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Demographic and psychosocial factors associated with limited health literacy in a community-based sample of older Black Americans

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Abstract

Objectives: Individuals with limited health literacy often experience suboptimal health outcomes. This study examined the frequency of limited health literacy and demographic and psychosocial factors associated with limited health literacy in a sample of older Black Americans.

Methods: Participants (n = 330) enrolled in a community-based intervention to promote colorectal cancer (CRC) screening completed baseline surveys assessing health literacy with the Rapid Estimate of Adult Literacy in Medicine, Revised (REALM-R) test, CRC awareness, cancer fatalism, Preventive Health Model (PHM) constructs, and demographics.

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Author contributions

Dr. Davis had a role in data management, analysis/interpretation, wrote/revised the article, and approved the final version. Drs. Wischhusen and Christy had a role in data management, analysis/interpretation, revised, and approved the final version. Dr. Sutton had a role in analysis/interpretation, revised, and approved the final version. Drs. Chavarria, Sutter, and Roy data acquisition, revised, and approved the final version. Drs. Meade and Gwede had a role in conception/design of the study, data acquisition, data analysis/interpretation, revised, and approved the final version.

Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Declaration of Competing Interest

None.

Results: Approximately 52% of participants had limited health literacy, the REALM-R score was 5.4 (SD = 2.7). Univariable correlates of limited health literacy were gender, employment, income, prior screening, cancer fatalism, CRC awareness, and PHM constructs (religious beliefs, salience/coherence, perceived susceptibility). Multivariable correlates of limited health literacy were male gender (OR = 2.3, CI = 1.4–3.8), unable to work (OR = 2.8, CI = 1.3–6.1), lower household income (OR = 3.0, CI = 1.6, 5.5), and higher PHM religious beliefs (OR = 1.1, CI = 1.0–1.2).

Conclusion: Limited health literacy was associated with multiple complex factors. Interventions should incorporate patient health literacy and low-literacy materials that can be delivered through multiple channels. Practice implications: Future studies are needed to understand the role of health literacy in an individual's health behavior and the provision of effective healthcare.

Keywords

Health literacy; African Americans; Colorectal cancer; Cancer prevention and screening

1. Introduction

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [1]. Health literacy is associated with general literacy, and includes critical thinking, information-seeking, decision-making, and communication skills [2]. Health literacy is required to understand and use health information, and therefore, plays a central role in improving health outcomes, empowering patients, and reducing overall healthcare inequalities [2–6].

Only 12% of Americans have “proficient” health literacy [7]. Approximately 36% of Americans have “basic” or “below basic” health literacy, meaning they are only able to read and comprehend a short set of health-related instructions [7]. Adults with lower education, income, and occupational status are disproportionately burdened by limited health literacy [2,6,29–31]. Limited health literacy is especially significant among 57% of Black Americans [7]. Black Americans living with limited health literacy experience a higher burden of disease, poorer health outcomes, and reduced access to quality healthcare [2,8].

American adults with limited literacy have difficulty with common health-related tasks such as completing medical forms or understanding patient education materials [7,9,10]. Limited health literacy is associated with poorer overall health, harmful health behaviors, worse health outcomes, lower use of health services, and lower illness-related knowledge [2,11]. While all individuals, regardless of health literacy level, face similar challenges regarding access to and usage of preventive health services, those who have limited health literacy may encounter additional challenges when navigating the health care system and making health care decisions [3,12,13]. Adults with limited health literacy are less likely to engage in preventive services such as cancer screening, including colorectal cancer (CRC) screening [14–16]. Lack of engagement in screening behaviors at recommended ages and screening intervals results in greater frequency of diagnosis of advanced stage cancer [17,18] and higher mortality [19,20].

Black Americans have the highest CRC incidence and mortality rates, along with the shortest survival rates, compared to all other racial and ethnic groups [21–23]. A major contributor to the burden of CRC in Black Americans is likely underutilization of CRC screening [24]. Health literacy may be an important, yet poorly understood contributing factor to CRC screening disparities among Black Americans. Moreover, adequate health literacy is an especially key imperative within a social justice framework for achieving health equity [25,26].

Limited health literacy among Black Americans has been documented across multiple studies [15,16,27–29]. However, many of these studies were conducted in primary care practices and may not apply to Black Americans within an underserved community setting [15,16,27,29]. The association between health literacy and CRC screening knowledge and attitudes is well established [7,15,27–29]. However, few studies have examined the relation between health literacy, CRC knowledge, and beliefs specific to CRC screening with the fecal immunochemical test (FIT)/fecal occult blood test (FOBT) [15,29–31], an increasingly preferred CRC screening choice due to decreased cost and ease of use.

Many drivers of health disparities are associated with health literacy. There is a crucial need to understand correlates of limited health literacy among Black Americans. By identifying correlates, it is possible to tailor interventions to improve health literacy or target subpopulations more likely to need intervention. This study examined (1) the frequency of limited health literacy in a community-based sample of older Black Americans and (2) the demographic and psychosocial factors associated with limited health literacy among this population.

2. Methods

2.1. Overview

Study participants were recruited as part of a community-based randomized control trial (titled “Increasing Access to Colorectal Cancer Testing for Blacks” [I-ACT]) designed to assess the impact of a culturally-targeted, minimal-intensity educational intervention on CRC screening with FIT among Black Americans in community settings. Intervention details for the I-ACT trial are described elsewhere [32]. This manuscript focuses on baseline data collected as part of the I-ACT trial, prior to intervention activities.

Participant enrollment took place between October 2011 and August 2014. Five hundred and sixty Black American men and women were evaluated for eligibility and 395 (70.5%) were eligible for participation. Among the men and women eligible, 330 (83.5%) agreed to participate and enrolled in the I-ACT trial in community locations throughout the Tampa Bay area [33]. Members of the community were eligible for the study if via self-report they: (1) self-identified as Black or African-American; (2) were aged 50–75 years; (3) were able to speak, read, and write English; (4) did not have a personal CRC diagnosis or presumptive symptoms of CRC; (5) self-reported not being up-to-date per CRC screening guidelines (i.e., never been screened or previously screened but not up-to-date per national recommendations); and (6) provided at least two forms of contact information to facilitate effective follow-up over two years. For those eligible, the study coordinator explained the

study details and obtained written informed consent in English. Participants providing informed consent completed the baseline questionnaire via face-to-face interview at a community location convenient for the participant. Participants received a \$20 gift card following completion of the baseline questionnaire. The University of South Florida Institutional Review Board approved study procedures.

2.2. Study measures

2.2.1. Health literacy—Health literacy was assessed using the revised version of the Rapid Estimate of Adult Literacy in Medicine (REALM-R) [34]. The REALM-R is a word recognition and pronunciation health literacy assessment that compares favorably to other health literacy assessments in terms of timeliness and administration within clinic constraints [35,36]. The REALM-R was designed to assess how well patients identify and pronounce words commonly encountered in a primary care setting [34]. Participants were asked to read 11 items in English; the first three items are included to minimize anxiety but do not count towards the health literacy score. The test score for each participant was then determined by the remaining eight items (on a 0–8 scale), with one point given for each word read aloud correctly [34]. Participants are considered to have limited health literacy if their REALM-R score is six or less.

2.2.2. Preventive health model (PHM) variables—Psychosocial correlates of CRC screening were assessed with seven factors, measured by 26 items reproduced from four studies [37–40]. The 26 items were scored on a five-point response scale ranging from “1” (strongly disagree) to “5” (strongly agree) [37–41]. Three items assessed perceived susceptibility, or perceptions regarding chances of developing CRC and/or polyps [37,40,42,43]. Salience and coherence, or beliefs about whether CRC screening was important for maintaining health and made sense in their life, was assessed with four items [37,39–42]. Response efficacy, or beliefs about whether early stage CRC can be cured and whether screening can prevent CRC, was assessed with two items [37,39,42]. Social influence, or perceptions of what one’s family members and health care providers thought about the participant having a CRC screening test and one’s desire to comply with the important others’ CRC screening attitudes, was assessed with four items [37,39,41,42]. Six items measured self-efficacy, or confidence one’s ability to collect a stool sample [37,38,40,41,44]. Cancer worry, or concerns about receiving a positive CRC test result was assessed with two items [37,39,41,42]. Religious beliefs, or the extent to which religious beliefs influence one’s health behaviors, was measured with five items [32,45].

2.2.3. CRC awareness—Thirteen items, adapted from the Health Information National Trends Survey, measured awareness and knowledge of CRC and CRC screening. Four items assessed whether participants previously heard of stool blood test, sigmoidoscopy, and colonoscopy and nine items assessed CRC and CRC screening knowledge [46]. One point was given for each correct response and items were summed for a total awareness score (potential for 13 points). Higher scores indicated greater knowledge and awareness.

2.2.4. Decisional conflict—The nine item *Decisional Conflict Scale* assessed difficulty making CRC screening decisions [47,48]. Response options on a 5-point scale, “1”

(strongly agree) to “5” (strongly disagree). Responses were summed with higher scores indicating more decisional conflict.

2.2.5. Cancer fatalism—The fifteen item Powe Fatalism Inventory measured cancer fatalism or the extent to which a participant believes death is inevitable when cancer has been diagnosed [49]. One point is given for each “yes” response. Responses were summed with higher scores indicating higher levels of fatalistic beliefs [50].

2.2.6. Trust in healthcare system—The ten item Healthcare System Distrust Scale assessed the level of trust in the healthcare system, hospitals, health insurance companies, and medical research [51]. Responses were measured on a 5-point scale from strongly agree to strongly disagree, and were summed with higher scores indicating higher levels of distrust.

2.2.7. Perceived discrimination—The eight item Everyday Discrimination Scale assessed the frequency of experiences of mistreatment in the healthcare system and in daily life [52]. Items were rated on a 4-point scale from “never” to “often”. Responses were summed with higher scores indicating perception of more frequent discrimination.

2.2.8. Demographic variables—Participants responded to items assessing demographic characteristics including age, gender, race, ethnicity, marital status, education level, income, employment status, place of birth (U.S. vs. outside of U.S.), health insurance status, whether they had a regular annual exam, and whether they had ever previously completed a CRC screening test.

2.3. Analysis plan

These secondary analyses sought to examine the frequency of limited health literacy in older Black Americans, along with exploring the demographic and psychosocial factors associated with limited health literacy. Statistical analyses were conducted using SAS software (version 9.4, SAS Institute Inc., Cary, NC). Descriptive statistics were calculated for demographic and psychosocial variables. Marital status was coded as married/living with partner, divorced/separated/widowed, or never married/single. Employment status was coded as employed, unemployed, retired, or unable to work (e.g., disabled). Household income was coded as less than or equal to \$25,000 or more than \$25,001.

Logistic regressions were conducted with individual demographic and psychosocial factors examined as potential correlates of limited health literacy (REALM-R score of 6 or less). Multivariable logistic regression was used to identify unique correlates that were not strongly conceptually linked to health literacy (e.g., PHM religious beliefs). Significant variables in univariable models with $p > 0.10$ were entered into a multivariable logistic regression model. Backward, stepwise selection procedures were applied to identify unique factors. This was first done within each variable domain. Those variables statistically significant in the final domain-specific multivariable model were entered into an overall multivariable model. Backward, stepwise procedures were used to identify a final set of unique correlates. Due to statistical covariation and high conceptual overlap with health

literacy score, education attainment ($r = 0.475$, $p < .0001$) and CRC awareness ($r = 0.423$, $p < .0001$) were not included in multivariable models.

3. Results

3.1. Frequency of individuals with limited health literacy

The mean REALM-R score was 5.4 ($SD = 2.7$) for the 330 participants. One hundred and fifty-nine (48.2%) scored 7 or 8, indicating adequate health literacy. The remaining 171 (51.8%) participants scored a 6 or less, suggesting limited health literacy. Among those with limited health literacy, 25 (7.6%) participants scored zero, 38 (11.6%) participants scored either a 1–2, 49 (19.9%) participants scored either a 3–4, and 59 (17.9%) scored either a 5–6.

3.2. Demographic factors associated with limited health literacy

For demographic variables, descriptive statistics and results of univariable analyses associated with limited health literacy are displayed in Table 1. The mean age was 56.4 years ($SD = 5.1$). The majority (93%) self-identified racial heritage of African-American, had a total household income of less than \$25,000 (67%), and was unemployed, retired, or unable to work (60%). Approximately half were male (52%) and had a high school diploma or less education (51%). Fifty-seven percent of the sample had health insurance (including private, government, and county-sponsored insurance). Forty-three percent did not have an annual physical exam. Seventy-two percent of participants self-reported never having had prior CRC screening.

In univariable analyses, male gender, racial heritage, having a high school diploma or less, being unable to work, having a household income less than \$25,000, and never having a prior CRC screening were the demographics significantly correlated with limited health literacy. In the final multivariable model, the following demographic variables were associated with limited health literacy: gender, annual household income, employment status, and prior CRC screening. Men (compared to women) (adjusted OR = 2.3, 95% CI = 1.4–3.8), individuals with a total household income less than \$25,000 (compared to those with a total household income of \$25,001 or greater), (AOR = 3.0, 95% CI = 1.7–5.5), those who were unable to work (compared to employed individuals) (AOR = 2.9, 95% CI = 1.4–6.1), and individuals without a prior CRC screening history (compared to those who have been screened in the past) (AOR = 1.9, 95% CI = 1.1–3.3), were more likely to have limited health literacy.

3.3. Psychosocial variables associated with limited health literacy

For psychosocial variables, descriptive statistics and results of univariable analyses associated with limited health literacy are presented in Table 2. Significant univariable correlates were cancer fatalism beliefs, lower CRC awareness, higher PHM perceived susceptibility, higher PHM religious beliefs, and lower PHM salience and coherence. Backward stepwise multivariable regression resulted in a final model that included PHM salience and coherence, PHM perceived susceptibility, and PHM religious beliefs. Lower salience and coherence (AOR = 0.85, 95% CI = 0.7–0.9), higher PHM susceptibility, (AOR

= 1.1, 95% CI = 1.0–1.2), and higher PHM religious beliefs, (AOR = 1.1, 95% CI = 1.1–1.2) were associated with limited health literacy.

3.4. Final multivariable model of variables associated with limited health literacy

A final multivariable analysis combined the four demographic and the three psychosocial factors that were statistically significant in their respective multivariable model. Backward, stepwise procedures generated the final model presented in Table 3. Male gender, being unable to work, household income less than \$25,000, and having higher religious belief scores were significant, independent correlates of limited health literacy in the final model.

4. Discussion and conclusion

4.1. Discussion

In prior literature, the association between health literacy and demographic and psychosocial factors in a sample of Black Americans has not been well-established. The current study provides a better understanding of the landscape of health literacy in this population. This secondary analysis examined the frequency of limited health literacy (as assessed by the REALM-R) and the demographic and psychosocial factors associated limited health literacy using a sample of older Black Americans enrolled in a CRC screening intervention study. Despite 83% of participants having at least a high school diploma, more than half of the participants had limited health literacy (REALM-R score of 6 or less). Results suggest that many individuals in our sample may have difficulty understanding healthcare-related information, which in turn affects their ability to evaluate preventive health informational materials for salience, credibility, and quality. Limited comprehension of educational information may influence their ability to understand the risks and benefits of preventive health behaviors (e.g., importance of annual repeat CRC screening with FIT) and make critical personal health care decisions.

In the final multivariable model, factors associated with limited health literacy were being unable to work, annual household income of less than \$25,000, male gender, and higher PHM religious beliefs. The associations of employment status and low household income well align with health literacy studies in diverse, non-exclusively Black American participant samples [2,53]. Limited health literacy can affect any American adult regardless of income level, however limited health literacy is correlated with low household income [3,7,54,55]. Low-income adults are disproportionality burdened with healthcare disparities, such as lack of insurance coverage, access to and use of care, and quality of care. Adults with limited health literacy, in addition to healthcare disparities, may have more trouble communicating their health history, may need additional help to understand health directions and navigating the healthcare system [2,3,55].

The association between gender and health literacy has been mixed in the literature. We found that men had limited health literacy, echoing results of a prior clinic-based study conducted among racially and ethnically diverse participants by the research team [31]. Contrary to what we observed in our data, another study of older Chinese adults found a relationship between female gender and limited health literacy [56]. Yet, other studies have

not found an association between gender and limited health literacy [14,57]. This warrants further research examining the interplay between gender and health literacy.

Religion has historically been a core part of many Black Americans' lives. The association between religion and health literacy has been previously studied [58]. Higher religious beliefs have been associated with limited health literacy among Hmong American immigrants [59] and in a racially and ethnically diverse clinical sample [31]. However, the association between religious beliefs (the extent to which religious beliefs influence one's health behaviors and decision-making) and health literacy have not been examined extensively in a sample of Black Americans. Our findings linking higher religious beliefs to limited health literacy fills a gap in the literature.

Health literacy is an important social determinant of health strongly linked to health disparities predicated by inequitable access and use of health services [2,3,60]. The current study's results linking health literacy to unemployment, annual household income, male gender, and the extent to which one's religious beliefs influence health behavior in a sample of Black Americans warrant additional research related interventions to increase adherence to CRC screening recommendations. Future research should examine which educational materials and combinations of interventions lead to greater perceived message relevance, increased comprehension of CRC screening information, and yield increased subsequent screening. For example, understanding the impact of low literacy CRC educational materials endorsed by religious leaders versus low literacy educational material tailored to gender, employment status, and income on CRC screening participation.

The REALM-R is one of many measures of health literacy. The REALM-R differentiates adequate vs. limited health literacy (or at-risk for potential health literacy difficulties) based upon the correct pronunciation of eight medical terms. It is important to note that the REALM-R is a word-recognition test. Thus, it does not measure understanding of the words and does not calculate a reading comprehension score. An individual's understanding of medical information is nuanced and depends on myriad factors such as background, culture, context, provider communication skills to name a few [61]. Providers require brief, easy-to-use tools in the clinic that allow efficiency in assessing patients' risk of low health literacy. Awareness of a patient's health literacy directs providers to use plain language materials, provide information in easy-to-understand terms, and use "teach back" methods to ensure patients understand the education [62].

While this study contributes to increased knowledge of correlates of health literacy in a community-based sample of Black Americans, two limitations must be acknowledged. The first is the cross-sectional nature of the data. While results are useful for generating hypotheses, they do not imply causality and should be interpreted cautiously. The second is that demographic characteristics of this sample may vary from a national or international sample. Black Americans are not a homogenous group, therefore characteristics of Black Americans aged 50–75 years may vary by region, and therefore caution is necessary when applying our findings to Black Americans in other regions of the United States.

Despite these limitations, this manuscript has several strengths. The first is the use of a robust community-based sample, as previous studies primarily explored health literacy in clinic settings [15,16,27,29,31]. This study addressed the dearth of research dedicated to exploring health literacy in diverse community settings and populations. Second, since our study was conducted in a large and diverse metropolitan area this enabled data collection from multiple different community locations, making our results more applicable to a far greater generalized audience of Black Americans in this age bracket [32,33].

4.2. Conclusion

Our findings indicate a significant association between limited health literacy and select demographic and psychosocial factors in a community-based sample of Black Americans aged 50–75 years. Negative health outcomes associated with limited health literacy stated in the literature can be partly mitigated by providing individuals with low literacy education materials. Our study findings have implications for the development and delivery of low-literacy educational materials. Educational materials should focus on simple language, focused information, clear text, and illustrations that are visually easy to interpret. Educational materials developed in this fashion do not have to rely solely on print materials, but can be conveyed to individuals via in-person instruction, teach-back method, video instructions, and demonstrations.

4.3. Practice implications

Providers should consistently engage patients, making them equal partners in their care. Specific health goals and information should be tailored toward patients' specific clinical situation and demographic/psychosocial characteristics. Patients are more likely to engage in their health care when interactions with medical providers create trust and when the information provided resonates with their lives.

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Table 1

Demographic variables correlated with limited health literacy in univariable analyses n = 330.

Variable	Level	n (%)	Limited Health Literacy		
			Odds Ratio (95% CI)	OR P-value	Type3 P-value
Age	Mean = 56.4, SD = 5.1	330 (100)	0.98 (0.94–1.03)	0.457	0.457
Gender	Male	173 (52)	2.24 (1.44–3.48)	<.001	
	Female	157 (48)	-	-	
Racial Heritage	African-American	22 (7)	0.33 (0.12–0.85)	0.022	
	Caribbean/Other	308 (93)	-	-	
Education	Less than diploma	55 (17)	7.45 (3.71–14.94)	<.001	<.001
	Diploma/GED	112 (34)	7.63 (4.42–13.19)	<.001	
	Beyond diploma	163 (49)	-	-	
Marital status	Separated/divorced/ widowed	118 (36)	0.83 (0.49–1.40)	0.481	0.759
	Never married/single	110 (33)	0.95 (0.56–1.64)	0.862	
	Married/Living with partner	102 (31)	-	-	
Employment status	Not employed	80 (24)	1.31 (0.75–2.29)	0.348	<.001
	Retired	51 (15)	1.62 (0.85–3.11)	0.143	
	Unable to work	67 (20)	5.01 (2.56–9.80)	<.001	
Household income, \$25K	Employed	132 (40)	-	-	
	<= \$25,000	221 (67)	3.69 (2.20–6.18)	<.001	
	> \$25,000	95 (29)	-	-	
Annual physical exam	No	143 (43)	1.33 (0.86–2.06)	0.207	
	Yes	184 (56)	-	-	
Prior CRC screening	No	234 (71)	2.61 (1.59–4.29)	<.001	
	Yes	94 (28)	-	-	
Insured	No	143 (43)	0.90 (0.58–1.39)	0.641	
	Yes	187 (57)	-	-	

Notes: Percentages may not sum to 100 due to rounding and/or missing responses.

CRC = colorectal cancer; OR = odds ratio; U.S. = United States.

Type 3 p-value applied for variables with more than two categories.

Table 2
Psychosocial variables correlated with limited health literacy in univariable analysis.

Variable	Mean (SD)	n	Limited Health Literacy	
			Odds Ratio (95% CI)	OR <i>p</i> -value
CRC awareness	7.0 (2.2)	330	0.66 (0.58–0.74)	<.001
PHM salience	19.0 (1.7)	329	0.84 (0.73–0.97)	0.019
PHM susceptibility	9.0 (3.2)	329	1.10 (1.02–1.18)	0.009
PHM response efficacy	8.8 (1.5)	329	0.99 (0.86–1.14)	0.858
PHM social influence	15.6 (3.9)	329	1.06 (1.00–1.12)	0.054
PHM religious beliefs	12.5 (5.1)	329	1.11 (1.06–1.16)	<.001
PHM self-efficacy	28.4 (2.7)	329	0.93 (0.85–1.01)	0.074
PHM cancer worry	5.1 (2.5)	329	1.00 (0.91–1.09)	0.928
Decisional conflict	13.1 (4.7)	329	1.00 (0.96–1.05)	0.900
Cancer fatalism	3.9 (3.2)	330	1.14 (1.06–1.22)	<.001
Trust in healthcare system	26.3 (7.9)	330	1.00 (0.97–1.03)	0.960
Perceived discrimination	15.6 (4.4)	330	1.03 (0.98–1.08)	0.310

Note: CRC = colorectal cancer; PHM = Preventive Health Model; OR = odds ratio.

Table 3

Multivariable correlates of limited health literacy.

Covariate	Level	Limited Health Literacy		
		Odds Ratio (95% CI)	AOR <i>p</i> -value	Type 3 <i>p</i> -value
PHM religious beliefs		1.09 (1.04–1.15)	<.001	
Gender	Male	2.26 (1.37–3.72)	0.001	
	Female	-	-	
Employment status	Unable to work	2.59 (1.18–5.68)	0.018	0.002
	Retired	1.08 (0.53–2.21)	0.838	
	Not employed	0.52 (0.25–1.09)	0.082	
	Employed	-	-	
Annual household income	≤ \$25,000	2.98 (1.63–5.47)	<.001	
	>\$25,000	-	-	

Notes: Number of observations in the original data set = 330. Due to missing data, the number of observations used = 315.

Backward selection with an alpha level of removal of .05 was used. The following variables were removed from the model: PHM salience, PHM susceptibility, and prior CRC screening.

Type 3 *p*-value applied for variables with more than two categories.

PHM = Preventive Health Model; AOR = adjusted odds ratio.