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Health-Related Quality of Life and Health Literacy among Mexican American and Black American Youth in a Southern Border State

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To cite this article: Steven Hoffman, Heidi Adams Rueda & Lauren Beasley (2020) Health- Related Quality of Life and Health Literacy among Mexican American and Black American Youth in a Southern Border State, Social Work in Public Health, 35:3, 114-124, DOI: <u>https://doi.org/10.1080/19371918.2020.1747584</u>

ABSTRACT

Among adults, health literacy and health-related quality of life are highly correlated constructs that are associated with tangible health outcomes. While the connection between these concepts and health outcomes among youth is still unclear, studying these factors among at-risk adolescent populations can provide researchers, policy-creators, and educators a quantifiable summary of the challenge they face in their efforts to reduce health disparities. The purpose of this study was to better understand the health of minority youth living in a Southern state near the US-Mexico border. Specifically, we sought to describe their health literacy and health-related quality of life, and identify how those concepts may be interrelated. Results indicated that our sample of primarily Mexican American and Black American youth living along the US-Mexico border may be struggling more than other known high-risk groups in terms of health literacy and health- related quality of life. Practical implications for families, schools, and border communities are discussed.

KEYWORDS

Health literacy; quality of life; US-Mexico border; youth

Although advances in the social and medical sciences have contributed to Americans living longer, healthier lives, achieving health equality continues to be a seemingly insurmountable task due to social, economic, and environmental disparities (US Department of Health and Human Services [DHHS], 2011). Health disparities impact individuals and groups throughout the US, and some of the most dramatic disparities are found within racial/ethnic minority communities (Kann et al., 2016; Sutton & Parks, 2013; Warnecke et al., 2008).

Much research has focused on reducing racial/ethnic disparities in the occurrence and treatment of specific health conditions (e.g., Golabi et al., 2016; Nolan et al., 2014). This information is valuable and needed, but is often relevant to only a particular sub-group of individuals affected by the disease or phenomenon under consideration. Another approach to reducing health disparities is through the analysis of geographically distinct communities and understudied populations. This method seeks to identify those who are at risk because of common problematic circumstances, cultural oppression, or social challenges. In line with the latter approach, the purpose of this study was to better understand the health of minority youth living in a Southern state near the US-Mexico border. Specifically, we sought to describe their health literacy (HL) and health-related quality of life (HRQOL), and identify how those concepts may be interrelated. Among adults, HL and HRQOL are highly correlated constructs that are associated with tangible health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). While the connection between these concepts and health outcomes among youth is still unclear (Hoffman, Marsiglia, Nevarez, & Porta, 2017; Navarra, Neu, Toussi, Nelson, & Larson, 2014), studying these factors among adolescent populations will provide researchers, policy-creators, and educators a quantifiable summary of the challenge they face in their efforts to reduce health disparities.

HL and HRQOL among minority populations

HL is the ability to read, understand, and use health information to make important health decisions (Parker, Ratzan, & Lurle, 2003; Sanders, Shaw, Guez, Baur, & Rudd, 2009). It also encompasses a variety of other skills such as effective listening, understanding diseases, and self-efficacy (American Medical Association, 1999; Milne et al., 2010). Low HL is associated with more visits to the hospital, poor adherence to care, poor health status, and higher mortality rates (Berkman et al., 2011). Health related quality of life (HRQOL) is an individual's ability to function at high levels physically, emotionally, and socially (Giachello, 1996). Although biological indicators have historically been the focus of health research, in recent years there has been a greater emphasis on holistic and patient-centered self-reported outcomes such as HRQOL (Quittner et al., 2010). Assessing HRQOL (i.e., one's own perception of their physical, mental, and social health) is particularly beneficial because emotional and social assets are important to both the prevention of physical health decline and offsetting the risk of disease (Boehm & Kubzansky, 2012; Thurston & Kubzansky, 2009).

Research has repeatedly suggested that racial/ethnic minority groups in the US have low HL compared to White Americans (Cha et al., 2014; Rikard, Thompson, McKinney, & Beauchamp, 2016; Schumacher et al., 2013). This was evidenced in the most recent National Assessment of Adult Literacy as Hispanics and Black Americans were found to have the lowest HL of all racial/ethnic groups (Cutillit & Bennett, 2009). There are many factors that influence HL and HRQOL, but the racial/ethnic disparities are only partially explained by differences in socioeconomic status, educational attainment, and confidence in health care providers (Mansour, Lanphear, & DeWitt, 2000; Nelson, 2003; Pereira, Palta, Mullahy, & Fryback, 2011). In addition to these barriers, Mexican Americans, particularly acculturating adults and youth that live in border communities, may have an even higher risk of limited HL as they are familiarizing themselves with a new culture and a second language (US DHHS, 2010; Mas, Ji, Fuentes, & Tinajero, 2015). Among Black Americans, despite limited research, low HL has been linked to a decreased understanding of health information and diseases, low self-efficacy, and poor adherence to medical protocols (Weeks, 2012).

As with HL, low HRQOL also disproportionately affects minority populations. In unique com- munities such as those near the US-Mexico border, research among adults has shown HRQOL to be negatively associated with minority status, disability, unemployment, poverty, and low levels of education (Centers for Disease Control and Prevention [CDC], 2001; Mier et al., 2008). Data from the Behavioral Risk Factor Surveillance System suggests that Black Americans are 40% more likely – and Hispanics twice as likely – to have poor HRQOL than White Americans (Chowdhury & Balluz, 2008). Only recently have researchers begun to look at the connection between HL and HRQOL. While more information on this topic is needed, the available research suggests that low health literacy is related to poor HRQOL in unique samples, including adult men from minority racial/ ethnic groups (Miller, Cage, Nowacki, Jackson, & Modlin, 2018; Sayah, Qiu, & Johnson, 2016).

Adolescent health outcomes

The connection between health knowledge and health outcomes is often unclear when studying adolescent populations (Hoffman et al., 2017; Navarra et al., 2014). This may be partially due to the consequences of inadequate health knowledge and damaging health decisions not being evidenced until adulthood (i.e., lung cancer caused by smoking does not develop overnight). Although many assume the association between one's knowledge and behaviors to be strong, intervention studies have often found that knowledge of health-associated risk is insufficient to influence behavior (Sheeran & Webb, 2016). Despite inconsistent findings and the dearth of longitudinal studies, the importance of studying HL among adolescent populations, particularly at-risk and underserved youth, is selfevident. Adolescents are establishing health habits that will affect them throughout their adult lives (Due et al., 2011; World Health Organization, 2018). Information is needed to quantify their needs during this critical period of physical, psychological, and social development so that appropriate methods of health promotion can be identified and implemented.

One of the clearest frameworks for studying adolescent HL was presented by Jennifer Manganello (2008). Her framework suggests that the various components of HL (e.g., functional, interactive, critical) are influenced by individual traits (i.e., demographic factors, social and cognitive skills, etc.), family influences, and social systems (i.e., mass media, education systems, health systems). A few years after

her framework was set forth, representatives from the US Department of Health and Human Services, Centers for Disease Control and Prevention, and Office of Disease Prevention and Health made a joint call for a systems approach to HL research (Koh, Baur, Brach, Harris, & Rowden, 2013). They outlined how the Affordable Care Act (ACA) and Health Information Technology Act have provided a unique opportunity for researchers and policy-makers to expand our perspective of HL beyond micro-level influences. In line with calls for an expanded approach to understanding adolescent health, we sought to obtain foundational HL and HRQOL information among minority youth in an underserved and understudied region of the US.

The present study

The border region refers to the counties in Arizona, California, New Mexico, and Texas along the US- Mexico border (Bhasvar et al., 2014). Although many quality of life indicators have improved in the border region since 2000 (Lee et al., 2013), the region still faces serious health challenges that lead us to consider them as being at high-risk for poor health outcomes. For example, individuals living on the US-Mexico border have higher rates of tuberculosis, HIV, diabetes, and adolescent pregnancy compared to the general population (Texas Health and Human Services, 2018). The increased risk for negative health outcomes may be related to the vulnerabilities of the border region that limit access to healthcare. The American Hospital Association (2016) identifies six characteristics of vulnerable and at-risk populations: (1) limited access to primary care; (2) low socioeconomic status; (3) lack of insurance; (4) cultural differences; (5) low education and limited literacy; and (6) environmental factors. The border region broadly fits this definition of an at-risk region. Specifically, 20% of the border population cannot access a doctor due to the cost of services, half of the counties in the border region are defined as persistent poverty counties under the United States Department of Agriculture definition, 11.7% of the border population are not proficient in English, 28.9% of the population under 65 in the border region are uninsured, 56% of the population does not have any type of post-secondary education, and individuals in border counties have less access to

recreational centers and healthy food sources than non-border communities (Bhasvar et al., 2014). Continued attention to the HL and HRQOL of adolescents in border communities is thus warranted due to these risk factors.

The overarching research questions guiding this investigation were: a) How health literate are youth living near the US-Mexico border? (i.e., within 150 miles); b) Are they at-risk of low HRQOL?; and c) What is the relationship between their HL and HRQOL? Based on the aforementioned health and health-related challenges facing border communities, we hypothesize that youth along the US- Mexico border will have low levels of both HL and HRQOL. Isolating problematic health indicators among youth living in high-risk border communities may help inform the development and funding of appropriate interventions aimed at reducing health disparities (Hoffman, Rueda, & Beasley, 2019; Manganello, 2008; Nelson et al., 2014).

Method

The governing Institutional Review Board approved this project and all its procedures. To recruit high-school-aged youth, our research team collaborated with three after-school programs within a large urban city within 150 miles of the US-Mexico border. The research team included the co- principal investigators and two graduate research assistants. Youth from each location were provided information about the study via an oral presentation from a member of the research team, and those who were interested were given consent forms in their preferred language (i.e., English/Spanish) to read with their parent/guardian. Students who returned signed forms were asked by members of the research team to review study procedures, provide assent, and individually complete a survey on basic demographic and health information. Administration of surveys took place either during a regularly-scheduled class period (high school), or in a designated place at an after-school club. Once a participant had completed their survey, they were taken to a separate private area and were administered two HL assessments by a trained member of the research team. The option to use Spanish language materials was offered to participants. A final sample of 102 youth ages 14–19

participated (female = 56%; *M* age = 15.89; *SD* = 1.54). See Table 1 for additional demographic information.

Measures

In addition to basic demographic information (i.e., age, race/ethnicity, gender, grade in school, parent education), the following three measures were utilized for the present study: The Rapid Assessment of Adolescent Literacy in Medicine (REALM-Teen; Davis et al., 2006); the Newest Vital Sign (NVS; Weiss et al., 2005); and the Pediatric Quality of Life Assessment (PedsQL; Varni, Burwinkle, Seid, & Skarr, 2003). The REALM-Teen is a widely-used adolescent HL word recognition test that has participants pronounce 66 health-related words (e.g., pill, exercise, depression). The number of correctly pronounced words corresponds to gradeschool reading level. The NVS, another measure of HL, evaluates reading comprehension and numeracy by having participants answer six questions about an ice cream nutrition label (e.g., "If you eat the entire container, how many calories will you eat?"), with the number of correct responses corresponding to the degree of HL (0-1 = ``high likelihood of limited health literacy''; 2-3 = ``possibility of limitedhealth literacy"; 4-6 = "adequate health literacy"). The PedsQL, the most widely-used measure of pediatric HRQOL, has been cited in over 600 published research articles (Varni, 2012). It is comprised of 23 Likert-scale questions, and responses are interpreted with a total QoL score, a physical QoL score, and a psychosocial QoL score. Each of these instruments has been tested among at-risk, low-income, minority youth, and all were found to be adequately reliable among participants in our study (REALM-Teen α =.95; NVS α = .57; PedsQL α = .85; see also Jordan, Osborne, & Buchbinder, 2011; Nelson et al., 2014; Trout, Hoffman, Epstein, Nelson, & Thompson, 2014).

Data analysis

Our data analysis plan was broken down into three stages. First, we descriptively assessed the adolescents' reading levels, health literacy, and health-related quality of life. Second, we determined risk by comparing descriptive scores

to pre-determined risk cutoffs established by instrument developers and high-risk youth from prior studies. Finally, we assessed whether health-related quality of life may be predicted by health literacy using regression analyzes controlling for age, race, gender, and parent education.

Variable	%
Age (N = 99; M = 15.89; SD = 1.54)	
14	23.2%
15	22.2%
16	21.2%
17	14.1%
18	13.1%
19	6.1%
Gender (N = 99; M =.42; SD =.50)	
Female	55.9%
Male	41.2%
Race (N = 88; M = 1.51; SD =.88)	
White	5.7%
Hispanic/Latino	55.7%
Black	22.7%
Mixed Race	13.6%
Other	2.3%
US Born (N = 97; M =.93; SD =.26)	
No	7.2%
Yes	92.8%
Grade (N = 99; M = 10.06; SD = 1.21)	
8	6.1%
9	35.4%
10	21.2%
11	21.2%
12	16.2%

Table 1. Descriptive statistics.

Results

The largest racial/ethnic group in our study was Mexican American youth, comprising 56% of our sample, with Black American youth representing an additional 23%. It is worth noting that 14% of our sample identified as multi-racial, and 14% of our sample did not report their race/ethnicity, possibly due to the delicate nature of race along the US-Mexico border. Students were between grades 8 and 12, with a majority (77.7%) in 9th through 11th grade (see Table 1). A descriptive cross tabulation depicting students' current grade level and the level at which they were reading is shown in Table 2. Most students (65%) were reading below their grade level, with many (15%) reading at a 5th grade level or lower. Just 52% of all high school students in our study were reading at or above an 8th grade level. A descriptive look at the health literacy assessment is provided in Table 3. Overall, just one-quarter of students demonstrated adequate HL as per the NVS assessment tool. With regards to health-related quality of life, we found that a high percentage of youth fell within the at-risk range (see Table 4). Our final analyzes looked at health literacy as a predictor of total health-related quality of life and the physical/psychosocial quality of life subscales. None of the predictor variables were statistically associated with the HRQOL outcome variables, and therefore regression results are not shown.

		Current Grade Level					
		8th	9th	10th	11th	12th	Total
Reading Level (REALM-Teen)	3rd Grade and Lower	1	1	0	4	1	7
-	4th – 5th Grade	2	3	1	1	0	7
	6th – 7th Grade	1	15	3	8	4	31
	8th – 9th Grade	2	10	9	4	3	28
	10th Grade and Higher	0	3	7	4	7	21
	Total	6	32	20	21	15	94

Table 2. Cross tabulation of REALM-teen reading level and grade level.

Table 3. Descriptive breakdown of	the Newest Vital Sign H	L Assessment
NVS Scores	N	%

NVS Scores	N	%
High Likelihood of Limited Health Literacy	29	30.2%
Possibility of Limited Health Literacy	44	45.8%
Adequate Health Litearcy	23	24.0%

Table 4. Descriptive breakdown of the PedsQL HRQoL Assessment

HRQoL Scores	M (SD)	% "At risk"
Total	71.88 (14.88)	34.3%
Physical	81.22 (19.05)	21.6%
Psychosocial	66.81 <i>(16.62)</i>	52.0%

Discussion

The purpose of this study was to better understand the health literacy and health-related quality of life among a sample of primarily minority youth (56% Mexican American, 23% Black American) living in an urban area of a US-Mexico border state. As there is no prior research to our knowledge concerning HL and HRQOL among youth along the US-Mexico border, our findings provide an initial look at key health-related challenges facing this unique population.

Youth in our study scored low on multiple health indicators, with 65% reading at least one grade below their current level and 75% having at least the possibility of limited HL.

Comparing our descriptive results with prior research among adolescent populations suggests that our sample of primarily minority youth living along the US-Mexico border may be struggling more than other known high-risk groups. For example, when looking at health-related quality of life scores among youth in a large residential treatment program located in the Midwestern United States who were assessed using the same instrument (i.e., the PedsQL; see Nelson et al., 2014), youth in our sample had 16.4% higher total risk (34.3% to 17.9%), 8.5% higher physical risk (21.6% to 13.1%), and 32.3% higher psychosocial risk (52.0% to 19.7%). Our sample also scored lower on the health literacy assessment than youth from the residential treatment program who were assessed using the same instrument (i.e., the NVS; see Trout et al., 2014). More youth in our sample scored in the highest risk category (30.2% to 23%), the moderate risk category (45.8% to 42%), and less scored in the low risk category (24.0% to 35%).

These findings are consistent with the many other studies suggesting that racial/ethnic minorities continue to suffer some of the greatest health disparities (Kann et al., 2016; Sutton & Parks, 2013; Warnecke et al., 2008), and that communities near the US-Mexico border experience heightened risk for health-related problems, such as diabetes (Casey, Rouff, & Jauregui-Covarrubias, 201) and chronic liver disease (Mrela & Coe, 2002). Additionally, research has found that individuals in border communities have high rates of teen pregnancy (Mrela & Coe, 2002) and excessive alcohol use (McKinnon, O'Rourke, Thompson, & Berumen, 2004), which may put them at risk for poor physical and mental health outcomes (United States-Mexico Border Health Commission, 2010). While there has been some attention given to health programming (i.e. community health screenings) specifically focused on at-risk adult populations along the US-Mexico border (Millard et al., 2017), there is limited research on programming specifically aimed at improving the health out- comes of border community youth. This is particularly

concerning in light of the results of this study as adolescence is a key developmental time in the prioritization of health as the individual begins to gain autonomy (Manganello, 2008). Further, border youth face unique challenges as they juggle competing sets of cultural norms (Matsunaga, Hecht, Elek, & Ndiaye, 2010). Unfortunately, our findings indicate that the youth sampled would have difficulty reading commonly utilized health language (e.g., asthma, pill, pneumonia) or understanding basic health information to care for their bodies (e.g., looking for an allergy-containing ingredient on a label; converting serving sizes to calorie intake).

Although only 7% of our sample was foreign-born, attention to the impact that immigration has on HL is important in this study's context for two main reasons. First, 16% of the border population is foreign-born (Bhasvar et al., 2014). Second, even if adolescents are born in the United States, their parents and/or guardians may be first-generation immigrants, resulting in cultural tensions. Research suggests that for Hispanic immigrants specifically, their level of acculturative stress may be linked to health outcomes (Abraido-Lanza, Echeverria, & Florez, 2016). For example, some studies link acculturation level and acculturative stress to obesity in Hispanic youth (Arandia et al., 2018; Simmons & Limbers, 2018). This may be due to the differing cultural practices in Mexican and American culture. Youth in border communities may be getting one type of health information at school and in the community, and another type of health information at home from first generation guardians, parents, grandparents, and/or extended family. Further, youth's level of acculturation may have a direct impact on the ability of youth in border communities to read and understand health information, especially if Spanish is the primary language at home. Indeed, knowledge of the English language has been found to be one of the highest predictors of adequate HL in Hispanic populations (Jacobson, Hund, & Soto Mass, 2016). However, it should not be incumbent on individuals to learn English to be able to access and understand important health information; services, especially in the multicultural border regions, should be provided in a culturally competent way, including providing materials in both English and Spanish. It is important to consider these and other cultural

considerations when thinking about youth-centered community health interventions.

The most recent National Assessment of Adult Literacy (NAAL) found that more than one-third of US adults have less than adequate HL, with Black American and Hispanic adults scoring lowest among racial/ethnic groups (US Department of Education, 2003). This suggests two distinct needs for educators and policy makers when creating adolescent health interventions in border communities. First, it is important to create culturally competent health education, which can include a range of cultural health practices as pertinent to diverse youths. Specifically, many of the same values within Mexican culture are also evident among Black Americans, particularly the emphasis on close-knit families and the tendency to seek help from informal sources (Boyd-Franklin, 2006; Manganello & Sojka, 2016). Second, as the inclusion of family is important cross-culturally, creating dual programming where parents, guardians, and other kin are enrolled in similar HL classes as their children may be a promising model (Hoffman et al., 2019). Such programs should be offered in both Spanish and English and provide child care and transportation to decrease barriers to access. Including the above strategies into health programming in border communities may help promote bicultural identity among Hispanic adolescents, which seems to have the best outcomes – health and otherwise – for immigrant Hispanic families (Dennis, Fonseca, Guiterrez, Shen, & Salazar, 2016).

In addition to its contributions to the literature on Hispanic youth along the US-Mexico border, this study begins to respond to a large gap in research with regard to Black American adolescents in border communities. There is a lack of empirical studies on the Black community in border regions, perhaps due to the fact that conducting research with this population is challenging as non-Hispanic Black Americans make up a small proportion of the border population. This limited available research on Black Americans along the US border has logically led to even less research on African American adolescent HL and health-related quality of life (Manganello & Sojka, 2016). In other locations, such as an exploratory study conducted by Manganello and Sojka (2016) in New York State, 2016) it was found that 65% of their African American adolescent sample had low HL, which is in line with the findings of our study. Interestingly, in that study it was found that when youth had lower HL they relied more on their families for health information (Manganello & Sojka, 2016), which is consistent with the importance of family and extended kin in the African American culture (Boyd-Franklin, 2006). It is also important to note that Black adolescents face several systemic barriers that can lead to worse health outcomes, related directly to physical stress, as well more mezzo- and macro-level issues such as neighborhood environment and socioeconomic status (Mays, Cochran, & Barnes, 2014). For example, studies have found that racial discrimination is linked to increased risk for inflammation (Brody, Yu, Miller, & Chen, 2015), obesity (Assari, Lankarani, Caldwell, & Zimmerman, 2016), and heart disease (Goosby, Malone, Richardson, Cheadle, & Williams, 2015) in the African American youth and adolescent populations. While the majority of current research focuses on Mexican-American adults and adolescents, there is a long history of Black immigration to the Southwestern United State (Whitaker, 2000) that warrants specific attention to needs of the Black border community.

Limitations

A few limitations should be noted. First, data were obtained via convenience sampling, so results are not generalizable. Second, youth were recruited from afterschool programs that are typically utilized by students from low-income backgrounds; therefore, the findings of this study may be skewed based on the limited socioeconomic variability among participants. Future research projects should target general high school populations and other adolescent-serving institutions that have less socioeconomic homogeneity. Third, the small sample size may not have been sufficient for detecting small effects between HL and HRQOL (Grissom & Kim, 2012). We anticipate that a larger sample size may have allowed us to detect a relationship between HL and HRQOL, just as previous studies among other populations have found high HL to be predictive of positive health and wellbeing (Berkman et al., 2011). Lastly, throughout this manuscript we refer to our sample as living in a border town approximately 150 miles from Mexico. While some official US agencies define border towns as those within 100 miles of the Mexico border, we use "border" terminology due to the similarities in racial makeup, income,

and lifestyle between those living in the area where this study took place and those in nearby towns officially classified as border communities. As per the US Census, the majority of people living in the area where this study took place are Latino and have a substantially lower median income than the US average (~ 20,000 USD less). Also, as per our experience working with this particular community we know that it is common for families/individuals to cross the US- Mexico border to see family or work.

Conclusion

It is imperative that teachers, health providers, social workers, and other professionals in adolescents' helping networks be aware that minority youth in border communities may experience challenges both in health literacy and in health-related quality of life. As the majority of the adolescents in this study were reading well below their grade level, all health materials and health education need to be written and presented at a level that can be comprehended. This is critical as the majority of health materials are written at more advanced reading levels than the literacy of the general population (Rudd, 2015; Rudd & Keller, 2009), and our study suggests youth in border-communities may be at an even higher risk, especially in light of potential language barriers.

Schools near the US-Mexico border should also be mindful of the health challenges facing their students, and may consider including practical, culturally competent health education in their curricula. For example, schools might include information on obtaining health insurance, seeking preventative care, or cooking healthy and culturally-informed meals on a budget. These curricular suggestions are consistent with recent legislation (i.e., the Every Student Succeeds Act of 2015), which tracks health outcomes and attempts to view adolescents' lives more holistically in school settings (Hampton, Alikhani, Auld, & White, 2017). Additionally, similar health courses can be offered in the community to target the HL of parents and caregivers. In conjunction with education providers, creating or expanding outreach health services via additional support and funding from local, state, or federal reserves may be necessary.

Disclosure statement

All authors declare no conflict of interest

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