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Health Literacy and Health Decision Making Attitudes in People with Human Immunodeficiency Virus

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Walden University
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Abstract

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MPHE, University of Puerto Rico-Medical Sciences Campus, 2007

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health - Community Health Promotion and Education

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Abstract

Health literacy has been recognized as a vital issue in the self-care management of persons living with HIV/AIDS (PLWHA). The purpose of this study was to determine the impact of functional, communicative, and critical health literacy dimensions on positive and negative attitudes toward health decision making. The transtheoretical model of health behavior change (TTM) provided the theoretical framework to explain this association. A culturally-adapted survey was used in this cross-sectional study to measure health literacy dimensions, positive and negatives attitudes toward health decision making, and other factors in 100 Puerto Ricans living with HIV/AIDS. Demographic factors and clinical and immunological variables were obtained from the HIV/AIDS Registry database. Bivariate analyses were conducted to determine associations and multiple logistic regression analyses were used to determine the extent to which health literacy and other factors, while controlling for demographic characteristics, disease duration, and stage of readiness, predicted positive and negative attitudes toward health decision making. Results revealed that Puerto Ricans living with HIV/AIDS with higher health literacy scores are more likely to have positive attitudes toward health decision making. HIV/AIDS disease-specific knowledge and self-report HIV medication adherence showed statistical significance for functional and critical health literacy. Social change implications included the identification of limited health literacy as a potential barrier for an active participation in health decision making. The development of interventions directed to increase health literacy skills to improve HIV medication adherence and disease management are needed.

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Dedication

I dedicate my doctoral dissertation work to my children, Edgardo and Adriana. All your love and joyfulness have inspired me to set and achieve higher standards. I also dedicate my dissertation to my parents, Antonio and Daisy; my siblings, Michel and Francisco; my friends, Dr. Wanda I. Figueroa and Dr. Yelitza Ruiz; and my mentors, Dr. Robert F. Hunter and Dr. Silvia E. Rabionet; and to many others that have significantly supported me throughout the entire doctoral program.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction to the Study

Puerto Rico has the eighth highest cumulative rate of AIDS diagnoses among United States mainland and territories with an incidence of 28.6 cases per 100,000 persons as of December 31, 2011 (Centers for Disease Control and Prevention [CDC], 2011). According to the Puerto Rico HIV/AIDS Surveillance Office report (2014), a total of 46,001 HIV/AIDS cases have been diagnosed from December 2003 to April 2014. Most infections occurred among males (73.8%) and 17% of the cases where reported in the Bayamon Health Region (Puerto Rico HIV/AIDS Surveillance Office, 2014). The most common modes of transmission among males and females are injection drug use (44.0%), heterosexual contact (29%), and male-to-male sexual contact (18.0%; Puerto Rico HIV/AIDS Surveillance Office, 2014). By the end of 2013, the Joint United Nations Programme on HIV/AIDS (UNAIDS) Coordinating Board requested stakeholders to propose a new treatment target to end the global AIDS epidemic (UNAIDS, 2014). The target is known as the 90-90-90: 90% HIV/AIDS diagnosis, 90% of people on antiretroviral treatment, and 90% viral suppression (UNAIDS, 2014). Research to advance health literacy skills is critically needed to improve health outcomes, health knowledge about preventable diseases, quality of health care, and unnecessary hospital care (Berkman et al., 2004; Guerra, Dominguez, & Shea, 2005; Lee, Gazmararian, & Arozullah, 2006; Lohr et al., 2007).

Health literacy has been recognized as a vital issue in the self-care management of PLWHA (Benotsch, Kalichman, & Weinhardt, 2004; Kalichman & Rompa, 2000; Kalichman et al., 2008). Limited health literacy in PLWHA has been found to be a

predictor of poor medication adherence and disease management (Kalichman, Ramachandran, & Catz, 1999; Kalichman & Rompa, 2000; Kalichman et al., 2008; Wolf et al., 2005). According to Kalichman, Ramachandran, and Catz (1999), health literacy is below functional level in minority groups. Limited health literacy among PLWHA poses challenges to their access to health care services and to understanding and maintaining self-care behaviors (Kalichman et al., 1999). PLWHA without adequate specific disease knowledge are less likely to be involved in their own care, do not understand treatment instructions, and consequently, are most likely to be non-adherent to HIV treatment (Wolf et al., 2005). Kalichman et al. (2008) confirmed than an association between functional limited health literacy and poor self-reported medication adherence exists after controlling for emotional distress, stigma, social support, educational level, and alcohol use. These researchers also noted that individual attitudes toward medical regimen might mediate the relationship between health literacy and medication adherence. Kalichman and Grebler (2010) indicated that depression, stigma, and substance abuse among other poverty related factors are associated with medication adherence among PLWHA and with limited functional health literacy.

The concept of health literacy has been defined as a potential asset for improving population health. In Chapter 1, an overview of background information about functional, communicative, and critical health literacy is presented. In this chapter, a brief background of the effect of health literacy on positive and negatives attitudes toward health decision making and HIV/AIDS clinical outcomes in a sample of Puerto Ricans living with HIV/AIDS is described. The purpose, research questions, significance of this

research, definition of the variables, assumptions, and limitation for the study are also discussed.

Background

According to the U.S. Department of Health and Human Services (HHS; 2000), low health literacy level is a key determinant of the population health. Kickbusch (2001) emphasized that education level and general literacy level are the two most important determinants of an individual's health among other factors such as income, distribution of income, employment, working conditions, and social environment. Researchers have linked low health literacy to low health status, low health knowledge about preventable diseases, a threat to quality of health care, and unnecessary use of hospital care (Berkman et al., 2004; Guerra, Dominguez, & Shea, 2005; Lee, Gazmararian, & Arozullah, 2006; Lohr et al., 2007). According to Paasche-Orlow and Wolf (2007), there is a strong association between low health literacy and socioeconomic indicators, access and utilization of health care, patient-provider interactions, and self-care. Low health literacy levels cost the U.S. economy over $106 billion annually by increasing hospitalization and comorbidities associated with health care costs (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007). Other factors that pose challenges to a population's health that have been associated with health literacy include educational level, income, employment, and social environment (Kickbusch, 2001).

Several initiatives have been developed to address health literacy as an asset for improving individual and population health outcomes. The 2003 National Assessment of Health Literacy (NAAL), a population-based health literacy assessment, identified health

literacy as a potential barrier for seeking health care services and obtaining health-related information (Kutner, Greenberg, Jin, & Paulsen, 2006). The NAAL assessment allowed the identification of individuals that lack health literacy skills including: (a) older adults, (b) individuals with low educational attainment, (c) individual with low income status, and (d) racial and ethnic minorities (Kutner et al., 2006). In 2004, the Institute of Medicine (IOM) Committee on Health Literacy developed a conceptual framework for planning and implementing interventions to address limited health literacy and other factors that affect cultural and social systems, educational systems, and health systems (Nielsen-Bohlman, Panzer, & Kindig, 2004). The 2004 IOM report highlighted the need of developing measures that include more advanced critical thinking skills, oral communication skills, and writing skills (Nielsen-Bohlman et al., 2004).

Another initiative to update research efforts and interventions directed to reduce the potential consequences of limited health literacy was held in 2006 at the Surgeon General's Workshop on Improving Health Literacy (HHS, 2006). This workshop led to the determination of a strong association between health literacy and health outcomes (HHS, 2006). The 2006 Surgeon General's Workshop on Improving Health Literacy suggested that health literacy efforts should be directed to the individual skills, the health system, and the development of plain language health education materials (HHS, 2006).

The Office of Disease Prevention and Health Promotion (ODPHP) and the HHS identified evidence-based strategies to improve limited health literacy and proposed a call for action to address this issue as a public health priority (HHS, 2010). The 2010 National Action Plan to Improve Health Literacy summarized negative and positive health

outcomes associated with limited health literacy levels (HHS, 2010). For example, higher hospitalization rates, lower use of preventive health care services, and poor medication adherence are negative outcomes associated with limited health literacy. The HHS Health Literacy Workgroup aligned the 2010 National Action Plan to Improve Health Literacy goals with the Health People national objectives. This alignment was an effort to reduce health disparities by improving population health literacy levels (HHS, 2010). The 2010 National Action Plan to Improve Health Literacy addressed the need to improve access to reliable health-related information and to develop individual cognitive skills needed for critically analyzing the overload of health-related information (HHS, 2010). The 2010 National Action Plan to Improve Health Literacy emphasized the role of mass media, public and private health organizations, and health professionals for the provision of health-related information and accessible services for individuals with limited health literacy as previously stated in the 2004 IOM Report (HHS, 2010). The 2010 National Action Plan to Improve Health Literacy also identified key strategies to address health literacy including patient-provider communication, informed decision making, and collective and political action (HHS, 2010).

Previous researchers have only measured functional health literacy or the patient's ability to read and understand health-related information (Kickbusch, 2001). This study examined if functional health literacy and advanced health literacy skills (i.e., communicative and critical) are essential for the successful management of HIV infection. This research determined if total health literacy is associated with positive attitudes toward health decision making among HIV infected Puerto Ricans after

controlling for the effects of gender, education level, income, and employment condition. The transtheoretical model of health behavior change (TTM) provided the theoretical framework to explain the association between total health literacy and health decision making. The social change implications for this research study included the identification of limited health literacy as a potential barrier in health decision making. The results from this study could lead to the development or adaptation of culturally sensitive interventions directed to improving the quality of life and health outcomes for minorities within the United States affected by HIV/AIDS.

Problem Statement

Low health literacy can result in poorer health care outcomes in persons living with HIV/AIDS (Kalichman et al., 2000). PLWHA with limited health literacy skills have lower levels of HIV knowledge, are less likely to understand the meaning and importance of HIV viral load and CD4 cell count, and are less likely to have an undetectable HIV viral load (Kalichman & Rompa, 2000; Kalichman et al., 2000). Limited health literacy may have an impact in health decision making due to shame (Baker et al. 1996 as cited in Street & Epstein, 2008) and lack of specific health-related knowledge (Davis et al.2002; Street as cited in Street & Epstein, 2008). Researchers have suggested that PLWHA with limited health literacy may be more sensitive to matters of shame and stigma which is incremented by having limited reading proficiency among other psychosocial issues (Parikh et al., 1996; Peretti-Watel, Pierret, Lert, & Obadia, 2006; Stirratt et al., 2006; Wolf et al., 2007b). The presence of perceived stigma is often a mediator between low literacy and poor health care outcomes (Parikh et al., 1996; Peretti

et al., 2006; Stirratt et al., 2006; Wolf et al., 2007a; Wolf et al., 2007b). According to Miller et al. (2003) and Wolf et al. (2007a), inadequate health literacy was associated with negative health care perceptions and experiences and poorer disease management among PLWHA.

Little research has been done to examine the impact of health literacy skills as a key component for improving health outcomes in the population being studied. In Puerto Rico, previous researchers have described the lowest dimension of health literacy or functional health literacy (Rivero-Mendez et al., 2010). This study addressed the knowledge gap that exists by examining the relationship of health literacy dimensions and positive and negatives attitudes toward health decision making among PLWHA.

Purpose of the Study

My quantitative research project examined the impact of the three dimensions of health literacy in HIV disease management and positive and negatives attitudes toward health decision making. The results from this study should improve current knowledge in the field and should lead to the development or adaptation of culturally sensitive interventions directed to improve the quality of life and health outcomes of Puerto Ricans living with HIV/AIDS. For the purpose of this research, health literacy, HIV knowledge, HIV medication adherence, self-efficacy, and perceived confidence in patient-provider communication were the independent variables. The outcome variable was positive and negative health decision making attitudes. Covariates were demographic variables and HIV/AIDS clinical and immunological variables.

Research Questions

RQ1: What is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS?

RQ2: What factors influence positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS?

$H_0$1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV medication adherence does not affect positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

H_A1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV medication adherence affect positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

RQ3: What is the relationship between health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS after controlling for the gender, education level, disease duration, and stage of readiness?

$H_0$2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are not related with positive and negatives attitudes toward health

decision making, as measured by the PABS-S, among Puerto Ricans living with HIV/AIDS.

H_A2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are related with positive and negatives attitudes toward health decision making, as measured by the PABS-S among Puerto Ricans living with HIV/AIDS.

Theoretical Framework of the Study

The TTM has been widely used to explain behavior change processes at the individual level for smoking cessation, cancer prevention screening tools, and HIV infection prevention programs (Prochaska, Redding, & Evers, 2008). The TTM constructs provide six stages of change: pre-contemplation, contemplation, preparation, action, maintenance, and termination. The stages of change may follow a nonlinear progression (Prochaska et al., 2008). In the first stage, pre-contemplation, the individual does not have the intention to take action due to lack of knowledge about the consequences of their behavior or to previous negative experiences (Prochaska et al., 2008). In the contemplation stage, the individual becomes aware of the costs and benefits of changing a behavior due to an increase in knowledge and motivation, but is still not ready for change (Prochaska et al., 2008). The preparation stage involves motivation for change such as consulting a health care provider or attending a health education class (Prochaska et al., 2008). The action stage requires that an individual reach a sufficient

criterion for behavioral change that is observable (Prochaska et al., 2008). In the maintenance stage, an individual's self-efficacy and termination play an important role to prevent relapses and maintenance of behavioral modifications (Prochaska et al., 2008). Finally, in the termination stage, the individual has a high sense of self-efficacy and zero temptations; therefore, behavioral modifications are not altered due to other factors such as depression, anxiety, or stress events (Prochaska et al., 2008).

The TTM is based on five critical assumptions: (a) behavioral change requires a comprehensive model, (b) behavioral change process involves a series of stages, (c) the stages of change are stable and open to change, (d) preparedness for changes varies across individuals, and (e) processes of change related with each stage of change should be emphasized (Prochaska et al., 2008). Prochaska et al. (2008) have identified 10 processes of change needed for successful behavioral change. The processes of change are the activities or actions needed to advance from one stage of behavior change to another (Prochaska et al., 2008).

In addition to processes of change, the TTM also incorporates decisional balance from Janis and Mann's decision-making model, self-efficacy from Bandura's self-efficacy theory, and temptation (Prochaska et al., 2008). Decisional balance, as proposed by Janis and Mann, requires that individuals weigh the advantages and disadvantages of behavioral change (Prochaska et al., 2008). Prochaska et al. (2008) added Janis and Mann's eight decision making constructs into the TTM: instrumental benefits to self, instrumental benefits to others, approval from self, approval from others, instrumental costs to self, instrumental costs to others, disapproval from self, and disapproval from

others" (p. 864). According to Prochaska et al. (2008), decisional balance process varies in each stage of change. Self-efficacy affects individual motivation and persistence for behavioral change (Prochaska et al., 2008).

Health literacy has been defined as a modifiable factor and as a mediating factor (Street & Epstein, 2008). Health literacy has been found to mediate the effect between a predictor variable and the outcome variable (Osborn, Paasche-Orlow, Davis, & Wolf, 2007). Osborn et al. (2007) found that health literacy mediates the relationship between race disparities and HIV medication adherence; however, health literacy remains a significant predictor of HIV medication adherence. Also, limited health literacy has been found to mediate the relationship between educational level and glycemic control (Schillinger, Barton, Karter, Wang, & Adler, 2006) and between educational level and hypertension knowledge, but health literacy is a predictor of hypertension control (Pandit et al., 2009).

Health literacy as a modifiable factor has been addressed by the development of culturally sensitive interventions and health-related information for individuals with limited health literacy to reduce health disparities (Osborn et al., 2007). Edwards, Wood, Davis, and Edwards (2012) proposed a health literacy conceptual framework that incorporates health literacy abilities, factors and barriers (i.e., personal, emotional, and access to health care services) for becoming health literate. The development of the health literacy pathway model emerged from a qualitative study to describe how patients develop advanced health literacy skills to have an active participation in health decision-making processes (Edwards, Wood, Davis, & Edwards, 2012). The model is divided into

five stages: building health knowledge, developing health literacy skills and practices, displaying health literacy actions, the production of inform options, and making an informed decision (Edwards et al., 2012). According to Edwards et al. (2012), active participation in health decision making is obtained by increasing disease specific knowledge and by promoting patient's empowerment.

Arora, Ayanian, and Guadagnoli (2005) developed the Patients Attitudes and Belief Scale (PABS) based on the TTM to identify modifiable determinants that have been positively or negatively associated with active participation in health decision making. These factors include age, educational level, and the severity of the illness (Arora, Ayanian, & Guadagnoli, 2005). For the purpose of this research, the PABS was used to predict positive and negative attitudes toward health decision making. Five-point Likert-type items were asked of participants to describe their TTM stage of readiness: medical decisions about my HIV/AIDS treatment are done by my health care provider and I intend to keep it that way (pre-contemplation phase), medical decisions about my HIV/AIDS treatment are done by my health care provider but I am thinking about participating in future medical decisions (contemplation phase), medical decisions about my HIV/AIDS treatment are done by my health care provider and in some degree by me (preparation phase), and medical decisions about my HIV/AIDS treatment are done by my health care provider and by me (action phase).

Nature of the Study

A cross-sectional study was done to describe health literacy dimensions and other potential factors among PLWHA. The independent variables were health literacy

dimensions, patient-provider communication, self-efficacy, HIV knowledge, and HIV medication adherence. The dependent variable was positive and negatives attitudes toward health decision making. The covariate variables were demographic factors and HIV/AIDS clinical and immunological variables. The Retrovirus Research Leadership Core (RRLC) at the Universidad Central del Caribe, School of Medicine is the primary custodian of the HIV/AIDS Registry database. Since its inception in 1992, the HIV/AIDS Registry has collected demographic, HIV/AIDS risk behaviors, and HIV/AIDS clinical and immunological data of Puerto Ricans living with HIV/AIDS. A total of 2,430 Puerto Ricans living with HIV/AIDS are included in the HIV/AIDS Registry database. Permission was granted to use obtained demographic factors and HIV/AIDS clinical and immunological data (see Appendix A).

Definitions

The following terms are key concepts that were used as part of this dissertation research inquiry:

Decision making: This term describes "a process that helps patients understand their choices fully and allows them to share treatment decisions with their clinicians" (Brownlee et al., 2011, p. 2).

Health literacy: "The achievement of a level of knowledge, personal skills and confidence needed to take action to improve personal and community health by changing personal lifestyles and living conditions" (World Health Organization [WHO], 1998, p. 10).

HIV knowledge: "HIV-related information relevant for awareness of sexual risk behavior, informed decisions, and behavior change" (Carey & Schroder, 2002).

Medication adherence: This term describes the "cognitive and functional ability to self-administer a medication regimen as it has been prescribed" (Maddigan et al. 2003, p. 333).

Patient-provider communication: Communication that "involves the guidance/information regarding prescription, but it is actually a set of knowledge sharing that focusing on the knowledge about the disease, risk factors/causes, guidance about the affective help seeking, and information about the drug regimens" (Khan, Hassali, & Al-Haddad, 2011, p. 250).

Self-efficacy: "Refers to beliefs that individuals hold about their capability to carry out action in a way that will influence the events that affect their lives" (WHO, 2006).

Assumptions

In this study, I expected to observe a high prevalence of limited health literacy skills among Puerto Ricans living with HIV/AIDS who have been enrolled at the HIV/AIDS Registry. I also assumed that there would be a positive relationship between limited health literacy and a less active participation in patient-provider decision-making process. I assumed that the culturally adapted scales had a moderate to strong Cronbach's α and are effective research instruments for measuring functional, communicative, and critical health literacy and other potential factors in the sample. I also assumed that excluding individuals with documented cognitive impairment, that are unable to read and

write Spanish, and that are too ill to participate would more accurately describe the impact of health literacy in health decision making.

Scope and Delimitations

Limitations

A cross sectional study was selected due to its advantages including one time data collection and its efficacy to determine an association between limited health literacy and positive and negatives attitudes toward health decision making. This type of study cannot establish cause and effect relationships. The research sample was a non-probability purposive sampling due to the accessibility of the study population. However, being representative of the population was not a barrier because the sample had a similar profile as the study population; PLWHA that are part of the HIV/AIDS Registry.

Significance

This research project identified the impact of the three dimensions of health literacy on positive and negatives attitudes toward health decision making. According to von Wagner, Steptoe, Wolf, and Wardle (2009), the study of health literacy and its implication for patient's participation in health care should include a thoughtful examination of the patient's existing knowledge and skills and his or her previous experiences in the health care setting. The implications for social change from this study included the identification of limited health literacy as a potential barrier in health decision making. This could lead to the development or adaptation of culturally sensitive interventions directed to improving the quality of life and health outcomes of minorities in the United States.

Summary

Chapter 1 provided an overview of the research study and background information about functional, communicative, and critical health literacy. In this chapter, a brief background of the effect of health literacy on positive and negatives attitudes toward health decision making and clinical outcomes in a sample of Puerto Ricans living with HIV/AIDS was presented. The purpose, research questions, significance of this research, definition of the variables, assumptions, and limitations for the study were discussed. Researchers have tested the effect of health literacy as a risk factor and as an asset. In my study, demographic factors, HIV/AIDS clinical and immunological variables, health literacy dimensions, HIV/AIDS knowledge and medication adherence, confidence in patient-provider communication, and self-efficacy were measured to determine if an association with attitudes toward participation in health decision making in the study group existed. In Chapter 2, relevant and significant previous research findings that have emphasized health literacy as a key component for improving health outcomes are described. The literature review encompassed a detailed description of low and advanced health literacy skills, the adapted comprehensive health literacy conceptual framework and other personal factors, positive and negatives attitudes toward decision making, and patient-provider interactions as expected outcomes.

Chapter 2: Literature Review

Introduction

The purpose of this research was to identify the impact health literacy dimensions have on positive and negatives attitudes toward health decision making. In this chapter, current literature will be examined to describe factors that have been associated with health literacy. The literature review covers previous knowledge related with health literacy instruments, health literacy and advanced health literacy skills, HIV/AIDS disease management, and health decision making.

Sources of Information

A literature review of the independent and dependent variables was completed. The search included peer-review articles published between 1990 and 2013 in the following databases: MEDLINE, CINAHL, PubMed, and Science Direct. The literature search included terms related with *health literacy, health literacy* and *HIV disease management* and *treatment adherence, health literacy* and *health decision making*. The literature review is presented as a thematically organized vertical list with no chronological order.

Health Literacy

The WHO adopted a health literacy definition as an outcome of health education and communication, both key operational strategies of health promotion:

> "Health literacy represents the cognitive and social skills which determine the motivation and ability of individual to gain access to, understand and use information in ways which promote and maintain good health. Health literacy

> implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment." (Nutbeam, 2008, pp. 2074-2075)

Nutbeam (2008) focused health literacy as an asset that supports individual empowerment in health decision making (See Figure 1). According to Nutbeam (2000), the development of public health interventions that improve health and social outcomes are influenced by intermediate outcomes (e.g., personal lifestyle behaviors, community environment, and access to health care services). Nutbeam's outcome model for health promotion also includes health promotion outcomes that can be modified in order to improve intermediate outcomes. These factors include patient's health literacy, social action and influence, healthy public policy, and organizational practice (Nutbeam, 2000).

According to Freebody and Luke 1990 (as cited in Nutbeam, 2000; Nutbeam, 2008), health literacy includes more than the patient's ability to read health information to comply with medical regimens, but also how the patient's previous knowledge, self-efficacy, and other factors allow him or her to critically analyze the information in order to actively participate in his or her own health. The dimensions of health literacy were classified as functional, communicative, and critical (Nutbeam, 2000; Nutbeam 2008). The functional level is related to the basic reading and writing skills needed to function in everyday situations (Nutbeam, 2000). The communicative or interactive health literacy

level is related to more advanced cognitive skills that promote an active participation in everyday situations and that allow individuals to apply new information and social skills to solve everyday situations (Nutbeam, 2000). The critical health literacy level allows individuals to apply advanced cognitive skills to critically analyze information and to apply this information and social skills to "exert greater control over life events and situations" (Nutbeam, 2000, p. 264).

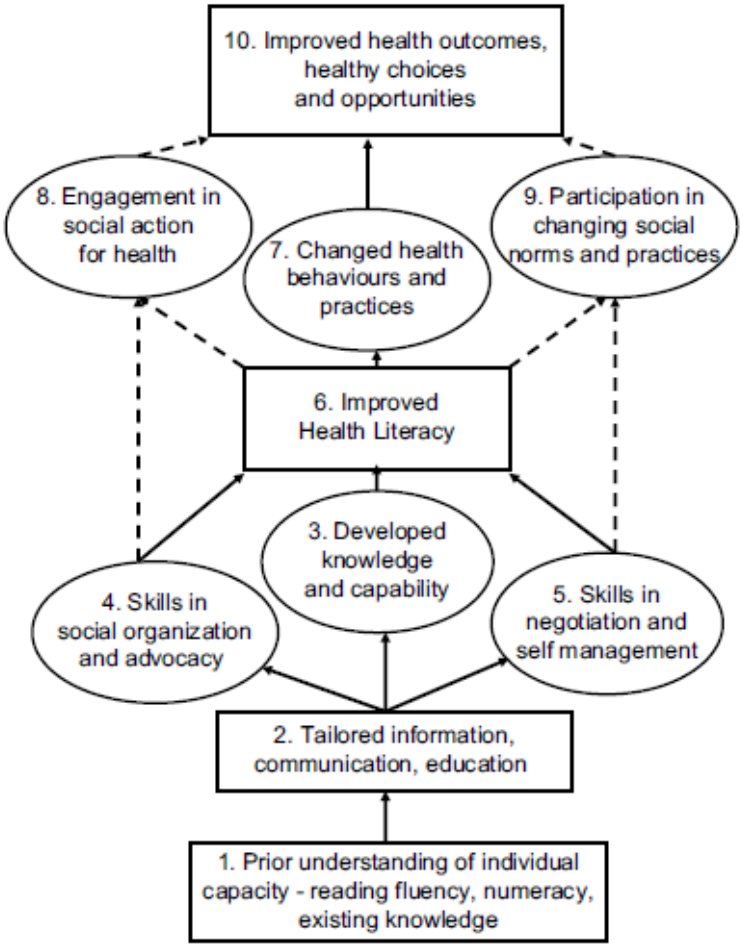

Figure 1. From "The Evolving Concept of Health Literacy" by D. Nutbeam, 2008, *Social Science and Medicine, 67*, p. 2074. Copyright 2008 by the Social Science and Medicine. Reprinted with permission.

Ratzan and Parker's (2000) definition of health literacy was adopted by the IOM and states that health literacy is "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Baker, 2006, p. 878). Baker (2006) developed a health literacy model that focused on individual capacities (i.e., reading fluency) and the prior knowledge needed to understand printed and oral health-related information based on the IOM definition. Baker addressed health literacy as a risk factor that along with other cultural factors and social norms contributes or hinders the acquisition of new knowledge, attitudes, self-efficacy, health behaviors, and health outcomes.

Paasche-Orlow and Wolf 2007 (as cited in Nutbeam, 2008, p. 2074) developed a logic model to explain health literacy as a risk factor for health outcomes at three critical points including access to health care, interaction between patients and health care professionals, and self-care. Previous researchers have documented that older age, language barriers, educational level, low socio-economic status, and suffering a chronic disease are risk factors of limited health literacy (Sun et al., 2013). Both Baker (2006) and Paasche-Orlow and Wolf (2007) measured the prior knowledge, prose literacy, and oral communication skills needed to access health care services and to enhance patient-provider interaction during the medical encounter.

Jordan, Buchdinder, and Osborne (2010) developed a conceptual framework to understand and measure the concept of health literacy from the patient's perspective. Jordan et al. explored how patients identify a health issue, seek health-related information and access health services, and employ patient-provider communication skills. This study led to the identification of patient health literacy abilities and patient-health provider factors, community factors, and societal factors that hinder or improve the patient's health outcomes (Jordan, Buchdinder, & Osborne, 2010). According to Jordan et al., patients with health literacy abilities are able to navigate and access health care systems successfully if they know where and when to seek health information, how to use verbal communication skills, how to be assertive, possess literacy skills, and how to retain, process, and apply health-related information. Jordan et al. affirmed that patient's health literacy is influenced by individual capacities and other factors at the community and societal level including social support and socioeconomic factors.

Researchers added basic reading and numeracy skills, oral health literacy skills, and more advance health literacy skills into health literacy frameworks (Waldrop-Valverde et al., 2010a; Waldrop-Valverde et al., 2010b). Ishikawa and Yano (2008) proposed a conceptual model based on Freebody and Luke's health literacy dimensions (i.e., functional, communicative, and critical) and the cognitive and social skills needed for gaining access to health-related information and to understanding and applying the information to improve their health. Ishikawa and Yano's model explained the relationship between health literacy, self-efficacy, and Diabetes disease knowledge, which is part of the health care process (See Figure 2). Jordan et al. (2010) stated that

health literacy is considered as an asset that can be developed in the continuum of care among individuals with different educational backgrounds. Lee et al. (2006) proposed that health literacy and health outcomes are mediated by knowledge, use of preventive care, risk behaviors, medication adherence, and moderated by social support.

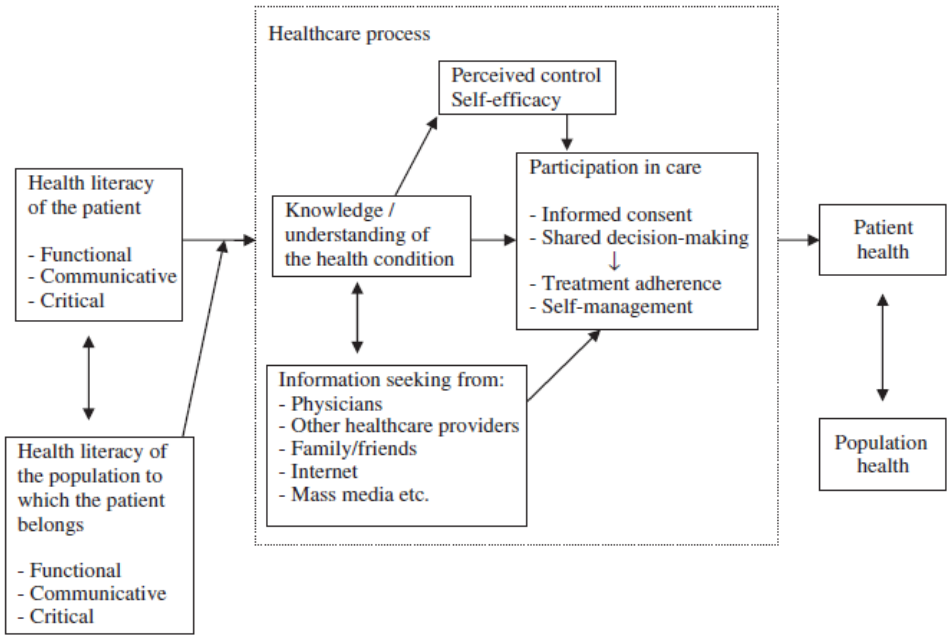

Figure 2. From "Patient Health Literacy and Participation in the Health-care Process," by H. Ishikawa and E. Yano, 2008, *Health Expectations*, *11*, p. 119. Copyright 2008 by the Health Expectations. Reprinted with permission.

Sun et al. (2013) used a path analysis to test a health literacy model built on Baker (2006), Paasche-Orlow (2007), von Wagner (2009) and McCormack's (2010) health literacy conceptual frameworks to address respiratory diseases. Sun et al.'s (2013) model included demographic factors (i.e., age, educational level, and income) and knowledge as moderators for the development of health literacy skills. Sun et al.'s model showed that educational level and age have a strong direct effect for the development of health

literacy and prior knowledge and age is a confounder factor between these variables. According to Sun et al., having adequate health literacy skills have a direct effect on health behavior, but health literacy mediates the effect of prior knowledge and health behavior. Moreover, health behavior influences health status, but health status is moderated by age (Sun et al., 2013).

Health Literacy Measurements

Jordan, Osborne, and Buchdinder (2011) classified 12 health literacy measurements into one of three categories: individual abilities, elicitation of self-report abilities, and proxy measures of health literacy in the population. In the first category, five main questionnaires were identified including the Rapid Estimate of Adult Literacy in Medicine (REALM), the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), the Medical Achievement Reading Test (MART), the Test of Functional Health Literacy in Adults (TOFHLA), and the Newest Vital Sign (NVS). In the second category, three instruments were identified including the Set of Brief Screening Questions (SBSQ), the Functional, Communicative, and Critical Health Literacy (FCCHL), and the eHealth Literacy Scale (eHEALS). Finally, in the third category four instruments were identified including the Demographic Assessment of Health Literacy (DAHL), the National Assessment of Adult Literacy (NAAL), the Health Activities Literacy Scale (HALS), and the Adult Literacy and Life Skills Survey (ALLS).

Rivero-Mendez et al. (2010) adapted and validated the full-length Spanish version instrument known as the TOFHLA for the Puerto Rican population. This instrument provides a measurement of the HIV patient's ability to read and understand health related

materials (Rivero-Mendez et al., 2010). Consistent with previous results, the adapted full-length version of TOFHLA is a valid and reliable measurement to evaluate functional health literacy (total $\alpha = 0.95$, numeracy $\alpha = 0.814$, and reading comprehension $\alpha = 0.953$; Nurss, Parker, & Baker, 2005; Rivero-Mendez et al., 2010). Rivero-Mendez et al. found that the total literacy score was higher for males (71.4%) than for females (43.8%) as previously reported by Waldrop (as cited in Rivero-Mendez et al., 2009). In 2013, I conducted a study using the SAHLSA to describe functional health literacy and disease management among 113 patients attending an ambulatory clinic in the Bayamon Health Region, Puerto Rico. Significant differences were observed among several variables including gender, educational level, sources of information, lack of disease knowledge, wrong perception of having a controlled disease, and lack of understanding of medical instructions. My study was different from previous studies because health literacy was studied in each of its dimensions including functional, communicative, and critical.

Health Literacy, TTM, and HIV Infection

Several researchers have studied the association between functional health literacy and HIV disease management (Murphy et al., 2010; Navarra et al., 2013; Nokes et al., 2007; Osborn et al., 2007). Cultural and personal factors have been associated with health literacy and HIV disease management including race, disease-specific knowledge, and medication adherence (Paasche-Orlow et al., 2006; Stirratt et al., 2006). The HIV/AIDS disease requires that patients adhere to strict medical regimen and regular medical appointments (Drainoni et al., 2008). Limited health literacy poses a challenge for successfully managing the HIV/AIDS disease due to a lack of skills and disease-

specific knowledge (Drainoni et al., 2008). Drainoni et al. conducted a study with PLWHA to identify health literacy levels, demographic factors, risk factors, and health indicators. About 28% of the sample had marginal or inadequate health literacy, the most likely to fall into this category were African Americans or Latinos, heterosexuals, Spanish speakers, and those with less than a high school education (Drainoni et al., 2008). Nokes et al. (2008) measured health literacy in a national sample of PLWHA in the United States with the REALM. Conversely to previous studies, Nokes et al. concluded that persons with limited health literacy reported knowing their CD4 cell count and viral load count. Moreover, persons with higher health literacy reported worse health outcomes than persons with limited health literacy (Nokes et al., 2008). According to Nokes et al., the REALM is not a sensitive enough measure to identify the relationship between health outcomes and health literacy. The need for further research to determine the profile of PLWHA with limited health literacy and its impactions on disease management and health decision making is evident.

Health Literacy and Disease-Specific Knowledge

Limited health literacy has been associated with a lack of HIV knowledge and non-adherence to HIV treatment (Kalichman et al., 2000; Miller et al., 2003; Wolf et al., 2005). Kalichman and Rompa (2000) and Kalichman et al. (2000) identified that limited health literacy was associated with a lack of HIV knowledge and a lack of understanding of HIV viral load and CD4 cell count concepts among HIV patients. Moreover, patients with limited health literacy are less likely to have an undetectable HIV viral load (Kalichman & Rompa, 2000; Kalichman et al. 2000). Gazmararian, Williams, Peel, and

Baker (2003) confirmed that health literacy is an independent predictor of patients' knowledge after controlling for age, disease duration, and prior disease-specific education participation. In this study, marginal or inadequate functional health literacy was found in 36% of the sample (Gazmararian, Williams, Peel, & Baker, 2003)). According to Gazmararian et al., older adults with marginal health literacy have less knowledge about their disease; however, disease duration was an important predictor of knowledge.

Wolf et al. (2005), in a sample of PLWHA on highly active antiretroviral therapy (HAART), found a significant association between sixth grade or below literacy level and a lack of disease-specific knowledge on CD4 cell count (39.0%, $p < 0.001$), viral load (22.0%, $p < 0.001$), and correct identification of HIV medications (43.0%, $p < 0.001$). Wolf et al. confirmed previous knowledge on disease-specific knowledge and limited health literacy. Wolf et al. also maintained that lack of medication adherence is a consequence of limited health literacy due to lack of HIV treatment knowledge. Hicks, Barragan, Franco-Paredes, Williams, and del Rio's (2006) study showed that health literacy and HIV knowledge have a strong positive association; therefore, strategies to improve patient's health literacy levels are needed to reduce HIV infection among high risks population. Conversely with previous studies, Bynum et al. (2013) did not find an association between disease-specific knowledge about HPV and health literacy in a sample of HIV positive women. Bynum et al. argued that health literacy has a greater influence on health-related behaviors and awareness than disease-specific knowledge.

Health Literacy and Medication Adherence

Previous researchers have examined lack of HIV medication adherence due to a lack on numeracy skills rather than on limited health literacy (Gakumo, Vance, Moneyham, Deupree, & Estrada, 2013). Waldrop-Valverde et al. (2009), Waldrop-Valverde et al. (2010a), and Waldrop-Valverde et al. (2010b) affirmed that medication management capacity (MMC) defined as the individual's cognitive and functional skills needed to follow a medical regimen as prescribed determines medication adherence. Waldrop-Valverde et al. found that both men and women perform similar in reading comprehension; however, men tend to perform better than women in numeracy skills. Waldrop-Valverde et al. maintained that patient's numeracy skills and other factors (i.e., disease duration and disease management practices) help to explain HIV medication management. Osborn et al. (2011) found that health literacy rather than health numeracy mediates this relationship among African Americans with Diabetes. Other factors that were found to mediate the effects of race and medication adherence in this population include the duration of the disease and socioeconomic status (Osborn et al., 2011).

Researchers have also examined the association between limited health literacy and HIV medication adherence and other factors. Osborn et al. (2007) examined health literacy as a mediating factor in the relationship between race and HIV medication adherence. Osborn et al. confirmed that limited health literacy mediates this relationship; however, health literacy remains a significant predictor of lack of HIV medication adherence. Kalichman et al. (2008) confirmed previous research that have found an association between functional limited health literacy and poor self-reported medication

adherence. Kalichman et al. argued that individual attitudes toward medical regimen might mediate the relationship between health literacy and medication adherence. Paasche-Orlow et al. (2006) in a sample of PLWHA with documented alcohol abuse on antiretroviral therapy (ART) tested the association between functional health literacy, self-report HIV medication adherence, and HIV-RNA suppression. Conversely, Paasche-Orlow et al. did not found an association between functional health literacy and lower odd of HIV medication adherence or viral suppression in this sample.

A study by Kalichman and Grebler (2010) identified depression, stigma, and substance abuse among other poverty related factors as mediating variables between medication adherence and limited health literacy as measured by the TOFHLA. Waite, Paasche-Orlow, Rintamaki, Davis, and Wolf (2008) examined social stigma as a mediating variable between health literacy and HIV medication adherence. Waite et al. (2008, p. 1367) found "that patients with low literacy were 3.3 times more likely to be non-adherent" to HIV treatment (95% *CI* 1.3–8.7; $p < 0.001$) whereas social stigma mediates this relationship (*OR* 3.1, 95% *CI* 1.3–7.7). Waite et al. affirmed that PLWHA with higher social stigma and limited health literacy are more likely to have poor HIV medication adherence.

Marks, Schectman, Groininger, and Plews-Ogan (2010) assessed the association between socioeconomic factors and health literacy as measured by the REALM in medication knowledge among patients with low socioeconomic status. Consistent with previous studies, health literacy was found to be a strong predictor of medication knowledge (Marks, Schectman, Groininger, & Plews-Ogan, 2010). Marks et al.

emphasized that the combination of age, educational attainment, and sex was also predictive of medication knowledge.

Murphy et al. (2010) did not found an association between health literacy and HIV medication adherence after adjusting for covariates in a sample of a HIV perinatally infected youths. In this sample only 14% had limited health literacy and 34% were adherent. However, an association between health literacy and medical care received was reported (Murphy et al., 2010). A study conducted with HIV infected youths by Navarra, Neu, Toussi, Nelson and Larson (2013) confirmed the association between functional health literacy and medication adherence. Moreover, Kalichman, Pellowski, and Chen (2013) conducted a study in a sample of PLWHA with limited health literacy that request assistance or who do not requested assistance with functional health literacy skills (i.e., reading and writing). Kalichman et al. found that PLWHA with limited health literacy requested informational assistance but lack of proper medication adherence.

Transtheoretical Model of Health Behavior Change (TTM) and HIV Infection

Researchers have used the TTM to explain HIV medication adherence and readiness to participate in HIV medical care. According to Riley, Lewis, Lewis, and Fava (2008), the TTM have been used to explain engagement in safer sexual practices among HIV negative women at high risk for HIV and among HIV infected women to prevent the spread of the disease. Riley et al. conducted a cross-sectional study to examine the application of the TTM for explaining engagement in healthy behaviors among HIV infected women with low income. In this study, emergent themes related with processes of behavioral change were identified including dramatic relief, consciousness raising, and

environmental reevaluation, helping relationships, self-liberation, and stimulus control (Riley, Lewis, Lewis, & Fava (2008).

Highstein, Willey, and Mundy (2006) developed stage of readiness and decisional balance instruments based on the TTM in order to measure ART adherence. Both instruments prospectively predicted 1-year HIV viral load which served to identify HIV positive women in needed for ART adherence interventions referrals (Highstein, Willey, & Mundy, 2006). Highstein et al. emphasized that readiness and decisional balance to start HIV medication prior to offer ART improves HIV medication adherence. Gardner et al. (2007) examined the predictor effects of psychological and behavioral factors for attending HIV medical care among recently diagnosed individuals. The TTM was used as theoretical framework for explaining behavioral change or attending HIV medical care for at least one time in each of two consecutive 6 months periods (Gardner et al., 2007). The number of months after HIV diagnosis, readiness to attend medical care, pros and cons of attending medical care, illicit drug use, and type of medical care referral were included as potential predictors of behavioral change (Gardner et al., 2007). Gardner et al. found that seeing a health care provider was more likely among individuals in the preparation stage than among those in the precontemplation stage. Colbert, Sereika, and Erlen (2013) found that functional health literacy was not associated with HIV medication adherence and self-efficacy; accordingly, self-efficacy was not found to mediate the relationship between them.

Advanced Health Literacy Skills

Communicative Health Literacy

Previous researchers have examined factors related with reading comprehension and numeracy both key components of the lowest level of health literacy or functional health literacy (Jensen et al., 2010). These dimensions are related with advance health literacy skills including oral health literacy. According to Roter (2011), the implications of limited oral health literacy are relevant to disease management due to the fact that most of the health related information is delivered orally. Roter documented that individuals with limited health literacy have reported shame and humiliation feelings, poorer communication skills, and less satisfaction with health care services. Roter identified several factors relevant to oral health literacy including the use of medical jargon, language complexity, contextualized language, and the dialog structure. Roter developed an oral health literacy conceptual framework to improve patient-provider communication among patients with limited oral health literacy.

Patient-provider communication and limited functional health literacy have been associated as determinants of poorer health outcomes including compliance with medical regimen (Cegala, 2003; Schillinger, Bindman, Wang, Stewart, & Piette, 2004). Cegala (2003) examined the impact of patient communication skills in health decision-making process. According to Cegala, information exchange requires patient's communication skills including information-seeking skills or questioning, information provision skills or disclosure, and information verifying skills. Schillinger, Bindman, Wang, Stewart, and Piette (2004) emphasized that poor communication skills among individuals with limited

functional health literacy was a predictor of unsuccessful disease management. According to Schillinger et al. emphasized that health care providers are unaware of the health literacy levels of their patients and tend to explain medical treatment using medical jargon which poses challenges in patient-provider communication. Schillinger et al. explained that patient-provider communication is affected by other factors including socioeconomic status, educational level, and ethnicity.

Jensen, King, Guntzviller, and Davis (2010) examined the association between limited health literacy, health numeracy, and optimism on patient-provider communication satisfaction in a sample of low income adults. Similar to previous studies, age, race, health literacy, and communication satisfaction with health care providers are predictors of patient's active participation in health care interactions (Jensen, King, Guntzviller, & Davis, 2010). Wynia and Osborn (2010) studied the impact of limited health literacy in patient-centered communication among a sample of patients with limited health literacy and low English proficiency (LEP) from different health care organizations. Wynia and Osborn found that after adjusting for LEP, health literacy was an independent predictor of patient perceptions of communication quality. According to Wynia and Osborn, patients with limited health literacy might perceived a poor communication quality due to low self-efficacy.

Lai, Ishikawa, Kiuchi, Mooppil, and Griva (2013) assessed the association of functional, communicative, and functional health literacy dimensions and self-management behaviors among diabetes patients with end-stage renal disease. Lai et al. affirmed that self-management behaviors are associated with patient's communicative

and critical skills. Contrary to previous research, Lai et al. findings showed that patients have higher scores in both the communicative and critical health literacy levels; however, the duration of disease and other health complications related with diabetes could explain this observed trend. Heijmans et al. (2015) and Lai et al. explained that communicative and critical health literacy skills are more significant for the successful disease management in patients suffering from chronic conditions.

Another factor that has associated with health literacy skills is recall of medical instructions. Clayman et al. (2010) emphasized that self-efficacy and recall of medical instructions are key factors that facilitates health decision making among individuals with limited health literacy. Clayman et al. developed a brief assessment to measure patient's ability to obtain, understand, and recall medical instructions known as AURA. A study conducted McCarthy et al. (2012) examined patient's ability to recall medical instructions in two hypothetical videos. The overall recall of information was poor in the sample composed of adults between 55 and 74 years old. McCarthy et al. found statistically significant differences among participants with adequate health literacy (M = 4.6 SD = 1.1) than among those with marginal (M = 3.5 SD = 1.3) or low (M = 2.5 SD = 1.3) health literacy in correctly recalling medical instructions.

Critical Health Literacy

Chinn (2011) expanded Freebody and Luke definition of critical health literacy. Critical health literacy as defined by Chinn (2011) includes advance cognitive, communication, and personal interaction skills needed to actively participate in own health. Chinn emphasized that critical health literacy includes: the critical appraisal of

information, the understanding of the social determinants of health, and collective action. Based on this new definition, Chinn and McCarthy (2013) developed the All Aspects of Health Literacy Scale (AAHLS). The AAHLS obtained a moderate internal consistency (Cronbach's $\alpha = .75$). As the FCCHL measurement, the AAHLS measures individual's ability to access and critically appraised health related information in order to promote collective action and the understanding of social determinants of health (Chinn, 2013). Sykes, Wills, Rowlands, and Popple (2013) emphasized that achieving critical health literacy skills entail the development of interventions to achieve effective patient-provider interactions and to facilitate informed decision making, empowerment, and political action. Schulz and Nakamoto (2013) affirmed that health literacy and empowerment concepts are often used as a measure of patient-provider communication; however, both concepts are no dependent of each other.

Health Literacy and Health Decision Making

Previous researchers have stated that health literacy plays an important role in the active participation of patients in health decision making. Charles, Gafni, and Whelan (1997) proposed an approach for shared decision making in which physicians and patients are involved in health care decisions, share health-related information, and discuss and reach an agreement about the best treatment options. Charles, Gafni, Whelan, and O'Brien (2006) affirmed that physicians paternalistic, shared or informed role in shared decision making should take into consideration the influences of culture during the medical encounter. Kremer and Ironson (2008) assessed PLWHA involvement in participatory decision making as measured by the Control Preferences Scale (CPS). In

this study, Kremer and Ironson compared self-reported and researcher rated decisional roles on the CPS scores with Charles's decision-making models. About 75% of the sample perceived a collaborative/active involvement in health decision making (Kremer & Ironson, 2008).

Ishikawa and Yano (2008) affirmed that active participation is lower among patients with limited health literacy and decisions often rely on family members, friends, or health care providers. Limited participation among patients with low health literacy is often associated with lower knowledge of disease (Kim et al. 2001 as cited in Ishikawa & Yano, 2008). According to Ishikawa and Yano, there is a need to identify mediators between health literacy and patient's participation in health care. Arora et al. (2005) documented that disease management and positive health outcomes results from an active participation in health decision making. Several factors have been positively or negatively associated with active participation in health decision making including age, educational level, and the severity of the illness (Arora et al., 2005). Arora et al. found that patients that are in the precontemplation phase have higher trust in their physicians and lower self-efficacy; therefore are less likely to participate in their own health due to lack of knowledge, lack of trust, and lack of competence.

Smith, Dixon, Trevena, Nutbeam, and McCaffery (2009) stated that limited health literacy and low educational attainment hinders shared health decision making-process which is most commonly observed among disadvantaged populations. Smith et al. conducted a qualitative study to explore the involvement of patients with different functional health literacy and educational attainment levels in health decision making

process. Patients with higher educational attainment described their level of involvement in health decision making process as a shared responsibility with their health care provider (Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). Moreover, patients with higher educational attainment search for health related information outside the medical encounter to verify the credibility of the information and perceived themselves as resources (Smith et al., 2009). Conversely, patients with lower educational attainment perceived their involvement in health decision making as "consenting" and do not seek health-related information nor confront their health care provider advice (Smith, et al., 2009). Smith et al. suggested that educational attainment have more influence than functional health literacy skills on how patients experience their involvement in health decision making. Yin et al. (2012) pointed out that oral health literacy and patient's communication skills play an important role in access to care. Yin et al. found that parents with limited health literacy perceived that accessing health care services was difficult after medical office hours and during weekends (64.9%, $p < 0.001$). Moreover, about 28% of parents with limited health literacy did not feel like a partner in the parent-provider relationship, 68.9% rely on the health care provider knowledge and 57.7% leave health decisions to them (Yin et al., 2012).

Summary

Chapter 2 consisted of a literature review of the previous scientific knowledge related with improving health literacy level in the United States. In addition, an explanation of other potential factors that have been associated with health literacy was also documented. Issues related with individuals abilities to seek for health-related

information or navigation skills were not covered by this research. In Chapter 3, a review of measurement instruments, the study population, and the methodological aspects of this research are described.

Chapter 3: Research Method

Introduction

This quantitative research project examined the impact of the three dimensions of health literacy regarding positive and negative attitudes toward health decision making. Puerto Ricans living with HIV/AIDS answered six culturally adapted questionnaires. This chapter outlines the research design and methodology that were carried out. The selection of a cross-sectional survey approach was chosen to determine the prevalence of limited health literacy in the study sample. The methods for the recruitment of participants, the culturally adapted instruments, and the protection of participants' right are detailed in this chapter. The statistical analysis and sample size calculation are also described.

Research Design and Rationale

A cross sectional study was conducted to examine the relationship between health literacy dimensions and positive and negatives attitudes toward health decision making among PLWHA that are part of the Puerto Rico HIV/AIDS Registry. The participants were asked to complete six culturally adapted instruments: (a) the Functional, Communicative, and Critical Health Literacy Scale (FCCHL-S) Spanish version that collects data on health literacy dimensions; (b) the Patient Confidence in Communication Scale (PCCS-S) Spanish version that collects data on patient-provider communication; (c) the Brief Estimate of Health Knowledge and Action (BEHKA-HIV-S) Spanish version that collects data on HIV/AIDS treatment knowledge and medication adherence; (d) the Perceived Efficacy in Patient-Physician Interactions (PEPPI-S) that collects data

on patient's self-efficacy at obtaining medical information and attention; (e) the Patient Attitudes and Beliefs Scale (PABS-S) that collects data on positive and negatives attitudes toward health decision making; and (f) the Stage of Readiness Scale (SRS-S) that collects data on TT stage of readiness. Demographic factors (i.e., age, education level, marital status, and employment status) and HIV/AIDS clinical and immunological variables were extracted from the HIV/AIDS Registry. Permission from the HIV/AIDS Registry Director was obtained on April 1, 2014. I asked the following questions to describe in which stage of readiness participants were: medical decisions about my HIV/AIDS treatment are done by my health care provider and I intend to keep it that way (pre-contemplation phase); medical decisions about my HIV/AIDS treatment are done by my health care provider, but I thinking about participating in future medical decisions (contemplation phase); medical decisions about my HIV/AIDS treatment are done by my health care provider and in some degree by me (preparation phase); and medical decisions about my HIV/AIDS treatment are done by my health care provider and by me (action phase).

Research Question(s) and Hypotheses

RQ1: What is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS?

RQ2: What factors influence positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS?

$H_0$1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV

medication adherence does not affect positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

H_A1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV medication adherence affect positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

RQ3: What is the relationship between health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS after controlling for the gender, education level, disease duration, and stage of readiness?

H_02: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are not related with positive and negatives attitudes toward health decision making, as measured by the PABS-S, among Puerto Ricans living with HIV/AIDS.

H_A2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are related with positive and negatives attitudes toward health

decision making as measured by the PABS-S among Puerto Ricans living with HIV/AIDS.

Justification of Design and Approach

A cross sectional study was selected due to its advantages including one time data collection and its efficacy to determine an association between limited health literacy and positive and negatives attitudes toward health decision making. The selection of a cross sectional study increased the external validity of the study by using a probability purposive sampling of Puerto Rican adults with documented HIV care at the Bayamon Immunological Clinic, located in the Bayamon Health Region of Puerto Rico. In this type of research design, general inferences about the general population are not possible; however, the use of statistical analysis allowed for the assessment of the relationship between the independent and dependent variables (Frankfort-Nachmias & Nachmias, 2008). This research design cannot be used to establish cause and effect; however, cross-tabulation and bivariate analysis were employed to reduce its methodological limitations (Frankfort-Nachmias & Nachmias, 2008). This study examined PLWHA's functional, communicative, and critical health literacy dimensions and positive and negative health decision making attitudes after controlling for demographic factors and disease duration. A cross-sectional survey design was needed to examine the research gap that existed between the dimensions of health literacy and its impact on positive and negatives attitudes toward health decision making in the selected population.

Methodology

Population

The setting of this study was the RRLC, which is a HIV/AIDS and health disparities research center located at the Universidad del Caribe, School of Medicine in Bayamon, Puerto Rico. The RRLC collects demographic data, clinical and immunological data, psychological data, risk behaviors, and health disparities data of Puerto Ricans living with HIV/AIDS. The HIV/AIDS Registry baseline questionnaire is completed at enrollment and every 6 months after enrollment. As of March 2014, the RRLC had enrolled 4,693 Puerto Rican adults living with HIV/AIDS with a gender distribution of 70% males and 30% females. A total of 37,351 patient's follow-up forms had been completed. Until December 2012, a total of 2,263 patients had died (48.2%). This center was chosen based on its location and the number of Puerto Ricans living with HIV/AIDS that are enrolled in the HIV/AIDS Registry. The sampling method that was used to recruit the participants, who are enrolled at the HIV/AIDS Registry, is non-probability sampling with purposeful selection criteria. This type of sampling methodology was chosen due to specific criteria and the availability of the targeted population at the research setting.

The RRCL enroll about three new patients per day and conducts about 10 follow-up visits per day. I was onsite at the RRCL for the recruitment of participants. The RRCL facilitated the recruitment of the participants by assigning a data abstractor for this purpose. The data abstractor identified potential participants. The following inclusion criteria were considered: men and women older than 21 years of age, with documented

HIV infection at Bayamon Immunological Clinic (IC), who are enrolled at the RRLC HIV/AIDS Registry patient's cohort, who are able to read and understand Spanish, and who voluntarily consent. Adults that are imprisoned, with documented diagnosis of dementia or other mental disorders, unable or unwilling to consent, unable to read and understand Spanish, and too ill to participate were not included as part of the study group.

I explained the research purpose to and obtained consent from potential participants at the RRLC recruitment office. I explained the informed consent document to each potential participant including the level of participation (e.g., completing six surveys) and the research benefits and risks. After informed consent was signed, participants were asked to answer six culturally adapted questionnaires including: the Functional, Communicative, and Critical Health Literacy Scale (FCCHL-S) Spanish version, the Brief Estimate of Health Knowledge and Action (BEHKA-HIV-S) Spanish version, the Patient Confidence in Communication Scale (PCCS-S) Spanish version, the Perceived Efficacy in Patient-Physician Interactions (PEPPI) Spanish version, and the Patient Attitudes and Beliefs Scale (PABS-S) Spanish version (see Appendix C). The time to complete the questionnaires was 20 minutes. I assisted the participants in the completion of the questionnaires if needed.

Sample Size Determination

About 41% of Hispanics living in the United States had inadequate health literacy as reported by the 2003 NAAL national survey (Kutner et al., 2006). For this study, a sample size of 100 participants was needed to obtain a 41% effect size. Sample size was

calculated using G*Power and by assuming an 80% statistical power, 0.05 of statistical significance, an estimated effect size.

Pilot Study

After IRB approval was obtained a pilot test was conducted with seven Puerto Ricans living with HIV/AIDS. The pilot test was used to measure the time to complete the culturally adapted questionnaires and to identify and address deficiencies in the design prior to conduct the study. These participants were not included in the research sample.

Instrumentation and Operationalization of Constructs

Table B1 summarizes the operationalization of variables and coding scheme of each scale including responses categories, variable type, and classification (See Appendix B). In October 2010, I was selected as a mentee of the Mentoring Institute for HIV and Maternal Health Research and Dr. Silvia E. Rabionet from Nova Southeastern University was appointed as my mentor. Since my enrollment there, I have been improving my research knowledge and skills and have developed a primary research interest for health literacy.

From February 2011 to February 2013, I conducted a cross-cultural adaptation of three of the questionnaires: the Functional, Communicative, and Critical Health Literacy scale (FCCHL), the Brief Estimate of Health Knowledge and Action (BEHKA-HIV), and Patient Confidence in Communication Scale (PCCS). I obtained permissions from the scale developers to conduct a cross-cultural adaptation of the research instruments (see

Appendix D). IRB approval was obtained in February 22, 2011 from the Universidad Central del Caribe, School of Medicine (IRB Protocol No.: 2011-10).

Following Gjersing, Caplephorn, and Clausen's (2010) guidelines for cross-cultural adaptation of instruments, each scale was translated into Spanish by a certified translator. Back translation process was done by another certified translator. This process allowed the identification of confusing or misleading items. A pretest analysis was used to do the final semantic adjustments of the new translated version. An evaluation of the operational equivalences of the instruments (e.g., questionnaire formats, instructions, mode of administration, and measurement methods) was completed. These scales are known as the FCCHL-S, the BEHKA-HIV-S, and the PCCS-S. The instruments were pretested with 27 Puerto Ricans living with HIV/AIDS during March and April 2012. Most patients were male (66.7%), unemployed (71.4%), with less than a high school education (53.8%), single (63.3%), and reported episodes of depression (66.8%).

A reliability analysis was conducted to assess the internal consistency using Cronbach's alpha. The internal reliability of FCCHL-S was as follows: Cronbach's α = .72; α = .69; α = .86; respectively, whereas the total health literacy was α = .63 (Miranda et al., 2012). The FCCH was rated on a 4-point scale, ranging from 1 (never) to 4 (often). The scores for the items in a scale are summed and divided by the number of items in the scale to give a scale score (theoretical range 1–4). The scores were reversed for functional health literacy; therefore, higher scores indicated higher health literacy (Ishikawa, Takeuchi & Yano, 2008).

The internal reliability of the PCCS-S was 0.92 (Miranda et al., 2012). The PCCS is a Likert-type scale that ranges from "strongly disagree" to "strongly agree" (Tran et al., 2004, p. 117). Patients' responses are summed and total scores are rescaled ranging from 0 to 100 (Tran et al., 2004). According to Tran et al. (2004), higher scores are related with higher patient-provider communication confidence.

The internal reliability of the BEHKA-HIV-S was 0.90 (Miranda et al., 2012). The BEHKA-HIV scores range from 0 to 8. The BEHKA-HIV scores are obtained by applying a simple frequency distribution to calculate tertiles in which patients were classified as having low (0-3), marginal (4-5), or adequate health literacy (6–8; Osborn, Davis, Bailey, & Wolf, 2010). The BEHKA-HIV was developed and validated to measure HIV specific knowledge and action to make health decisions (Osborn et al., 2010). The instrument is also a strong predictor of HIV medication adherence and a reliable measure of HIV health literacy (Osborn et al., 2010).

The PEPPI Spanish version was provided by the scale developer. The PEPPI consists of five items that range from 1 (not confident at all) to 5 (extremely confident) and was used to measure self-efficacy. The scale has a score range of five to 25 points (Maly et al., 1998). The PEPPI had a strong internal consistency 0.91 (Maly et al., 1998).

The PABS was also cross-culturally adapted for the Puerto Rican population. The PABS has been used to identify modifiable determinants that have been positively or negatively associated with active participation in health decision making (Arora et al., 2005). The PABS consists of a 12-item Likert five-point scale that range from "strongly agree" to "strongly disagree." The PABS scale average raw pros and average raw cons

scores were summed and linearly transformed to a 0-100 scale. The PABS decisional balance variable was created by subtracting the average cons from the average pros scores. The PABS Spanish version was tested with seven Puerto Ricans living with HIV/AIDS after IRB approval was obtained on September 9, 2014. These participants were not part of the research sample.

The RRLC Director, Dr. Robert F. Hunter, provided a dataset that included demographic variables (i.e., age, education level, marital status, and employment status) and HIV/AIDS clinical and immunological variables. The dataset was matched with the research database by a unique ID number. The dataset included the following variables: age, gender (male or female), educational level (≤ sixth grade, seventh-ninth grade, 10-12th grade, 13-16th grade, Masters, MD, or PhD), marital status (single, married, consensual union, widowed, divorced, or separated), job status (employed or unemployed), time since the diagnosis of HIV/AIDS, HIV viral load, CD4 cell count, AIDS diagnosis (yes or no), name of HAART medications, number of hospitalizations in the last 12 months, number of outpatient visits in the last 12 months, and number of emergency room visits in the last 12 months.

In order to describe the participant's stage of readiness the following 5-point Likert-type items were asked: medical decisions about my HIV/AIDS treatment are done by my health care provider and I intend to keep it that way (pre-contemplation phase); medical decisions about my HIV/AIDS treatment are done by my health care provider but I thinking about participating in future medical decisions (contemplation phase); medical decisions about my HIV/AIDS treatment are done by my health care provider

and in some degree by me (preparation phase); and medical decisions about my HIV/AIDS treatment are done by my health care provider and by me (action phase). As with the PABS instrument this scale was tested with seven Puerto Ricans living with HIV/AIDS after IRB approval was obtained.

Statistical Analysis and Hypothesis Testing

The first research question (RQ1) is what is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS? The FCCHL-S had an ordinal rank. The FCCHL-S scores were categorized into one of four groups: (a) never, (b) rarely, (c) sometimes, or (d) often. A descriptive statistical analysis (i.e., frequencies and percentages) was done.

The second research question (RQ2) is what factors affect positive and attitudes toward health decision making among Puerto Ricans living with HIV/AIDS? The data were collected by different culturally adapted instruments. The data were used to identify factors such as demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, and HIV medication knowledge and medication adherence, and stage of readiness related with positive and negative attitudes toward health decision making. The demographic factors included age, gender, educational level, and income. The patient-provider communication was classified as a scale. The PCCS-S scores were categorized into one of six groups: (a) strongly disagree, (b) disagree, (c) slightly disagree, (d) slightly agree, (e) agree, or (f) strongly agree. The health literacy and self-efficacy scales have an ordinal rank. The HIV medication knowledge and medication adherence is additive scale that measures HIV medication knowledge and HIV

medication adherence. A Chi-square test for independence and multiple logistic regression analyses were done.

The third research question (RQ3) is what is the relationship between health literacy, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negative attitudes health decision making among Puerto Ricans living with HIV/AIDS? This data were collected from the FCCHL-S, PEPPI, PCCS, and the PABS-S. The PABS-S version scores were categorized into one of five groups: (a) strongly agree, (b) agree, (c) neutral, (d) disagree, or (e) strongly disagree. A multiple logistic regression analysis was done to determine the relationship between health literacy, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negative attitudes toward health decision making after adjusting for covariates (i.e., gender, educational level, employment condition, disease duration, and stage of readiness).

Data Analysis Plan

Table 1 summarized the research questions, hypotheses, variables of interest, and statistical procedures. For Research Question 1, univariate analyses were used to determine the distribution of each health literacy dimensions in the sample. For Research Question 2, bivariate analyses were performed to measure the relationship among the independent variables and the dependent variable. Chi-square was used for independence analyses to determine the statistical association for categorical variables. For Research Question 3, multivariate logistic regression was done to estimate the relationship of each

independent variable in relation to positive and negative attitudes toward decision making after controlling for gender, education level, disease duration, and stage of readiness.

Table 1

Statistical Analyses Conducted per Research Question

Research Questions	Null Hypothesis	Variables	Statistical Procedure
What is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS?			Descriptive statistics
What factors influence positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS?	$H_0$1: Demographic factors, health literacy dimensions as measured by the FCCHL-S, patient-provider communication as measured by the PCCS-S, self-efficacy as measured by the PEPPI, and HIV medication knowledge and HIV medication adherence as measured by the BEHKA-HIV-S, and stage of readiness does not affect positive and negative attitudes toward health decision making, as measured by the PABS-S.	IV: Demographic factors IV: Health literacy IV: Patient-provider communication IV: Self-efficacy IV: HIV medication knowledge and medication adherence IV: stage of readiness DV: Positive and negative attitudes health decision making	Chi-square test for independence & multiple logistic regression

Research Questions	Null Hypothesis	Variables	Statistical Procedure
			(table continues)
What is the relationship between health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS after controlling for the gender, education level, disease duration, and stage of readiness?	$H_0$2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are not related with positive and negatives attitudes toward health decision making, as measured by the PABS-S, among Puerto Ricans living with HIV/AIDS.	IV: Health literacy DV: Positive and negative attitudes health decision making	Multiple logistic regression analysis

Confounders

Previous researchers have established a strong association between knowledge and health literacy (Baker, 2006; Drainoni et al., 2008; Paasche-Orlow & Wolf, 2007; Sun et al., 2013). Lack of medication adherence due to lack of HIV treatment knowledge have been associated with limited health literacy in HIV disease management (Kalichman & Rompa, 2000; Miller et al., 2003; Wolf et al., 2005). Confounders were discussed in Chapter 2.

Ethical procedures

PLWHA were enrolled in the study after they agreed to participate and after an informed consent was explained, discussed, and signed. A copy of the informed consent

was provided to the participants. All 100 participants completed six questionnaires. The time to complete the questionnaires was approximately 20 minutes. The information collected in the questionnaires were used for research purposes only. The RRLC Director, Dr. Robert F. Hunter, agreed to cooperate on participants' recruitment and data sharing. For this purposes, a letter of cooperation and data use agreement letter were signed. There was very minimal potential risk to the participants of the study. The risk of an abridgement of this confidential information was minimal.

The recruitment and informed consent process were done by the investigator. A data abstractor from the RRLC assisted me in the identification of potential participants. Participants were scheduled to complete the questionnaires during the screening process. The investigator assisted the participants in the completion of the questionnaires if needed. All questionnaires and inform consents were maintained confidential by using a unique ID number. These documents were kept under locked file at the RRLC. None identifiable private information was collected during the survey. The RRLC director provided a de-identified dataset that include demographic variables (i.e., age, education level, marital status, and employment status) and HIV/AIDS clinical and immunological variables. The dataset was matched with the research database by a unique ID number. The research study consisted of one visit. If a participant decided to withdraw from the study after signing the informed consent, their data were not included in dataset. A $15.00 gift card was given to each participant after completing the instruments.

I completed the online CITI "Protecting Human Research Participants" and HIPAA courses on April 2014. The protocol, informed consent document, and

questionnaires were approved by the Institutional Review Board (IRB) at Universidad Central del Caribe, School of Medicine on September 9, 2014 (IRB Number: 2014-16). Walden University IRB approval was obtained on October 31, 2014 (IRB Number: 10-31-14-0258910). The Universidad Central del Caribe, School of Medicine IRB is the IRB of record.

Summary

Chapter 3 provided an overview of the research study methodology and research instruments. It also described the ethical procedures implemented to collect data. A detailed process of the cultural adaptation of the measurement instruments, sampling procedures, data collection procedures, and data analysis were also described.

Chapter 4: Results

Introduction

A quantitative, cross-sectional study design was used to examine the impact of health literacy on positive and negative attitudes toward participation in health decision making. The relationship between health literacy and positive and negative attitudes toward health decision making was answered by three research questions:

RQ1: What is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS?

RQ2: What factors influence positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS?

$H_0$1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV medication adherence does not affect positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

H_A1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV medication adherence affect positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

RQ3: What is the relationship between health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negatives attitudes toward health decision making among

Puerto Ricans living with HIV/AIDS after controlling for the gender, education level, disease duration, and stage of readiness?

$H_0$2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are not related with positive and negatives attitudes toward health decision making, as measured by the PABS-S, among Puerto Ricans living with HIV/AIDS.

H_A2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are related with positive and negatives attitudes toward health decision making as measured by the PABS-S among Puerto Ricans living with HIV/AIDS.

This chapter summarizes the data collected and the univariate, bivariate, and multivariate analyses performed for the purpose of this study. For Research Question 1, univariate analyses were used to determine the distribution of each health literacy dimensions in the sample. Bivariate analyses were performed to measure the relationship among the independent variables and the dependent variable as indicated by Research Question 2. Chi-square was used for independence analyses to determine the statistical association for categorical variables. Finally, for Research Question 3, multivariate logistic regression was done to estimate the relationship of each independent variable in

relation to positive and negative attitudes toward decision making after controlling for gender, education level, disease duration, and stage of readiness. IBM SPSS version 21 was used as the statistical software.

Pilot Study

A pilot test was conducted with seven Puerto Ricans living with HIV/AIDS at the research site. The pilot test was used to measure the logistics of the study, to document the time needed to complete the culturally adapted questionnaires, and to identify and address deficiencies in the design content of the survey prior to conducting the study. Of the participants in the pilot, 57% were women (n = 4) and 43% were men (n = 3) with a mean age of 50.42 ± 9.00 years ranging from a minimum age of 37 to a maximum age of 66. Approximately 57% (n = 4) of the sample completed a high school education, 29% (n = 2) had a middle school education, and 14% (n = 1) had higher than a high school education. Most participants had a live-in partner (43%, n = 3) and 86% were unemployed (n = 6). The time it took participants to complete the six questionnaires was approximately 20 minutes. No deficiencies in the design were observed.

Data Collection

Upon IRB approval, patient recruitment began on November 2014. For this study, a sample size of 100 participants was needed to obtain a 41% effect size. The data collection phase ended on December 2014. The participants for this study were selected from the RRLC HIV/AIDS Registry. The research site was chosen based on its location and the number of HIV/AIDS patients that were enrolled in the HIV/AIDS Registry. I was onsite for the recruitment of participants. A signed letter of cooperation and data use

agreement letter were obtained. The data abstractor assisted me in the identification of potential participants that were men and women: older than 21 years of age, with documented HIV infection at Bayamon Immunological Clinic, who were enrolled at the RRLC HIV/AIDS Registry patient's cohort, who were able to read and understand Spanish, and who voluntarily consented. After informed consent was discussed and signed, the participants completed six culturally adapted questionnaires.

Data Preparation

Prior to data analysis, the variables were recoded and computed. The dependent variable, positive and negative attitudes toward health decision making was measured with the PABS Spanish version instrument. The average scores from raw PABS pros and cons scores were linearly transformed to a 0 to 100 scale. As specified by the scale developer, a decisional balance variable was created by subtracting the average cons scores from the average pros scores. Then, a dichotomous variable was created from the PABS decisional balance scale where negative values indicated negative decisional balance (0) and positive values indicated positive decisional balance (1). The mean scores for each item of the PABS Spanish version scale and subscales were computed.

The independent variable, HIV/AIDS knowledge and self-report HIV medication adherence, was measured with the BEHKA-HIV Spanish version instrument. I created the variable, HIV/AIDS knowledge, with the sum function from the BEHKA-HIV knowledge subscale, (i.e., CD4 cell count knowledge, HIV/AIDS viral load knowledge, and correct identification of HIV/AIDS treatment). Current HIV/AIDS treatment was cross-checked with the HIV/AIDS Registry database. Also, the sum function was used to

create the self-report HIV medication adherence variable, which included five items from the BEHKA-HIV action subscale. As previously classified by Osborn et al. (2010), the HIV/AIDS health literacy score was obtained by applying a simple frequency distribution using the sum function. Participants were classified into three cut off points as having low (0-3), marginal (4-5), or adequate health literacy (6-8). For the purpose of this analysis, low and marginal were recoded as low HIV/AIDS health literacy (0) and adequate HIV/AIDS health literacy (1). The mean scores for each item of the BEHKA-HIV Spanish version scale and subscales were computed.

The independent variable, health literacy, was measured with the FCCHL Spanish version instrument. A dichotomous variable was created from raw data to classify into two groups, the lower score group (0) and the higher score group (1), using the cutoff point of above and below the median. The FCCHL-S Spanish scale scores were summed and divided by the number of items in the scale to give a scale score (theoretical range 1 to 4). The scores were reversed for functional health literacy.

The independent variable, perceived patient-provider communication, was measured with the PCCS Spanish version instrument. The PCCS scores were summed and total scores were rescaled from 0 to 100. A dichotomous variable was created from the PCCS score of above and below the mean, with the lower score group (0) and the higher score group (1). The mean scores for each item of the PCCS Spanish-version scale were computed.

The independent variable, perceived efficacy in patient-physician interactions, was measured with the Short PEPPI Spanish version instrument. The PEPPI scores were

summed to form a scale that ranges from 5 to 25. A dichotomous variable was created from the PEPPI score of above and below the mean, with the lower score group (0) and the higher score group (1). The mean scores for each item of the PEPPI Spanish-version scale were computed.

The independent variable, stage of readiness scale, was measured using Likert-type items. The associations among each of the four items were medium (r = .35-0.67, p < .01). The responses were dichotomized as strongly disagree/ disagree (0) and agree/strongly agree (1); neutral responses were excluded. I selected the action stage item to reflect participants' positive attitudes toward health decision making. The first action stage item was: "medical decisions about my HIV/AIDS treatment are done by my health care provider and by me." The median scores for each item of the SRS-S scale were computed. Demographic data and HIV/AIDS clinical and immunological data were obtained from the HIV/AIDS Registry database and were matched with the participant questionnaires using a unique ID number. The database contained information from the baseline questionnaires or the last available follow-up questionnaires from each participant. As shown in Table B1, variables were recoded before data analysis. Most variables were not manipulated. The variable educational level was recoded as less than a high school education (0) or higher than a high school education (1). The number of hospitalizations, emergency room visits, and ambulatory clinic visits were used as a continuum.

For the purpose of this research, a reliability analysis was conducted to assess the internal consistency using Cronbach's alpha in the study sample (N = 100). The values

for coefficient alpha indicate satisfactory reliability for each of the FCCHL Spanish-version subscales and scale (α = .78, α = .78, α = .86, and α = .80, respectively). Also, the internal consistency indicated satisfactory reliability for the PCCS Spanish-version scale (α = .94), for the PEPPI Spanish-version scale (α = .91), for the BEHKA-HIV Spanish-version action subscale (α = .93), and for the PABS pros subscale (α = .74). However, the Cronbach's α for the BEHKA-HIV knowledge subscale and for the PABS cons subscale were unacceptable.

Table 2 presents the correlation coefficients computed for positive and negative attitudes toward health decision making and the study scales. Correlation coefficients were computed between five scales with the PABS scale. The Bonferroni (Green & Salkind, 2011) approach was used to reduce Type I errors; therefore, a *p* value of less than 0.002 was required for significance. The results of the correlation analysis showed that 12 out of 18 correlations were statistically significant and were greater than or equal to 0.26. The correlations of HIV/AIDS knowledge and self-report HIV medication adherence with communicative health literacy tended to be lower, but significant. The correlations of self-efficacy with communicative, critical, and total health literacy also tended to be lower, but significant. The correlations of functional, communicative, and critical health literacy with total health literacy tended to be high and significant.

Table 2

Pearson's Correlations Among Positive and Negative Attitudes Toward Health Decision Making and Participation and Study Variables

Measures	1	2	3	4	PABS	*M*	*SD*
Functional HL	---	0.141	0.213*	0.651**	0.179	2.91	0.76
Communicative HL	0.141	---	0.556**	0.755**	-0.020	3.18	0.68
Critical HL	0.213	0.556**	---	0.787**	0.055	3.21	0.83
Total HL	0.651**	0.755**	0.787**	---	0.107	3.09	0.56
PEPPI	0.099	0.287**	0.271**	0.294**	-0.015	23.08	3.23
PCCS	0.030	0.356**	0.300**	0.303**	-0.102	80.39	21.09
BEHKA-HIV	0.210	0.260**	0.221	0.313**	-0.078	5.53	2.23
Action stage	0.037	0.039	-0.152	-0.031	0.212	3.92	1.31
PABS	0.179	-0.020	0.055	0.055	---	0.76	0.43

Note. 1= Functional health literacy, 2= Communicative health literacy, 3= Critical health literacy, and 4= Total Health Literacy.
*$p < .05$, **$p < .002$.

Univariate Analysis

The HIV/AIDS Registry database contained demographic and HIV/AIDS clinical and immunological variables from both the participants baseline questionnaires (n = 21) or the last available follow-up questionnaires (n = 79). The sample consisted of 100 PLWHA, 63% were men (n = 63) and 37% were women (n = 37) with a mean age of 52.04 ± 11.58 years ranging from a minimum age of 22.25 to maximum age of 80.35. The mean time since the diagnosis of HIV/AIDS was 11.39 ± 6.78 years. Approximately 42% of the sample completed a high school education, 29% had higher than a high school education, 18% had a middle school education, and 11% had less than a sixth grade

education. Most participants were single (53.8%, *n* = 43), followed by married (16.3%, *n* = 13), divorced (11.3%, *n* = 9), consensual union (7.5%, *n* = 6), widowed (7.5%, *n* = 6), and separated (3.8%, *n* = 3). Marital status data were not available for 20 participants. In terms of employment status, 85% (*n* = 69) were unemployed and 15% (*n* = 12) were employed. Employment status data were not available for 19 participants.

About 47% had a diagnosis of AIDS during their lifetime and 43% had more than 11 years of living with HIV/AIDS. The HIV viral load was divided into categories: 62% (*n* = 57) had < 200 copies/ml, 13% (*n* = 12) had 200-10,000 copies/ml, 9.8% (*n* = 9) had 10,001-50,000 copies/ml, and 15.2% (*n* = 14) had > 50,000 copies/ml. Approximately 18% had a CD4 cell count equal or less than 200 cells/µl, 40% had a CD4 cell count of 201-499 cells/µl, and 41% had a CD4 cell count equal or higher than 500 cells/µl. The mean number of hospitalizations was 0.03 ± 0.178 (range: 0.00-1.00) hospitalizations. The mean number of emergency room visits was 0.06 ± 0.322 (range: 0.00-2.00) visits. The mean number of ambulatory clinic visits was 4.67 ± 2.44 (range: 0.00-14.00) visits.

The distribution of the study variables is shown in Table 3. The average score of positive attitudes toward health decision making was 70.91 ± 17.03, and the average score of negative attitudes toward health decision making was 56.40 ± 15.90. Approximately 76% (*n* = 75) had positive attitudes and 24% (*n* = 24) had negative attitudes toward health decision making based on the PABS decisional balance score.

The average score of the BEHKA-HIV health literacy scale was 5.53 ± 2.23. About 37% of the sample correctly answered the open question, “What is a CD4 count?” and among correct answers, 97% selected the correct HIV/AIDS treatment goal in terms

of CD4 count. Forty-five percent of the sample correctly answered the open question, "What is a viral load?" and about 85% selected the correct HIV/AIDS treatment goal in terms of HIV/AIDS viral load. The percentage of correct answers in the open question, "What medicines are you currently taking to treat HIV?" was 85%. Only 18% correctly answered all 3 items of the BEHKA-HIV knowledge subscale. In terms of self-report HIV medication adherence 67% were adherent to HIV/AIDS treatment. About 62.7% (*n* = 54) of the sample were taking two or more HAART medications, 32.5% (*n* = 28) were taking one HAART medication, whereas 4.7% (*n* = 4) were out of treatment and HAART data were not available for 14 participants.

Most participants had adequate HIV/AIDS health literacy (66%, *n* = 65). Similar percentages were found of participants with marginal (17%, *n* = 17) and low (16%, *n* = 16) HIV/AIDS health literacy. The average score of the PCCS scale was 80.39 ± 21.09. Approximately 67% (*n* = 67) had higher confidence and 33.0% (*n* = 33) had lower confidence in patient-provider communication. The average score of the PEPPI scale was 23.08 ± 3.23. Approximately 65% (*n* = 65) had higher self-efficacy and 35% (*n* = 35) had lower self-efficacy in patient-physician interactions.

Likert-type items were asked to describe their TTM stage of readiness. About 61% (*n* = 61) responded affirmatively to the premise "medical decisions about my HIV/AIDS treatment are done by my health care provider and I intend to keep it that way" (pre-contemplation phase). Fifty-three percent (*n* = 53) responded affirmatively to the premise "medical decisions about my HIV/AIDS treatment are done by my health care provider, but I thinking about participating in future medical decisions"

(contemplation phase).; Fifty-seven percent (n = 56) responded affirmatively to the premise "medical decisions about my HIV/AIDS treatment are done by my health care provider and in some degree by me" (preparation phase). And 71% (n = 71) responded affirmatively to the premise "medical decisions about my HIV/AIDS treatment are done by my health care provider and by me" (action phase).

Table 3

Frequencies and Percentages of Demographic and HIV/AIDS Clinical and Immunological Data

Variable	Category
PABS pros subscale	
	Mean = 70.91 *SD* = 17.03 Median = 74.28 Mode = 88.57 Range = 17.14 – 100.00
PABS cons subscale	
	Mean = 56.40 *SD* = 15.90 Median = 56.00 Mode = 60.00 Range = 20.00 – 100.00

(table continues)

PABS decisional balance scale	
	Mean = 14.50 Median = 13.71 Mode = 5.71 Range = -32.57 – 62.86
BEHKA-HIV knowledge scale	
	Mean = 1.54 Median = 1.00 Mode = 1.00 Range = 0.00 – 3.00
BEHKA-HIV medication adherence subscale	
	Mean = 4.11

Variable	Category
	Median = 5.00
	Mode = 5.00
	Range = 0.00 – 5.00
BEHKA-HIV subscale	
	Mean = 5.53 *SD* = 2.23
	Median = 6.00
	Mode = 6.00
	Range = 0.00 – 8.00
PCCS scale	
	Mean = 80.39 *SD* = 21.09
	Median = 86.11
	Mode = 100.00
	Range = 16.67 – 100.00
PEPPI scale	
	Mean = 23.08 *SD* = 3.23
	Median = 25.00
	Mode = 25.00
	Range = 11.00 – 25.00
Readiness item 1	
	Median = 4.00
	Mode = 5.00
	Range = 1.00 – 5.00
Readiness item 2	
	Median = 4.00
	Mode = 4.00
	Range = 1.00 – 5.00
Readiness item 3	
	Median = 4.00
	Mode = 5.00
	Range = 1.00 – 5.00
Readiness item 4	
	Median = 4.00
	Mode = 5.00
	Range = 1.00 – 5.00

Research Questions

Research Question 1

What is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS?

The first research question was related to describe the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS. The average raw score for functional health literacy was 14.53 ± 3.81 (range: 5.00-20.00), for communicative health literacy raw score was 15.92 ± 3.41 (range: 7.00-20.00), for critical health literacy raw score was 12.86 ± 3.34 (range: 4.00-16.00), and total health literacy raw score was 43.31 ± 7.68 (range: 17.00-56.00). Average raw health literacy scores indicate that the sample had higher communicative health literacy followed by functional health literacy and critical health literacy. Table 4 shows results on total health literacy. For the purpose of this research, raw score was classified into two groups: higher score group (n = 54, 54%) and lower score group (n = 46, 46%) using as cut off point of above and below the median (Mdn = 44).

The average mean scores for critical health literacy was 3.21 ± 0.83 (range: 1.00-4.00), for communicative health literacy was 3.18 ± 0.68 (range: 1.40-4.00), and for functional health literacy was 2.91 ± 0.76 (range: 1.00-4.00). The average mean score for the total health literacy scale was 3.09 ± 0.55 (range: 1.21-4.00). In terms of average health literacy mean scores the sample had similar critical and communicative health literacy and lower functional health literacy.

Table 4

Frequencies and Percentages of Demographic and HIV/AIDS Clinical and Immunological Data

Variable	Category	Frequency	Percent
Functional health literacy subscale			
	Mean = 2.91 *SD* = 0.76 Median = 3.00 Mode = 2.60 Range = 1.00 – 4.00		
Communicative health literacy subscale			
	Mean = 3.18 *SD* = 0.68 Median = 3.40 Mode = 4.00 Range = 1.40 – 4.00		
Critical health literacy subscale			
	Mean = 3.21 *SD* = 0.83 Median = 3.50 Mode = 4.00 Range = 1.00 – 4.00		
Total health literacy scale			
	Mean = 3.09 *SD* = 0.55 Median = 3.14 Mode = 3.50 Range = 1.21 – 4.00		
Raw health literacy scores			
	High scores	54	54
	Low scores	46	46

Research Question 2

What factors influence positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS?

$H_0$1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and self-report HIV medication adherence does not affect positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

H_A1: Demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and self-report HIV medication adherence affect positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS.

This question tested the null hypothesis that demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, self-report HIV medication knowledge, and self-report HIV medication adherence does not affect positive and negatives attitudes toward health decision making. The results for the first hypothesis were analyzed using chi-square test statistic for independence. No significant associations were found between these factors and positive and negatives attitudes toward health decision making ($p > 0.05$; see Table 5).

The percentage of participants who had positive attitudes toward participation in health decision making was 81.5% for the group with higher health literacy scores and 68.9% for the group with lower health literacy scores, as measured by FCCHL scale. The percentage of participants who had positive attitudes toward participation in health decision making was 74% for the group with adequate HIV/AIDS health literacy and 78% for the group with low/marginal HIV/AIDS health literacy, as measured by BEHKA-HIV. The percentage of participants who had positive attitudes toward

participation in health decision making was 75% for the group who perceived a higher confidence in their ability to effectively communicative with their physicians and 78% for the group that perceived a lower confidence in their ability to effectively communicative with their physicians, as measured by the PEPPI. The percentage of participants who had positive attitudes toward participation in health decision making was 71% for the group who perceived a higher confidence in their ability to effectively interact with their physicians and 85% for the group with lower confidence in their ability to effectively interact with their physicians. None of the noted differences were statistically significant.

Table 5

Comparison of Positive Attitudes Toward Health Decision Making by Categorical Variables

Variables	Categories	Positive Attitudes Toward Health Decision Making		χ^2	*p*
		Yes *n* (%)	No *n* (%)		
Gender	Female	31 (86)	5 (14)	3.30	0.069
	Male	44(70)	19(30)		
Education	< 12 grade	23 (82)	5 (17)	1.00	0.317
	12 grade or higher	50 (72)	19 (27)		
Employment	Unemployed	49 (72)	19 (28)	0.044	0.833
	Employed	9 (75)	3 (25)		
Health literacy	Lower	31 (69)	14 (31)	2.120	0.145
	Higher	44 (81)	10 (18)		
HIV/AIDS health literacy	Low	12 (80)	3 (20)	0.260	0.876
	Marginal	13 (76)	4 (23)		
	Adequate	48 (74)	17 (26)		
Medication adherence	Non-adherent	24 (80)	6 (20)	0.709	0.400
	Adherent	46 (72)	18 (28)		

(table continues)

Variables	Categories	Positive Attitudes Toward Health Decision Making		χ^2	*p*
		Yes *n* (%)	No *n* (%)		
Patient-provider communication	Lower	25 (78)	7 (22)	0.144	0.704
	Higher	50 (74)	17 (25)		
Self-efficacy	Lower	29 (85)	5 (15)	2.560	0.109
	Higher	46 (71)	19 (29)		

Note. Pearson Chi-Square for Independence.

Research Question 3

What is the relationship between health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS after controlling for the gender, education level, disease duration, and stage of readiness?

$H_0$2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are not related with positive and negatives attitudes toward health decision making, as measured by the PABS-S, among Puerto Ricans living with HIV/AIDS.

H_A2: Health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and HIV/AIDS health literacy after controlling for the effects of gender, education level, disease duration, and stage of readiness are related with positive and negatives attitudes toward health decision making as measured by the PABS-S among Puerto Ricans living with HIV/AIDS.

This question tested the null hypothesis that health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy were not related with positive and negatives attitudes toward health decision making among PLWHA after controlling for the effects of gender, education level, disease duration, and stage of readiness. Albeit no significant associations were found on bivariate analyses I conducted a multivariate logistic regression based on the literature to explore if these factors were related with positive and negatives attitudes toward health decision making.

A multivariate logistic regression analysis was conducted to predict positive attitudes toward health decision making for PLWHA using health literacy, patient-provider communication, self-efficacy, and HIV/AIDS health literacy as predictors. The control variables were gender, disease duration, and educational level. A select cases command was applied to include participants that respond affirmatively to the action stage premise (n = 71). A test of the full model against a constant only model was statistically significant, indicating that health literacy is a predictor between positive and negative attitudes toward participation in health decision making ($\chi^2 = 4.85$, $p < .02$ with $df = 1$). Prediction success overall was 80.6% (26.7% for decline and 96.2% for accept). The Wald criterion indicated that health literacy was a statistically significant predictor of positive attitudes toward health decision making (see Table 6). Puerto Ricans living with HIV/AIDS with higher scores in health literacy were 4.85 times (95% *CI* [1.99, 22.48], $p < .05$) more likely to have positive attitudes toward health decision making.

Table 6

Logistic Regression Analysis by Positive Attitudes Toward Health Decision Making (N=71)

Predictors	*B*	*SE B*	Wald	*df*	*p*	*OR*	95% CI	
							LL	*UL*
Gender	-1.50	0.90	2.77	1	.10	0.22	0.04	1.30
Education level	-0.96	0.87	1.22	1	.27	0.38	0.07	2.11
Disease duration	-0.56	0.68	0.68	1	.41	0.57	0.15	2.17
BEHKA	-0.50	0.75	0.44	1	.51	0.61	0.14	2.66
PCCS	0.67	0.75	0.81	1	.37	1.96	0.45	8.50
PEPPI	-1.15	0.77	2.19	1	.14	0.32	0.07	1.45
FCCHL	1.65	0.75	4.85	1	.02*	5.19	1.20	22.48
Constant	3.25	1.29	6.35	1	.01	25.92		

Note. *$p < .05$.

Ancillary Analyses

Ancillary analyses were conducted to evaluate functional health literacy, communicative health literacy, critical health literacy, and total health literacy using independent sample *t*-test and one-way analysis of variance (ANOVA). Bivariate relationships of health literacy dimensions with other measures are shown in Table 7.

The *t*-test was significant for communicative health literacy ($p < .05$) and with self-report HIV medication adherence. Participants with higher communicative health literacy scores had higher HIV medication adherence. The *t*-test was significant for functional health literacy ($p < .01$) and critical health literacy ($p < .05$) and HIV/AIDS health literacy. Participants with higher functional and critical health literacy scores had higher HIV/AIDS health literacy. The *t*-test was significant for communicative health literacy ($p < .01$) and critical health literacy ($p < .01$) and patient-provider communication confidence. Participants with higher communicative and critical health literacy scores had higher patient-provider communication confidence. Finally, the *t*-test was significant for

functional health literacy ($p < .01$), communicative health literacy ($p < .05$), and critical health literacy ($p < .05$) and AIDS diagnosis. Participants with higher functional, communicative and critical health literacy scores have not had an AIDS diagnosis.

A one-way ANOVA was conducted to evaluate the relationship between each health literacy dimension and educational level. The one-way ANOVA, for functional health literacy ($p < .01$) and for total health literacy ($p < .01$) showed statistically significant differences between groups. A post-hoc Scheffe test was conducted to evaluate differences among educational level categories on health literacy. The post-hoc analyses revealed significant ($p < .01$) differences between ≤ sixth grade and 10^{th}-12^{th} grade educational level, and between ≤ sixth grade and higher than high school educational level for functional health literacy. Those with 10^{th}-12^{th} grade and above high school education compared to those with ≤ sixth grade education demonstrated significantly higher functional health literacy. The one-way ANOVA was not statistically significant for health literacy dimensions and CD4 count categories.

Table 7

Bivariate Relationship of Health Literacy Dimensions with Other Measures

Variables	Functional health literacy		Communicative health literacy		Critical health literacy	
	M (*SD*)	*p*	*M* (*SD*)	*p*	*M* (*SD*)	*p*
Gender		0.897		0.204		0.656
Male	2.90 (0.70)		3.12 (0.66)		3.25 (0.74)	
Female	2.92 (0.86)		3.30 (0.71)		3.16 (0.99)	
Educational level		0.001**		0.117		0.854

Variables	Functional health literacy		Communicative health literacy		Critical health literacy	
	M (*SD*)	*p*	*M* (*SD*)	*p*	*M* (*SD*)	*p*
≤ sixth grade	2.20 (0.94)		2.96 (0.87)		3.07 (1.06)	
Middle school	2.67 (0.93)		2.90 (0.85)		3.14 (0.94)	
High school	3.00 (0.61)		3.24 (0.50)		3.29 (0.71)	
Higher than high school	3.17 (0.59)		3.33 (0.68)		3.19 (0.89)	
Job status		0.601		0.696		0.547
Employed	3.05 (0.80)		3.33 (0.62)		3.02 (0.65)	
Unemployed	2.83 (0.83)		3.15 (0.69)		3.27 (0.87)	
Disabled	3.06 (0.81)		3.23 (0.82)		3.00 (1.23)	
CD4 count		0.401		0.962		0.564
<200 cells/ µl	2.74 (0.67)		3.22 (0.71)		2.98 (0.85)	
200-499 cells/ µl	2.92 (0.82)		3.17 (0.70)		3.21 (0.83)	
≥500 cells/µl	3.03 (0.72)		3.17 (0.69)		3.24 (0.87)	
AIDS diagnosis		0.007**		0.050*		0.037*
Yes	2.69 (0.66)		3.03 ± (0.81)		3.03 ± (0.96)	
No	3.10 (0.81)		3.31 (0.51)		3.38 (0.67)	

(table continues)

Medication adherence		0.194		0.048*		0.161
Yes	2.97 (0.72)		3.28 (0.62)		3.29 (0.83)	
No	2.76 (0.78)		2.98 (0.77)		3.03 (0.87)	

Note. *$p < .05$, **$p < .01$.

Summary

Secondary data and survey research were used to perform a cross-sectional study. In this chapter, I described and examined the relationship between health literacy and positive and negatives attitudes toward health decision making. Three research questions were answered with univariate, bivariate, and multivariate statistical analyses. I failed to reject the null hypothesis for Research Question 1. In the bivariate analysis, demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, and self-report HIV medication adherence did not significantly influence positive and negatives attitudes toward health decision making. The null hypothesis for Research Question 2 was rejected. Multivariate logistic regression indicated that higher scores in health literacy were statistically related with positive attitudes toward health decision making after controlling for covariates. Puerto Ricans living with HIV/AIDS and with higher scores in health literacy and higher self-efficacy ($p < .05$) were more likely to have positive attitudes toward participation in health decision making. Ancillary analysis was performed to confirm previous research findings related with health literacy. As with previous studies, functional health literacy and advance health literacy skills were related with self-reported HIV medication adherence, patient-provider communication confidence, HIV/AIDS health literacy, and higher educational attainment. The implications of my research findings are elaborated on in Chapter 5 including study limitations and future research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

This quantitative study was used to examine the impact of the three dimensions of health literacy in HIV/AIDS disease management and positive and negative attitudes toward participation in health decision making among PLWHA. This chapter presents an interpretation of the data analysis based on previous research findings and recommendations for future research. A total of 100 PLWHA in Puerto Rico were recruited and completed six culturally sensitive questionnaires related to the research questions. This study examined the association between health literacy and positive and negative attitudes toward health decision making. PLWHA (54%) in the sample had higher raw health literacy scores. Results revealed that Puerto Ricans living with HIV/AIDS in the action stage and with higher health literacy scores were more likely to have positive attitudes toward health decision making.

Interpretation of the Findings

Research Question 1

RQ1: What is the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS?

The first research question was used to describe the level of functional, communicative, and critical health literacy among Puerto Ricans living with HIV/AIDS. The average total health literacy scores were high. Health literacy scores were higher for critical health literacy and communicative health literacy than for functional health literacy. Ishiwaka et al. (2008) found lower critical health literacy scores and similar functional and

communicate health literacy scores in a Japanese sample with type 2 diabetes. Also, Heijmans et al. (2015) found higher scores on functional health literacy than in communicative and critical health literacy in a Dutch sample with chronic diseases. Similar to my findings, Lai et al. (2013), in a sample of patients with end-stage renal disease with diabetes on hemodialysis, found similar communicative and critical health literacy scores. According to Freebody and Luke's health literacy model (as cited in Nutbeam, 2000), health literacy dimensions are based on the complexity of skills needed to understand and apply health-related information. Further studies should be done to examine differences on health literacy dimensions, specifically functional health literacy and demographic characteristics.

Research Question 2

> RQ2: What factors influence positive and negative attitudes toward health decision making among Puerto Ricans living with HIV/AIDS?

The second research question tested if there was an association between demographic factors, health literacy dimensions, patient-provider communication, self-efficacy, HIV medication knowledge, self-report HIV medication adherence, and health decision making. In bivariate analyses, no significant associations were found between these factors and positive attitudes toward health decision making. According to Ishikawa and Yano (2008), health decision making is lower among patients with limited health literacy. Moreover, Kim et al. 2001 (as cited in Ishikawa & Yano, 2008) stated that limited health decision making participation among patients with low health literacy is often associated with lower knowledge of disease.

Research Question 3

RQ3: What is the relationship between health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy and positive and negatives attitudes toward health decision making among Puerto Ricans living with HIV/AIDS after controlling for the gender, education level, disease duration, and stage of readiness?

This question tested the null hypothesis that health literacy dimensions, patient-provider communication, self-efficacy, and HIV/AIDS health literacy were not related with positive and negative attitudes toward health decision making among PLWHA in Puerto Rico. No significant associations were found on bivariate analyses. A multivariate logistic regression analysis was conducted to predict positive attitudes toward health decision making for PLWHA using study variables as predictors after controlling for the effects of gender, education level, disease duration, and action stage. The Wald criterion indicated that health literacy ($p < .05$) is a statistically significant contributor to prediction. Puerto Ricans living with HIV/AIDS with higher scores in health literacy were 4.53 times more likely to have positive attitudes toward health decision making.

The relationship between health literacy and positive and negative attitudes toward health decision making among PLWHA should be further examined. Ishikawa and Yano (2008) affirmed that participation in health decision making is lower among patients with limited health literacy skills. Also, health care decisions often rely on health care providers or family members (Ishikawa & Yano, 2008). One of the factors that hinder participation in health decision making includes the lack of health specific

knowledge (Kim et al. 2001 as cited in Ishikawa & Yano, 2008), but it was not found statistically significant in the bivariate analysis. Other factors that affect participation in health decision making is low educational attainment more commonly observed among disadvantaged populations (Smith et al., 2009). This factor was also non-significant. However, Smith et al. (2009) affirmed that higher educational attainment rather than adequate health literacy plays an important role in shared health decision making. Another study examined the relationship between communicative health literacy and patient-provider communication as factors related with access to health care (Yin et al., 2012). Confidence in patient-provider communication was also found to be non-significant.

Previous researchers have developed pathways to explain health literacy as a risk factor and as an asset. One model proposed by Edwards et al. (2012), describes the advanced health literacy skills needed for an active participation in health decision making processes. Disease specific knowledge and the patient's empowerment are key determinants for becoming involved in health decision making (Edwards et al., 2012). A few instruments based on the TTM have been developed to assess health decision making. For the purpose of this research, the PABS was used to predict positive and negative attitudes toward health decision making. A stage of readiness instrument, constructed by Arora et al. (2005), was modified to assess a participant's readiness for health decision making. The results of this research confirmed that PLWHA in the action stage of readiness are prone to have more positive attitudes toward health decision making than PLWHA in the pre-contemplation, contemplation, and preparation stages.

Ancillary Results

HIV/AIDS disease specific knowledge and self-report HIV medication adherence showed statistical significance for functional ($p < 0.01$) and critical health literacy ($p < 0.05$). Wolf et al. (2005) confirmed that lack of HIV medication adherence is a consequence of limited health literacy due to lack of HIV treatment knowledge. In my sample, adherent participants on average had higher functional, communicative, and critical health literacy than those non-adherence participants. Also, participants with adequate HIV/AIDS health literacy had higher functional, communicative, and critical health literacy as opposed to those with low or marginal HIV/AIDS health literacy as measured by BEHKA-HIV. Hicks et al.'s (2006) study showed that health literacy and HIV knowledge have a strong positive association. Converse to previous studies, Bynum et al. (2013) did not find an association between HPV disease specific knowledge and health literacy in a sample of HIV positive women. Bynum et al. (2013) argued that health literacy has a greater influence on health-related behaviors and awareness than disease-specific knowledge.

Another factor that has been related with health decision making is patient-provider communication as perceived by the patient; however, in my study, it was not statistically significant. My results showed that participants with higher scores in patient-provider communication confidence had higher functional health literacy, communicative health literacy, and critical health literacy as opposed to those with lower scores in patient-provider communication confidence. Schillinger et al. (2004) affirmed that poor communication skills among individuals with limited functional health literacy were a

predictor of unsuccessful disease management. Furthermore, Schillinger et al. (2004) explained that limited functional health literacy is related with the patient-provider communication explanatory/participatory dimensions. The explanatory dimension focused on how health care providers inform patients about their health care needs and treatment options to successfully manage their disease based on their health literacy levels (Schillinger et al., 2004). The participatory dimension focused on passive communication and low participation in medical interactions among patients with limited health literacy due to shame or being uninformed (Schillinger et al., 2004). Schillinger et al. concluded that patient-provider communication is affected by other factors including socioeconomic status, educational level, and ethnicity.

In terms of self-efficacy participants with higher self-efficacy in patient-physician interactions had similar functional health literacy and higher communicative and critical health literacy as opposed to those with lower self-efficacy. However, it was not statistically significant. Conversely, Clayman et al. (2010) found that self-efficacy and recall of medical instructions were key factors that facilitated health decision making among individuals with limited health literacy.

Limitations

The selection of the TTM to guide this study contributed to new knowledge about how health literacy dimensions were associated with positive and negative attitudes toward health decision making in the study population. Despite the advantages of using the TTM in this study, some study limitations were encountered. First, the SRS-S scale was used as Likert-type items; therefore, statistical analyses by each stage of readiness

were not possible. For the purpose of this research, the action stage premise, "medical decisions about my HIV/AIDS treatment are done by my health care provider and by me," was used to perform the multivariate analysis.

In this study, the use of a cross-sectional design allowed data collection during a short period of time in a single HIV/AIDS clinic in Bayamon, PR with patients who had on average, more than 11 years of living with HIV/AIDS. However, in this type of research design, determining a direct influence of an independent variable over other variables is not possible (Frankfort-Nachmias & Nachmias, 2008). The sample was chosen by non-probability purposive sampling, which posed other limitations to them being representative of the population due to researcher subjective judgment (Frankfort-Nachmias & Nachmias, 2008). However, having representation of the population was not a barrier because the sample had a similar profile of the Bayamon Immunologic Clinic clientele. Another limitation was sample size, due to the number of variables studied. Further studies with a larger sample size followed longitudinally could be used to confirm research findings and identify potential confounders. The findings represent health literacy skills and positive attitudes toward health decision making of PLHWA that attended the Bayamon Immunologic Clinic. Due to the nature of this study, generalizations to the general population cannot be made.

Recommendations

This study provided the opportunity to use culturally sensitive instruments to determine the impact of functional, communicative, and critical health literacy dimensions on positive and negative attitudes toward health decision making in a sample

of Puerto Ricans living with HIV/AIDS. Further research with minority populations with chronic diseases should be examined. In studies conducted with a foreign born population, acculturation and language barriers should be considered as factors that might hinder active participation in health decision making process. The TTM readiness scale developed by Arora et al. (2005) was used as Likert-type items; therefore, statistical analyses on each stage of readiness were not possible. Other stage of readiness scales should be evaluated to perform advanced statistical analysis on each stage of change. Moreover, instruments that measure advanced health literacy skills are needed. In 2011, a new instrument known as the AAHLS, which expanded the critical health literacy definition by including the social determinants of health, was published (Chinn, 2011). This instrument could provide more information about necessary advanced health literacy skills and their role in health decision making. Another recommendation is to study the type of sources of information used by individuals with limited health literacy. Also, further studies should focus on how health care providers perceived patients involvement in health decision making and the challenges posed by limited health literacy.

Implications

The social change implications of this research included the identification of limited health literacy as a factor that might play a role in positive attitudes toward the health decision making process among PLWHA. The TTM framework was useful in determining the association of health literacy on positive attitudes toward health decision making. Arora et al. (2005) emphasized that patient's involvement in health decision making processes result in proper disease management and better health outcomes.

Previous factors have linked age, educational level, and the severity of the illness with positive and negative attitudes toward health decision making (Arora et al., 2005). Patients in the precontemplation stage have higher trust in health care providers and lower self-efficacy; therefore, they have negative attitudes toward participation in health decision making (Arora et al., 2005). The results of this research confirmed that PLWHA in the action stage of readiness are prone to have more positive attitudes toward health decision making.

Health literacy is one of the social determinants of health (Nutbeam, 2000). Health literacy as a health promotion outcome measures individual factors such as knowledge, attitudes, behavioral intentions, personal skill, and self-efficacy (Nutbeam, 2000). In each medical encounter, patients' health literacy skills should be considered as an asset or risk factor. Therefore, providing tools for health care providers to assess individuals' health literacy can help to develop positive attitudes toward health decision making and improve health outcomes. Some of these tools are using plain language to design health-related information printed materials and web sites (DeWalt et al., 2010). Also, the brown bag method and teach-back method have been successful to address limited health literacy (DeWalt et al., 2010).

Limited health literacy was found in 46% of the sample. Health literacy should be considered as an important factor of the HIV care continuum to properly diagnose people living with HIV, retain PLWHA in care, to increase HIV treatment and adherence, and to achieve viral suppression (UNAIDS, 2014). Limited health literacy skills have implications for public health policy and access to care. Health systems should develop

patient navigation systems and health-related information materials for individuals with low health literacy (McCormack et al., 2010). Also, training health care providers and health insurers about the financial burden and usage of health care services among individuals with limited health literacy should be considered.

Conclusions

This research study explored Freebody and Luke's (1990) health literacy dimension that focused on how individuals understand and apply health-related information. Higher communicative and functional health literacy among the sample was found, which is not consistent with other studies. Communicative health literacy was related with self-report HIV medication adherence and patient-provider communication confidence. Critical health literacy was related with HIV/AIDS health literacy, which includes HIV/AIDS knowledge and self-report HIV medication adherence. In this study, self-efficacy and demographic factors did not significantly differ with any of the health literacy dimensions except for functional health literacy and educational level. After controlling for gender, disease duration, educational level, and action stage of readiness, health literacy and self-efficacy were related with positive attitudes toward health decision making.

Limited health literacy poses challenges to health care outcomes. The development or adaptation of culturally sensitive interventions to address this public health problem is needed to improve the quality of life and health outcomes for minorities in the United States. The positive social change that might result from this research is a

reduction of unnecessary hospitalizations and emergency room visits, higher use of preventive screening services, and improving HIV medication adherence.

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Appendix A

Data Use Agreement

DATA USE AGREEMENT

This Data Use Agreement, effective as of April 2014, is entered into by and between Christine Miranda Diaz (Data Recipient) and Dr. Robert F. Hunter, Director of the Retrovirus Research Center (Data Provider). The purpose of this Agreement is to provide Data Recipient with access to a Limited Data Set ("LDS") for use in research in accord with the HIPAA Regulation.

1. Definitions. Unless otherwise specified in this Agreement, all capitalized terms used in this Agreement not otherwise defined have the meaning established for purposes of the "HIPAA Regulations" codified at Title 45 parts 160 through 164 of the United States Code of Federal Regulations, as amended from time to time.

2. Preparation of the LDS. Data Provider shall prepare and furnish to Data Recipient a LDS in accord with any applicable HIPAA Regulation

3. Data Fields in the LDS. No direct identifiers such as names may be included in the Limited Data Set (LDS). In preparing the LDS, Data Provider shall include the **data fields specified as follows**, which are the minimum necessary to accomplish the research (list all data to be provided):

Sociodemographic factors		
ID Number		
Age	Numerical	Age in number
Gender	Nominal	Male=1; Female=2
Education Level	Ordinal	≤6th grade=1; 7-9th grade=2; 10-12th grade=3; 13-16th grade=4; Master, MD, PhD=5; Not known=6
Marital Status	Nominal	Single=1; Married=2; Consensual union=3; Widowed=4; Divorced=5; Separated=6; other=7; Not known=8
Employment status	Nominal	Employed=1; Unemployed=2; Disabled=3; Veteran=4; Other=5; Not known=6
Clinical and immunological factors		
HIV disease duration	Numerical	Date of first HIV positive test
AIDS diagnosis	Numerical	Date of AIDS diagnosis
CD4	Numerical	CD4 during the last 12

		months
CD8	Numerical	CD8 during the last 12 months
HIV viral load	Numerical	HIV viral load during the last year (viral copies/ml)
Number of hospitalization	Numerical	Number of hospitalization during the last 12 months
Number of outpatient visits	Numerical	Number of outpatient visits during the last 12 months
Number of ER visits	Numerical	Number of ER visits during the last 12 months

4. Responsibilities of Data Recipient. Data Recipient agrees to:

    a. Use or disclose the LDS only as permitted by this Agreement or as required by law;

    b. Use appropriate safeguards to prevent use or disclosure of the LDS other than as permitted by this Agreement or required by law;

    c. Report to Data Provider any use or disclosure of the LDS of which it becomes aware that is not permitted by this Agreement or required by law;

    d. Require any of its subcontractors or agents that receive or have access to the LDS to agree to the same restrictions and conditions on the use and/or disclosure of the LDS that apply to Data Recipient under this Agreement; and

    e. Not use the information in the LDS to identify or contact the individuals who are data subjects.

5. Permitted Uses and Disclosures of the LDS. Data Recipient may use and/or disclose the LDS for its Research activities only.

6. Term and Termination.

    a. Term. The term of this Agreement shall commence as of the Effective Date and shall continue for so long as Data Recipient retains the LDS, unless sooner terminated as set forth in this Agreement.

    b. Termination by Data Recipient. Data Recipient may terminate this agreement at any time by notifying the Data Provider and returning or destroying the LDS.

c. Termination by Data Provider. Data Provider may terminate this agreement at any time by providing thirty (30) days prior written notice to Data Recipient.

d. For Breach. Data Provider shall provide written notice to Data Recipient within ten (10) days of any determination that Data Recipient has breached a material term of this Agreement. Data Provider shall afford Data Recipient an opportunity to cure said alleged material breach upon mutually agreeable terms. Failure to agree on mutually agreeable terms for cure within thirty (30) days shall be grounds for the immediate termination of this Agreement by Data Provider.

e. Effect of Termination. Sections 1, 4, 5, 6(e) and 7 of this Agreement shall survive any termination of this Agreement under subsections c or d.

7. Miscellaneous.

a. Change in Law. The parties agree to negotiate in good faith to amend this Agreement to comport with changes in federal law that materially alter either or both parties' obligations under this Agreement. Provided however, that if the parties are unable to agree to mutually acceptable amendment(s) by the compliance date of the change in applicable law or regulations, either Party may terminate this Agreement as provided in section 6.

b. Construction of Terms. The terms of this Agreement shall be construed to give effect to applicable federal interpretative guidance regarding the HIPAA Regulations.

c. No Third Party Beneficiaries. Nothing in this Agreement shall confer upon any person other than the parties and their respective successors or assigns, any rights, remedies, obligations, or liabilities whatsoever.

d. Counterparts. This Agreement may be executed in one or more counterparts, each of which shall be deemed an original, but all of which together shall constitute one and the same instrument.

e. Headings. The headings and other captions in this Agreement are for convenience and reference only and shall not be used in interpreting, construing or enforcing any of the provisions of this Agreement.

IN WITNESS WHEREOF, each of the undersigned has caused this Agreement to be duly executed in its name and on its behalf.

DATA PROVIDER

Signed: _____

Print Name: Robert Hunter

Print Title: Director RRC

DATA RECIPIENT

Signed: _____

Print Name: Christine Miranda

Print Title: PhD Student

Appendix B

Table B1

Operationalization of Variables and Coding

Variable	Classification	Categories
Functional health literacy (I) Communicative health literacy (I) Critical health literacy (I)	Ordinal	1= Never 2= Rarely 3= Sometimes 4= Often
Patient-provider communication (I)	Scale	1= Strongly disagree 2= Disagree 3= Slightly disagree 4= Slightly agree 5= Agree 6= Strongly agree
Self-efficacy (I)	Scale	0= Not confident at all 5= Extremely confident
HIV/AIDS treatment knowledge and medication adherence (I)	Additive Scale	1= Up 0= Down 0= Up 1= Down 1= Correct 0= Incorrect 0= Agree 0= Not sure 1= Disagree
Stage of readiness (C)	Ordinal	1= Strongly disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly agree
Health decision making (D)	Scale	1= Strongly disagree 2= Disagree 3= Neutral 4= Agree 5= Strongly agree
Age (I)	Numerical	Age in number
Gender (C)	Nominal	1= Male 2= Female

Variable	Classification	Categories
		(*table continues*)
Education level (C)	Ordinal	1= ≤6th grade 2= 7-9th grade 3= 10-12th grade 4= 13-16th grade 5= Master, MD or PhD 9= Not known
Marital status (I)	Nominal	1= Single 2= Married 3= Consensual union 4= Widowed 5= Divorced 6= Separated 7= Other 9= Not known
Employment condition (I)	Nominal	1= Employed 2= Unemployed 3= Disabled 4= Veteran 5= Other 9= Not known
HIV disease duration (C)	Numerical	Date of first HIV positive test
AIDS diagnosis (I)	Numerical	Date of AIDS diagnosis
CD4 (I)	Numerical	CD4 during the last 12 months
CD8 (I)	Numerical	CD8 during the last 12 months
HIV viral load (I)	Numerical	HIV viral load during the last year (viral copies/ml)
HAART medications (I)	String	Name of HAART medication in the last six months
Number of hospitalization (I)	Numerical	Number of hospitalization during the last 12 months
Number of outpatient visits (I)	Numerical	Number of outpatient visits during the last 12 months
Number of ER visits (I)	Numerical	Number of ER visits during the last 12 months

Note. (D)= dependent variable, (I)= independent variable, and (C)= co-variable/confounder.

Appendix C

Questionnaires English Version

Functional, Communicative, and Critical health literacy scale (FCCHL)

Functional health literacy				
In reading instructions or leaflets from hospitals/pharmacies, you. . .	**Never**	**Rarely**	**Sometimes**	**Often**
1. found that the print was too small to read.	1	2	3	4
2. found characters and words that you did not know.	1	2	3	4
3. found that the content was too difficult.	1	2	3	4
4. needed a long time to read and understand them.	1	2	3	4
5. needed someone to help you read them.	1	2	3	4
Communicative health literacy				
Since being diagnosed with HIV, you have. . .	**Never**	**Rarely**	**Sometimes**	**Often**
1. collected information from various sources.	1	2	3	4
2. extracted the information you wanted.	1	2	3	4
3. understood the obtained information.	1	2	3	4
4. communicated your thoughts about your illness to someone.	1	2	3	4
5. applied the obtained information to your daily life.	1	2	3	4
Critical health literacy				
Since being diagnosed with HIV, you have. . .	**Never**	**Rarely**	**Sometimes**	**Often**
1. considered whether the information was applicable to your situation.	1	2	3	4
2. considered the credibility of the information.	1	2	3	4
3. checked whether the information was valid and reliable.	1	2	3	4
4. collected information to make health-related decisions.	1	2	3	4

Patient Attitudes and Beliefs Scale (PABS)

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. I have the right to make my own medical decisions; after all it's my life.					
2. Doctors aren't perfect, so it's important that I'm involved in my medical decisions.					
3. I'd rather be given many choices about what's best for my health than to have the doctor make the decision for me.					
4. Participating in my medical decisions is good for my health.					
5. I tend to get a second opinion when faced with a serious medical decision.					
6. Making my own medical decisions allows me to be in control of my health.					
7. I'm foolish to trust my doctor completely.					
8. I make lousy decisions.					
9. I would have less confidence in my doctor if he/she didn't tell me what to do.					
10. It would offend my doctor if I were to make my own decision(s).					
11. I don't know enough to make my own medical decisions.					
12. If I make the treatment decision, it'll be my fault if it turns out to be a bad choice.					

Patient Confidence in Communication Scale (PCCS)

	Strongly disagree	Disagree	Slightly disagree	Slightly agree	Agree	Strongly agree
1. I can easily list problems or barriers that get in the way of good patient-doctor communication.						
2. I can easily list the reasons why I need to communicate effectively with my doctor.						
3. I can easily give examples of what my role, as a patient, should be when I talk to my doctor.						
4. I can easily list goals I want to achieve when talking to my doctor.						
5. I can easily give examples of what a good doctor's role should be when he/she interacts with me.						
6. I know ways to improve my communication with my doctor.						

Perceived Efficacy in Patient-Physician Interactions (PEPPI)

The following 5 questions are about how you interact with doctors as a patient. **Please circle the number** that tells me how CONFIDENT you feel in your ability to do each of the following things. Remember, these questions are about your ability to do these things in general and not about any particular doctor.

Rate your confidence on a scale of 0 to 5, with 5 meaning extremely confident and 0 meaning not confident at all.

How confident are you in your ability:

1. To know what questions to ask a doctor:

[0 = not confident at all, 5 = extremely confident]

0 1 2 3 4 5

How confident are you in your ability:

2. To get a doctor to answer all of your questions:

[0 = not confident at all, 5 = extremely confident]

0 1 2 3 4 5

How confident are you in your ability:

3. To make the most of your visits with your doctors:

[0 = not confident at all, 5 = extremely confident]

0 1 2 3 4 5

How confident are you in your ability:

4. To get a doctor to take your chief health concern seriously:

[0 = not confident at all, 5 = extremely confident]

0 1 2 3 4 5

How confident are you in your ability:

5. To get a doctor to do something about your chief health concern:

[0 = not confident at all, 5 = extremely confident]

0 1 2 3 4 5

Brief Estimate of Health Knowledge and Action (BEHKA-HIV)

Part I: Knowledge—‘‘We would like to know if patients are familiar with two HIV terms: a CD4 count and viral load.

Would you mind if I ask you a few questions about that? Ok...’’

1a. What is a CD4 count? Determine if correct

1b. If 1a is correct, is the goal of treatment to make the CD4 count go up or down?
UP [1] DOWN [0]

2a. What is a viral load? Determine if correct

2b. If 2a is correct, is the goal of treatment to make the viral load go up or down?
UP [0] DOWN [1]

3. What medicines are you currently taking to treat HIV?

Respondent must identify all medications in HAART regimen to be correct
CORRECT [1] INCORRECT [0] DON’T KNOW [0]

Part II: Action—‘‘Please tell me if you agree, are not sure, or disagree with these 5 statements...’’

1. I don’t take my medicines when they make me feel bad.
AGREE [0] NOT SURE [0] DISAGREE [1]

2. I don’t take my medicines when I am too tired.
AGREE [0] NOT SURE [0] DISAGREE [1]

3. I don’t take my medicines when I am feeling down or low.
AGREE [0] NOT SURE [0] DISAGREE [1]

4. I don’t take my medicines because it tastes bad.
AGREE [0] NOT SURE [0] DISAGREE [1]

5. I don’t take my medicines when I feel good.
AGREE [0] NOT SURE [0] DISAGREE [1]

Stage of readiness

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. Medical decisions about my HIV/AIDS treatment are done by my health care provider and I intend to keep it that way.					
2. Medical decisions about my HIV/AIDS treatment are done by my health care provider but I thinking about participating in future medical decisions.					
3. Medical decisions about my HIV/AIDS treatment are done by my health care provider and in some degree by me.					
4. Medical decisions about my HIV/AIDS treatment are done by my health care provider and by me.					

Appendix D

Questionnaire Developers' Letters of Permission

Functional, Communicative, and Critical Health Literacy Scale

Date: Tue, 8 Mar 2011 10:44:22 +0900
From: hirono-tky@umin.ac.jp
To: christine_mirand@hotmail.com
Subject: Re: Request permission to use the Functional, Communicative, and Critical Health Literacy Scale

Dear Mrs. Miranda

Thank you for your interest in our scale. Your project sounds interesting. The attached is an English version of our HL scale. So far, several researchers in other countries (including US, Australia, Netherlands, Germany, Sweden, etc) contacted us for validation of the HL scale in their language. I am very much interested in how the scale works in the Spanish context as well.

Best regards,
Hirono Ishikawa
-

Hirono Ishikawa, PhD
Department of Health Communication
School of Public Health, The University of Tokyo
Address: 7-3-1 Hongo, Bunkyo-ku, Tokyo
113-8655, Japan
Phone: +xx-x-xxxx-xxxx
Fax: +xx-x-xxxx-xxxx
email: hirono-tky@umin.ac.jp

Patient Attitudes and Beliefs Scale (PABS)

From:Arora, Neeraj (NIH/NCI) [E] (aroran@mail.nih.gov)
Sent: Monday, April 07, 2014 9:47:33 PM
To: CHRISTINE MIRANDA (christine_mirand@hotmail.com)

Sure Christine, I would be delighted. This is a crazy week for me. Would you do me a favor and send me an email reminder next week
Thanks and good luck

Neeraj

Patient's Confidence in Communication Scale

From: Dr Anh Tran, Ph.D. (anh.tran@duke.edu)
Sent: Wednesday, June 01, 2011 2:23:35 PM
To: Christine Miranda (christine.miranda@uccaribe.edu); anhtran@email.unc.edu (anhtran@email.unc.edu)
Cc: christine_mirand@hotmail.com (christine_mirand@hotmail.com)

Dear Christine,

Thank you for your message and your interest in our Patient's Confidence in Communication Scale (PCCS). Your project sounds very interesting and worthwhile. You are welcome to use and translate the PCCS as long as you include the article citation under the scale. If you could forward me a copy of your Spanish translated scale, I would appreciate it as well. Would also love to hear an update about what your discover in your research.

Best wishes with your project!
Anh Tran

****

Anh N. Tran, PhD, MPH
Program Director
Master of Health Sciences in Clinical Leadership
Assistant Professor
Division of Community Health
Department of Community and Family Medicine
Duke University Medical Center, Box 104425
Durham, NC 27710
xxx.xxx.xxxx

Perceived Efficacy in Patient-Physician Interactions (PEPPI)

From:Maly, Rose C., M.D. (RMaly@mednet.ucla.edu)
Sent: Thursday, May 31, 2012 1:43:50 PM
To: CHRISTINE MIRANDA (christine_mirand@hotmail.com)

Dear Mrs. Miranda,

Attached are the Spanish and English versions of the interviewer administered questionnaires and the English version of the self-administered version. I also attach the original validation article.
Best of luck with your research.
Rose Maly

_____

Rose C. Maly, MD, MSPH
Associate Professor of Family Medicine
David Geffen School of Medicine at UCLA
10880 Wilshire Blvd., Suite 1800
Los Angeles, CA 90024
Phone: xxx-xxx-xxxx
Fax: xxx-xxx-xxxx
E-Mail: rmaly@mednet.ucla.edu

Brief Estimate of Health Knowledge and Action (BEHKA-HIV)

From:Osborn, Chandra (chandra.osborn@Vanderbilt.Edu)
Sent: Tuesday, March 01, 2011 1:03:33 PM
To: CHRISTINE MIRANDA (christine_mirand@hotmail.com)

Hi Christine,

You have our permission to use the measure in your work. We look forward to hearing what you learn.

Best of luck,

CO

Chandra Y. Osborn, PhD, MPH
Assistant Professor of Medicine
Division of General Internal Medicine & Public Health
Center for Health Services Research
Vanderbilt University Medical Center
1215 Twenty-First Ave South
Ste 6000, MCE - North Tower
Nashville, TN 37232-8300
Phone: (xxx) xxx-xxxx
Fax: (xxx) xxx-xxxx
Email: chandra.osborn@vanderbilt.edu

Appendix E

Figures Use Permission Letters

Figure 1. The evolving concept of health literacy

From: Vice-Chancellor <vice-chancellor@soton.ac.uk>
Sent: Wednesday, April 16, 2014 8:01AM
To: CHRISTINE MIRANDA (christine.miranda@waldenu.edu)

Dear Christine

happy to agree, good luck with your work

kind regards

Professor Don Nutbeam
Vice-Chancellor
University of Southampton
Highfield Campus
Southampton
SO17 1BJ
Tel: +xx (x)xx xxxxx xxx
Email:vice-chancellor@soton.ac.uk

Figure 2. Patient Health Literacy and Participation in the Health-care Process

From: Hirono Ishikawa <hirono-tky@umin.ac.jp>
Sent: Tuesday, April 29, 2014 9:02 pM
To: CHRISTINE MIRANDA (christine.miranda@waldenu.edu)

Dear Christine,

I have received the following reply. So you are welcome to use it in your dissertation.
-
Hirono Ishikawa, PhD
Department of Health Communication
School of Public Health, The University of Tokyo
Address: 7-3-1 Hongo, Bunkyo-ku, Tokyo
113-8655, Japan
Phone: +xx-x-xxxx-xxxx
Fax: +xx-x-xxxx-xxxx
email: hirono-tky@umin.ac.jp

Forwarded by Hirono Ishikawa hirono-tky@umin.ac.jp
---------- Original Message ----------
From: Wiley Global Permissions permissions@wiley.com
To: Hirono Ishikawa hirono-tky@umin.ac.jp
Date: Tue, 29 Apr 2014 14:26:59 -0400
Subject: RE: Permission to use a figure

Dear Dr. Ishikawa:

Yes, it's fine to relay the permission directly. I'm forwarding language you can also include with the permission. Permission is hereby granted for the use requested subject to the usual acknowledgements (author, title of material, title of book/journal, ourselves as publisher). You shall also duplicate the copyright notice that appears in the Wiley publication in your use of the Material. Any third party material is expressly excluded from this permission. If any of the material you wish to use appears within our work with credit to another source, authorization from that source must be obtained. This permission does not include the right to grant others permission to photocopy or otherwise reproduce this material except for accessible versions made by non-profit organizations serving the blind, visually impaired and other persons with print disabilities (VIPs).

Best wishes,
Paulette Goldweber, Associate Manager, Permissions/Global Rights
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