant Family Teacher). Youth come from a variety of religious, socioeconomic, as well as cultural backgrounds and are referred most often through social service agencies, juvenile courts, or human service professionals. The program aims to work with schools, families, and community organizations to teach youth the necessary skills to help them achieve success in school, work, and with their families. Youth (ages 14-19) were recruited from the residential high school for a brief in-person interview. Youth that expressed interest signed a flyer giving the research team permission to seek consent from their Family Teacher. Family Teachers were then contacted by staff members of the residential program, and permission was granted by 100% of those contacted.

Participants included 61 assenting youth in grades 9-12 who were receiving special education services. Youth were predominantly male (72.1%) with a mean age of 16.89 years

($SD = 1.21$; range = 14 to 19 years). Slightly over forty-percent (40.9%) were Caucasian, 27.8% were African-American, 13.1% were Hispanic, 8.2% were American Indian or Alaska Native, and 9.8% identified two or more ethnicities. Overall, the highest percentage of participants were in the 12th grade (36.1%), followed by sophomores (24.6%), juniors (21.3%) and freshman (18.0%). Slightly over one-third (37.7%) were state wards and had an average of 2.44($SD = 1.16$) psychiatric diagnoses. An overwhelming majority (84.5%) was diagnosed in one special education disability category, 13.8% in two disability categories, and 1.7% in three disability categories. The highest percentage of primary disability category was identified under the category Learning Disability (LD; 34.5%), 29.3% Other Health Impairment (OHI), 19.0% Emotional/Behavior Disorder (EBD), 8.6% Eligible Individual (EI), 3.4% Speech Language Impairment, 3.4% Mild Mental Handicap (MMH), and 1.7% Autism. The group had a mean Full Scale IQ of 88.45($SD = 13.02$).

Measures

Two health literacy measures were used to assess the health literacy status of youth with disabilities. The measures were selected because they were psychometrically sound, had been used in several studies of youth health literacy and fit within the typical assessment context of schools. Youth were given an envelope with these measures enclosed.

The Newest Vital Sign (Weiss, Mays, Martz, Castro, DeWalt, Pignone, & Hale, 2005) assesses reading comprehension and numeracy by asking individuals questions about a specially designed ice cream nutrition label (e.g., If you eat the entire container, how many calories will you eat?). The NVS is scored by adding up the total number of correct answers. Scores range from 0-6, with each question being worth 1 point. Scores of 0-1 suggest high likelihood of limited literacy; 2-3 indicate the possibility of limited literacy, and 4-6 indicate adequate literacy (Weiss et al., 2005).

The psychometric status of the NVS has been determined to be acceptable with both typical (Warsh et al., 2011) and residential (Hoffman et al, in press) samples of adolescents.

The Rapid Estimate of Adult Literacy-Teen (REALM-Teen; Davis et al., 1993) is a 66-item word recognition test that assesses the ability of an individual to pronounce 66 health-related words (e.g., weight, prescription, tetanus). The REALM-Teen is scored by adding up the total number of words pronounced correctly. Scores range from 0-66, and are expressed as grade-level reading estimates (<37words correct=3rd grade and below; 38-44=4th-5th grade; 45-58=6th-7th grade; 59-62=8th-9th grade; 63-66=10th grade and above; Davis et al., 2006). The psychometric status of the REALM-Teen was determined in a study of youth ($N=1,533$) attending public schools in Louisiana and North Carolina (Davis et al., 2006), and has been used in establishing the validity of other health literacy measures (Chisolm & Buchanan, 2007).

Procedures

Three data collectors were trained by the principal investigators (PIs). A structured training session was conducted and included an overview of the study's purpose, an introduction to the measures, detailed instructions on working with participants, and an opportunity to role play. Following training, data collectors were tested by the PIs on key data collection protocol and were required to pass the test with a score of 95% or higher. During implementation of the assessments, youth were individually removed from class, read an assent form, and given an opportunity to ask questions. Assenting youth then completed one of three assessment packets which were identical, however the assessments were randomized to counterbalance any order testing effects. Assessment packets included an opening script read aloud by researchers and specific directions for administering each measure. It took participants an average of 21 minutes to complete their packet.

Methods of Research Data Analysis

First, descriptive statistics were generated to provide an overview of the sample on demographic, academic, behavior, and family variables. Second, means and standard deviations were calculated for each of the continuous variables assessed. Frequencies were calculated for each of the discrete variables assessed. Third, an independent sample t-test and ANOVA tests were conducted to identify differences between gender, ethnicity, and primary special education eligibility category among youth with disabilities. A Bonferonni post-hoc test was also used to identify specific differences between groups.

Research Results

The NVS includes items which assess both the reading comprehension and numeracy aspects of health literacy. The overall mean score for this sample was 2.41 ($SD = 1.66$). Almost half (45.9%) of the youth scored in the *possibility of limited literacy* category, over one quarter (26.2%) in the *likelihood of limited literacy* category, and slightly over a quarter (27.8%) in the *adequate literacy* category.

The REALM-Teen assesses health literacy as individuals are asked to read and pronounce health-related words. Over half of the sample (59%) was reading at least two grade levels below their current grade level, 36% indicated reading one grade level below their current grade, and 5% were reading at or above grade level.

Gender, ethnicity, and primary eligibility category differences were examined. There were no significant special education disability category or gender differences found on either measure. For analysis purposes, a total of four disability categories (i.e., Other Health Impaired, Learning Disabilities, Emotional/Behavioral Disorders, and Other) were used to examine differences between primary eligibility categories. Given the low frequency youth with Autism, Speech Language Impairment, Mild Mental Handicap, or Eligible Individual, an “other” category was created. Scores on the REALM-Teen ($f = 4.406, p < .001, ES = .49$) were significantly different with respect to ethnicity. Specifically, post-hoc tests revealed significant differences between African-American and multiracial youth ($f = 3.382, p < .05$) as well as African-American and Caucasian participants ($f = 2.239, p < .01$). Overall, African-American youth scored the lowest on the REALM-Teen followed by Hispanic/Latino participants. Multiracial youth scored the highest on both assessments.

Discussion

Youth in care facilities are faced with challenges that may potentially impact their ability to independently monitor and evaluate their own health care. Research has demonstrated that youth with disabilities present additional risks particularly in areas of academics, behavior, and mental health (Chmelka et al., 2011; Trout et al., 2009) which relate directly to aspects of adequate health literacy. More importantly, youth with disabilities in residential care have been found to have significantly more medical conditions including asthma and problems of the digestive system as well as high medical utilization than youth not in residential care. Functional levels of youth health literacy are important for several reasons including knowing how various health needs relate to one another, accessing support while in and out of care, and during the transition to adulthood where healthcare management is critical for positive long term health outcomes. Therefore, the objectives of this study were to better understand the health literacy status of youth with disabilities among a sample of residential youth.

Results indicate that the majority of youth scored in the “possibility” and “likelihood” range of limited literacy on the NVS and over half of the participants scored at least two grade levels below on the REALM-Teen. Given that most health-care materials are written at a 10th grade-level or higher (Davis et al., 1993; Sheridan, Harris, & Wolf, 2003; Wallace, 2006), this finding brings to light the concern of the ability of youth with disabilities to obtain, process, and understand basic health care information as nearly three-fourths of the participants were

reading well below this reading level. Furthermore, previous research has identified that below grade reading level has an impact on adolescent risk behavior and health care (Davis et al., 2006), which presents an additional challenge for this subgroup of youth in care. Provided that youth with disabilities already demonstrate increased risk in areas of academics, behavior, mental health, physical health, and medication needs, the need for adequate and continuous health care will likely be an ongoing challenge for this population. These findings suggest that when faced with health related tasks and decisions, youth with disabilities are very likely to struggle with reading and comprehending health-related materials including instructions, prescriptions, and information.

Similar to results found in prior studies (Davis et al., 2006) significant differences were found between youth of different ethnic backgrounds. Specifically, African-American and Hispanic/Latino youth tended to report the lowest rates of health literacy on both measures, but statistically significant differences with medium effects were found only on the REALM-Teen. This suggests additional efforts should be made to ensure that these youth leave care well prepared to navigate the health system and access supports.

Implications

Results reveal that youth with disabilities are at elevated risk for low health literacy. Although additional research is needed, these findings suggest important implications for practitioners and researchers working to improve outcomes of youth with disabilities in residential care. First, treatment providers should consider incorporating health literacy measures that can be used to gather a comprehensive picture of the youth's health knowledge, management, and functioning at entry to care. These results can be used to develop specific goals that could be written into the youth's treatment plan and transition portion of the youth's Individualized Education Plan (IEP) in order to increase health literacy, in the short-term, and to help youth understand the importance of managing their own health care, in the long-term. Third, prior to departure, service providers should work to inform youth and families of health-related resources in the community and connect them with necessary health-care providers such as physicians, psychiatrists, and psychologists as a proactive step towards establishing independence in health care monitoring. Finally, as future steps are taken to develop curricula and interventions designed to improve health literacy, it is imperative that treatment providers acknowledge differences in how youth with disabilities interpret, process, and comprehend health related information. Interventions and programs seeking to promote health literacy among youth with disabilities may need additional consideration such as differentiating the curriculum and readability levels, offering small group instruction, shortened lessons, or scaffolding, as these strategies are effective academic supports for students with disabilities (Friend & Bursuck, 2009).

Limitations and Future Research

Limitations of this study should be acknowledged and addressed in future research. First, the sample was from one residential setting. Because residential programs offer various approaches to treatment and education, the results and generalizability from this study may not be representative of youth in other residential settings. Replication of this study in other settings is needed to determine if the health literacy status is similar across agencies. Second, although the NVS and REALM-Teen are widely used measures (Nielsen-Bohlman, Panzer, & Kindig, 2004) and have demonstrated psychometric adequacy for use with youth in residential settings (Hoffman et al., in press), they do not provide a comprehensive overview of youth health literacy. Specifically, these scales primarily measure health literacy by assessing fluency, comprehension, and numeracy, but do not provide information on a youth's ability to navigate the health care system including health knowledge related to prevention and treatment. Therefore, future studies assessing these additional domains would provide a more comprehensive understanding of health literacy among youth with disabilities. A

fourth limitation was not including a standardized measure of reading literacy to serve as a measure of convergent validity for this population of youth and more importantly to assess how related reading literacy and health literacy is in this group of youth. Finally, this study was limited to youth with specific primary eligibility categories (e.g., LD, BD, OHI) and had a very limited number of participants in some of the eligibility categories. Therefore, future researchers should look at including a more diverse and larger sample of youth receiving special education services to explore if there are additional differences which may exist among specific categories of youth with disabilities in order to better understand how to best prepare this population to manage their health care needs.

Conclusion

The importance of understanding the health literacy of different populations is increasing as health care reform continues to be a primary topic of debate in many countries. Although European societies are among some of the most educated and healthiest in the world (Albert & Davia, 2010), establishing a population that has proficient health literacy continues to be a priority (European Commission, 2010). Certain characteristics have been identified as indicators of low health literacy, and youth in residential care are one group that poses a greater risk for low health literacy based on their identified challenges (i.e., increased mental health, elevated family problems, poorer physical health, low academic achievement). Furthermore, additional risks are present for youth with disabilities in residential care. Compared to the general population of youth in care, youth with disabilities scored poorly in health literacy recognition and comprehension and demonstrated an overall risk for low health literacy. These results suggest that additional research and supports in health literacy are needed to ensure youth are able to access health-related information and make informed decisions regarding their own health care. Finally, as future steps are taken to design intervention targeted at improving health literacy, it is imperative that researchers and practitioners acknowledge and take into consideration how youth with disabilities interpret, process, and comprehend health information.

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Summary

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Although the general population of youth in residential care tends to demonstrate broad risks, youth with disabilities may be at increased risk for poor health literacy due to elevated risk in areas such as academics, behavior, family stability, and co-occurring physical health challenges. For example, in a study of youth served in a residential setting, Trout et al. (2009) found that youth with disabilities are at elevated risk in several academic areas including reading fluency, spelling, and reading comprehension—all essential components of health literacy. In the same study, youth with disabilities were also significantly more likely to have substance abuse, social problems, and externalizing behaviors than their peers in care without disabilities. The physical health and medical conditions of students with

school-identified disabilities both in and out of residential care has become a focus for researchers in the past few years.

While youth with disabilities in residential care are likely at increased risk for low health literacy due to co-occurring behavioral, academic, family, and physical health challenges, they also have a documented high prevalence of medical conditions, continued need for medication management and health care support following departure from care, making health literacy of particular importance. Yet, research has not evaluated the health literacy of this high-risk population.

Object of the research – the health literacy status of youth with disabilities in a residential treatment setting.

The purpose of this study was to examine the health literacy status of youth with disabilities in a residential setting. Health literacy status along with the relationship between health literacy and key youth demographic characteristics such as gender, race/ethnicity, and disability category were examined.

All procedures were approved by the Institutional Review Boards at the authors' university institution and the participating residential program. The residential program is comprised of 61 community-based family style homes (Family Home Program) in which 6 to 8 youth, 12 to 18 years of age live with a married couple (Family Teachers) and one assistant (Assistant Family Teacher). Participants included 61 assenting youth in grades 9-12 who were receiving special education services. Youth were predominantly male (72.1%) with a mean age of 16.89 years ($SD = 1.21$; range = 14 to 19 years). Slightly over one-third (37.7%) were state wards and had an average of 2.44 ($SD = 1.16$) psychiatric diagnoses. An overwhelming majority (84.5%) was diagnosed in one special education disability category, 13.8% in two disability categories, and 1.7% in three disability categories.

There were used The Newest Vital Sign (Weiss et al., 2005) assesses reading comprehension and numeracy instrument and The Rapid Estimate of Adult Literacy-Teen (REALM-Teen; Davis et al., 1993) test as well.

Descriptive statistics were generated to provide an overview of the sample on demographic variables; means and standard deviations and frequencies were calculated for each of the continuous variables assessed; an independent sample t-test and ANOVA tests were conducted to identify differences between gender, ethnicity, and primary special education eligibility category among youth with disabilities. A Bonferonni post-hoc test was also used to identify specific differences between groups.

Results of the study let us to draw conclusions:

The importance of understanding the health literacy of different populations is increasing as health care reform continues to be a primary topic of debate in many countries. Although European societies are among some of the most educated and healthiest in the world (Albert & Davia, 2010), establishing a population that has proficient health literacy continues to be a priority (European Commission, 2010). Certain characteristics have been identified as indicators of low health literacy, and youth in residential care are one group that poses a greater risk for low health literacy based on their identified challenges (i.e., increased mental health, elevated family problems, poorer physical health, low academic achievement). Furthermore, additional risks are present for youth with disabilities in residential care. Compared to the general population of youth in care, youth with disabilities scored poorly in health literacy recognition and comprehension and demonstrated an overall risk for low health literacy. These results suggest that additional research and supports in health literacy are needed to ensure youth are able to access health-related information and make informed decisions regarding their own health care. Finally, as future steps are taken to design interventions targeted at improving health literacy, it is imperative that researchers and practitioners acknowledge and take into consideration how youth with disabilities interpret, process, and comprehend health information.