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An Evaluation Study Examining the Understandability of STI/HIV Health Education Print Materials Provided by Health Clinics Serving Hispanic and Latino Populations of DeKalb County, Georgia

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An Evaluation Study Examining the Understandability of STI/HIV Health Education Print
Materials Provided by Health Clinics Serving Hispanic and Latino Populations of DeKalb
County, Georgia

By

Rebecca L Butler

Health Promotion and Behavior

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of Georgia State University in Partial Fulfillment
of the
Requirements for the Degree

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ATLANTA, GEORGIA
30303

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Table 1.1 Simple Statistical Summary of PEMAT-P Section Scores for Print Materials (n=11)

	Mean	Std. Deviation	Min	Max
Understandability Score (max =17)	12	2.56	7	15
Actionability Score (max=7)	3.54	1.03	1	5

Table 1.2 Rater Agreed PEMAT-P Scores (%) for All Items About the Use of Visual Aids

Item #	Agree=1 point (frequency)	Disagree=0 points (frequency)	N/A=0 points (frequency)	n=
15. The material uses visual aids whenever they could make content more easily understood (e.g., illustration of healthy portion size).	3	8		11
16. The material’s visual aids reinforce rather than distract from the content.	9	1	1	11
17. The material’s visual aids have clear titles or captions.	5	5	1	11
18. The material uses illustrations and photographs that are clear and uncluttered.	9	1	1	11
19. The material uses simple tables with short and clear row and column headings.	7	1	3	11

Table 1.4 Adapted From: Shoemaker SJ, Wolf MS, Brach C. Patient Education Materials Assessment Tool for Printable Materials (PEMAT- P). (Prepared by Abt Associates under Contract No. HHS290200900012I, TO 4). Rockville, MD: Agency for Healthcare Research and Quality

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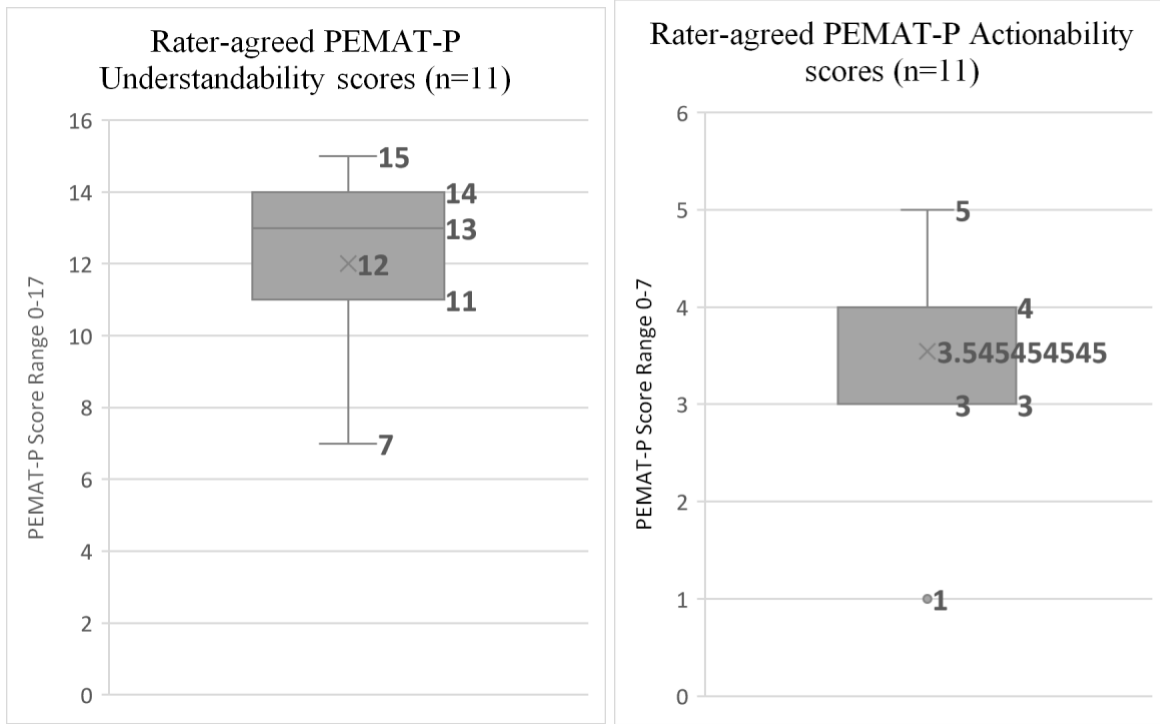
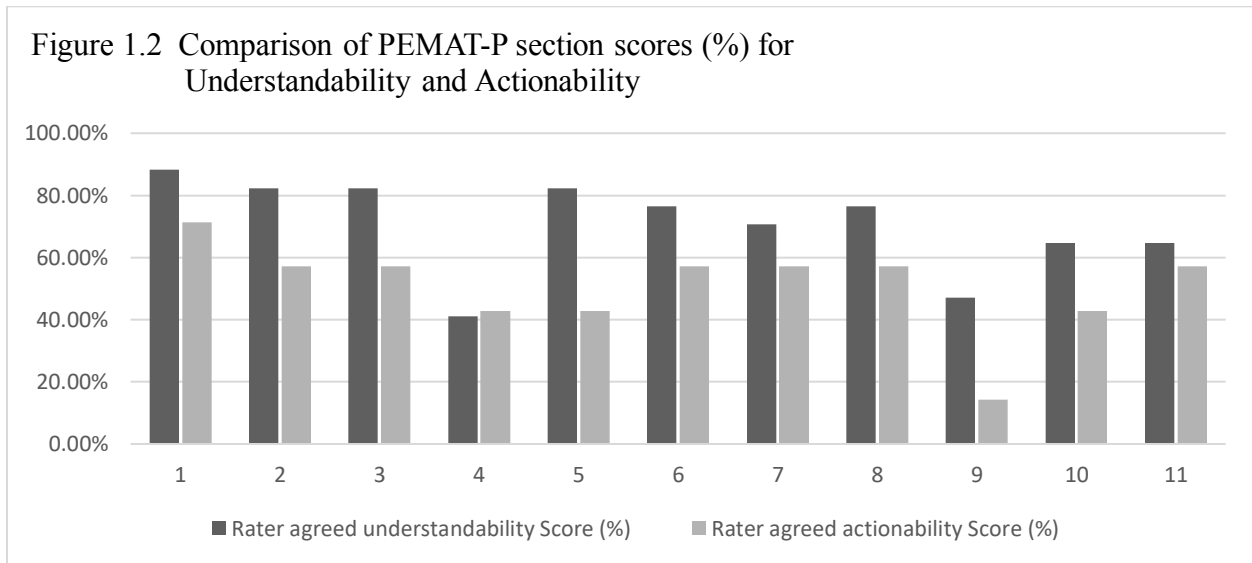


Figure 1.2 Comparison of PEMAT-P section scores (%) for Understandability and Actionability



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April 18, 2019

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ABSTRACT

The prevalence of Human Immunodeficiency Virus (HIV) in Hispanic and Latino populations in the United States is on the rise. In 2015, 26% of all HIV diagnoses in the United States were among Hispanic and Latinos. To effectively combat the prevalence of HIV in this population, it is necessary to examine the efficacy and accessibility of current interventions. Printed educational materials (i.e. pamphlets, brochures, and fact sheets) are low-cost and effective intervention strategies if the material is clear to the reader. This study aims to provide further evidence of the understandability of printed educational resources on safe sex practices and HIV in health clinics

CHAPTER 1

An Evaluation Study Examining the Understandability of STI/HIV Health Education Print Materials Provided by Health Clinics Serving Hispanic and Latino Populations of DeKalb County, Georgia

Great strides have been made to improve health-related outcomes for patients receiving early treatment for HIV. However, the rate of transmission and prevalence of diagnosis remains a major public health concern. Although risk factors for the virus are the same across all populations, HIV disproportionately affects racial and ethnic minority populations (CDC, 2017). In 2016, the Hispanic and Latino population accounted for 25% (n=9813) of all new HIV diagnoses in the United States (CDC, 2017). If the Centers for Disease Control and Prevention is to achieve their primary goal of a future free from HIV (CDC, 2018), as outlined in the Division of HIV/AIDS Prevention's (DHAP) Strategic Plan (CDC, 2017), research and resources must specifically address HIV-related disparities in Hispanic and Latinos.

Health literacy refers to the ability of an individual to obtain and understand health information as part of the process of making informed, appropriate healthcare decisions (U.S. Department of Health and Human Services, 2000). Individual and systemic factors influence health literacy including,

- Environmental and economic access to care
- Cultural attitudes towards health and disease prevention
- The efficacy of communication between the patient and healthcare provider
- The structure of the healthcare system (U.S. Department of Health and Human Services, 2001)

The ability of an individual or group to access, understand, and act on evidence-based information yields positive health outcomes. Conversely, published studies across disciplines find that low health literacy yields negative health outcomes (Berkman et al., 2011). In 2016, the World Health Organization prioritized health literacy as a cornerstone goal of their *Moving Forward, A Plan for the Next Fifteen Years* agenda as part of the 9th Global Conference on Health Promotion (WHO, 2018). There is a need for research that examines the impact and efficacy of HIV prevention communication materials for Hispanic and Latino populations living in the United States.

Prevalence of HIV in southeastern United States

HIV is not evenly distributed across the United States (CDC, 2018). Per 100,000 people, the rate of diagnosis in the southern region (i.e. AL, AR, DE, DC, FL, GA, KY, LA, MD, MS, NC, OK, SC, TN, TX, VA, WV) is the highest in the country at 24.9 (CDC, 2018). Surveillance data indicates that,

1. More than half of all HIV diagnoses (n=38739) in 2017 were distributed across the southern states. CDC surveillance for the same year indicates that Hispanics and Latinos accounted for 21% of new HIV diagnosis by race in the south (CDC, 2016).
2. Southern states have the greatest number of individuals estimated to be living with HIV (CDC, 2015)
3. In 2016, the CDC's *Morbidity and Mortality Weekly Report* indicated that just 60% of Hispanics/Latinos were linked to medical care within 90 days

of diagnosis. This is well below the national benchmark of 85% set forth by the U.S. Department of Health and Human Services.

United States federal health agencies have urged state health departments, policymakers, and prevention partners to prioritize HIV prevention efforts in regions and populations with the greatest disparities. In 2018, the CDC allocated \$216 million dollars to the southern United States for the purpose of improving HIV prevention and care outcomes (CDC, 2018). The *National HIV/AIDS Strategy for the United States* (2015) sets forth specific prevention guidelines for Hispanic and Latino populations in southern states including, “Requiring partners to use the latest, most cost-effective interventions and increasing cultural competency and tailoring prevention programs” (HIV.gov, 2017).

Print materials, such as brochures and pamphlets, are a commonly utilized, low-cost prevention strategy for disseminating health information. The aim of this study is to provide further evidence of the understandability of printed educational resources on HIV in health clinics in northeast Dekalb County, Georgia. This county was selected for its high rate of Hispanic and Latino residents within its municipalities including the cities Doraville and Chamblee (U.S. Census Bureau, 2018). The study methodology is designed to answer the following questions,

1. Do free and low-cost clinics that offer HIV testing in within a 10-mile radius of the Dekalb County zip code, 30341 provide educational print materials about HIV and safe-sex practices?
2. Do the evaluated print materials promote understandability and actionability when they are evaluated via a health literacy assessment tool?

3. How do the evaluated print materials make use of visual aides to promote understandability?

Terminology

Hispanic or *Latino* are identifiers that are assigned to an ethnic category of people who are of a Spanish or Latin American country of origin. To refer to a population as *Hispanic* or *Latino* does not refer to a racial category (OMB, 1997). *Hispanic* and *Latino* are often referred to together or interchangeably when denoting a demographic category in published research. In 1997, the Federal Office of Management and Budget revised the standards for the classification of federal data on race and ethnicity to include, “Hispanic or Latino” (OMB, 1997). The classification, *Hispanic and Latino* will be used henceforth to describe the population of interest for this research.

Chapter II

REVIEW OF THE LITERATURE

Transmission Categories and Associated Health Outcomes for Hispanic/Latinos with HIV in the United States

Transmission category statistics are paramount to identifying subpopulations who are particularly at-risk for HIV for the purpose of developing tailored prevention plans. The epidemiological mode of transmission for HIV is distributed amongst 6 categories. In adolescent and adult males, HIV acquisition is most frequently attributed to male-to-male sexual contact. In adolescent and adult females, HIV is most frequently attributed to heterosexual contact with a person known to have, or be at risk for HIV (CDC, 2017). In 2016, 85.6% of all Hispanic or Latinos diagnosed with HIV attributed their infection to sexual contact (n=8810).

Espinoza et al. (2008) looked for trends in mode of transmission and illness progression of HIV/AIDS in foreign-born Latino and Hispanic individuals residing in the United States. Espinoza et al. (2008) analyzed secondary CDC surveillance data to identify trends in incidence of HIV diagnosis, the progression of HIV to AIDS, and mortality of individuals who received an AIDS diagnosis based on country of birth. Data was analyzed by applying Poisson regression “to calculate the estimated annual percentage change in the number and rate of HIV diagnoses” (Espinoza et al., 2008). A logistic regression model was used to examine possible associations between birthplace and HIV-to-AIDS intervals that occurred in under 12 months. Qualifying criteria for inclusion in this study were reported diagnoses of HIV among Hispanics in the United States from 2003-2006 who reported a birthplace. Results indicate that 60% (n=14,954) of participants reported being born outside the United States. Additionally, Espinoza et al., found significant characteristic differences in HIV acquisition based on birthplace,

The transmission categories for HIV infection in US-born Hispanics were distributed as follows: male-to-male sexual contact (50%), followed by high-risk heterosexual contact (26%), IDU (18%), and male-to-male sexual contact and IDU (4%). Among persons born in Puerto Rico, larger proportions had been infected through high-risk heterosexual contact (40%) and IDU (33%) than through male-to-male sexual contact (23%)

The findings of this study highlight the number of foreign-born Hispanic and Latino individuals in the United States who have been diagnosed with HIV and inspires further inquiry about what HIV the prevention challenges that immigrant populations face. Furthermore, the categorial breakdown of qualifying participants by birthplace highlights the demographic diversity of Hispanics and Latinos with HIV living in the United States. Because the mode of transmission and rates of survival significantly vary based on Hispanic subgroups, our interventions should not be *one size fits all* (Freiman, 1998). The findings of this study encourage further investigation into what types of HIV educational materials are available to Latino and Hispanics seeking testing and treatment in a healthcare setting.

Determinants of HIV in Hispanic and Latino populations in the United States

Ryan et al. (2009) conducted a qualitative study to examine the impact of familial rejection on predicting of negative health outcomes in self-identifying lesbian, gay, and bisexual young adults. The authors of this study developed quantitative scales to assess the associated frequency of family and caregiver rejection of participants' sexual orientation based on a previous qualitative study of in-depth interviews that were thematically coded for behaviors of

acceptance and rejection. The survey also contained indicators of negative health outcomes related to mental health and high-risk sexual behaviors. The population of interest for this study was n=244 white and Latino gay, lesbian, and bisexual young adults between the ages of 21 and 25. Participants completed a self-reported computer survey. Survey outcomes were combined with a dichotomous scoring system to create a Family Rejection Scale, with values ranging from 0 to 51. High rates of family rejection were positively associated with negative health outcomes. Latino men reported the highest rate of family rejection (mean=24.52) during adolescence of a gay, lesbian, or bisexual sexual orientation. LGB adults of all races were 3.4 times more likely to engage in unprotected sex if they reported a high level (>35.2) of family rejection in adolescence. This study exemplifies possible cultural barriers for familial support for minority LGBTQ populations' ability to be open about their sexual orientation. Furthermore, this study suggests a possible relationship between family rejection, unprotected sex, and negative health outcomes. When considered in a larger context, one such recommendation that could be made with regard to health literacy about HIV and safe sex practices may be to include resources for counseling and mental health services in communications literature that is consumed by minority, LGBTQ populations.

Previous Health Literacy Research

In 2003, the National Assessment of Adult Literacy (NAAL) published its first national survey of estimated health literacy by state. The data indicates that 12% of U.S. adults scored at or above the NAAL's definition of proficient health literacy. Task examples for this category include, the ability to define a medical term within a complex prose document and the ability to use a table to calculate a share of employee health

insurance costs (Kutner et al., 2006). The report also indicates that 35% of adults that fell below the group of *basic health literacy* identified as Hispanic. One such task example for this category is, “read a short set of instructions and identify what is permissible to drink before a medical test” (Kutner et al.). The most significantly associated variables for health literacy across all racial categories were highest level of educational attainment and insurance status (CDC, 2017).

Edward et al. (2018) assessed the impact of health literacy in Hispanic and Latino populations on their ability to access and utilize health insurance. This study measured health literacy (HL) and health insurance literacy (HIL) on healthcare enrollment of minority populations in Massachusetts. The study design utilized a community engagement model to enroll participants and conduct activities in Spanish-speaking churches. N=239 participants 18 years of age and older, who self-identified as Hispanic or Latino, who met the enrollment criteria, participated in this study. Participants completed a detailed demographic survey that included questions about insurance status, general health status, and the frequency of utilizing healthcare. (Edward et al., 2018).

Health insurance literacy was assessed through the use of a knowledge-based survey that asked participants to define words such as, “copay”, “premium”, and “deductible”. Participants were scored as having “adequate” HIL if they were able to define at least one of these terms and were scored as having “inadequate” HIL. Health literacy was measured by using an 18-item Short Assessment of Health Literacy Scale in Spanish (SAHL-S). Scores for the SAHL-S range from 0 to 18, with a score between 0 to 14 suggesting inadequate health literacy and scores between 15 and 18 indicating adequate health literacy (Edward et al., 2018). Edward et al. (2018)

found that 60.9% of participants had health insurance at the time of the study, and 70% of participants reported having accessed health care in the United States in the last year. 56% (n=77) participants scored low on the Health Literacy Scale in Spanish. 93% of participants (n=129) participants and were unable to define at least one basic health insurance term and were designated as having “inadequate” health insurance literacy. This study emphasizes a lack of health insurance literacy in Spanish and Latino populations and highlights a barrier to care to the utilization of health services.

In an effort to describe the impact of health literacy on chronic disease management in the Hispanic and Latino population, Williams and Parker, (1998) conducted a cross-sectional survey to examine the literacy of hypertension and diabetes patients. Participants (n=516) were recruited during a three-month period from two public hospitals; Harbor-UCLA Medical Center in Los Angeles, California and Grady Memorial Hospital in Atlanta, Georgia. Eligible participants for the study were individuals over 18 years of age who had no psychiatric illness and who had a confirmed diagnosis of hypertension or Type I and Type II diabetes. Participants gave relevant demographic information and completed a 50-question and 17-question numeracy survey called, the Test of Functional Health Literacy in Adults¹ (TOFHLA) (eg. Reading prescription bottles, appointment slips, and instructions for diagnostic tests [Williams & Parker, 1998]). The TOFHLA was administered in the preferred language for each participant. Scores for this survey range from 0-100 and are classified into categories (*0-59 inadequate score, 60-75 marginal, and 76-100 adequate for literacy*). Additionally, each participant was surveyed about specific knowledge related to his or her disease. 69% of Spanish-speaking participants were classified as having inadequate and marginal health literacy. Williams and Parker (1998) also

established a correlation between health literacy and patients' knowledge about their illness. For example, the mean diabetes knowledge of patients who were classified as having inadequate health literacy (n=50) was 5.2 ± 6.4 (CI=95%).

Williams and Parker, (1998) effectively identified a relationship between low health literacy and low knowledge about the diseases included in the study design for Hispanic and Latino participants. This study also highlights the challenge of how to educate low-literacy patients with quality and appropriate print materials that are understandable. Similar to HIV, hypertension is a chronic illness that requires early intervention and home management for favorable health outcomes.

The Utilization of Health Literacy Assessment Tools in Previous Research

The *National Action Plan to Improve Health Literacy* (HHS, 2010) cites evidence-based research that emphasizes the importance of plain language health communications. Such literature most be written in a manner that promotes *understandability* and *actionability* in its content. Additionally, this report cites evidence that established a link between limited health literacy and limited English proficiency (LEP). The report states, "Therefore, interventions for vulnerable populations, such as those with LEP, should focus on health literacy *and* language to promote two-way, interactive communication" (HHS, 2010).

Shoemaker et al. developed the questionnaire in response to this report as a "new measure of understandability and actionability" for patient information (Shoemaker et al., 2014) that is comprehensive, yet simple enough to be reliably applied by health professionals and lay people alike. To develop the PEMAT, Shoemaker et al. reviewed existing health literacy instruments for items and concepts to be included. The methodology for the development of the

PEMAT was to first, garner ideas from a panel of experts in “health literacy; health communications; content creation, patient engagement and health information technology” (Shoemaker et al., 2014). Together, the panel and research team worked to develop assessment items for each scale of the questionnaire. The final item pool was refined and decided upon by conducting four rounds of reliability testing using a total of 22 raters. The authors of this study found,

For construct validation with consumers ($n = 47$), we found significant differences between actionable and poorly-actionable materials in comprehension scores (76% vs. 63%, $p < 0.05$) and ratings (8.9 vs. 7.7, $p < 0.05$). For understandability, there was a significant difference for only one of two topics on consumer numeric scores.

Chapter III

METHODS AND PROCEDURES

The study design is a qualitative assessment of the health literacy of primary data of print health communications materials from clinics and healthcare providers. Inclusion criteria clinic selection stipulates that,

Clinic results were filtered and refined under the following criteria:

1. The provider is located within a ten-mile radius of the zip code 30341
2. The provider is free or low-cost
3. The provider offers a free HIV test *or* a Conventional Blood HIV Test

Print materials were collected from qualifying clinics under the following criteria,

1. The data collected must be a print material defined in *The Patient Education Materials Assessment Tool (PEMAT) and User's Guide* as being a “brochure, pamphlet, or materials that can be printed from websites like PDFs”
2. The print material must be free and visibly on display in the waiting room area of each clinic
3. The print materials collected must contain the language, “Human Immunodeficiency Virus” (HIV) or “PrEP” in the title
4. The language of the print materials collected may be English or Spanish

All print materials with language that specifically contain *Human immunodeficiency virus (HIV)*, *Acquired immunodeficiency syndrome (AIDS)*, or *Pre-exposure prophylaxis (PrEP)* were collected from the designated public waiting area of each clinic that met the inclusion criteria.

A quality assessment of the print materials gathered was conducted using the Patient Education Materials Assessment Tool for Printable Materials (PEMAT-P) evaluation tool.

Selection of the Evaluation Tool

The PEMAT-P is a 17-item questionnaire that produces a numeric score for understandability and actionability of the content of each print material examined. The PEMAT-P was selected as an evaluation tool for this study because it is an approved evaluation method

by the Agency for Healthcare and Research Quality, and because it is designed to be administered by health professionals and lay people (Shoemaker & Brach, 2013).

Raters

Because the assessment tool is scored by an objective rater assessment of each material, and an inter-rater agreement score was determined for each item. Two additional raters were recruited from Georgia State University's School of Public Health. Each rater was required to read *The Patient Education Materials Assessment Tool (PEMAT) and User's Guide* prior to viewing the questionnaire or viewing collected data.

For the evaluation session, each rater was independently given a notebook with each print material collected in a sheet protector, for ease of the front and back of each item. To improve ease of rating, scoring, and data analyses, the PEMAT-P questionnaire was reproduced from its original published PDF form as an online survey using the Qualtrics platform. The section headings and question items were directly copied from the PEMAT-P assessment tool originally published to the Agency for Healthcare Research and quality website². Responses were coded to auto sum a 1 or 0 for each item. Each rater was given a unique link to the survey via email. Each print material was assigned a letter that indicated to the rater which material to enter into the Qualtrics survey.

Scoring

Raters were instructed to complete a PEMAT-P questionnaire for each print material (n=11) to be assessed. Raters were asked not to rely on prior knowledge when answering each questionnaire statement and to refer only to the content of the print material being evaluated to

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answer the PEMAT-P questionnaire. Raters are instructed to mark each item as, “Agree”, “Disagree”, or “Not Applicable” for a 17-item section for *Understandability* and a 7-item section for *Actionability*. Example PEMAT-P items include (Shoemaker & Brach, 2013),

“The material uses common, everyday language.”

“The material’s visual aids have clear titles or captions”

“The material uses the active voice”

“The material uses visual aids whenever they could make it easier to act on the instructions”

The user is instructed to rate an item as, “Agree” if the question characteristic true of the content in the printed material being assessed between 80-100% of the time. The questionnaire utilizes a binary scoring system wherein “Agree” gets a score of 1, “Disagree” gets a score of 0, and “Not Applicable” is not scored. The material’s scores are calculated by calculating the percentage score of “Applicable” questions for the understandability and actionability sections of the PEMAT-P, respectively.

Evaluation plan

In order to answer the research questions,

- A simple statistical analysis will be conducted to determine the prevalence of free, printed literature with information about HIV, AIDS, STIs and PrEP made available in clinics that meet the inclusion criteria
- The PEMAT-P assessment tool will be used to generate an *understandability score* and an *actionability score* for each print material. Three raters will independently complete a PEMAT-P survey for n=11 print materials
- Independent raters will come together to review each response as a group to determine an inter-rater agreement response for each item of the PEMAT-P

- Data analysis of user-agreed response frequency of all survey items relating to *The Use of Visual Aids* in the Understandability section of the PEMAT-P will be conducted

CHAPTER IV RESULTS

Prevalence of qualifying data for evaluation

A total of n=11 print materials were collected from 8 clinics in Dekalb County, Georgia. Clinics were selected from the Center for Disease Control's online *Get Tested: National HIV and STD Testing* directory (CDC, 2018). Of the 10 clinics and healthcare providers that met the inclusion criteria at the time of data collection, 8 had at least one educational pamphlet, brochure, or post card that displayed qualifying content for analysis. Two clinics did not have print literature that met the inclusion criteria.

For each evaluated print material, the PEMAT-P rater-agreed Understandability section scores ranked higher than rater-agreed Actionability section scores. On a scale of 0-17, the mean Understandability section score was 12 (70.5%). On a scale of 0-7, the mean Actionability score was 3.54 (50.6%). There were no statistical outliers for the frequency of "Agree" or "Disagree" response categories for any of the 24 PEMAT-P questionnaire items.

CHAPTER V DISCUSSION AND CONCLUSION

Discussion of Research Questions

The findings of this study highlight the need for an intensive focus on what kind of health communications content is most effective for Hispanic and Latino individuals in the United States. The CDC's directory database indicates that there is sufficient access to low-cost and free clinics within a 10-mile radius of the Doraville, GA zip code, 30341. Furthermore, 80% of the clinics that met the selection criteria had literature about HIV and safe-sex practices. For each evaluated print material, the PEMAT-P Understandability section score ranked higher than the Actionability section score. On a scale of 0-17, the mean Understandability section score was 12 (70.5%). On a scale of 0-7, the mean Actionability score was 3.54 (50.6%). Thus, it cannot be asserted that the evaluated print materials promote understandability and actionability in content and design. Congruent scores between raters that met the 80% threshold indicative of understandability and actionability of the printed materials were 27% and 0%, respectively. 3 brochures contained Spanish translations on the back of English content, however these materials did not rate significantly higher for understandability and actionability when compared to English-only materials.

Study Strengths and Limitations

Using a dual rater approach, this study successfully utilized the Patient Education Materials Assessment Tool for Print Materials (PEMAT-P) to assess the constructs of *understandability* and *actionability* of health information resources developed for public audiences. Rater feedback indicated that the PEMAT-P user's manual and the scoring form were user-friendly and intuitive. Furthermore, the CDC's *Get Tested* database directory was a ready-made database from which to identify free and low-cost clinics for inclusion in the study.

The limitations of a very small sample size (n=11) yielded limited options for statistical analysis. Though simple statistical analysis was conducted to find the minimum, maximum, and mean scores for each summed section of the PEMAT-P assessment tool, non-parametric statistical analysis such as the Mann-Whitney U Test could have been employed to examine the difference in means between the Understandability and Actionability scores for evaluated materials. Furthermore, the experience of training and utilizing raters was time consuming. Coming to absolute agreement in inter-rater reliability scores for each PEMAT-P item for each material set back the timeline of this study by three weeks.

Recommendations for Future Research

Because the mode of transmission and rates of survival significantly vary based on Hispanic subgroups, our interventions should not be *one size fits all* (Freiman, 1998). The findings of this study encourage further investigation into what types of HIV educational materials are available to Latino and Hispanics seeking testing and treatment in a healthcare setting.

Educational print materials that promote HIV prevention strategies represent low-cost resources with potential to reach Hispanic/Latino populations. However, careful review of the content's understandability and potential to trigger protective behavior among recipients in the intended populations is critically important. The results of this research reveal that there is vast potential for public health professionals improve effectiveness of educational safe sex promotional materials intended to reach vulnerable populations. There is a need for future research that assesses motivating factors towards actionability for this population as well as the impact of well-constructed visual aids on content understandability for this population in light of established barriers to care, including language barriers and limited medical health literacy

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Appendix A: Reference list of materials gathered for the study

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