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ACCEPTANCE

This dissertation, PRECEPTIONS OF AN HIV TESTING MESSAGE TARGETED FOR AT-RISK ADULTS WITH LOW FUNCTIONAL HEALTH LITERACY, by SUSAN L. HUNTER, was prepared under the direction of the candidate's Dissertation Advisory Committee. It is accepted by the committee members in partial fulfillment of the requirements for the degree Doctor of Philosophy in the College of Education, Georgia State University.

The Dissertation Advisory Committee and the student's Department Chair, as representatives of the faculty, certify that this dissertation has met all standards of excellence and scholarship as determined by the faculty. The Dean of the College of Education concurs.

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ABSTRACT

Perceptions of an HIV Testing Message
Targeted for At-Risk Adults with Low
Functional Health Literacy
by
Susan Lee Hunter

This study analyses warehoused data collected by Georgia State University and Centers for Disease Control and Prevention (GSU/CDC) researchers after developing an HIV testing message for urban adults with low functional health literacy. It expands previous work by examining data collected when 202 primarily African-American homeless clients of an urban community based organization (CBO) reviewed both the low literacy brochure (Wallace et. al., 2006) and a standard HIV brochure (Georgia Department of Human Resources, 1997). Participants' health literacy was assessed using 2 measures; the Rapid Estimate of Adult Literacy in Medicine or REALM (Davis, Crouch, Long & Green) and the Test of Functional Health Literacy Assessment or TOFHLA (Nurss, Parker & Baker, 2001). HIV risk was determined using an interview questionnaire developed by the research group (Belcher, Deming, Hunter & Wallace, 2005) which allowed participants to self-report recent alcohol and drug use, sexual behavior, sexually transmitted disease (STD) history and exposure to abuse and sexual coercion. Open-ended response questions regarding readability, understanding, main message, and importance for each brochure provided the qualitative data.

This analysis confirms previous work showing accessibility, readability, cultural sensitivity and user-friendly formatting are important when attempting to engage at-risk adults with varying levels of functional health literacy in an HIV testing message. The visual aspects of the brochure can be essential in capturing the reader's attention and should be relevant to the target audience (Wallace, Deming, Hunter, Belcher & Choi, 2006). Mono-colored graphics may be perceived as dated and irrelevant or worse yet, threatening to some readers. Whenever possible culturally appropriate color photos of people depicting relevant content should replace excess text and difficult medical terms should be eliminated. Wording on the cover and within the brochure should be used to focus the reader on a single main message.

This data also shows that many participants considered the quantity of information just as important. For reasons not elucidated here, many respondents equated quantity of information with message quality. Based on these results it is important to further clarify how much information is enough to maintain legitimacy and the reader's attention while simultaneously avoiding confusing mixed messages.

PERCEPTIONS OF A HIV TESTING MESSAGE TARGETED
FOR AT-RISK ADULTS WITH LOW FUNCTIONAL
HEALTH LITERACY

by
Susan L. Hunter

A Dissertation

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2011

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TABLE OF CONTENTS

	PAGE
List of Tables	v
Abbreviations	vi
 Chapter	
1 LITERATURE REVIEW MANUSCRIPT	1
Introduction	1
Literature Review	11
Health Literacy	15
Health Literacy and HIV/AIDS	19
Determining Health Literacy Levels	20
Readability of Standard HIV/AIDS Brochures.....	22
Prior Development of Low Literacy HIV Testing Message	26
Prior Focus Group Study	28
Context of Prior Focus Group Study	29
Prior Qualitative Data Collection	30
Results of the Prior Focus Group Study	30
Focus Group Participants' Previous Experiences with Reading Health Messages	31
Readability and Layout of Standard HIV Testing Message	33
Readability and Layout of Experimental Low Literacy HIV Testing Message	35
Survey Study	37
Survey Study Participant Recruitment	38
Determination of Functional Health Literacy	39
Qualitative Data Collected During the Survey Study	43
Consistency and Reproducibility of the Survey Research	44
Strengths and Limitations of the Warehoused Data	45
Quantitative Data Analysis	47
Qualitative Data Analysis	48
Conclusion	49
References	52
 2 HIV TESTING MESSAGES AS VIEWED BY LOW INCOME, URBAN ADULTS	 60
Abstract	60
Citation	61

Introduction	61
Methods	65
Procedures.....	67
Quantitative Data Analysis	70
Qualitative Data Analysis	71
Results	72
Demographics	72
Functional Literacy Level	74
Table 1: Participant sex * TOFHLA Functional Health Literacy Level *	
Converted REALM Score Cross-tabulation.....	75
Results from Qualitative Data	76
Table 2: Participants' Perceptions of Brochures by Response Category.....	78
Table 3: Categorical Distribution of Responses to "What was the Main Message of this Brochure".....	83
Table 4: Distribution of Responses Regarding Preference for Brochure "Pickup" and "Relate".....	86
Discussion	88
Warehoused Data Strengths	88
Warehoused Data Limitations	89
Conclusion	90
Acknowledgements.....	92
References	93
Appendixes	96

LIST OF TABLES

CHAPTER 1

Table	PAGE
1 NAAL Literacy Levels.....	16
2 Readability Program Results.....	25
3 Comparison of Standard & Experimental Brochures.....	28
4 REALM Score Interpretation.....	42
5 TOFHLA Functional Health Literacy Levels.....	44

CHAPTER 2

1 Participant sex * TOFHLA Functional Health Literacy Level * Converted REALM Score Cross-tabulation.....	75
2 Participants' Perceptions of Brochures by Response Category.....	78
3 Categorical Distribution of Responses to "What was the Main Message of this Brochure".....	83
4 Distribution of Responses Regarding Preference for Brochure "Pickup" and "Relate".....	86

ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
AMA	American Medical Association
CBO	Community-based Organization
CD4+ T	Cluster of Differentiation 4 positive T Lymphocytes
CDC	Centers for Disease Control and Prevention
CMV	Cytomegalovirus
FOG	Frequency of Gobbledygook
GSU	Georgia State University
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
IRB	Institutional Review Board
M	Men's focus group
NAAL	National Assessment of Adult Literacy
NAAS	National Academy on an Aging Society
NALS	National Adult Literacy Survey
NCHS	National Center for Health Statistics
NRC	National Research Council
OECD	Organization for Economic Cooperation and Development
OMH	Office of Minority Health
PCP	Pneumocystis carinii pneumonia
PISA	Program for International Student Assessment
REALM	Rapid Estimate of Adult Literacy in Medicine
SMOG	Simple Measure of Gobbledygook
SPSS	Statistical Package for the Social Sciences
STI	Sexually Transmitted Infections
TOFHLA	Test of Functional Health Literacy in Adults
W	Women's focus group
WRAT	Wide Range Achievement Test

CHAPTER 1

LITERATURE REVIEW MANUSCRIPT

Introduction

In the world of academia, the daily realities of those with low functional literacy may be difficult to comprehend. Few reading this would know what it is like to look at print that does not make sense; to feel the frustration of reaching out for vital, potentially life-saving, information and not being able to grasp the meaning of the text, or even know how to ask for help. Subsequent to a traumatic brain injury at age 19, I lost much of what I had previously taken for granted, such as my ability to read, and became all too familiar with these feelings. My encounters with the medical establishment were unpleasant and unproductive for more than two years. After finally being properly diagnosed and treated, I was able to begin the difficult re-training process that allowed me to regain my ability to read and comprehend written material. Upon becoming a PhD student in Science Education at Georgia State University (GSU) and working with the Centers for Disease Control and Prevention (GSU/CDC research group), I became aware that many Americans face this same dilemma, an inability to read and comprehend written text, especially those related to medical issues. Even general health care information can be very complicated with its scientific jargon that often includes terminology originating from languages such as Latin and Greek unfamiliar to most Americans. Health care information, with its discussion of causes, effects, and varieties of treatment options, often reflects the complex and continuously evolving nature of clinical medical practice. At the absolute minimum, the complexity of health care today requires consumers to be able to read, write, and speak with more than minimal proficiency; or put another way, to

possess functional health literacy.

Providers often use pamphlets and information sheets to inform patients of the need for vital diagnostic tests and information on potential treatment alternatives. These messages may include dosage instructions for prescription drugs, warnings about potential side effects and contraindications, informed consents, hospital discharge instructions, and other health education materials. It is imperative then that consumers of health care services are able to read and comprehend the myriad types of written documents presented to them by their health care providers. The difficulty of this material pales when compared to the complexity of insurance forms or Medicare or Medicaid applications many Americans are required to submit in order to help with the ever increasing costs of medical treatment. Because of the complex nature of essential health care messages, and my own personal experience with reading difficulties, I decided to investigate health literacy in general and specifically those educational materials related to Human Immunodeficiency Virus or Acquired Immunodeficiency Syndrome (HIV/AIDS) in more detail.

The HIV/AIDS epidemic in the United States has been changing over time, becoming increasingly more common in minority and disenfranchised populations. Peterman and colleagues found that 18 of the 20 counties with the largest proportional increases in the incidence rates of AIDS are located in the southern United States (Peterman, Lindsey, & Selik, 2005). Counties with the largest increases in reported AIDS cases also had a higher proportion of minorities, as well as lower income, education, and literacy levels (Peterman et al., 2005).

Adimora and colleagues examined the social contextual factors that contribute to the higher rates of sexually transmitted infections (STI) including HIV within minority populations. A synthesis of this research supports the assertion that the disproportionate representation these populations have in new cases of HIV infections is a complex, multifaceted problem impacted by a number of economic, social and cultural factors. Socio-cultural contextual factors regarding social networks; such as high levels of concurrent relationships and increased interaction between the general population and high-risk, high-prevalence subgroups, plays an important role in the increased incidence of STI including HIV (Adimora, Schoenbach, & Doherty, 2006; Doherty, Leone, & Aral 2007). Additionally, reduced quality of education often experienced by young people in disadvantaged populations may perpetuate the lack of acquisition of written, verbal and other life skills needed to develop functional health literacy (Hurd, 1998). The increasing interdependence of everyday life and socio-scientific issues in general along with the rapidly evolving nature of clinical medical practice make the competencies of adaptive critical thinking and life-long learning an essential skill set for today's functionally literate citizens (Zeidler, Sadler, Simmons, & Howes, 2005).

Research confirms poor functional health literacy impedes not only an individual's ability to fully comprehend personal health issues, but also to effectively participate in essential treatment. This is especially true when dealing with complex medical syndromes such as HIV/AIDS. In one study of individuals receiving care at a community-based clinic in the southern US, 48 percent of patients were reading below the 9th grade level. One-third of these patients could not name the medications they were taking to treat their HIV infection and 58 percent could not correctly describe how these

drugs should be taken (Wolf et al., 2004). Additionally, participants with low functional health literacy were not only significantly more likely to receive laboratory test results indicating a higher number of virus particles in the blood and more compromised immune functioning as measured by CD4+ T cell count but were also less likely to understand the meaning and significance of these commonly used determinants in predicting the progression from HIV infection to AIDS (Kalichman & Rompa, 2000; Wolf et al., 2004). Participants with lower health literacy were also more likely to have misperceptions about the preventive effects of treatment on HIV transmission, increasing their risk for potentially transmitting treatment-resistant strains of HIV (Baker, Parker, Williams, Clark, & Nurss, 1997). These findings indicate individuals with lower functional health literacy may suffer higher rates of HIV infection than do those with higher literacy skills, and after becoming infected, they are less likely to understand and adhere to the complex treatment regimen required to prolong the progression of the infection to AIDS and death (Wolf et al., 2007).

Understanding and prevention of high risk behaviors are essential to avoiding HIV infection. Early diagnosis and properly administered antiretroviral treatment can be the key to shifting HIV infection from a death sentence to a manageable, chronic disease. Although disparities in health literacy alone do not account for the increase in HIV/AIDS in at risk populations, it is clear that inaccessibility to culturally-sensitive appropriate HIV-related health education materials is a major factor. In order to fully understand the advantages of knowing one's HIV status, individuals with low functional health literacy need a more tailored approach to HIV education and treatment programming (Wallace, Deming, Hunter, Belcher, & Choi, 2006). The work presented here attempts to analyze

previously collected data in order to increase our understanding of the participants' perceptions of the design and effectiveness of this type of tailored message.

Rationale and Significance of the Problem

A search of the literature reveals that many adults in the United States have severely limited access to health-related information. One of the primary reasons for this limited access is having a low level of functional health literacy which makes these materials incomprehensible (Hills-Briggs & Smith, 2008). According to the American Medical Association (AMA), (1999), many health care materials, including disease specific informational brochures, pharmaceutical package inserts and various types of treatment consent forms are written far above the reading levels of the average patient.

How do we know the reading level of the average American? In 1992, 26,000 Americans were interviewed using the National Adult Literacy Survey (NALS). The survey measured participants' ability to use the written word for everyday tasks. It was scored on five levels. Level one included individuals whose reading level was at or below the 5th grade. This category included 40-44 million functionally illiterate adults who had difficulty reading a story on the front page of the newspaper and answering questions about its content (Kirsch, Jungeblut, Jenkins, & Kolstad, 1993). Additionally, some 50 million adults demonstrated a proficiency of level two on the literacy scales. This meant they could usually locate information in texts and make general inferences using printed materials, but their skills were still quite limited. Ultimately this study revealed some 90 million Americans, almost half of the adult population, had either literacy deficiencies, numeracy deficiencies or both (Kirsch et al., 1993).

The medical establishment admits that much of the educational literature produced to inform patients and help them make appropriate choices regarding their own health care is written at the 10th grade level or higher (AMA, 1999; Berkman et al., 2004; Potter & Martin, 2005). This means much of the essential information health care practitioners attempt to communicate is inaccessible to a large percentage of their patients. Frequently, patients' lack of understanding is not revealed during the usually brief, often pressure filled, consultations patients have with their health care providers. Individuals with low health literacy use a variety of established behaviors to hide their literacy inadequacies. These cues can be subtle and easy for providers to miss, such as saying "I will read this later, I forgot my glasses." or simply nodding affirmatively when asked if they understand, but all are designed to hide the shame and embarrassment people feel about not being able to read materials or comprehend verbal instructions (Mayer & Villaire, 2003; Wallace et al., 2006).

The impact of health literacy has far reaching consequences for the health outcomes of many patients. According to the Agency for Healthcare Research and Quality, low functional health literacy is associated with several adverse health outcomes, including low health knowledge, increased incidence of chronic illness, poorer intermediate disease markers, and less than optimal use of preventive health services (Berkman et al., 2004). When the literacy of patients in a health care setting is below the functional level, they run the risk of misreading and misusing prescription or non-prescription medication, using medical devices or equipment incorrectly, and not following other essential treatment instructions (Chew, Bradley, Flum, Comia, & Koepsell, 2004). They may be discharged from a trauma center without any idea how to

change dressings or recognize and avoid complications that could prevent effective recuperation from their injuries (Alpach, 2004).

The consequences of low functional health literacy are even greater for patients living with complex syndromes involving multiple organ systems requiring sophisticated multi-component treatment regimens that must be undertaken simultaneously. There are many examples of these complex medical conditions, yet one of the most glaring is AIDS, which has already resulted in the deaths of more than 576,000 people in the United States (CDC HIV/AIDS Surveillance Report, 2005).

Inadequate health literacy also has substantial economic consequences for the United States health care system. A study conducted by the National Academy on an Aging Society (NAAS) determined that having low functional literacy skills increases annual health care expenditures by \$73 billion in 1998 adjusted dollars (NAAS, 1998). These extra costs are primarily caused by the more frequent and longer hospital stays required for patients with low functional health literacy. The majority of these additional expenditures, some 47 percent, are financed through the Medicaid system. An additional 19 percent is covered by Medicare and 14 percent by employers. The remainder is covered through out-of-pocket payments by patients who have the poorest health literacy skills (Porter & Martin, 2005).

The population characteristics of individuals with literacy skills below the functional level overlap those identified as having disproportionately higher risk of health problems, including HIV/AIDS. Those who do not complete high school or who learn English as a second language not only have a greater chance of having low functional health literacy, but also of becoming infected with HIV (CDC HIV/AIDS Surveillance

Report, 2005; CDC Office of Minority Health [OMH], 2007). The Office of Minority Health (OMH) at the CDC reports ethnic minorities represent only about 29 percent of the US population, yet they represent more than half of new AIDS cases. HIV/AIDS has become the number one cause of death in African-American men ages 35 to 44 and 78 percent of women infected with HIV are minorities who became infected through heterosexual transmission (CDC/OMH, 2007). The reported statistics are even more staggering when considering pediatric AIDS cases. Low functional health literacy clearly has an impact on the vertical transmission of HIV. This is evidenced by the fact that in 2000, African-American and Hispanic children represented 80 percent of pediatric AIDS cases (CDC National Center for Health Statistics [NCHS], 2006).

The initial phase of the health literacy research project, completed by the GSU/CDC research group, focused on an examination of the accessibility of many standard health care materials, specifically those related to HIV/AIDS, in terms of their readability and design elements. Next, the group established a model for developing a more readable and culturally sensitive brochure related to HIV (Wallace et al, 2006). Once developed, the experimental brochure was used, along with a standard brochure, in a focus group study with a targeted audience of adults with low health literacy at risk for HIV infection. The focus group study informed the researchers' understanding of three primary constructs; participants' experience with reading health messages; their perceptions of the readability and layout of the experimental brochure and a readily available standard brochure on HIV/AIDS; and their suggestions for improving the experimental message.

Minority populations of the United States bear the greatest burden of new HIV infections (CDC/OHM, 2007; CDC 2010), and of those newly diagnosed some 40 percent progress to AIDS within one year (CDC, 2007). Early diagnosis and preventive education are critical to reducing this trend. The analysis presented in this dissertation examines archived data collected when the focus group study was expanded by introducing the improved experimental brochure to a broader sample of primarily African-American men and women who were clients of an urban community based organization in downtown Atlanta, Georgia. It is hoped this analysis will provide more explicit evidence of the benefits of a more culturally sensitive HIV education program designed specifically to help at risk adults with low functional health literacy understand why knowing their HIV status is so beneficial not only to them personally but also the community at large.

In completing the initial phase of the GSU/CDC group investigation I found many standard medical brochures fail to consider the literacy level of the target population, many of whom function at a low level (Wallace et. al., 2006). To guide its decision making regarding what would constitute an HIV testing message designed to be easily accessible to adults with low functional health literacy, the group established operational definitions for both functional literacy and functional health literacy (Wallace et. al., 2006). Participation in this investigation helped form the foundation of my understanding of the extent and complexity of health literacy issues.

One legitimate question may be; why use the term “functional literacy”? Traditional notions of adult literacy as simply the ability to read and write at the high school level no longer apply in the information driven, technologically sophisticated

society we live in today. Individuals must be able to identify, critically evaluate, and make educated decisions about whether to assimilate or reject the myriad of information with which they are bombarded on a daily basis. Therefore, the research group adopted a definition of literacy embracing the concept that to be literate one must be able to function effectively in daily life. Functional literacy is defined as “having sufficient basic skills in reading and writing to be able to function effectively in everyday situations” (DeGray, 2003, p. 501).

One type of functional literacy is health literacy. In a time when the health care system becomes more complex and difficult to navigate almost on a daily basis, while at the same time requiring patients take on ever increasing levels of responsibility for their own care, it is essential that the decision making abilities of consumers of health care services become more sophisticated and discerning. The term functional health literacy is a type of literacy defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Healthy People 2010, Objectives 11-2 and 11-6). Since the start of this multi-phase project, others have elaborated on this definition to include the continuously evolving nature of health care, the understanding of which is essential in our society if we are to eliminate the health care disparities currently experienced by disadvantaged populations. Therefore, I have adopted a more inclusive definition of functional health literacy which is “the evolving skills and competencies needed to find, comprehend, evaluate, and use health information and concepts to make educated choices, reduce health risks, and improve quality of life” (Zarcadoolas, Pleasant, & Greer, 2003, p. 119). In its broadest definition, this concept must include oral

communication and the ability to integrate new information, conceptualize risk, and take action based on knowledge gained (Hixon, 2004).

Research shows targeted health communications alone will not completely eliminate the knowledge and self-efficacy disparity between the low-education, low-income groups and the groups with higher education and income (Kilbourne, Switzer, Hayman, Crowley-Matoka & Fine, 2006). However; it is likely that establishing a health communications infrastructure accessible to everyone, especially those with low functional health literacy, is an essential step in eliminating health disparities. If medical researchers and practitioners can target health care resources and education materials to those at highest risk, it may be possible to increase understanding and support the behavioral change required to reduce the numbers of new HIV infections.

The open-ended responses in the archived data set provided by the study participants will better inform me about the perceived strengths and weaknesses of the low literacy experimental HIV testing message. Differences in perceptions of the message and brochure layout among individuals with inadequate, moderate and adequate functional health literacy levels were examined. The operational hypothesis was that the qualitative data confirms, in practice, the readability, accessibility, and user-friendly nature of the experimental brochure within the target population of adults at risk of HIV infection. If confirmed, it is hoped the HIV testing message developed by the GSU/CDC research group can be distributed throughout the state and that this work can provide a model for how to design more efficacious low literacy education materials which focus on a variety of other topics related to health issues.

Literature Review

Although much has been written about health literacy in general and the relationship between health literacy and specific diseases such as cancer, diabetes, asthma and hypertension, less has been written about the relationship between functional health literacy and persons at risk for HIV infection. This discussion begins with a general overview of health literacy issues and continues with a dialogue of functional health literacy as it relates to HIV and AIDS. After the literature review, this paper will describe previous work conducted to determine the readability of currently available HIV testing messages collected from a variety of sites in the greater Atlanta area. Finally, details of the work done by the GSU/CDC research team to develop a more readable, accessible, and user-friendly HIV testing message used in the survey study during which the data to be analyzed in this work was collected are presented.

Literacy in Disadvantaged Populations

As stated previously, the 1992 National Adult Literacy Survey (NALS) found that about half of the United States adult population had limited or extremely limited reading and quantitative skills (Kirsch et al., 1993). Of these adults, 21 to 23 percent have significant difficulty using reading, writing, and computational skills for everyday tasks. Further, study participants who reported having a health condition which limited their lifestyle were far more likely to fall within the two lowest levels of literacy (Kirsch et al., 1993). The statistics become more problematic when the data is examined for racial and ethnic minority groups. Some 48 percent of all adults who scored within the lowest level of literacy were racial/ethnic minorities. In all three literacy domains, an average of 78 percent of Black and Hispanic Americans scored within the first two literacy levels. Although the difference in performance between White Americans and those of

racial/ethnic minorities reflect the impact of a number of variables, one primary reason for the apparent disparity was level of education achieved. Black and Hispanic Americans had attained an average of 11.6 years and 10.2 years of formal education respectively compared to the 12.8 years reported for White Americans (Kirsch et al., 2003). A second major factor influencing the performance of Hispanic Americans was the language barrier. “One fourth of those in the lowest reading level are immigrants whose native language is not English” (Parker, Baker, Williams, & Nurss, 1995, p. 1).

Because an understanding of the processes and products of science are essential to full participation in life, the education of young people living in disadvantaged communities is particularly important. Meaningful experiences with the language of science are especially important if we are to empower young people to make better choices that will impact their physical and mental health for years to come (Fang, 2005). Making the connection between what is learned at school and essential skills needed to make efficacious decisions in everyday life can help young people avoid some of the pitfalls they face while living under difficult and stressful circumstances. Specifically, the development of an understanding of science as a “way of knowing” may improve their ability to critically evaluate scientifically based information and develop authentic scientific literacy (Zeidler et al., 2005). In other words: “In a world filled with the products of scientific inquiry, scientific literacy has become a necessity for everyone” (National Research Council [NRC], 1996, p1).

The publication of results from the 2006 Program for International Student Assessment, or PISA, elegantly reinforces the fact that socio-economic and educational disparities greatly impact literacy development in disadvantaged populations in the

United States. Although the PISA was designed to assess scientific, mathematical and reading literacy, it was based on an expanded framework for scientific literacy which focuses on how well students are prepared for life beyond school (Cavanagh, 2007). This assessment was administered to some 400,000 15-year olds in 57 countries, including 5,611 in the United States. The program reported US students scored below the average established by Organization for Economic Cooperation and Development (OECD), ranking 17th in science and 23rd in math out of the 30 industrialized nations taking part in the assessment (OECD, 2006). One analysis accompanying the test results found that an estimated 18 percent of the variation in science scores attained by American students was related to their socioeconomic circumstances. This percentage was considered significantly higher than average (Cavanagh, 2007).

The reduced educational quality often experienced by young people in disadvantaged populations may be due to a number of complex factors. Cutbacks in health and social services have lead to a disruption of the social networks that support adequate physical and emotional health (Freudenberg, 2000). The subsequent reduction in support of basic needs leads to lower educational achievement and reduced retention. Together with other socio-cultural issues, lower educational attainment directly contributes to economic disparities including lack of viable employment opportunities, decreased access to decent housing, inadequate access to medical care and an overall community infrastructure that promotes health disparity (Doherty et al., 2007; Sudore et al., 2006). More targeted research is needed to investigate how meaningful science education in general and functional health literacy in particular may impact decisions made by youth at high risk for STI including HIV.

Health Literacy

In 2003, the National Assessment of Adult Literacy (NAAL), a second nationally representative assessment of English language literacy skills of American adults was conducted. In an effort to more comprehensively assess participants' functional literacy levels the NAAL added oral reading and a health literacy component to what was asked in the 1993 assessment (Kutner, Greenberg, Jin, and Paulsen, 2006). The NAAL assessed abilities within the following literacy domains:

- Prose – which measured participants' ability to search, comprehend and use information written in sentences and paragraphs.
- Document – which measured participants' ability to search, comprehend and use information presented in various non-continuous formats.
- Quantitative – which measured participants' ability to identify and perform computations with numbers embedded within written materials.

The U.S. Department of Education reported the results of the NAAL assessments using four literacy levels; Below Basic; Basic; Intermediate; and Proficient. The following table describes the scores and abilities associated with each of the four literacy levels (Kutner et al., 2007).

Table 1 *NAAL Literacy Levels*

Literacy Level with Score Ranges	Abilities Associated with Level
Below Basic Prose – 0-209 Document – 0-204 Quantitative – 0-234	Adults with Below Basic literacy range from non-literate to having the ability to: <ul style="list-style-type: none"> • Locate easily identifiable information in short commonplace texts • Follow simple written instructions • Locate and use numbers to perform simple mathematical operations, primarily addition, when the information is very familiar
Basic Prose – 210-264 Document – 205-249 Quantitative – 235-289	<ul style="list-style-type: none"> • Read and understand information in commonplace prose texts • Read and understand information in simple documents • Locate easily identifiable quantitative information and use it to solve simple, one-step problems when the operation is stated or easily inferred
Intermediate Prose – 265-339 Document – 250-334 Quantitative – 290-349	<ul style="list-style-type: none"> • Read and understand moderately dense prose text as well as summarize, make simple inferences, and recognize the author's purpose • Locate information in dense documents and make simple inferences about the information • Locate quantitative information and use it to solve problems when the operation is not clearly specified or easily inferred
Proficient Prose – 340-500 Document – 335-500 Quantitative – 350-500	<ul style="list-style-type: none"> • Read lengthy, complex, abstract texts, synthesize the information and make complex inferences • Integrate, synthesize, and analyze multiple pieces of information located in multiple documents • Locate more abstract quantitative information and use it to solve multi-step problems when the operation is not easily inferred.

SOURCE: Hauser, Edley, Koenig, & Elliott (2005)

This comparative study showed there had been no significant change in the average prose and document literacy of the adult US population between 1992 and 2003. The average quantitative literacy had increased by 1.1 percent, from 275 to 283 on a 500 point scale (Kutner, et al., 2007). The percentage of Americans demonstrating Proficient literacy decreased from 15 to 13 percent, while the percentage of those at the Intermediate level increased significantly for two of the domains, document and quantitative literacy (Kutner et al., 2007).

The health literacy component of NAAL determined that 36 percent of the US adult population has Below Basic or Basic health literacy. This means that more than 105 million U.S. adults have a health literacy level that ranges between non-literate and being able to read and understand short commonplace prose texts, follow written instructions in simple documents, and use quantitative information to solve simple, one-step problems (Kutner et al., 2006). These statistics become even more alarming when one considers disadvantaged members of the population which includes those more likely to suffer multiple serious or chronic medical conditions, including HIV/AIDS. The NAAL report states that 57 percent of U.S. adults receiving Medicare or Medicaid had Below Basic health literacy (Kutner et al., 2006).

Literacy and its link to health-related materials has become part of a national agenda to reduce health disparities, since this information is vital to the health and well being of all adults. Research in health literacy indicates self-reported health is strongly related to health literacy. Those patients who report poor health are more likely to have inadequate literacy (Baker, et al., 1997; Sudore et al., 2006). Further, patients with low literacy are less likely to know general information about their condition as well as lifestyle and dietary factors important for their treatment (Williams, Baker, Honig, Lee & Nowlan 1998; Williams, Baker, Parker, & Nurss, 1998; Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Wolf, Gazmararian, & Baker, 2005). In one study by Schillinger and colleagues, diabetics with low literacy had less ability to maintain appropriate blood glucose levels as measured by tests for hemoglobin A_{1c}, thereby increasing the potential for serious disease complications (Schillinger et al., 2002). The association between low functional health literacy, diabetes mellitus and an overall poorer health status has been

subsequently confirmed by a number of researchers (Cutilli, 2007; Sudore et al., 2006; Wolf et al., 2005).

Patients with low literacy are less likely to understand the purpose of necessary tests and procedures (Lindau et al., 2002), correctly follow preoperative medication instructions (Chew, Bradley, Flum, Comia, & Koepsell, 2004), or to report accurate information about their medical history (Wolf et al., 2005). Patients with low literacy skills are also less likely to utilize preventative health services (Gazmararian, Williams, & Baker, 2002; Scott, Gazmararian, Williams, Peel & Baker, 2003; Sudore, et al, 2006). Saffer and Keenan report that patients with low health literacy have poor adherence to recommended interventions and postpone making important decisions that directly influence health care outcomes (Safeer & Keenan, 2005).

The Agency for Healthcare Research and Quality report confirms that low functional health literacy is associated with poor health outcomes. Individuals with low functional health literacy have more than twice the number of hospital stays than those with higher literacy skills. These individuals also require longer hospital stays; more frequently use emergency department services; and generate nearly four times greater annual health care costs than those with adequate functional health literacy skills (Berkman et al., 2004). In a white paper policy statement, the Joint Commission recognizes the communications gap between patients and caregivers endangers patient safety (The Joint Commission, 2007a). In a press release regarding the policy statement, Dennis S. O'Leary, M.D., president, states; "Effective communication is a cornerstone of patient safety. If patients lack basic understanding of their conditions and the whats and

whys of the treatments prescribed, therapeutic goals can never be realized, and patients may instead be placed in harm's way" (The Joint Commission, 2007b).

Health Literacy and HIV/AIDS

Numerous studies have demonstrated the population characteristics of those with low literacy skills overlap with those identified at highest risk for health problems, including HIV/AIDS (Baker et al., 1997; Kalichman & Rompa, 2000; Sudore et al., 2006). Although advances have been made to improve health communication for individuals with low literacy, important information contained in health education materials remains largely inaccessible to a significant proportion of the US population. Looking specifically at the research of health literacy with HIV positive patients, the findings are even more disturbing. In several studies, patients with low literacy were up to four times more likely to be non-adherent to their treatments than those with higher literacy skills (Kalichman, Ramachandran, & Catz, 1999; Kalichman & Rompa, 2000; Osborn, Paasche-Orlow, Davis, & Wolf, 2007). Additionally, low literacy HIV positive patients were more likely to experience side effects, feel depressed, or be confused and vulnerable to misinformation (Kalichman et al., 1999; Kalichman & Rompa, 2000; Benotsch, Kalichman, & Weinhardt, 2004). These results show the importance of developing information that effectively communicates the process and benefits of HIV testing and early effective treatment.

The introduction of new medications, such as protease inhibitors, and highly active antiretroviral therapy (HAART) in the mid 1990s, have made the time between HIV infection and progression to AIDS very unpredictable (CDC HIV/AIDS Surveillance Report, 2005). If and when an HIV infection progresses to AIDS now depends on several factors. These factors include, but are not limited to, how early in the

course of infection diagnosis occurred; whether a person is prescribed the appropriate medications; whether the medications are taken as prescribed; and how well the medication works for that person (CDC HIV/AIDS Surveillance Report, 2005). Thus, the incomprehensibility of health information and lack of access, or non-adherence to treatment, means that members of disadvantaged populations who do become infected with HIV, have a greater probability of progression to AIDS and death (Wolf et al., 2004, Stone, 2004, CDC HIV/AIDS Surveillance Report, 2005).

These NAAL and CDC HIV/AIDS Surveillance Report findings taken together with studies conducted within groups of HIV-positive patients indicate that individuals with lower functional health literacy may suffer higher rates of HIV infection than do those with higher literacy skills. In addition, after being diagnosed, they are less likely to understand and adhere to the complex treatment regimen required to prolong progression of the infection to AIDS and death. Clearly, individuals with low functional health literacy who are at risk for HIV infection need a more tailored, culturally competent approach to HIV patient education and treatment instruction (Wallace et al., 2006).

Determining Health Literacy Levels

Research in health literacy confirms that in medical settings, patients' self-reported level of education may not provide an accurate estimate of their ability to read and comprehend health education materials (Davis, Michielutte, Askov, Williams, & Weiss, 1998). Instruments have been developed to provide a more accurate estimate of an individual's health literacy. The Rapid Estimate of Adult Literacy in Medicine or REALM (Davis, Crouch, Long, & Green, 1993) was developed to give medical practitioners and researchers a way to quickly estimate a patient's literacy level. The

REALM is a word recognition test used to assess an adult patient's ability to read aloud words commonly used in medical settings. The Test of Functional Health Literacy in Adults or TOFHLA takes a more functional approach. It assesses health literacy by sampling patients' ability to read and comprehend actual hospital and medical texts (Parker et al., 1995). Both assessments were used in the collection of literacy data during the survey study.

Researchers vary in their description of the percentage of scores on health literacy assessments indicating low literacy. For instance, Kalichman and Rompa (2000) classify low literacy with TOFHLA scores falling below 80 percent. However, Kalichman, Rompa, and Cage (2000) use 85 percent as the determining score, while Baker et al., (1997) use 75 percent as the cutoff score. Further, the three passages used in the modified Cloze section of the TOFHLA have tremendous variance in their level of readability at 4.3, 10.4, and 19.5 respectively (Williams et al., 1998b). Therefore, it may be difficult using only the TOFHLA to fully understand how *low* the label of low literacy really is. Users must determine what cutoff score they will employ to specify the low literacy level.

Interpreting the meaning of low literacy is one issue within the literature. Another issue deals with the health materials themselves. While studies evaluating the readability of health materials in areas such as smoking, diabetes and cancer have been conducted (Williams et al., 1998a, Williams, et al., 1998b; Friedman & Hoffman-Goetz, 2007) none of the aforementioned studies in HIV health literacy tackle the readability issue. One study by Wells (1994) did examine the readability of different types of HIV educational materials using the SMOG index. That study found the reading level of materials

designed for the general public averaged grade 12. Additionally, that study confirmed an understanding of the literacy level of the target audience is essential to produce appropriate materials (Wells, 1994).

Consequently, more examinations must be conducted and interventions designed to identify and reduce the difficulties encountered by patients who have inadequate health literacy (Kalichman et al., 1999; Kalichman & Rompa, 2000; Davis et al., 2006; Osborn et al., 2007). Therefore, during the initial phase of the health literacy project the research group set out to understand the readability of commonly available HIV/AIDS health messages, particularly those that advocate testing behaviors. The following sections detail what we discovered.

Readability of Standard HIV/AIDS Brochures

As part of the GSU/CDC research group I investigated the accessibility of information provided by available HIV/AIDS brochures. In that study, sixteen commonly available HIV/AIDS brochures were collected from various locations around the downtown Atlanta area. Each brochure was then evaluated for readability, complexity, layout, and design by literacy experts from GSU. Researchers discovered that many of the standard brochures failed to consider the literacy level of the target population, many of whom operate below the functional level (Wallace et. al., 2006). As a result, some brochures used medical and technical terms with which the target population may not be familiar. In addition, many brochures provided too much information, attempting to explain difficult medical concepts not required to grasp the intent of the message. For example, the CDC (2000) brochure provided a too detailed definition about HIV using technical terms: “HIV- the human immunodeficiency virus- is

a virus that kills your body's 'CD4 cells'. CD4 cells, also called T-helper cells, help your body fight off infection and disease.” The Georgia Department of Human Resources (1997) provided unnecessary information when it used the phrase “Transfusions of HIV-contaminated blood have caused a small number of HIV infections.” The brochure produced by Channing L. Beta Co., Inc. (1996) listed scientific names of diseases such as, “Pneumocystis carinii pneumonia (PCP), a lung infection, certain cancers, such as Kaposi’s sarcoma, viral infections, such as cytomegalovirus (CMV)” in an effort to illustrate how AIDS is diagnosed. Additionally, some brochure pages were too heavily decorated, not providing enough white space or context-based visual aids to support meaning making by the reader (Georgia Department of Human Resources, 1997; Channing L. Beta Co., Inc., 1996). Others failed to provide representative, culturally appropriate images to which the intended audience might relate, sometimes including cartoon-like images (Channing L. Beta Co., Inc., 1994, 1996, 1998). For an example of a standard brochure, Appendix A shows a sample page from *Should You Be Tested for HIV?* This message, produced by the Georgia Department of Human Resources (1997), was selected as a representative standard brochure and was used first in the focus group study and later in the larger survey study during which the warehoused data this work proposes to analyze was collected.

Once the brochures were evaluated by literacy experts, I processed them for use in the readability evaluation program. The exact written content of each brochure was typed into a computer word processing program and saved as a text only file. Each text file was then edited according to the specific instructions required for entering passages to be used as samples in the readability evaluation program (Micro Power & Light Co., 2000).

In response to suggestions from research group literacy experts the following formulas were used to evaluate each sample. The subsequent list includes the name and a brief description of each formula chosen to evaluate the sample texts.

- The *Dale-Chall* Formula was used because it is normally applied to upper elementary and secondary level materials. It uses an established word list plus the word total and number of sentences in the sample to calculate the readability.
- The *Flesch Reading Ease* Formula was chosen because it is generally applied to materials intended for adults. This calculation focuses on the number of words, syllables and sentences in the sample. The formula reports a numerical readability score between 0 and 100, with more difficult material rating a lower score. Usually, a score falling below 30 is considered very difficult and a score above 70 is considered easy.
- The *FOG* Formula utilizes the word total, the number of words of three or more syllables, and the number of sentences to calculate a readability score. Literacy experts have determined that publications identified as a specific type should score within a particular range. Below 14 is considered appropriate for a technical publication, 12 or below for general business materials and 8 or below for general clerical documents.
- The *SMOG* Formula was chosen because it determines the grade level that would most likely achieve 100 percent comprehension of the sample and makes its calculations based upon the total number of words in the sample containing three or more syllables.
- The *Fry Graph* is a general tool utilized in the evaluation of text intended for any grade level, from elementary through college. The graph is displayed as a series of radiating lines representing the different grade levels. The position of the resulting point on the graph is determined by the correlation of the average number of sentences per 100 words, with the average number of syllables found within the same sample. This tool was used to help ensure reliability of the input data and editing. If the point did not fall between the lines of the graph the result is considered invalid, and the sample text was checked for errors and re-run (Micro Power & Light Co., 2000).

In addition to the results of the application of each formula chosen to evaluate a given text sample, the program also indicates the number of words, syllables, and sentences.

The number of monosyllabic words, words with three or more syllables, and two

categories of difficult words are also counted. The result displays the average number of syllables per word; the number of sentences, syllables, monosyllabic and polysyllabic words per 100 words; the number of words per sentence, and the percentage of words not on the Dale-Chall list. A sample of the results format displayed by the program is presented below. The text used to produce this sample report was the abstract of my prospectus.

Table 2 *Readability Program Results*

Date:	7-26-2007
Time:	13:34:46
Sample Begins:	Perceptions of the efficacy...
Sample Ends:	...reaction to hiv testing messages.
Words:	329
Syllables:	754
Monosyllabic words:	192
Words of 3-or-more Syllables:	100
Difficult Words (FOG):	91
Difficult Words (Dale-Chall):	148
Sentences:	13
Syllables / Word:	1.93
Syllables / 100 Words:	192.35
Monosyllabic Words / 100 Words:	48.98
Polysyllabic Words / 100 Words:	25.52
Sentences / 100 Words:	3.32
Words / Sentence:	30.16
Percent of Words Not in the Dale-Chall List:	37.76
Dale-Chall Grade Level:	11.1
Flesch Reading Ease:	13.51
FOG Grade Level:	18.9
SMOG Grade Level:	18.2

A number of measures were taken to verify the reliability and reproducibility of the readability evaluation program results. First, text samples of known grade level taken from a basic reading inventory were processed in the same manner as the collected HIV/AIDS brochures and then run through the program.

Additionally, a random brochure was chosen to be input into the computer and edited at two separate times to check for reproducibility. Finally, if a sample result fell outside of the grade lines on the Fry Graph, indicating an invalid result, the sample was then re-edited to check for mistakes and run again. If the sample still did not produce a valid Fry result it was divided up into sections and re-run in order to identify specific anomalies.

Prior Development of the Low Literacy HIV Testing Message

After examining the standard brochures and investigating best practices used to develop health messages, the GSU/CDC research group set out to develop a readable and user-friendly brochure related to HIV more accessible to adults with low health literacy. Instead of the complex, multidimensional messages found in the standard brochures, the HIV testing message developed by the research group centered on one simple message; get tested now!

The group determined that health literacy materials should be written in a clear, simple, and logical style. To be effective with low literacy adults, best practices dictate these materials have a definite organizational format with a simple contextual or background type of introduction, a body composed of main points with supporting evidence and details, and a concluding summary. Sentences should be written in the

active voice using simple vocabulary, easily understandable examples and recognizable sources (Wallace et. al., 2006).

The research group determined that layout is equally as important as content. The text should be printed in an easily read print type, such as serif, in 12 point size. Line spacing of 1.2-1.5 should be used, with both upper and lower case letters. To make the words easier to read they should be printed on a light background with ample white space separating distinct thoughts or concepts. Pages should be attractive and well organized. If charts or graphics are utilized, they should be clearly labeled and closely associated with the text they are explaining (Wallace et. al., 2006). Finally, it is important that the text does not try to cover too many ideas at one time. Having only one or two main messages per article is advisable (Wallace et al., 2006).

The experimental brochure developed by the research group, used in the survey study which provided the archived data for this work, can be found in Appendix B. This low-literacy brochure was designed to be culturally responsive to the targeted audience, including artwork and photography reflective of the urban physical setting and predominantly African-American inner-city community from which the sample population for the focus group study and the larger survey study were recruited. The brochure was intended to send one simple yet action-based message: “Get tested for HIV today!” Throughout the message, peer language was used instead of technical language. Further, the brochure was written to engage the reader in thinking about why they may be personally at risk for HIV, rather than simply targeting the message to a group or community of others. For example, it starts by asking the reader questions such as: “Have you had sex without a condom? Have you shared your works?” Additionally, the

layout of the brochure was specifically created so the images could be used to support meaning making using lines to direct the readers' attention to the next piece of text (see Appendix B) (Wallace et al., 2006).

The accessibility of the information in the experimental brochure was confirmed through review by literacy experts and evaluation by the Readability Calculations program. A direct comparison between the readability of a standard HIV/AIDS brochure and the experimental HIV testing message developed by the research group can be seen in Table 3. This comparison confirms that the experimental brochure has a number of characteristics determined to be essential in a message intended for adults with low functional health literacy. These parameters include, but are not limited to, the fact that the experimental brochure is shorter, has fewer difficult words and most importantly is likely to be clearly understood by an individual with no more than a 5th grade reading level (Wallace et. al., 2006).

Prior Focus Group Study

To achieve the primary public health goals of increasing Americans' knowledge of their HIV status and decreasing new HIV infection rates the US must reduce the disproportionate burden of illness and poor health borne by disadvantaged populations.

Table 3 *Comparison of Standard & Experimental Brochures*

	Experimental Brochure	Standard Brochure
Total Words	120	1085
Polysyllabic Words / 100	2.51	6.18
Difficult Words	10	186
Flesch Reading Ease	98.61	84.05
FOG Formula	3.1	6.2
SMOG Formula	5.0	7.2
Dale-Chall Formula	5.2	6.8

Therefore, to gauge the appropriateness of the newly developed low literacy brochure the GSU/CDC research group invited clients of an urban CBO in downtown Atlanta, Georgia to serve as participants in the focus group phase of its research. This section will detail the results and conclusions of the focus group study comparing the experimental brochure to a representative standard brochure in order to gather feedback from adults with documented low health literacy at risk for HIV infection.

Context of the Prior Focus Group Study

Once the research group had what was believed to be a culturally sensitive, HIV testing message appropriate for adults with low health literacy, a focus group study was designed to preview the brochure with a targeted audience. This phase of the work was intended to inform the research team about participants' experience with reading health messages; their perceptions of the readability and layout of the experimental brochure and a readily available standard brochure on HIV/AIDS; as well as gather their suggestions for improving the experimental message (Deming, Wallace, Hunter, & Belcher).

Individuals participating in the focus groups were recruited from a local CBO in downtown Atlanta, during July and August 2004. Because the primary focus of this phase of the work was adults with low health literacy levels, the REALM was administered to potential participants and a cut off score for focus groups eligibility was set at 44 prior to the screening of any potential participants.

Out of a total of 58 participants who began the screening process for the focus group study, only one declined to give verbal consent to continue. Of the 57 participants who completed the screening, 22 (38.6%) scored higher than 44, and 35 (61.4%) scored 44 or below on the REALM. The majority of individuals, 39, screened were male (69%).

Only 18 (31%) were female. Fifty one (89%) classified themselves as African American, five Caucasian, and one self-identified as a Pacific Islander. Of the 35 participants who scored within the qualifying range on the REALM, eight participants were disqualified by further screening. Three were disqualified due to lack of risk behaviors, three reported being tested for HIV within the past six months, and two identified themselves as having a known positive HIV status. Ultimately, 27 respondents qualified to participate in one of the four planned focus groups. Of those that qualified, 22 actually attended and participated in one of the focus group discussions (Deming et al.).

Prior Qualitative Data Collection

As previously described (Deming et al.) four focus groups were conducted. In an effort to reduce any potential embarrassment and promote ease of discussion two groups were set up to include only male participants and two of females. An experienced focus group facilitator, using an informal conversational format, moderated each of the groups (Deming et al.).

Following the informed consent procedures, the focus group moderator began each of the four focus groups by sharing his background and inviting participants to share their backgrounds. Then, the moderator asked the participants to recount experiences with healthcare and reading health messages (brochures and other materials). As the session progressed, two HIV testing brochures were examined and then discussed by the group (see Appendices A and B): a standard testing message available at area clinics and the low-literacy message designed by the researchers (Deming et al.).

Results of the Prior Focus Group Study

As reported in the manuscript by Deming et al., during all focus groups, participants were willing to candidly discuss their experiences. As the themes found in the dialog transcripts were analyzed by members of the research group, particular attention was paid to the participants' reports of previous experience with reading health messages and the readability and layout of the standard and low literacy HIV testing messages (Deming et al.).

Participants spoke openly of their prior experiences with reading health messages. This dialogue provided researchers with important data used to substantiate the groups' understanding of a number of relevant issues. These issues included, but were not limited to, the participants' comfort with health messages and the level of support they needed to facilitate understanding of important health messages. Additionally, since all participants were screened based on literacy, their experiences would further substantiate researchers' understanding of health messages targeting individuals with low functional health literacy. Throughout the data analysis, it became clear that participants recognized there were positive attributes to health messages; however, they confirmed having difficulty reading and comprehending such messages. Further, some participants expressed lack of help from medical staff in understanding these important messages (Deming et al.).

Focus Group Participants' Previous Experiences with Reading Health Messages

Some positive aspects of health messages were expressed by a number of participants. Some participants indicated that brochures and pamphlets can appeal to many people because of their availability. Others noted the design of the message could aid in accessibility; which was especially important as participants recognized they have difficulty reading (Deming et al.).

Participants receiving treatment at various local facilities are given information in a variety of ways. While the focus group participants recognized both the positive attributes and importance of the health messages described in these written materials, many expressed frustration in reading and understanding them. Several participants described the messages as difficult because they contained words unfamiliar to the patients they were intended to enlighten. Other participants reported their lack of understanding as a source of anxiety and even fear (Deming et al.).

Another troubling aspect revealed during these focus group discussions was the frustration expressed by participants at the lack of help they received from medical staff. One participant reported; “when I asked what they was trying to say I was told to get a dictionary and look up the words” (W2, p. 4) (Deming et al.). “They give you pamphlets that I don’t know what the words are saying. There’s no one there really to sit down and explain to you what’s going on” (M2, p. 2) (Deming et al.). Not having the time to assist patients in understanding health messages is one issue, but participants also shared experiences in hospitals and clinics in which the staff was rude and aloof (Deming et al.).

Some participants perceived the problem of getting the attention of the medical staff as depending on their financial status; whether they had insurance or not. One participant shared the importance of having insurance: “... they [doctors] so far intellect to the patients...unless you are in the medical field, you aren’t not going to really know what they’re saying anyway...” (M2, p. 2). “I don’t have insurance so nobody want to touch me that’s what it really boils down to. The head doctor wouldn’t even talk to me, he left and went home,” (M2, p. 3). “But if they think you just some homeless bum, you

know what I mean, they're just going to, let him go die somewhere else basically" (M2, p. 4) (Deming et al.).

It is important to note that not all focus group participants' experiences with medical staff were negative. One male patient had a positive experience with a doctor: "Dr...she go into detail and she explain to me thoroughly what you are dealing with you know. I don't even have to ask her and she tell you, she'll get the pamphlets and go through them and then if she run across a problem, she's going to explain to you what it, what's the symptoms, what [you] got to do to correct it" (M2, p. 8) (Deming et al.).

Readability and Layout of Standard HIV Testing Message

All four focus groups were presented with a standard HIV testing brochure (see Appendix A). Participants read the message and discussed their reactions in the group setting. With regard to the standard brochure, participants talked about the readability and the layout (or design) of the message (Deming et al.).

The first reactions to the standard brochure were varied and changed depending on whether they had seen the standard brochure first, or after the experimental brochure. Where the standard brochure was introduced first, participants said the reading was easy, but as they began to talk, some voiced concern with certain words or concepts, particularly those using medical terms such as immunodeficiency (Deming et al.). Participants described this brochure as being difficult for someone with problems reading. As the discussion continued, one female participant said, "There was a... couple of words in here that I saw and I thought, I wonder if this is something they [the other participants] know or they just skip over it and keep going. I saw more than one word in here... I'm just wondering" (W2, p. 15) (Deming et al.).

When asked about the main message of the standard brochure, participants in the all-women focus groups had varying responses. They cited a number of possibilities. Main messages ranging from AIDS prevention to testing opportunities to contracting HIV were all suggested (Deming et al.).

Like the women, male participants started out agreeing that the brochure was simple and easy to read (M1, p. 21) (Deming et al.). Through conversation, however, that initial assessment changed for some of the participants. Some of the men found the standard pamphlet hard to read because of the difficult vocabulary. One male participant admitted that he could not read the brochure at all and asked that a researcher read it to him. Some participants even stated they were scared by the message: “I didn’t want to read no more because that part is saying there is no cure, wait, hold up. Don’t tell me that. Tell me something else first” (M2, p. 17) (Deming et al.). Others pointed out confusion regarding information within the message. For example, when a sign of HIV emerges, “Is this the blood that you take the first time or you wait six months later? It doesn’t state it right there” (M1, p. 24). Confusion was also expressed as to how to find the test result when they don’t give names (M1, p. 25). One participant said the brochure was not comprehensive enough because it did not contain an explanation about the incubation period described in the text (M1, p. 31) (Deming et al.).

When participants in the all-men focus groups were asked about the main message of the standard brochure, they, like the women, did not agree on what the main message could be. Some said the main message was about the risk factors of contracting HIV, others suggested it was practicing safe sex, still others said the main message was getting tested (Deming et al.).

In one all-female and one all-male focus group, participants made general comments indicating that they liked the layout (e.g. pictures) (W2, p. 7 & M1, p. 29 -30) as well as how the layout related to the information (W2, p. 8 - 9) (Deming et al.). However, while some women said that the message had a lot of information, others indicated it was too much to read (too much per page), especially if someone had difficulty reading (W2, p. 13 - 14) (Deming et al.). One male participant said “the most thing that caught my attention was what you were talking about on that first page... where it’s got a man in the bed” (M1, p. 30) (Deming et al.).

Readability and Layout of Experimental Low Literacy HIV Testing Message

As with the standard brochure, all four focus groups in the prior study were presented with the experimental low literacy HIV testing message (see Appendix B). Participants read the brochure and discussed their reactions in the group setting. Again, resultant conversations revolved around the readability and layout (or design) of the brochure. With the experimental brochure, the discussions concerning readability and layout were woven together within participants’ responses (Deming et al.).

First reactions to the experimental brochure indicated that participants believed this brochure was easy to read. One participant clarified that while she thought the standard brochure was easy, “This one was real easy” (W2, p. 10). A male participant agreed “It was easy because the words were bigger [larger font] and then at least it got a picture ---because some people can guess what that at is when they can see the pictures they can’t read” (M2, p. 9). Participants were able to indicate just what made this brochure easy to read: layout, less text, bigger font, color, tag line, and realistic pictures (W2, p. 12, 13, 15). Male participants liked the illustrations, the colors, the layout, and

the fact the message was short (M2, p. 11, 12). In fact, it was said that the layout/pictures helped participants to follow the printed message (W2, p. 10-11). Some participants stated that the finger prick and colorful pictures caught their eyes (M1, p. 33-4) (Deming et al.).

Other participants said they found the question and answer format of the experimental brochure motivating. Participants in one group agreed that – if it [the message] connects to you, you want to be tested (W2, p. 12). Other participants shared how the brochure related specifically to them: “Because I’ve done that” (W2, p. 17); “And this was years ago. I’ve shared needles” (W2, p. 17). Some pointed out positive aspects of the experimental brochure as the fact it asks simple questions relevant to their personal lives and the graphics depicted everyday people to which they could relate (M1, p. 37 - 38) (Deming et al.).

When asked about the main message of this brochure, all participants agreed the experimental brochure had a single obvious main message, which was to “Get tested” (W1, M2, p.10). In addition, they all claimed that the pamphlet motivated them to get tested. “...it really related to me. It really makes you want to get tested” (M2, p. 10) (Deming et al.).

All participants in one focus group agreed that someone with difficulty reading could read the experimental brochure: “This here is, is like short and to the point and the words are[n’t] big, you know, and they’re simple, you know, simple words” (W2, p. 14). In another focus group, participants echoed these comments and added that the message was “simple to read,” “to the point,” “in layman terms,” and “short and sweet” (M1, p. 34) (Deming et al.).

The focus group participants recommended a single important change for the experimental brochure. Several participants expressed the need for having the contact information printed on the back of the brochure. “Having the information of where to go. It says, go get tested but it don’t have any information on where to go” (W2, p. 17, M2, p. 18) (Deming et al.). The appropriate contact information was added to the brochure for use in the larger survey study (see appendix B).

As stated previously, research shows a clear association between low functional health literacy, reduced understanding of the need for and access to preventive care, decreased ability to self-manage personal medical issues or participate in treatment decisions and an overall poorer health status (Safeer & Keenan, 2005; Shalowitz & Wolf, 2004; Mika, Kelly, Price, Franquiz, & Villarreal, 2005). Low functional health literacy also plays a major role in disparities in access to and utilization of health care services by disadvantaged populations (Osborn et al., 2007). Efforts to eliminate health care disparities are particularly important if we are to meet the public health goals of increasing Americans’ knowledge of their HIV status, avoid delayed diagnosis and decrease new HIV infection rates in the United States which are disproportionately borne by disadvantaged populations (Mayben et al., 2007).

The qualitative data from the focus group study described above confirmed the accessibility, readability, cultural sensitivity and user-friendly nature of the low literacy HIV testing message designed by GSU/CDC research group (Deming et al.). The next logical step was to introduce the new brochure to a larger population of adults (n = 202) at risk for HIV infection without restriction by literacy level.

Survey Study

The warehoused data analyzed in this work comes from that collected during a survey study conducted previously by the GSU/CDC health literacy research group. This prior study was a mixed method, cross-sectional survey designed to explore the relationship between health literacy, HIV-related knowledge, HIV testing history and intentions, and HIV risk reduction behavior in a sample population including predominantly low income, urban, English-speaking African-American men and women at risk for HIV infection.

The previous work referred to above involved introducing the improved experimental brochure to a broader sample of 102 men and 100 women clients of an urban CBO in downtown Atlanta, Georgia during the summer of 2005. The majority of the recruits were clients of an employment readiness program designed to prepare disadvantaged individuals for reentry into the workforce.

Survey Study Participant Recruitment

Approved flyers calling for participants were posted throughout the two facilities and announcements were made with the help of CBO employees and volunteers. The flyers and announcements explained that a research study sponsored by GSU and the CDC was being conducted. Because of the transient nature and inherent vulnerability of the homeless, researchers knew it would be difficult to contact most potential participants outside of the facility. Therefore, a researcher remained stationed at the facility during peak flow hours to discuss the proposed study with potential participants and to make appointments to conduct the survey at a later time convenient for them. Participants who completed the health literacy assessments and the survey instrument were given \$30 for

their time and travel. The funding was provided through a grant from the CDC (Wallace et al., 2006).

As anticipated, once the survey began, other potential participants were recruited through word-of-mouth from individuals who had previously been surveyed. Although some researchers have considered this type of snowball-based sampling methodology problematic, others have recognized its utility in helping researchers access hidden populations. This type of sampling can provide researchers with access to hard-to-reach populations whose members do not have stable, easy-to-locate lives (Faugier & Sargent, 1997). It is a practical approach, providing researchers with an expanding set of potential contacts within populations where some degree of trust is required on the part of the participant that the researcher has characteristics associated with being an insider or group member (Atkinson & Flint, 2001; Deming et al.).

Determination of Functional Health Literacy

Although each participant's level of functional health literacy was tested using two measures; the REALM and the TOFHLA, participation in the study was not restricted to individuals demonstrating low functional health literacy. This was done to inform researchers of the utility of the experimental brochure with a larger, more inclusive sample of the population.

The REALM (Davis et al., 1993) is a word recognition test used to assess and adult patient's ability to read aloud words commonly used in medical settings. The instrument consists of 66 items including common medical words and layman's terms for body parts and illnesses that are arranged in three columns based on item difficulty. The easier words are deliberately placed in the first column to enhance patient confidence and

reduce performance anxiety. The number of correct responses given is added to produce a raw score which is then converted into a grade range equivalent (Davis et al., 1993).

The REALM assessment takes approximately two to three minutes to administer and score and has high face validity, high criterion validity, and high test-retest reliability (Davis et al., 1998). Although the REALM is not designed to assess comprehension or interpretation of medical words, it has been shown to provide a valid estimate of an individual's health literacy level (Murphy, Davis, Long, Jackson & Decker 1993). However, the REALM is limited in that it is not related specifically to HIV/AIDS and assigns grade range estimates, instead of specific grade levels.

The TOFHLA (Parker et al., 1995) utilizes written materials commonly found in hospital settings to determine low, marginal, or high levels of functional health literacy. Results are calculated using a 50-item multiple-choice modified cloze procedure and a 17-item numeracy test. During test administration, the participant is instructed to read passages in which every fifth to seventh word has been deleted. The participant is then asked to choose one of four words that would correctly complete each phrase of the passage. Additionally, the TOFHLA has participants respond to prompts, such as prescription bottle instructions and appointment slips, producing a measure of patients' ability to use basic numerical information commonly found in medical settings. Thus, the TOFHLA measures both the numeracy and reading comprehension aspects of functional health literacy. The TOFHLA literacy measurement has been noted as being highly correlated to other measurements of English literacy skills including: the Wide Range Achievement Test (WRAT) reading subtest, and the REALM (Parker et al., 1995).

Each potential participant was shown to a private area within the CBO facility and asked a series of questions to establish eligibility. To be eligible for participation each individual was required to be over 18 years of age, speak English as a first language and be capable of giving verbal consent to participate in research. Once the potential subject gave verbal consent to participate in the research study they were again asked to verify that they were over 18 years of age by giving the year of their birth. Each participant was then assigned a numbered packet containing the documents used to record the results of the literacy assessments and the survey instrument. From this point forward the participant would be identified by number only. The researcher or trained assistant then explained that they were about to administer two health literacy assessments.

During the administration of the REALM participants with corrected vision were asked to use their glasses if they had them. However, the large print version of the word list, which is designed to accommodate individuals with 20/200 vision (the level of legal blindness), was used consistently to avoid participant embarrassment or difficulties due to visual acuity. Each potential participant was then asked to say each word aloud. Acting as unobtrusively as possible, the researcher placed a check mark next to each word the participant pronounced correctly, using the dictionary pronunciation as the standard. If the participant stopped or stalled on a particular word, and was unable to say that word, he or she was asked to skip the word and move on to one that he or she could say. Any word that was correctly articulated by the participant or self-corrected after a faulty attempt was counted as correct. The total number of correct words for each column was then tallied, and the total score was listed in the “Raw Score” blank at the bottom of the score sheet. Participants were not informed of their total scores. If asked, the researcher

would simply reply, with compassion and respect, the participant had done fine. At the conclusion of the REALM, if a participant asked about a specific word, the correct pronunciation the word and its meaning were provided. Upon the conclusion of the interview, the participants' raw score was compared with the score interpretation (Table 4) and the grade range equivalent would be recorded on the score sheet.

Upon completion of the REALM, the TOFHLA was administered. As described previously, the TOFHLA has participants respond to prompts which consist of materials commonly encountered in a health care setting, such as pill bottle instructions and appointment slips, thus measuring patients' ability to use basic numerical information.

To ensure uniformity of administration and scoring of the TOFHLA, each prompt was presented in the large font version and was accompanied by specific information that instructs the researcher on how to administer that prompt (Nurss, Parker & Baker, 2001).

Table 4 *REALM Score Interpretation*

Raw Score	Grade Range Equivalent	Literacy Skills
0-18	3 rd Grade and Below	Individual is not able to read most low literacy materials & will probably not be able to read appointment slips or prescription labels. Patient will need repeated, individual oral instructions.
19-44	4 th to 6 th Grade	Individual may not be able to read low literacy materials independently. Patient will need low literacy materials with accompanying verbal instructions.
45-60	7 th to 8 th Grade	Individual will struggle with many patient education materials. Patient may be able to pronounce words but not fully comprehend the message.
61-66	High School	Individual will be able to read most patient education materials.

SOURCE: Davis et al., 1993

The respondent accumulated one point for each correct answer and the sum was used to calculate the Numeracy Raw Score, which was recorded on the test booklet. The raw numeracy result was then converted to a Weighted Numeracy Score based on the chart provided by the test designers and recorded on the back cover of the test booklet (Nurss et al., 2001). This concluded the numeracy portion of this functional literacy assessment.

The second portion of the TOFHLA uses a 50-item multiple choice modified cloze procedure to assess reading comprehension. During the test participants were instructed to read passages in which every fifth to seventh word has been deleted. The participant was then asked to choose one of four words that correctly completed each phrase of the passage. As with the REALM, large font versions of the passages were used to avoid difficulties due to visual acuity.

As soon as test administration was complete, each section of the TOLFHLA was scored. The answers given by the respondent were compared to the answer key provided with the version of the test used. In the score box provided, a one was circled if the answer was correct and a zero was circled if the answer was incorrect. Each page was summed, and a subtotal was recorded at the bottom of the page in the space provided. The subtotals were summed to give the Reading Comprehension Raw Score. The respondent's total TOFHLA score was then calculated by adding the weighted numeracy score and reading comprehension raw scores (Nurss et al., 2001). The respondent's functional health literacy level was then determined using the scale presented in Table 5.

Table 5 *TOFHLA Functional Health Literacy Levels*

Functional Health Literacy Level	TOFHLA Score	Functional Health Literacy Description
Inadequate	0 – 59	Respondent unable to read & interpret health texts.
Marginal	60 – 74	Respondent has difficulty reading & interpreting health texts.
Adequate	75 – 100	Respondent can read & interpret most health texts.

SOURCE: Nurss et al., 2001

Quantitative Data Collected During the Survey Study

The warehoused quantitative data collected from survey respondents includes demographic information on age, education level, income, and housing status. Although data from epidemiologic studies have shown a number of behaviors are closely linked to transmission of HIV (Anderson, Mosher, & Chandra, 2006), researchers conducting the survey study focused on four primary factors to investigate an individual's risk for HIV infection (Anderson et al., 2006). A small, ethnically diverse group of trained female interviewers asked participants to self-report recent alcohol and drug use, recent sexual behavior, history of STD, and exposure to abuse or sexual coercion. A series of questions designed to inform researchers about participants' perceived risk of acquiring HIV, prevention strategies such as HIV testing history and condom use, as well as understanding of other HIV/AIDS issues and their level of trust in sources of information about the prevention of HIV/AIDS were also included in the survey questionnaire developed by the GSU/CDC research group (Belcher et. al.). Questions used in the survey instrument to assess HIV risk behavior and prevention strategies were the same as those used in the National Survey of Family Growth conducted by the CDC National

Center for Health Statistics (Anderson et al., 2006). The exact wording of the questions was also reviewed by literacy experts at GSU. A copy of the survey instrument provided by the GSU/CDC research group can be found in Appendix C (Belcher et al.).

Consistency and Reproducibility of the Survey Research

A number of measures were undertaken during the collection of the survey data to ensure consistency and reproducibility of the interview process. First, prior to beginning any interaction with potential participants, five master's level students were recruited to assist me in conducting the interviews. Each research assistant attended two training sessions to ensure understanding of the health literacy and survey instruments; consistency of question delivery and scoring; as well as assist in anticipation of problems and establish protocols for handling of problems that may arise during the interview process. Secondly, each research assistant was assigned a researcher's packet, containing laminated copies of all reusable materials and numbered copies of the interview document required to conduct each day's interviews. All participant recruiting, interviews and data collection was conducted by me or one of these trained research assistants using identical copies of the interview materials. Once the research assistant's shift was completed a discussion of the day's events was conducted and all documents were returned to me. Documentation was kept by on a daily basis in the scheduling calendar. At the end of every day during the data collection period I reviewed each interview document completed by the research assistants. Any pertinent issues were discussed with the research group and, if needed, were addressed with all research assistants. Any required retraining was completed immediately during the discussion sessions.

Strengths and Limitations of the Warehoused Data

The data analyzed in this work was collected over a 5 week period during July and August, 2005 and has a number of strengths for studying health literacy, sexual behavior and HIV prevention strategies in the urban homeless population. Some of these strengths are outlined below.

- Due to the comfort level of potential participants with the presence and interaction with the researchers the conductors of the survey study enjoyed an extremely high response rate.
- Research indicates a greater proportion of the risk for HIV/AIDS is borne by low income, minority communities (CDC, 2007). The survey data used in this study was collected within a primarily African-American homeless community.
- The face-to-face interview technique used to collect the data allowed for completion of all survey questions which helped to minimize the customary problem of missing data seen with traditional paper and pencil surveys.
- The use of a small, ethnically diverse group of trained interviewers helped to maintain internal consistency of the data set.

The data included in this analysis may also have a number of limitations. The following items describe some of these limiting factors.

- Although snow-ball sampling has been demonstrated effective for use in vulnerable populations such as the homeless (Faugier & Sargent, 1997), it is not a rigorous design that allows results to be generalized to larger, more inclusive populations.

- Due to the relatively small overall sample size, subgroups having specific characteristics may be small.
- As with any survey conducted using face-to-face interviews resulting data could be affected by underreporting of risk behaviors.
- The survey participants fall into an age range of between 19 and 66 with a meaning that younger individuals also at risk for HIV infection were not represented in this sample.
- Numbers of participants having already undergone HIV testing may be higher than expected due to the requirements of the employment readiness program from which a majority of the subjects were recruited.

Quantitative Data Analysis

Once the working data set was established, a number of analytical procedures were undertaken. Descriptive frequencies were run to determine the demographic characteristics of participants. These included but were not limited to age, sex, highest grade completed in school, current HIV status, marital standing, current housing type and financial circumstance.

The warehoused data provided both participants' numerical test results and categorical interpretations for both health literacy measures. Consequently, both linear regression and Chi Square cross tabulation analysis were used to compare the results of the REALM and TOFHLA.

Using the affirmative answers to related survey questions, a number of transformed variables were developed in order to group responses and classify HIV risk characteristics into each of three broad categories. Survey questions 13, 14, 18-21 and 22

were used to determine HIV risk due to drug or alcohol abuse. Risk due to sexual behavior was determined by first comparing incidence of vaginal sex with condom use and then combining those who reported unprotected sexual encounters, anal sex and those at risk due to history of sexual coercion (questions 34-39). Finally, risk due to prior diagnosis of STD was determined using survey questions 12 and 17 which includes those who had, at the time of the survey, identified themselves as being HIV positive. These transformed variables were then used to determine the HIV risk profile of the sample population. The precise wording of questions from the survey instrument used to determine the transformed variables can be found in Appendix C (Belcher et al., 2005).

Qualitative Data Analysis

Analysis of participants' responses during the interview process were used to provide insights into the relationship between functional health literacy and the participants' engagement with and reaction to both the standard (Georgia Department of Human Resources, 1997) and experimental (Wallace et al., 2006) HIV testing messages (Appendices A and B respectively). In an effort to minimize any potential researcher bias during qualitative data collection interviewers alternated the presentation of the brochures. Even numbered participants were shown the experimental low literacy message first and those assigned odd participant numbers were shown the standard testing message first.

All participant responses were entered into SPSS by this researcher then reviewed independently for accuracy. Constant comparative analysis (Lincoln & Guba, 1985) was used to develop a series of seven broad themes, with appropriate examples, for the qualitative data associated with each open response question. The categorical themes

used to describe the general subject of each response included: visual, testing, wording, prevention, feelings, treatment and general HIV knowledge. These themes were assigned codes which were then used to develop categorical variables within the data set. Each statement given by a participant in response to a given question was then coded by this researcher. Participants gave from one to three responses to each open ended question. In an effort to assess inter-rater reliability, a percentage of the data was reviewed and coded by an independent researcher using the established theme categories and a comparison was run to identify the level of agreement.

The qualitative data set was also saved as a portable Excel spreadsheet and sorted for manual analysis. The response data was organized according to the following scheme: by which brochure was seen first by the participant, sex and then by functional health literacy level. Parts of the data set were then reorganized in a number of ways in order to answer specific questions as they arose.

In addition to a manual analysis of the open ended question responses, SPSS was used to develop a generalized linear model which provided count totals and percents for each of the seven theme categories. These counts were then used to run linear regression analysis for each question. This analysis was used to investigate the influence, if any, the order in which the brochures were viewed or the functional health literacy level had on the type of responses expressed by participants.

Conclusion

Low functional health literacy plays a major role in disparities in access to and utilization of health care services by disadvantaged populations (Osborn et al., 2007). Efforts to eliminate health care disparities are particularly important if we are to meet the

public health goals of increasing Americans' knowledge of their HIV status, avoid delayed diagnosis and decrease new HIV infection rates in the U.S. which are disproportionately borne by disadvantaged populations (Campsmith, Rhodes & Hall, 2006). One important part of these efforts must be to ensure at-risk, minority populations have access to culturally sensitive informational brochures they find interesting and relevant (Wallace et al., 2006). These educational materials must attractively, yet clearly, convey the importance of knowing one's HIV status (Deming et al.).

This analysis confirms previous work conducted by the GSU/CDC research group which determined that accessibility, readability, cultural sensitivity and user-friendly formatting are important when attempting to engage at-risk adults with varying levels of functional health literacy in an HIV testing message (Wallace et al., 2006). This supports what has been determined by other literacy specialists producing health educational materials in general and HIV prevention and treatment materials in particular for adolescents and adults (Osborn et al., 2007; Mayben et al., 2007).

However; this data shows that many members of this population sample consider the quantity of information just as important. For reasons not elucidated by this data, many survey participants, including those with low functional health literacy, seemed to equate quantity of information with importance or the quality of the message. Additional research will be required to further clarify this issue. Base on these survey results it is clearly important to determine how much information is enough to maintain legitimacy and the reader's attention while simultaneously avoiding confusing mixed messages.

The visual aspects of the brochure can be essential in capturing the reader's attention and should be relevant to the target audience. Mono-colored graphics may be

perceived as dated and irrelevant or worse yet, threatening to some readers. Whenever possible culturally appropriate color photos of people depicting relevant content should be used rather than excess text and difficult medical terms should be eliminated (Wallace et al., 2006). If the brochure is intended to inspire the reader to learn their HIV status, wording on the cover and within the brochure should be used to focus the reader on this single main message.

African-Americans continue to bear a disproportionate amount of the STIs burden, including HIV, in the U.S. today (National Center for HIV/AIDS, 2010). This work highlights the utility of direct feedback from stakeholders in the development of community-specific health education materials in general and HIV testing messages in particular. Further research incorporating more of this type of direct feedback from members of target populations at high risk for HIV infection is needed if we are to learn how to best focus our message and expend HIV prevention resources to the greatest effect.

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CHAPTER 2

TITLE: HIV TESTING MESSAGES AS VIEWED BY LOW INCOME, URBAN ADULTS

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ABSTRACT

This study investigates the relation of health literacy level with perceptions of HIV testing brochure design and effectiveness among low income, urban adults at risk for HIV infection. It expands prior research by examining participant perceptions of a low literacy brochure as compared to a commonly available standard brochure advocating HIV testing. We surveyed 202 primarily low income, African-American clients of an urban CBO in Atlanta, Georgia. Participants' health literacy was tested using both the REALM and TOFHLA. Self-reported recent alcohol and drug use, sexual behavior, STD history and exposure to abuse and sexual coercion were used to determine HIV infection risk. Open-ended questions about the main message, relevance, ease of understanding and importance of each brochure provided the qualitative data. This paper highlights the utility of direct feedback from stakeholders in the development of community-specific HIV education materials. It supports prior assertions that accessibility, readability, cultural sensitivity and user-friendly formatting are important when attempting to engage at-risk adults with varying levels of functional health literacy in an HIV testing message yet also determined many community members believe quantity of information is just as important.

KEYWORDS: health literacy, HIV/AIDS, urban homeless population, health communications, health disparities.

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INTRODUCTION

The HIV/AIDS epidemic in the United States has been changing over time, becoming increasingly more common in minority and disenfranchised populations. The Centers for Disease Control and Prevention (CDC) reports, when categorized by race/ethnicity, African Americans bear the highest burden of HIV at all stages of the disease, from new infection to death (CDC, 2011). Additionally, AIDS diagnoses in the most populated states were highest in the South and Northeast regions (Peterman, Lindsey & Selik, 2005). According to the American Community Survey (US Census Bureau, 2009), the South is where the highest proportion of African Americans live. Finally, although the data affirm more Americans report being tested for HIV, nearly one third of new diagnoses still occurs late in the progression of the disease (CDC, 2011). We clearly have more work to do reducing the transmission of HIV among high risk minority groups by effectively communicating the process and benefits of HIV testing, increasing early diagnosis and connecting HIV positive individuals to effective treatment.

Research shows a clear association between low functional health literacy and reduced understanding of the need for and access to preventive care, decreased ability to self-manage personal medical issues or participate in treatment decisions and an overall poorer health status (Mika, Kelly, Price, Franquiz, & Villarreal, 2005; Safeer & Keenan, 2005; Shalowitz & Wolf, 2004). Low functional health literacy also plays a major role in disparities in access to and utilization of health care services by disadvantaged populations (Osborn et al., 2007). Efforts to eliminate health care disparities are particularly important if we are to meet the public health goals of increasing Americans' knowledge of their HIV status, avoid delayed diagnosis and

decrease new HIV infection rates in the United States which are disproportionately borne by disadvantaged populations (Mayben et al., 2007).

Adimora and colleagues examined the social contextual factors that contribute to the higher rates of sexually transmitted infections (STI) including HIV within minority populations (Adimora, Schoenbach & Doherty, 2006). A synthesis of this research supports the assertion that the disproportionate representation these populations have in new cases of HIV infection is a complex, multifaceted problem impacted by a number of economic, social and cultural factors (Adimora, Schoenbach & Doherty, 2006).

Socio-cultural contextual factors regarding social networks; such as high levels of concurrent relationships and increased interaction between the general population and high-risk, high-prevalence subgroups, play an important role in the increased incidence of STI including HIV (Adimora et al., 2006; Doherty, Leone & Aral, 2007). Additionally, reduced quality of education often experienced by young people in disadvantaged populations may perpetuate the lack of acquisition of written, verbal and other life skills needed to develop functional health literacy (Hurd, 1998). The increasing interdependence of everyday life and socio-scientific issues in general along with the rapidly evolving nature of clinical medical practice make the competencies of adaptive critical thinking and life-long learning an essential skill set for today's functionally literate citizens (Zeidler, Sadler, Simmons & Howes, 2005).

Research confirms that poor functional health literacy impedes not only one's ability to fully comprehend personal health issues, but also to effectively participate in essential preventative and treatment strategies. Patients with low literacy are less likely to understand the purpose of necessary tests and procedures (Lindau et al., 2002), correctly follow preoperative medication instructions (Chew, Bradley, Flum, Comia, & Koepsell, 2004), or to report accurate

information about their medical history (Wolf et al., 2005). Patients with low literacy skills are also less likely to utilize preventative health services (Gazmararian, Williams, & Baker, 2002; Scott, Gazmararian, Williams, Peel & Baker, 2003; Sudore, et al, 2006). Saffer and Keenan report that patients with low health literacy have poor adherence to recommended interventions and postpone making important decisions that directly impact health care outcomes (Safeer & Keenan, 2005).

This is especially true when dealing with complex medical syndromes such as HIV/AIDS. In one study of individuals receiving care at a community-based clinic in the Southern US, 48% of patients were reading below the 9th grade level. One-third of these patients could not name the medications they were taking to treat their HIV infection and 58% could not correctly describe how these drugs should be taken (Wolf et al., 2004). Additionally, participants with low functional health literacy were not only significantly more likely to have higher viral loads and more compromised immune functioning as measured by CD4+ T cell count but were also less likely to understand the meaning and significance of these commonly used determinants in predicting the progression from HIV infection to AIDS (Kalichman & Romps, 2000; Wolf et al., 2004). These findings indicate individuals with lower functional health literacy may suffer higher rates of HIV infection than do those with higher literacy skills, and after becoming infected, they are less likely to be connected to care or understand and adhere to the complex treatment regimen required to prolong the progression of the infection to AIDS and death.

Understanding and prevention of high risk behaviors take us a long way down the path to avoiding HIV infection. Early diagnosis and properly administered highly active antiretroviral treatment can be the key to shifting HIV infection from a death sentence to a manageable,

chronic disease, particularly among disproportionately represented minority groups. A number of factors, collectively known as low socioeconomic status (SES) have been shown to have a significant impact on health disparities experienced by these groups and even to increase mortality in HIV infected persons. A recent study by McMahon et al. (2010) demonstrated low quality education, poverty and homelessness have both direct and indirect negative effects on markers used by clinicians for monitoring patients' HIV disease. HIV positive individuals with low SES are more likely to have lower CD4+ cell counts and higher viral load levels compared to those not living under these adverse conditions. Consequently, these individuals have increased incidence of opportunistic infections and other complications which are known indicators of disease progression (McMahon et al., 2010). Therefore; it is particularly important that successful HIV prevention strategies be designed specifically for and implemented within these populations.

Although disparities in health literacy alone do not account for the disproportionate burden of HIV/AIDS in high risk minority populations, inaccessibility to culturally-sensitive appropriate HIV-related health education materials is a factor. In order to fully understand the advantages of knowing one's HIV status, individuals with low functional health literacy need a more tailored approach to HIV education and treatment programming. A readability study of commonly available HIV testing brochures showed that these materials are routinely written using medical terms and lengthy descriptions of potential problems associated with HIV/AIDS. These educational materials typically contain about 1000 words, over 200 of which are described as difficult by literacy experts (Wallace et al., 2006). The research described here attempts to contribute to these efforts by accessing primary stakeholders' opinions directly. Members of a low income urban minority community were questioned regarding their perceptions of a

commonly available HIV testing message compared to a more culturally sensitive message designed to be accessible to all adults, particularly those with low functional health literacy. The purpose of this analysis is to examine the relation of functional health literacy level and perceptions of HIV testing brochure design and effectiveness among primarily African-American low income, urban adults at risk for HIV infection living in a southern US city.

METHODS

The data used for this analysis were collected as part of a mixed method, cross-sectional survey study conducted previously by the GSU/CDC health literacy research group (Deming, Hunter, Belcher, Wallace & Choi). The original study was designed to explore the relationship between health literacy and HIV risk as well as HIV-related knowledge, HIV testing history and HIV risk reduction behavior. A separate IRB application was submitted and approved prior to the start of the subsequent analysis of qualitative data collected during that survey study.

Each participant's level of functional health literacy was tested using two measures; the Rapid Estimate of Adult Literacy in Medicine or REALM (Davis, Crouch, Long & Green, 1993) and the Test of Functional Health Literacy in Adults or TOFHLA (Nurss, Parker & Baker, 2001). These two instruments are most commonly used in research involving the effect of health literacy on a number of health issues (Davis, Michielutte, Askov, Williams & Weiss, 1998; Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004).

The REALM is a word recognition test used to assess an adult's ability to read aloud words commonly used in medical settings. This assessment takes approximately two to three minutes to administer and score and has high face validity, high criterion validity, and high test-retest reliability (Davis et al., 1998). However, the REALM is limited in that it is not related specifically to HIV/AIDS and assigns grade range equivalents, instead of specific grade levels.

The grade equivalents group participants' literacy skills into four categories: 3rd grade and below, 4th to 6th grade, 7th to 8th grade and high school (Davis et al., 1993).

The TOFHLA is a two part comprehension assessment which tests a participant's ability to understand written text of varying difficulty levels. It takes up to 22 minutes to administer and score and has good content validity; given it uses commonly used text from real health care settings (Nurss et al., 2001). During part I participants respond to prompts consisting of materials such as pill bottle instructions and appointment slips, thus measuring an individual's ability to use basic numerical information. Part II of the TOFHLA uses a 50-item multiple-choice modified cloze procedure to assess reading comprehension. The respondent's total TOFHLA score is then calculated by adding the weighted numeracy and reading comprehension raw scores. The total score is then used to determine a functional health literacy level of inadequate, marginal or adequate (Nurss et al., 2001).

In addition to the health literacy assessments, a survey questionnaire designed by the research group was also administered. Questions used in the survey instrument to assess HIV risk behavior were inspired by those used in a number of national surveys including the National Survey of Family Growth conducted by the CDC National Center for Health Statistics (Anderson, Mosher & Chandra, 2006). The survey study focused on four primary factors to investigate an individual's risk for HIV infection. These included asking participants to self-report recent alcohol and drug use, recent sexual behavior, history of STD and exposure to abuse or sexual coercion.

The survey instrument also included a series of questions designed to inform researchers about participants' perceived risk of acquiring HIV, prevention strategies such as HIV testing history and condom use. Data regarding participants' understanding of other HIV/AIDS issues

and their level of trust in sources of information about the prevention of HIV/AIDS were also included in the survey questionnaire but not used in this analysis.

Procedures

The following is a summary of procedures used to conduct the survey study during which the data for the present study were collected. These procedures include participant recruitment, functional health literacy assessment, the development and administration of the survey instrument, as well as the data collection methods used.

During the recruitment phase approved flyers calling for potential participants were posted throughout two facilities and announcements were made with the help of CBO employees and volunteers. Because of the transient nature of the CBO clients, researchers knew it would be difficult to contact most potential participants outside of the facilities. Therefore, a researcher was stationed at each facility during peak flow hours to discuss the study requirements with potential participants and to make appointments to conduct the survey at a later time convenient for them.

As anticipated, once the survey began, potential participants were also recruited through word-of-mouth from already surveyed individuals. Although some researchers have considered this type of snowball-based sampling methodology problematic, others have recognized its utility in helping researchers access hidden populations (Faugier & Sargent, 1997). This type of sampling enables researchers' access to hard-to-reach populations whose members do not have stable, easy-to-locate lives. This practical approach provides researchers with an expanding set of potential contacts within populations where some degree of trust is required that the researcher has characteristics associated with being an insider or group member (Atkinson & Flint, 2001). Trust was further enhanced by the fact that at least three members of the research team

responsible for conducting the survey study had prior experience working with the clients served by the CBO from which the participants were recruited. Additionally, participants were given the opportunity to meet the small, ethnically diverse group of interviewers in advance and choose the date and time of their interview.

Each potential participant was shown to a private area within the facility and asked a series of questions to establish eligibility. Once the potential subject was deemed eligible and gave verbal consent to participate in the study they were again asked to verify they were over 18 years of age by giving the year of their birth. Each participant was then assigned a numbered packet containing the documents used to record the results of the literacy assessments and the survey instrument. From this point forward the participant would be identified by number only. The researcher or trained assistant then explained they were about to administer two health literacy assessments.

During the administration of the first instrument, the REALM, participants with corrected vision were asked to use their glasses if they had them. However, the large print version of the word list, which is designed to accommodate individuals with 20/200 vision (the level of legal blindness), was used consistently to avoid participant embarrassment or difficulties due to visual acuity. Each participant was then asked to say each word aloud. Any word correctly articulated by the participant or self-corrected after a faulty attempt was counted as correct. Participants were not informed of their total scores. If asked, the researcher would simply reply, with compassion and respect, the participant had done well.

Upon completion of the REALM, the TOFHLA was administered. To ensure uniformity of administration and scoring of the TOFHLA, each prompt was presented in the large font version and was accompanied by specific information that instructs the researcher on how to

administer that prompt (Nurss et al., 2001). The raw numeracy result was converted to a Weighted Numeracy Score and recorded on the back cover of the test booklet (Nurss et al., 2001).

During the reading comprehension portion of the TOFHLA, participants were instructed to read passages in which every fifth to seventh word had been deleted (Nurss et al., 2001). The participant was then asked to choose one of four words that correctly completed each phrase of the passage.

As soon as the interview was complete, each section of the TOLFHLA was scored using the answer key provided with the version of the test used (Nurss et al., 2001). The subtotals were summed to give the Reading Comprehension Raw Score. The respondent's total TOFHLA score was then calculated by adding the weighted numeracy score and reading comprehension raw scores. The respondent's functional health literacy level was then determined using the inadequate, marginal or adequate scale interpretation provided by the test designer (Nurss et al., 2001).

Upon completion of the literacy instruments the Literacy Project Survey designed by the GSU/CDC research group was administered. The quantitative data collected from survey respondents included demographic information on age, education level, marital standing, income, and housing status. Although data from epidemiologic studies have shown a number of behaviors are closely linked to transmission of HIV (Anderson, Mosher & Chandra, 2002) researchers conducting the survey study focused on four primary factors to investigate an individual's risk for HIV infection. Interviewers asked participants to self-report recent alcohol and drug use, recent sexual behavior, history of STD, and exposure to abuse or sexual coercion. A series of questions designed to inform researchers about participants' perceived risk of

acquiring HIV, prevention strategies such as HIV testing history and condom use, as well as understanding of other HIV/AIDS issues were also included in the survey questionnaire developed by the GSU/CDC research group. Although questions used in the survey instrument to assess HIV risk behavior and prevention strategies were the same as those used in national surveys the exact wording of the questions used were also reviewed by literacy experts at GSU. Participants who completed the health literacy assessments and the survey instrument were given \$30 for their time and travel. The funding was provided through a grant from the CDC.

All data collected were de-identified using a participant numbering system. The data from each instrument were then entered using the IBM SPSS (2009) Statistics program version 18 with a variable scheme designed by this researcher. The data were warehoused in a file and saved for later analysis. This researcher used the original data sources only to verify the accuracy of all 240 variables on each of the 202 participants found in the data set. During this data validation process it was determined that one interviewer failed to follow established research protocol on one occasion by allowing participants to be interviewed together. Thus all data from participants 170, 171 and 191 were administratively dropped from the data set for this analysis. This established the working data set made up of 199 valid subjects, 98 male and 101 female from which this analysis was taken.

Quantitative Data Analysis

Once the working data set was established, several analytical procedures were undertaken. Descriptive frequencies were run to determine the demographic characteristics of participants. These included but were not limited to age, sex, highest grade completed in school, current HIV status, marital standing, current housing type and financial circumstance.

The warehoused data provided both participants' numerical test results and categorical interpretations for both health literacy measures. Consequently, both linear regression and Chi Square cross tabulation analysis were used to compare the level of agreement between results of the REALM and TOFHLA.

Using affirmative answers to related survey questions, a number of variables were developed to group responses and classify HIV risk characteristics into each of three broad categories. Survey questions 13, 14, 18-21 and 22 were used to determine HIV risk due to drug or alcohol abuse. Risk due to sexual behavior was determined by first comparing incidence of vaginal sex with condom use and then combining those who reported unprotected sexual encounters, anal sex and those at risk due to history of abuse or sexual coercion (questions 34-39). Finally, risk due to prior diagnosis of STD was determined using survey questions 12 and 17 which included those who had, at the time of the survey, identified themselves as being HIV positive. These variables were then used to determine the HIV risk profile of the sample population.

Qualitative Data Analysis

Analysis of participants' responses during the interview process were used to provide insights into the relationship between functional health literacy and the participants' engagement with and reaction to both the standard (GDHR, 1997) and low literacy (Wallace, et al., 2006) HIV testing brochures. In an effort to minimize any potential researcher bias during qualitative data collection interviewers alternated the presentation order of the brochures. Even numbered participants were shown the low literacy brochure first and those assigned odd numbers were shown the standard brochure first.

All participant responses were entered into SPSS then reviewed independently for accuracy. Constant comparative analysis (Glaser, 1965) was used to develop a series of seven broad themes, with appropriate examples, for the qualitative data associated with each open response question. The categorical themes used to describe the general subject of each response included: visual, testing, wording, prevention, feelings, treatment and general HIV knowledge. These themes were assigned codes which were then used to develop categorical variables within the data set. Each statement given by a participant in response to a specified question was then coded by this researcher. Participants gave from one to three responses to each open ended question. To assess inter-rater reliability, a percentage of the data were reviewed and coded by an independent researcher using the established theme categories and a comparison was run to identify the level of agreement.

The qualitative data set was also saved as a portable Excel spreadsheet and sorted for manual analysis. Data were organized according to the following scheme: order of brochure presentation, sex and then by functional health literacy level. Parts of the data set were then reorganized in a number of ways in order to answer specific questions as they arose.

In addition to a manual analysis of the open ended question responses, SPSS was used to develop a generalized linear model which provided count totals and percents for each of the seven theme categories. The theme category percents were then used to compare the distribution of responses between literacy groups for each question.

RESULTS

Demographics

The sample used for this analysis ultimately consisted of 98 males and 101 females, most of which (over 89%) were African-American, ranging in age from 19 to 67 years with a mean

age of 43.7 years. The largest individual group of participants (43.3%) self-reported as never having married. Another 47.7% said they were divorced, separated or widowed and only 9% reported being married.

The majority (63.8%) of participants described their current living arrangement as a shelter, welfare hotel or other similar facility. Ten percent reported currently living on the street and only 26.2% claimed living in a home or apartment. Greater than 90% of participants reported having a lower monthly income than the poverty threshold of \$902.50 determined by the U.S. Department of Health and Human Resources (2009). Twenty-five percent of participants reported having no monthly income. Another 26.2% identified as having \$150 or fewer dollars per month to live on; 14.5% reported between \$150 and \$300 of monthly income; 22% acknowledged having between \$330 and \$800; and only 9.5% claimed more than \$815 dollars of monthly income.

Reported educational attainment was similarly lower than the 62.4% published rate for Georgia during 2005-2006 (Cataldi, Laird & Kewal-Ramani, 2009). When participants were asked to report the last grade completed in school 37.5% reported never graduating from high school, with 12.6% having completed only the 9th grade or below. The 33.7% of participants who reported completing the 12th grade includes those completing a GED or equivalent certificate. Nearly twenty percent (19.6%) indicated having between one and two years of college level education and a further 22 participants (11%) reported having from three to five years of education beyond high school.

A recent study by Campsmith, Rhodes and Hall (2006) of the CDC confirms the disproportionate burden of undiagnosed HIV infection borne by racial minorities and further highlights the essential role comprehensive testing plays in stemming the tide of new infections

in the US. The warehoused data used for this analysis showed a greater proportion of participants having been tested for HIV, at least once, than would be expected among the urban homeless due to requirements of the employment readiness program from which 64% of the subjects were recruited. Some 89% of participants reported already having agreed to HIV testing. However, 7% of those tested never went back to get the results so fewer than 82% stated they knew their HIV status. Specifically, 76% reported their last test showed they were HIV negative; 6% identified being HIV positive; 7% said they were not sure and 11% stated they had never been tested.

Survey data also showed the degree of misperception many participants harbored regarding their level of risk for infection with HIV. Although 91% of participants agreed that AIDS is a serious problem in their community, after excluding those participants who reported being HIV positive, only 41.2% worry they have the AIDS virus and 34.2% agreed they currently need an HIV test. Additionally, 76% of participants stated they had a “very good” or “excellent” understanding of how to protect themselves from HIV infection and 66.3% reported their life style as “very safe”. However analysis of reported behavior from non-HIV positive participants showed 66.8% were at increased risk of HIV infection due to drug or alcohol abuse, 94.7% were at increased risk due to sexual behavior, and 43% reported a prior history of STD. Cumulatively, 98.4% of non-HIV positive study participants were at increased risk for acquiring HIV due to reporting one or more of these risk factors.

Functional Literacy Level

The warehoused data provided the numerical test results and categorical interpretations of the REALM and TOFHLA for each study participant. Consequently, both linear regression and Chi Square cross tabulation analysis of the results were completed. This analysis confirms that

these two measures demonstrate a high degree of correlation (Pearson's $R = .776$). Table 1 shows the cross-tabulation analysis of participant results, by sex, for both measures.

Nearly 12% of study participants scored 59 or less, within the inadequate range on the TOFHLA. Another 12% scored in the marginal range, between 60 and 74. The majority of participants (76%) demonstrated adequate functional health literacy by scoring 75 or above. The proportion of respondents in this study having a functional health literacy level of inadequate or marginal was less than the 36% of adults demonstrating basic or below on the health literacy component of the 2003 National Assessment of Adult Literacy (Kutner, Greenberg, Jin & Paulsen, 2006). For purposes of this analysis those participants scoring 0-74 (inadequate or marginal) on the TOFHLA were grouped together and designated as having less than adequate functional health literacy.

Table 1: *Participant sex * TOFHLA Functional Health Literacy Level * Converted REALM Score Cross-tabulation*

Converted REALM Score		TOFHLA Functional Health Literacy Level						Total
		0-59 Inadequate		60-74 Marginal		75-100 Adequate		
0-6th grade	male	13	13%	5	5%	4	4%	22
	female	7	7%	6	6%	2	2%	15
	*Total	20	10%	11	6%	6	3%	37
7th- 8th grade	male	3	3%	2	2%	28	29%	33
	female			6	6%	29	29%	35
	*Total	3	2%	8	4%	57	29%	68
high school	male			2	2%	41	42%	43
	female			3	3%	48	48%	51
	*Total			5	3%	89	45%	94

* Percent of total participants

Results from Qualitative Data

As stated previously, in order to collect the qualitative data, participants were shown each HIV testing brochure and asked a series of open-ended response questions regarding the presentation and understandability of each brochure as well as the importance of its main message. Researchers alternated the viewing of the two brochures with an accuracy of 96%. The order in which the brochures were viewed appeared to influence participants' responses to some survey questions.

Individual participants gave from one to three responses to each question, providing a total of 2,453 comments. Each response was subsequently categorized by subject and cross-tabulation was used to produce data tables for summary analysis. Reliability of response categorization was confirmed by an independently trained researcher rating 786 (32%) of the statements. Rating agreement exceeded 94%. Any comment rated differently was discussed and a consensus was reached. Table 2 shows the distribution of categorical responses to three of the questions: "What got your attention"; "What was important to you"; and "What made it understandable" posed after the participant viewed the each brochure.

The majority of survey participants (86%) either agreed or strongly agreed the standard brochure got their attention. When asked to describe what got their attention, the majority of participant responses (74.6%) focused on three areas prevention, testing and general HIV knowledge. The major between group differences included responses categorized as testing and general HIV knowledge. Those with less than adequate health literacy commented more on testing (25% vs. 19%); while comments from those with adequate health literacy were more often categorized as general HIV knowledge (28% vs. 20%).

Responses concerned with prevention included a number of comments like; "different

ways to get HIV” or “how simple it is to catch AIDS” and “how to protect yourself and using condoms the right way” or “the part about using protection for oral sex”. Responses classified as HIV knowledge included general references to prior knowledge like; “I knew a lot of what was in the brochure” and “I had a HIV class and the brochure brought the things about the class to my memory” as well as more specific references such as; “how AIDS can start off not that serious and then get worse with full blown AIDS” and “what percentage of women have AIDS and their age group”. While those concerned with testing included phrases like; “the different ways of getting tested” and “get tested will help you live longer”.

When asked if the low literacy brochure got their attention, an even larger proportion of participants (89.9%) agreed or strongly agreed. However, when asked to explain what got their attention a far greater proportion of responses concerned the visual aspect of the brochure while far fewer were classified as general HIV knowledge within both literacy groups.

Most of the comments categorized as visual concerned the pictures presented in the low literacy brochure. Responses ranged from generic comments given by those with less than adequate functional health literacy such as “it’s colorful and simple” or “the graphic pictures” and “the photos reminded me of events in my life” to specific references from those with adequate health literacy like “the guy injecting himself” or “the young lady being provocative”. Others commented on the layout of the brochure, making statements such as “the layout is really good” and “the arrow lines for the statements”. One participant who viewed the low literacy brochure second commented “it has a comic book format and layout” while another said it was “more realistic” because of the color pictures.

Table 2: *Participants. Perceptions of Brochures by Response Category*

	STANDARD BROCHURE						LOW LITERACY BROCHURE					
	What Got Your Attention?		What Was Important to You?		What Made it Understandable?		What Got Your Attention?		What Was Important to You?		What Made it Understandable?	
HEALTH LITERACY CATEGORY	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE
	percent											
Visual	6.8	10.2	3.5	0	26.7	26.1	31.6	25.6	3.7	2.8	40.0	28.3
Testing	25.4	19.2	17.2	23.7	5.0	3.3	21.0	29.0	35.2	51.4	3.3	2.6
Wording	10.2	15.6	0	4.1	36.7	51.6	12.3	16.3	1.8	5.0	43.3	57.6
Prevention	28.8	24.5	58.6	47.9	16.7	4.9	10.5	12.8	31.5	22.9	5.0	4.2
Feelings	3.4	0.6	3.5	4.7	0	1.6	3.5	2.9	5.6	1.1	3.3	2.1
Treatment	5.1	1.8	6.9	5.3	6.6	4.9	15.8	7.0	9.3	10.6	0	2.1
HIV Knowledge	20.3	28.1	10.3	14.2	8.3	7.6	5.3	6.4	12.9	6.2	5.0	3.1
	number											
Total Number of Comments	59	167	58	169	60	184	57	172	54	179	60	191
Participants per literacy level	47	152	47	152	47	152	47	152	47	152	47	152

Similar results were observed when participants were asked if the standard brochure said something important to them. Some 74.6% of participants with less than adequate and 88.8% of those with adequate health literacy agreed or strongly agreed the standard brochure said something important.

When asked what they found important about the standard brochure, prevention was the common theme for participants of both literacy levels. Of the 227 total comments recorded, 115 (50.6%) mentioned prevention. General comments classified as being concerned with

prevention included; “the risk factor of catching HIV”; “how to protect yourself”; and “how to be cautious and what to be cautious of”. More specific responses such as; “the information on oral sex, using protection with it”; “that you shouldn’t have unprotected sex and always use condoms”; as well as “not getting HIV means not having sex” and “abstinence was the best message” were concerned mainly with safe sex practices. In addition, nearly 15% of the prevention comments mentioned vertical transmission of HIV from mother to child. These included responses such as; “... passing HIV along to children”; “knowing that if you’re pregnant the baby may get it too”; and “information I didn’t know like breast milk”.

The second highest response category for what participants found important about the standard brochure concerned testing. After viewing a brochure titled “Should You Be Tested for HIV”; only about 1 in 5 comments from those in either literacy category could be classified as testing. These included simply “get tested” and “getting tested can ease my mind” from participants with less than adequate literacy. A few adequately literate participants mentioned “you have to get tested every six months” and “it may be too early to know if you’re negative or positive”.

Different results were observed when participants were asked what was important about the low literacy brochure. The majority of responses (51.4%) from participants with adequate health literacy focused on the rapid test described in the brochure. Comments such as “the 20 minute test” and “the easy way to take the test, the shorter wait time” were used frequently. Based on their responses, it was clear the low literacy HIV brochure evoked thoughts of testing in the minds of many participants.

The 54 comments from those with less than adequate health literacy were more equally distributed among testing (35.2%) and prevention (31.5%) with the final third covering the

remaining categories combined. More of these participants mentioned actions they observed in the realistic photos used in the low literacy brochure rather than simply focusing on the text.

After viewing the low literacy brochure, one participant with less than adequate literacy reported the action photos were a “reminder of when I was killing myself and thinking that I was happy about it”.

Although alternating the presentation of the standard and low literacy brochures was undertaken in an effort to negate unintentional bias toward either document, this process appeared to have noteworthy effects on participants’ perceptions of the different brochures. This included whether a particular brochure was difficult to understand and if it provided too much information.

Of those who viewed the standard brochure first, only two participants stated the brochure was difficult to understand. When asked about what made it difficult one participant with less than adequate health literacy said; “it may have a couple of words people don’t really understand”. Another participant, with adequate health literacy, was more concerned about how the standard brochure looked stating; “it’s antique, doesn’t have enough information about cleaning needles, statistics need to be up to date”. Only four of these participants agreed the standard brochure provided too much information.

Yet among those who viewed the low literacy brochure first, when asked if the standard brochure was understandable, 11 (>10%) said “no” and two admitted they “didn’t know”. Additionally, some 18% (19) reported the standard brochure provided too much information.

When asked what made it difficult to understand the majority of comments focused on the brochure’s wording. Statements such as “it was too wordy”; “too many passages”; “it had too many numbers” and “the big words” were common. One participant with adequate health

literacy focused on the feelings inspired by the brochure saying “There is no cure for AIDS. It seems hopeless. It should say we can treat the symptoms”.

Reported observations regarding the accessibility of information provided in the low literacy brochure appeared to be less effected by the alternation of brochure viewing. Unlike the standard brochure, when asked if the experimental brochure was understandable fewer than 4% said no regardless of whether they viewed it before or after the standard brochure. The same result was observed when respondents were asked if the low literacy brochure provided too much information. About 4% agreed or strongly agreed that the low literacy brochure provided too much information; 3.9% for those who viewed it first and 4.2% of those who viewed it after the standard brochure.

The majority of study participants agreed the standard brochure was understandable. The 60 comments provided by those with less than adequate health literacy focused mainly on wording (36.7%), visual (26.7%) and prevention (16.7%) categories. Responses classified as wording included “when I come to word I don’t know I just continue to read the rest of the paragraph, 9 out of 10 times it comes together so I can understand it” and “by just scanning the brochure, I didn’t see any hard words”. Others like the layout saying “it was broken down into sections”. Comments like “the pictures show you what is going on” and “the picture of doctors, where they are checking blood” were categorized as visual. The response “it explained what people should do in terms of sexual contact and sharing needles” was representative of those categorized as prevention.

Responses regarding what made the low literacy brochure understandable were more tightly clustered within the wording and visual categories. Of the 60 comments made by participants with less than adequate health literacy, 26 (43.3%) concerned the wording and 24

(40%) described visual aspects of the low literacy brochure. The wording category included statements such as “it makes you look at things differently, with easy to understand words” and “it was easy to read and it is short, so if a person was just browsing, they would still get the information”. Whereas comments categorized as visual most often concerned the photos of real people saying “the pictures included are on your mind” and “these are things that happen every day”.

Participants with adequate health literacy provided 191 comments when asked what made the low literacy brochure understandable. Some 110 (57.6%) of these statements can be represented by comments such as “it’s simple, to the point” or “it’s plain and simple, no big words, not too many words” and “its precise, no long definitions or hard medical terms”. Some participants did make reference to the brochure’s formatting by saying “the questions used”, “it’s not a bunch of bigger paragraphs and a lot of space” or “the big writing” and “the lines take you through it”.

Although the intention was to convince readers of the importance of knowing one’s HIV status there was no clear consensus on a single main message conveyed by the standard brochure. Table 3 shows a comparison of the comments made by participants within both literacy groups when asked about the main message of the standard brochure. All participants appeared to be equally conflicted about this question; however, the majority reported the main message was about prevention. As with questions regarding the accessibility of information in the two brochures, responses about the main message of the standard brochure were also influenced by the order in which the brochures were viewed.

More than half (54.4%) of responses about the standard brochure’s main message from participants with less than adequate health literacy were classified as prevention. Statements

such as “how to get HIV and how to prevent it” or “how to keep from catching AIDS” were common. Only 21% of these participants thought the main message was about testing. This sample was represented by comments like “if you are at risk get tested” or simply by reciting the title of the standard brochure: “Should you be tested for HIV? I think everybody should”.

Although less overwhelming, the largest single category of responses (44.3%) from those with adequate health literacy was also prevention. Several participants within this group mentioned directly that they got a “mixed message” from the standard brochure. One participant reported “there is not a main message, it talks about all different things” while another stated “the front said ‘should you be tested?’ but the inside had too much information”.

Table 3: *Categorical Distribution of Responses to “What was the Main Message of this Brochure”*

	WHAT WAS THE MAIN MESSAGE OF THIS BROCHURE?			
	Standard		Low Literacy	
HEALTH LITERACY CATEGORY	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE
	percent			
Visual	1.8	0.0	0.0	0.0
Testing	21.0	38.7	40.3	54.3
Wording	0.0	3.1	0.0	0.5
Prevention	54.4	44.3	45.1	33.7
Feelings	7.0	0.5	1.6	3.0
Treatment	7.0	5.1	6.5	7.0
HIV Knowledge	8.8	8.3	6.5	1.5
	number			
Total Number of Comments	57	194	62	199
Participants per literacy level	47	152	47	152

Just over a third of these participants' responses (38.7%) mentioned testing as the main message. Statements such as "if you are doing risky behavior, you should get tested" and "don't be complacent, get tested" were common. Many of those participants who did mention testing also noted the contact information in the standard brochure and advised "take responsibility to reach out to the health center" or "talk to your doctor".

These proportions did change for those who viewed the low literacy brochure before the standard brochure. When examined from this prospective the proportions of standard brochure main message responses classified as prevention and testing were 38.9% and 38.2% instead of 55% and 30.8% respectively.

Study participants were decidedly clearer about the main message of the low literacy brochure. The 152 participants with adequate health literacy gave 199 comments about the low literacy brochure's main message, 54.3% of which concerned testing. The phrase "get tested" was repeated more than 90 times. Other participants advised "don't be afraid to get tested" and "it's easier now because it takes 20 minutes to get the results".

More than 53% of participants (25) with less than adequate health literacy mentioned testing as the main message of the low literacy brochure. Several of these respondents restated a phrase directly from the brochure "be sure, be safe, get tested today". However; overall a greater proportion of total responses were categorized as prevention (45.1%) rather than testing (40.3%) because participants made statements like "stop sharing needles, stop having so many sex partners" and "if you want to live longer protect yourself" before repeating "get tested". Others made reference to the actions depicted in the brochure saying "if you've been doing the wrong thing, you need to get tested" and "if you think you are at risk, get tested". Those making no mention of testing included statements such as "try to keep from getting infected, take care of

yourself” or “be safe, not sorry” and “there is some new medicine to help you live longer.

The final two questions of the survey asked the participants to compare the two brochures. These questions asked respondents; “If you were at a clinic, which brochure would you pick up to read” and “Which brochure did you relate to more”? Once a stated preference was declared each participant was asked to explain why they made that choice.

The majority of participants (50.8%) stated they would pick up the standard brochure while 44.2% chose the low literacy brochure and 5% stated they would pick up both brochures. The participant’s choice of brochure did not appear to be significantly influenced by their health literacy level or the order in which the brochures were viewed. Yet when asked to describe why they would pick up a particular brochure first some interesting responses were noted.

When asked why they chose the standard brochure over the low literacy brochure, quantity, rather than accessibility of information, appeared to have greater influence. Nearly 70% of comments from both literacy groups classified as wording. Among the 110 responses given by these 101 participants the phrase “it has more information” was repeated 52 times. Comments such as “it’s thicker”; “it has more pages” and “it’s more detailed” were also common. A few participants with adequate functional health literacy stated that the standard brochure was “more in depth” or “more thorough” while one admitted simply “because it looks like it has more information”. Many of the 88 participants who stated a preference for the low literacy HIV brochure also commented on the amount of information the brochure provided. Responses such as “it’s short and to the point”; “it’s less to read” and “it has less pages” were common. Table 4 shows a summary of this data.

A greater proportion of the comments from those who preferred the low literacy brochure concerned the brochure’s visual aspects than those who chose the standard brochure; 47.8%

compared to 21% respectively. The graphic colors were a common source of interest. Several participants made general comments such as “it’s colorful”; “the vibrant colors make it more appealing” and “it looks more ‘magazine-ish’ while the other pamphlet looks like a boring hospital type”. While others commented on the photos in particular reporting “it shows an urban setting, which is how Atlanta is” and “the color, actual photos of real people”. Others liked the cover and the large print saying “the graphics and message on the front is clear”.

Those participants who declared they would pick up both brochures expressed a belief the brochures were complementary. This was evidenced by comments like “they are informative and go together” and “they both tell you about HIV, what to expect and what not to do”.

Table 4: *Distribution of Responses Regarding Preference for Brochure “Pickup” and “Relate”*

	WHICH BROCHURE WOULD YOU PICK UP TO READ?						WHICH BROCHURE DID YOU RELATE TO MORE?					
	Standard		Low Literacy		Both		Standard		Low Literacy		Both	
HEALTH LITERACY CATEGORY	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE	INADEQUATE	ADEQUATE
	percent											
Visual	15.4	22.6	47.6	47.9	30.0	28.6	14.3	9.1	50.0	32.3	0.0	0.0
Testing	0.0	3.6	0.0	3.2	0.0	0.0	0.0	1.0	8.3	9.1	0.0	0.0
Wording	69.2	67.9	38.1	39.4	30.0	14.3	54.3	67.7	29.2	43.4	0.0	50.0
Prevention	7.7	2.4	0.0	1.1	0.0	0.0	17.1	9.1	0.0	4.0	0.0	0.0
Feelings	7.7	1.2	9.5	8.5	30.0	28.6	8.6	8.1	4.2	9.1	100.0	50.0
Treatment	0.0	0.0	0.0	0.0	0.0	14.3	2.9	0.0	4.2	2.0	0.0	0.0
HIV Knowledge	0.0	2.4	4.8	0.0	10.0	14.3	2.9	5.1	4.2	0.0	0.0	0.0
	number											
Total Number of Comments	26	84	21	94	10	7	35	99	24	99	1	6
Participants per literacy level	24	77	17	71	6	4	27	81	19	67	1	4

When asked to declare which brochure they would “relate to more” results similar to those regarding brochure pickup were observed. The majority of participants (54.3%) claimed they relate more to the standard brochure while 43.2% chose the low literacy brochure and 2.5% stated they related equally to both brochures. Once again, those who failed to report a preference for a particular brochure focused on the complementary nature of the information. One participant with inadequate health literacy stated “it’s like part 1 and 2”.

As shown in Table IV, when asked why, the 108 participants who reported relating more to the standard brochure made a total of 134 statements. Some 60% of these comments concerned the quantity of information presented. Once again, the most common reason given was the standard brochure “has more information”, “is more detailed” or “has more reading”.

Some participants related more to specific aspects of the brochure. A few participants stated that they related more to the standard brochure because it had information about “pregnancy” or “it showed the mother and baby”. While others reported that the standard brochure was “more clinical looking” because it showed “doctors”. Four participants stated that they (or a close family member) have HIV and they “want everyone to know how serious this disease is”.

The 86 participants who stated they relate more to the low literacy brochure made a total 123 comments when asked why. Almost 41% of these comments referred to the brochure’s wording. Among these, statements such as “it’s simple” and “it gets to the point” were repeated 36 times. A few participants commented “it talked to me in an easy way to understand” and “it’s more on my level”. Still others related to the title and “bold lettering”.

Participants seemed very interested in the fact that the low literacy brochure featured color photos of real people. More than 40% of the participants who reported relating more to the

low literacy brochure made reference to the photos. These references included comments such as “it showed real people you’d see on the street”, “it shows people doing things that are risky” and “I lived most of the lifestyles in this brochure so the pictures remind me of past behavior”. A few respondents expressed their feelings by saying “the second one would make you more afraid to get tested, the first one would make you less afraid” and “it’s more to the point, not as threatening and doesn’t tell readers don’t do risky things”. Others thought the color photos made the brochure look “newer” and “more up to date”.

Those participants whose comments focused on testing were interested in the rapid HIV test discussed in the low literacy brochure. These respondents were best represented by comments such as “it’s more simple and has information about the rapid test” and “I’m curious of the 20 minute testing”.

DISCUSSION

Warehoused Data Strengths

The data analyzed here had a number of strengths and limitations for studying health literacy, sexual behavior and HIV prevention strategies in the low income, urban populations.

- Due to the high comfort level of potential participants with the presence and interaction with the researchers the conductors of the survey study enjoyed an extremely high response rate.
- The survey data used in this study was collected within an urban, low income, primarily African-American community.
- The face-to-face interview technique used to collect the data allowed for completion of all survey questions which helped minimize the customary problem of missing data seen with traditional paper and pencil surveys.

- The use of a small, ethnically diverse group of trained interviewers helped to maintain internal consistency of the data set.

Warehoused Data Limitations

- Although snow-ball sampling has been demonstrated effective for use in vulnerable populations such as the homeless (Faugier & Sargent, 1997), it is not a rigorous design that allows results to be generalized to larger, more inclusive populations.
- Due to the relatively small overall sample size, some subgroups having specific characteristics were small.
- As with any survey conducted using face-to-face interviews resulting data could be affected by underreporting of risk behaviors.
- The survey participants fall into an age range between 19 and 66 years meaning that younger community members also at risk for HIV infection were not represented in this sample.
- Numbers of participants having already undergone HIV testing may be higher than would otherwise be expected due to the requirements of the employment readiness program from which a majority of the subjects were recruited.

After verifying the functional health literacy of study participants and confirming the HIV risk potential of this sample of the low income, urban population the goal of this analysis was to use primary qualitative data to increase our understanding of how a target audience, in this case low income African-American adults, at risk of HIV infection, feels about HIV testing messages and the relation functional health literacy has on these perceptions.

In general, this analysis confirmed that the majority of the population sampled was low SES, minority adults with adequate functional health literacy at increased risk of HIV infection.

Nearly all participants agreed that both the standard and low literacy brochures got their attention and said something important to them. Yet about one in ten participants reported the standard message difficult to understand mainly because of the medical terms used.

When asked about the main message of the standard brochure most responses given by participants were categorized as something other than testing. Although a number of important messages, such as those dealing with prevention and general HIV knowledge were cited only about one in three participants who viewed the standard brochure got the intended message about being tested for HIV. That proportion increased slightly for those participants in both literacy groups who viewed the standard brochure after viewing the low literacy brochure.

This was not the case with the HIV testing message presented in the low literacy brochure. Few participants found this brochure difficult and more than two out of three participants reported the main message of the low literacy brochure was to get tested for HIV. This result remained consistent regardless of brochure presentation order.

Although about half stated if in a clinic they would pick up the standard brochure and they relate to it more, most survey participants reported interest in the culturally relevant color photos depicted in the low literacy brochure as well as the format used. When asked why they choose a particular brochure, participants cited the quantity rather than the accessibility of the information provided by the brochure as the major factor.

CONCLUSION

Low functional health literacy plays a major role in disparities in access to and utilization of health care services by disadvantaged populations (Osborn et al., 2007). Efforts to eliminate health care disparities are particularly important if we are to meet the public health goals of increasing Americans' knowledge of their HIV status, avoid delayed diagnosis and decrease new

HIV infection rates in the United States which are disproportionately borne by disadvantaged minority populations (Campsmith et al., 2009; Osborn et al., 2007; & Mayben et al., 2007). One important part of these efforts must be to ensure at-risk, minority populations have access to culturally sensitive informational brochures they find interesting and relevant (CDC OMH, 2007). These educational materials must attractively, yet clearly, convey the importance of knowing one's HIV status (Wallace et al., 2006).

This analysis confirms previous work conducted by the GSU/CDC research group which determined that accessibility, readability, cultural sensitivity and user-friendly formatting are important when attempting to engage at-risk adults with varying levels of functional health literacy in an HIV testing message. This supports what has been determined by other literacy specialists producing health educational materials in general and HIV prevention and treatment materials in particular for adolescents and adults (Osborn et al., 2007 & Estey, Musseau & Keehn, 1991).

However; this data shows many members of this population consider the quantity of information just as important. For reasons not elucidated by this data, many survey participants, including those with low functional health literacy, seemed to equate quantity of information with importance or the quality of the message. Additional research will be required to further clarify this issue. Based on these survey results it is clearly important to determine how much information is enough to maintain legitimacy and the reader's attention while simultaneously avoiding confusing mixed messages.

The visual aspects of the brochure can be essential in capturing the reader's attention and should be relevant to the target audience. Mono-colored graphics may be perceived as dated and irrelevant or worse yet, threatening to some readers. Whenever possible culturally appropriate

color photos of people depicting relevant content should be used rather than excess text and difficult medical terms should be eliminated (Wallace et al., 2006). If the brochure is intended to inspire the reader to learn their HIV status, wording on the cover and within the brochure should be used to focus the reader on this single main message.

African-Americans continue to bear a disproportionate amount of the STIs burden, including HIV, in the US today (CDC, 2011). This work highlights the utility of direct feedback from stakeholders in the development of community-specific health education materials in general and HIV testing messages in particular. Further research incorporating more of this type of direct feedback from members of target populations at high risk for HIV infection is needed if we are to learn how to best focus our message and expend HIV prevention resources to the greatest effect.

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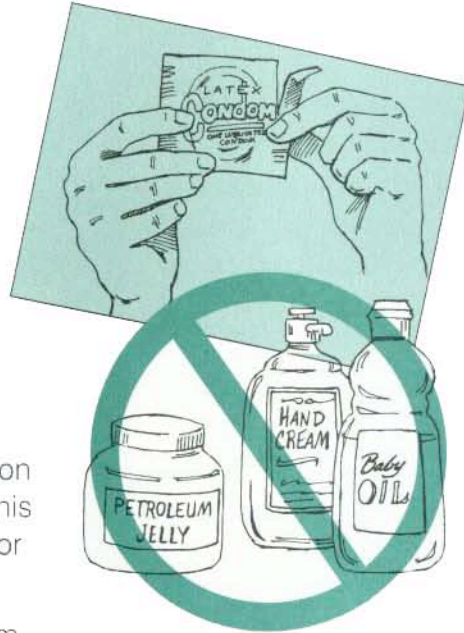
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Use condoms the right way.

If you have sex, use a new latex condom.

Use a new one for each act of vaginal, anal, or oral sex. Remember, you can get STDs (including HIV) from anal and oral sex, too.



For anal and vaginal sex:

- Put the condom on as soon as the penis is hard. Do this before any vaginal, anal, or oral contact.
- Hold the tip of the condom. Unroll it to the base of the penis. Make sure there is no air in the tip.
- Use a water-based lubricant (like K-Y® Brand Jelly) for vaginal and anal sex.
- Do not use any oils, petroleum jelly, lotions, or vaginal products that have oil. These can make latex condoms break.
- Pull out right after coming. Hold on to the condom as you pull out.

Condoms do not make you 100% safe from HIV.

But, if you use them right every time you have sex, they can help protect you and your partner.



Shooting drugs puts you at risk for HIV.

If you shoot drugs, get help to stop.

Call:

- Helpline Georgia
1-800-338-6745
- the Georgia AIDS Information Line
—1-800-551-2728
—404-870-7775 (in Atlanta)
—404-870-7773 (TTY).

They can refer you to a drug treatment center.



Until you stop using drugs, be careful.

- Never share drug equipment.
- Clean your drug equipment with water, bleach, and more water—before and after each use. (Call Helpline Georgia for instructions.)
- Protect yourself and your partner every time you have sex.



Stay away from alcohol and other drugs, too.

You may do things that put you at risk.

Have you had **sex**
without a condom?



Did you answer **yes**
to one of these
questions?

Then,
Get Tested for **HIV** Today.

Have you **shared**
your works?



**Why get
tested now?**



There is a NEW test.
It is called the Rapid  test.

The test is QUICK.
It only takes 20 minutes.



This test is EASY.

It only takes a finger prick
with a small needle.

It is a good test.

You can trust the results.



What if the test says
I have HIV?



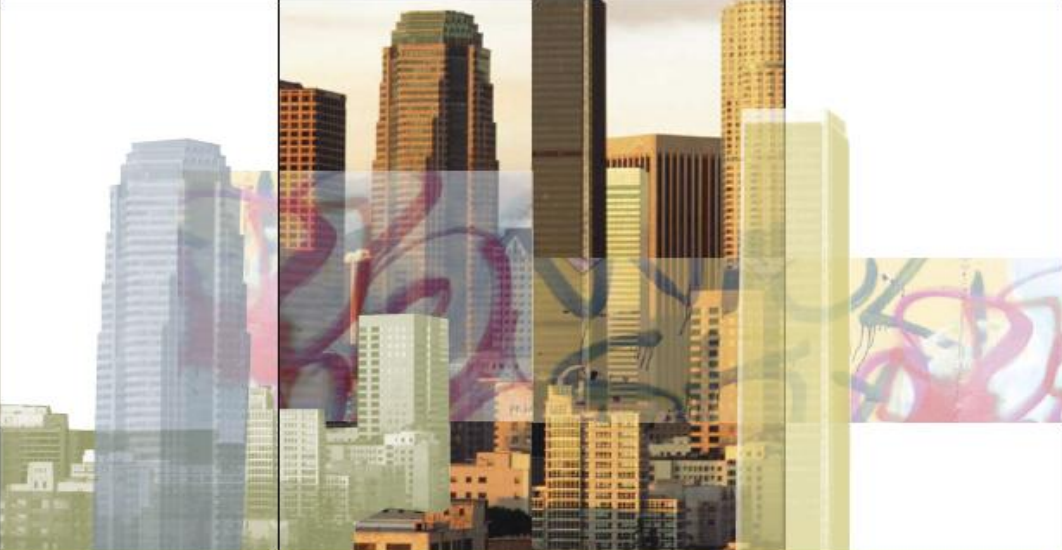
Why wait?

Be sure. Be safe.
Get Tested for HIV Today.

There is new
medicine for HIV.

This medicine will
help you live
a LONGER,
HEALTHIER life.



		
<p>CDC-INFO (Formerly known as the CDC National AIDS Hotline) Phone: 1-800-CDC-INFO (1-800-232-4636) TTY: 1-888-232-6348 In English, en Español 24 Hours/Day</p>	<p>AID Atlanta 1438 W. Peachtree St. NW Suite 100 Atlanta, GA 30309-2955 Phone: (404) 870-7775 TTY: (404) 870-7773 Georgia AIDS & STD Infoline: (800) 551-2728</p>	<p>Be sure. Be safe. Get Tested for HIV Today.</p>
<p>Georgia Department of Public Health Division of Public Health Two Peachtree Street, NW Atlanta, Georgia 30303-3186 Phone: (404) 657-2700 Public Health Questions: gdphinfo@dhr.state.ga.us Website Questions: phwebmaster@dhr.state.ga.us</p> <p><small>© 2006 CDC. All rights reserved.</small></p>		

Researcher Signature

Date

LITERACY PROJECT

INTERVIEW

Participant ID Number: _____

Interviewer ID Number: _____

Date of interview _____/_____/_____

Begin time: _____ AM / PM

End time: _____ AM / PM

INTRODUCTION

Hi, (researchers name). Thanks for participating in our project.

Before we start, I'd like to go over a few details with you, just to remind you of what we'll be doing today. It will probably take us about an hour to cover all of the material in today's interview, and when we are done we will give you \$30.00 for your time and effort. Before we start, I will go over with you the types of questions I'm going to ask and the process of doing the interview. Do you have any questions before we begin?

O.K. then let me tell you of how we do these interviews. First, I assure you that everything you tell me during this interview will always be kept in strict confidence. During portions of the interview, I'm going to be asking you questions about your life. Some of the questions will be very personal; some will be very detailed and may require you to take some time to think about them. I want to stress that there are no right or wrong answers to the questions that I will be asking. The most important thing is that you respond honestly and accurately.

The interview includes different types of questions, sometimes I will be asking you for a number or name, and at other times I will ask you to pick from a set of answers that I read to you. Take as much time as you need to answer any question. If you do not understand any of the questions, please ask me to explain it

Lots of questions that I am going to ask you are about things that you have done or that have happened to you in the past 90 days. I've brought this calendar to help you remember things that might have happened in that period (SHOW CALENDAR; POINT OUT PREVIOUS 90 DAYS). Think back over the time since (DATE), about the places you have been, the things you have done, and the people that you have been with. Are any of the days in this period, from (DATE) to today particularly memorable for you? (PROBE: any others?) Do you have any questions? OK, let's get started.

DEMOGRAPHICS

1. **What is your date of birth?** _____/_____/_____

2. **What is the highest grade or year that you actually completed in school?**

6	7	8	9	10	11	12	13	14	15	16	17+
---	---	---	---	----	----	----	----	----	----	----	-----

3. **Are you currently married, separated, divorced, widowed, or have you never been married?**
MARRIED
SEPARATED
DIVORCED
WIDOWED
NEVER MARRIED

4. **Thinking back over the past four weeks, (show calendar) about how many hours, if any, did you work for pay each week? (IF NONE, ENTER A "0" AND SKIP TO #6)**
OF HOURS WORKED _____

5. **How much money do you have to live on each month?**
\$ _____

6. **Where does your income come from? (PROBE: Any others?) (CIRCLE ALL THAT APPLY).**
WAGES OR SALARY FROM JOB
FRIENDS/FAMILY/SEXUAL PARTNER
CHILD SUPPORT
DISABILITY
WELFARE/AFDC/SSI/TANF/FOOD STAMPS
UNEMPLOYMENT INSURANCE/WORKMAN'S COMPENSATION
SAVINGS or SELLING PERSONAL ITEMS
OTHER (SPECIFY) _____

7. **Where do you live now?**
IN MY OWN HOME OR APARTMENT
IN MY FAMILY'S HOME OR APARTMENT
IN SOMEONE ELSE'S HOME OR APARTMENT (NOT FAMILY)
IN A ROOMING HOUSE OR SINGLE ROOM HOTEL

IN A WELFARE HOTEL

IN A SHELTER

IN A HALFWAY HOUSE

IN A GROUP HOME

IN AN INSTITUTION

ON THE STREET (PARK, STEAM VENT, DOORWAY, ETC.)

OTHER SPECIFY: _____

8. **How long have you lived there?** Years: _____ and/or Months: _____

HIV Testing History

The next few questions are about being tested for HIV.

9. **Have you ever been tested for HIV?**

Yes

No (SKIP TO #13)

Refuse to answer

10. **When was the last time you were tested for HIV?**

--	--	--	--	--	--

Month

Year

Refuse to answer

IF THE RESPONDENT ENTERS A YEAR PRIOR TO 1985: "THIS TEST WAS NOT AVAILABLE BEFORE 1985. PLEASE ENTER A YEAR FROM 1985 – 2004."

11. **Did you get the results of your last HIV test?**

Yes

No

Refuse to answer

12. **What was the result of your last HIV test?**

HIV-negative

HIV-positive

Don't know/not sure

Refuse to answer

HIV Risk History

Now I am going to ask some questions about your HIV risk history. Some of the questions are very personal, but it is important that you answer honestly. Please answer to the following questions YES or NO.

	YES	NO
13. Have you ever used needles to inject (shoot-up) drugs?	1	2
14. Have you had a sexual partner who you think used needles to shoot-up drugs?	1	2
15. Have you ever traded sex for money, drugs, or a place to stay?	1	2
16. Have you ever had sex with a man who you think may have had sex with other men?	1	2
17. Have you ever had a sexually transmitted disease (STD) such as Syphilis, Gonorrhea, Herpes, or Chlamydia?	1	2

Alcohol

Please answer the following questions Yes or No.	Yes	No
18. Have you ever felt you ought to cut down on your drinking?	1	2
19. Have people ever annoyed you by criticizing your drinking?	1	2
20. Have you ever felt bad or guilty about your drinking?	1	2
21. Have you ever had a drink first thing in the morning to steady your nerves or to get rid of a hangover?	1	2

Recent Drug Use

22. Now I would like to talk with you about your use of other drugs. In the past 90 days, have you used any of the following drugs?

Yes No

a. Marijuana or hashish?	1	2
b. Crack or freebase?	1	2
c. Sniffing or snorting cocaine or heroin?	1	2
d. Methamphetamine?	1	2
e. Other drugs? Specify_____	1	2

3 MONTH Sexual Behavior

Now I'd like to talk with you about the sex that you have had during the past 90 days. These questions are also very personal. Please remember that everything you tell us in the interview is kept strictly confidential.

23. **Thinking back over the past 90 days, did you have vaginal sex ?**

NO (SKIP TO #24)

YES

23a. **If YES, how many times?** _____

23b. **Of those (repeat #) times, did you or your partner ever use a condom?**

NO (SKIP TO #24)

YES

23c. **How many times?** _____

24. **During the past 90 days, did you have anal sex?**

NO (SKIP TO #25)

YES

24a. **How many times?** _____

24b. **Of those (repeat #) times, did you or your partner ever use a condom?**

NO (SKIP TO #25)

YES

24c. **How many times?** _____

25. **During the past 90 days, have you had sex with someone to get money and/or drugs?**

NO (SKIP TO #26)

YES

25a. With how many partners? _____

26. During the past 90 days, have you had sex with someone to get food or a place to stay?

NO (SKIP TO #27)

YES

26a. With how many partners? _____

RISK PERCEPTION

Please tell me how much you agree or disagree with the following statements.

	Strongly Disagree	Disagree	In the Middle	Agree	Strongly Agree
27. I am concerned that I have the AIDS virus.	1	2	3	4	5
28. I am concerned that someone I know has the AIDS virus.	1	2	3	4	5
29. I worry about getting AIDS.	1	2	3	4	5
30. I need to get tested for HIV.	1	2	3	4	5
31. I think that AIDS is a serious problem in my community.	1	2	3	4	5
32. I have thought about getting tested for HIV.	1	2	3	4	5

33. Now I would like you to think about all of your sexual partner(s) and the sex you have had over the past 90 days. How risky or safe would you say your behavior was in terms of HIV infection during that time?

Very risky

Somewhat risky

Slightly risky

Undecided-not sure

Slightly safe

Somewhat safe
 Very safe
 Refuse to answer

Abuse and Sexual Coercion

I have just a few more questions about your personal life. Please answer each question YES or NO. Have any of the following things ever happened to you?

34. **Has someone that you were involved with hit you?**

NO
 YES

35. **Have you had sexual intercourse (anal or vaginal sex) even though you didn't want to because your partner threatened to leave you?**

NO
 YES

36. **Have you ever had sexual intercourse even though you didn't want to because someone threatened to use physical force to make you?**

NO
 YES

37. **Has anyone ever forced you to have sex when you didn't want to?**

NO
 YES

38. **Have you ever been afraid to ask to use condoms because a partner might leave you?**

NO
 YES

39. **Have you ever been afraid to ask to use condoms because a partner might hit you?**

NO
 YES

HIV Treatment Optimism

Now please tell us how much you disagree or agree with the following statements about HIV treatments.

40. Because of new treatments for HIV, I think people are taking more sexual risks.

Strongly disagree
 Disagree
 Neither disagree nor agree
 Agree
 Strongly agree

Refuse to answer

41. **Because of new treatments for HIV, I'm more willing to have unprotected sex with someone whose HIV status I do not know.**

Strongly disagree

Disagree

Neither disagree nor agree

Agree

Strongly agree

Refuse to answer

42. **Because of new treatments for HIV, I'm more willing to have unprotected sex with someone whose has HIV.**

Strongly disagree

Disagree

Neither disagree nor agree

Agree

Strongly agree

Refuse to answer

43. **Because of new treatments for HIV, I'm less concerned about being infected by someone else.**

Strongly disagree

Disagree

Neither disagree nor agree

Agree

Strongly agree

Refuse to answer

Source Credibility

The following questions ask about your trust in some sources of information about the prevention of HIV/AIDS. Please rate each information source from 1 (Do not trust at all) to 10 (Trust completely).

For giving me reliable and accurate information about HIV / AIDS, I trust...

44. My doctor, nurse or health care professional.

1	2	3	4	5	6	7	8	9	10
Do not									Trust
trust at all									Completely

Not applicable

Refuse to answer

45. AIDS organizations in my local community, like AID Atlanta, Our Common Welfare etc.

1	2	3	4	5	6	7	8	9	10
Do not									Trust
trust at all									Completely

Not familiar with organization

Refuse to answer

46. Centers for Disease Control and Prevention (CDC)

1	2	3	4	5	6	7	8	9	10
Do not									Trust
trust at all									Completely

Don't know

Refuse to answer

Understanding of HIV /AIDS Issues

The following questions ask about your understanding of HIV-related risk.

47. How would you rate your understanding of how to protect yourself from HIV?

Poor

Fair

Good

Very good

Excellent

Refuse to answer

48. How would you rate your understanding of the risks of different behaviors for transmitting HIV?

- Poor
- Fair
- Good
- Very good
- Excellent
- Refuse to answer

49. How would you rate your understanding of how having HIV / AIDS affects your body?

- Poor
- Fair
- Good
- Very good
- Excellent
- Refuse to answer

50. How would you rate your understanding of HIV treatment (such as what treatment involves, how I would access treatment in this area etc.)?

- Poor
- Fair
- Good
- Very good
- Excellent
- Refuse to answer

HIV Testing Message Brochure

Now there is just one last thing to do. Please take a moment to read these two brochures and tell me what you think of them. (*Present first brochure. Ask participant to read.*)

51. This brochure got my attention.

- Strongly disagree
- Disagree
- Neither disagree nor agree (If disagree, SKIP TO #52)
- Agree
- Strongly agree
- Refuse to answer

51a. If you agree, what got your attention?

52. This brochure said something important to me.

Strongly disagree

Disagree

Neither disagree nor agree (If disagree, SKIP TO #53)

Agree

Strongly agree

Refuse to answer

52a. If you agree, what was important to you?

53. This brochure provided too much information.

Strongly disagree

Disagree

Neither disagree nor agree

Agree

Strongly agree

Refuse to answer

54. In general, do you think the brochure you viewed is understandable?

Yes

No

I don't know

Refused to answer

54a. If yes, what do you think made it understandable?

54b. If no, what made it difficult to understand?

55. What is the main message of this brochure?

Now please take a look at this final brochure. (*Present second brochure. Ask participant to read.*) I am going to ask the same questions I asked about the first brochure.

56. This brochure got my attention.

Strongly disagree

Disagree

Neither disagree nor agree (If disagree, SKIP TO #57)

Agree

Strongly agree

Refuse to answer

56a. If you agree, what got your attention?

57. This brochure said something important to me.

Strongly disagree

Disagree

Neither disagree nor agree (If disagree, SKIP TO #58)

Agree

Strongly agree

Refuse to answer

57a. If you agree, what was important to you?

58. This brochure provided too much information.

Strongly disagree

Disagree

Neither disagree nor agree

Agree

Strongly agree

Refuse to answer

59. In general, do you think the brochure you viewed is understandable?

Yes

No

I don't know

Refused to answer

59a. If yes, what do you think made it understandable?

59b. If no, what made it difficult to understand?

60. What is the main message of the brochure?

Finally, I would like you to compare these two brochures.

61. If you were at a clinic, which brochure would you pick up to read? WHY?

62. Which brochure did you relate to more? WHY?

Thank you very much for taking the time to participate in this research project today. Do you have any more questions about anything we talked about today? If you feel you need more information about HIV, want to be tested or just need someone to talk to please contact a counselor at AID Atlanta, the number is on the back of this brochure. If you are a client at Café 458 or the Employment Readiness Program you can speak to your case worker. If you would just sign this receipt, the interview can be concluded.