

**LITERACY AND CULTURE AS DETERMINANTS OF HEALTH:  
DESIGNING EDUCATION FOR IMPROVED OUTCOMES**

A dissertation submitted to the Caspersen School of Graduate Studies  
Drew University in partial fulfillment of  
the requirements for the degree,  
Doctor of Medical Humanities

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August 2015



## ABSTRACT

Literacy and Culture as Determinants of Health:  
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The poor state of health literacy in the United States has been a growing concern over the past several decades. Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand basic information and services needed to make appropriate decisions regarding their health. It is estimated that more than 90 million Americans cannot understand basic health information, often leading to inadequate care for these families. Many of those with low health literacy are members of socio-economically disadvantaged minority populations. In addition to health disparities suffered by these groups, often due to preventable illness, inadequate health literacy contributes significantly to rising healthcare costs by way of increased use of emergency and illness services.

Government agencies, private foundations, and healthcare systems have identified low health literacy as one of the central challenges that faces the American healthcare system. The Institute of Medicine (IOM), in its 2004 report *Health Literacy: A Prescription to End Confusion* noted that health literacy provides an effective area to focus the fight to eliminate health disparities because adult literacy can be potentially improved across a person's lifespan. The report recommends that healthcare systems

develop and support programs to reduce the negative effects of limited health literacy, and that such health education programs must be sensitive to cultural and language preferences.

The purpose of this study is to examine the effectiveness of a health literacy teaching program I designed for economically and educationally disadvantaged Hispanic women who attend the Oasis Program in Paterson, NJ. The program consists of four weekly sessions of sixty to ninety minutes and covers the topics of child care, nutrition, and physical activity. Through culturally competent teaching methods, based on health literacy research and behavioral theory, I hope to observe healthful lifestyle changes by the program participants and their families as a result of their newly gained knowledge. Further, I expect that the anticipated success of the program will make possible its replication in other comparable settings.

## **Dedication**

For  
my father,  
who taught me everything

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## **Acknowledgments**

I would like to thank my professors in the Medical Humanities Program at Drew University for helping me to begin the process of inquiry into the humanity of the healthcare experience. In particular, my dissertation readers, Dr. Rosemary McGee and Dr. Phil Scibilia, provided invaluable insight and guidance to my writing.

I am extremely grateful to Jim Walsh and the volunteers at the Oasis Program who offered their facility and ongoing support for my health education program.

I also appreciate the love and patience of my husband John, who encouraged me throughout the lengthy process of this work.

Lastly, I could not have completed this project without the participation of the women who were my students in the program; any benefits they gained as a result of our interactions were equally matched by what I learned from them—I truly enjoyed their enthusiasm!

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## **Chapter 1**

### **Introduction**

The purpose of this study is to explore the impact of health literacy on population health outcomes. I will initially present the overarching problem of health disparities across populations in the United States as a public health concern. I will then identify health literacy as one of a complex web of issues that contribute to the unequal health states between groups of different socioeconomic and cultural backgrounds in this country. The survey of existing discussions from government public health entities, social science and education research, among other sources, will facilitate a connection for the reader between how much people know and understand about health and ultimately what quality of health they experience. Furthermore, those who belong to ethnic minority groups with little English speaking proficiency will experience added barriers to accessing, interpreting and following up with resources to improve their health. I propose that by improving health literacy in individuals and families, the health behaviors and outcomes of those population groups will change for the better and ultimately contribute to the reduction of the larger problem of health disparities, in particular among ethnic minority populations.

To investigate this thesis, I have developed and implemented a health education program for a select population of families whose children attend an after-school program in Paterson, New Jersey. A detailed description of the setting and the participants will be provided in the “Study” section of this paper; however, the predominant population in

this program is Hispanic immigrants and first generation Hispanic Americans. The role of culture in health beliefs and practices is fundamental to my exploration of factors contributing to differences in health outcomes among populations, so my research in the development of this study centers on health literacy and disparity issues in Hispanic populations living in urban, economically deprived neighborhoods.

Prior to the course, attendees completed a health literacy screening tool (see Appendix A) which focused on reading and language comprehension as well as health knowledge and confidence in accessing health resources. Pre- and post-class questionnaires were used to determine what learning took place and how useful the participants found this information (see Appendices B & C). Those participants who agreed were contacted one month following the program for follow up to discern the ways in which they perceived how their health behaviors had changed as a result of what they had learned and retained. This research centered on behaviors such as prevention of everyday health risks, identifying and caring for illness at home, and when it is appropriate to call the doctor or seek emergency care. An added benefit of improved health literacy may be a decrease in the inappropriate overutilization of emergency room care which has been statistically identified as significantly contributing to this country's spiraling healthcare costs (Institute for Healthcare Advancement, 2012). For the purpose of this study, I will focus on an expansion of healthcare knowledge and improved behaviors with increased self-reported health by participants as outcomes; reduction in utilization and costs of emergency services is a trend that needs to be measured over time and so holds valuable implications for future study. The goal of my study is to contribute

to the development of evidence-based health literacy programs that can be applied across populations at risk for disparate health outcomes, incorporating socio-cultural considerations.

### **The US Health Paradox**

The United States healthcare system has become increasingly plagued by issues relating to three elements: cost, access, and quality (Center for Medicare and Medicaid Services, 2010). Healthcare costs continue to rise, not everyone can get the care they need, and oftentimes the care available is not that good. A disturbing paradox emerges from the great amount of data compiled pertaining to the current state of this country's health care. Expenditures on health care in the United States surpassed \$2.3 trillion in 2008 and accounted for 16.2 percent of the country's Gross Domestic Product (GDP); this is among the highest of all industrialized nations (Center for Medicare and Medicaid Services, 2010). Despite the vast amount of money this country spends on health care, US health outcomes have been found to be significantly lacking when compared to other major nations (University of Washington, 2013). Life expectancies are one of the most commonly used measures for international health comparison. In 2009, the United States ranked 27th and 26th out of 33 countries within its peer group of Organization for Economic Co-operation and Development (OECD) countries for life expectancy at birth for females and males, respectively. Another significant marker of the quality of a population's health is the infant mortality rate in which the US ranked 28<sup>th</sup> in the same comparison (Xu et al., 2010).



Years of potential life lost (YPLL) is a summary measure of premature mortality. It represents the total number of years not lived by people who die before reaching a given age. Deaths among younger persons contribute more to the YPLL measure than deaths among older persons. YPLL is based on the number of deaths at each age up to some limit. For example, in the United States, the age limit is often placed at 75. People who die before age 75 are defined as having lost some potential years of life. Although YPLL statistics have improved in the United States over the past decade, they are often higher than those of comparable countries and even some less wealthy nations. For the 31 OECD countries for which recent data were available, the United States ranked 29th for females and 27th for males (Centers for Disease Control and Prevention, 2009).

The World Health Organization (WHO) and the Institute of Medicine (IOM) measure health systems performance along dimensions of equity, efficiency, and healthy life years. Compared with sixty other industrialized countries, the WHO survey ranked the US health system 37<sup>th</sup> in the world on these dimensions. The US was 24<sup>th</sup> in terms of health attainment, 32<sup>nd</sup> in terms of equity of health outcomes across its population; and 54<sup>th</sup> in fairness of financial contributions toward health care (World Health Organization, 2000). To date it seems that little progress has been made on these issues.

Even without comparison to other countries, many health-related statistics in the US are discouraging. Among them: one-half of the population is considered to be overweight or obese; one-fourth of the population smokes despite widespread publicity about the dangers of smoking, with smoking rates growing rapidly among women and teens; and many children are not immunized against preventable diseases (US

Department of Health and Human Services, 2010). Physical and mental sick days measure the number of days in the past 30 that individuals rated their physical or mental health as not good. In 2009, individuals in the United States reported on average 3.6 physically unhealthy days and 3.4 mentally unhealthy days in the past 30 days (Institute of Medicine, 2009). A telling statistic about where the most healthcare money is spent further illuminates the problem. Expenditures for tertiary (sick) care in this country far exceed the dollars spent for support and funding of primary (prevention) and secondary (screening) services; that is, we wait until people get sick, often from preventable illness, to pay for care which may or may not be compensated or effective (US Department of Health and Human Services, 2010). Another concern relating to cost and outcomes is the inappropriate and expensive use of emergency room services by those with no primary care providers or the knowledge and resources to help them manage their illness at home. It is logical that we would do much better statistically and reduce costs by helping people to stay healthy.

Such concerns about how broken our system has become grew into the rallying cry for those supporting a massive overhaul of the US healthcare delivery system, also known as the Patient Protection and Affordable Care Act (PPACA), or simply the Affordable Care Act (ACA), or the even more well-known moniker, “Obamacare” (One Hundred Eleventh Congress of the United States, August 25, 2010). The extensive research and mining of data which preceded the ACA proposals for reform highlighted a predicament much closer to home than just the inferiority of US health outcomes compared to our global counterparts. Among populations within the United States itself

there exist many dimensions of disparity, particularly in health. When a health outcome is seen in a greater or lesser extent between populations, there is disparity. Healthy People 2020, the third installment of the original US Public Health document intended to improve national health outcomes, refers to health disparities as “differences in the incidence, prevalence, mortality, and burden of disease and other adverse health conditions that may exist among specific population groups....” (US Department of Health and Human Services, 2010, pp. P.L 106-525). Health disparities have been documented between genders, among groups with different educational and socioeconomic levels, and in racial and ethnic minority populations (Agency for Healthcare Research and Quality, March, 2013). For the purposes of this study, I will pay particular attention to data concerning minority health.

The government first explored the issue of ethnic health disparities in 1985; the US Department of Health and Human Services (USDHHS) Secretary’s Task Force on Human Health published a significant report on minority health which identified disparities seen in US Black, Hispanic, Asian/Pacific Islander, and Native American populations. The report found that 80 percent of excess mortality experienced by minority groups is linked to causes such as cancer, cardiovascular disease, diabetes, infant mortality, unintentional injury, and chemical dependency (Secretary's Task Force on Minority Health, 1985). The Task Force made specific recommendations that provided a blueprint for subsequent federal policy initiatives to address these disparities. The recommendations include establishment of outreach campaigns to distribute health information targeting minority populations, patient education programs sensitive to

minority population needs, and a federal research agenda prioritizing minority health, focusing on educational interventions and socio-cultural influences (Secretary's Task Force on Minority Health, 1985).

In September 1990, the USDHHS released Healthy People 2000, the first comprehensive set of disease prevention and health promotion objectives for the nation. As one of its two overarching goals for the decade, this initiative called for the elimination of health disparities across populations (US Department of Health and Human Services, 1990). The USDHHS has reviewed and updated Healthy People goals and objectives each subsequent decade; the current document (Healthy People 2020) highlights the persistence of unequal health states between white and minority, ethnic groups, and calls attention to social and environmental factors that play a key role in determining health outcomes (US Department of Health and Human Services, 2010).

Another important report addressing disparities in health care was *Unequal Treatment*, issued by the Institute of Medicine. Notable findings from this report document that racial and ethnic minorities in the US received lower-quality health care, even after controlling for insurance status, income, and other access factors (Smedley, Stith, & Nelson, 2003). The authors assert that multilevel social and cultural characteristics present barriers to achieving equal health states between minority and non-minority populations. The federal level Agency for Healthcare Research and Quality (AHRQ) annually publishes the National Healthcare Disparities Report. This report monitors the nation's progress in eliminating the differences in the quality of and ability to access healthcare services for different populations. Chapter 10 of the 2012 report,

Priority Populations, summarizes data concerning disparities in health quality and care, with racial and ethnic minorities at the forefront (Agency for Healthcare Research and Quality, March, 2013). The report found health care quality and access remain suboptimal, especially for minority and low-income groups, summarizing “that racial and ethnic minorities and poor people often face more barriers to care and receive poorer quality of care when they can get it (p. H-2).”

The Affordable Care Act requires all federally funded health programs and population surveys to collect and report data on race, ethnicity, sex, primary language, and disability, and supports the use of data to analyze and track health disparities. Such data as analyzed by the Joint Center for Political and Economic Studies reveals that:

Racial/ethnic disparities in health and health care in the United States are persistent and well documented. Communities of color fare far worse than their white counterparts across a range of health indicators: life expectancy, infant mortality, prevalence of chronic diseases, self-rated health status, insurance coverage, and many others. As the nation’s population continues to become increasingly diverse—people of color are projected to comprise 54% of the U.S. population by 2050 and more than half of U.S. children by 2023—these disparities are likely to grow if left unaddressed. Recent health care reform legislation, while not a panacea for eliminating health disparities, offers an important first step and an unprecedented opportunity to improve health equity in the United States (Andrulis, Siddiqui, Purtle, & Duchon, July 2010, pp. 1-2).

Key provisions of the Affordable Care Act (ACA), passed in 2010 and slated for implementation in 2014, seek to confront disparities through increased access to care, change in the focus of care and the way in which services are delivered. These include but are not limited to: access to affordable health insurance for low- and moderate-income Americans; Medicaid coverage for more Americans; investments in primary care

and prevention programs: and investments in innovative models of healthcare delivery, emphasizing care that is culturally competent and meeting the unique needs of population groups (Pulcini & Hart, 2012).

In addition to government agencies, private foundations have also prioritized the investigation and elimination of health disparities. The Kaiser Family Foundation has sponsored a number of policy reports such as *Examining Racial and Ethnic Disparities at the State Level* (James, Salganicoff, Thomas, Ranji, & Wyn, June 2009). This document describes the continuing existence of health disparities in this country and provides a state-level examination of disparities across race and ethnicity as well as socio-cultural factors that may impact health and well-being.

A common thread throughout the data collected and summarized by these various sources is that circumstances external to individuals, which may or may not be within their control, will strongly affect how well they can achieve and maintain a healthy state. A further exploration of such determinants serves not only to support this theme, but to allow the reader to appreciate that modifiable determinants can be identified and strategies can be developed to reduce those negative consequences for affected populations.

### **Social Determinants of Health**

Factors that influence an individual's or population's health are known as determinants of health (US Department of Health and Human Services, 2010). Race or ethnicity, gender, age, disability, socioeconomic status, and geographic location all contribute to an individual's ability to achieve good health. Over the past three decades,

data compiled for the Healthy People documents have highlighted the impact that social determinants have had on health outcomes of specific populations. Researchers such as Marmot (2006) and Navarro (2013) describe certain social factors that put groups at increased risk for poor health. Apart from a biologic or genetic predisposition to disease, those with lower income and education, racial minority groups, and families living in environmentally disadvantaged neighborhoods often bear a greater burden of ill health. The Healthy People 2020 Topics and Objectives, as well as the Leading Health Indicators (LHI) were updated to recognize the influence of social determinants on population health outcomes:

A range of personal, social, economic and environmental factors contribute to individual and population health. For example, people with a quality education, stable employment, safe homes and neighborhoods, and access to preventive services tend to be healthier throughout their lives...powerful, complex relationships exist between health and biology, genetics, and individual behavior, and between health and health services, socioeconomic status, the physical environment, discrimination, racism, literacy levels, and legislative policies. These factors, which influence an individual's or population's health, are known as Social Determinants of Health.... Social Determinants are in part responsible for the unequal and avoidable differences in health status within and among communities... The selection of Social Determinants as a Leading Health Topic recognizes the critical role of home, school, workplace, neighborhood, and community in improving health (US Department of Health and Human Services, 2014).

The document describes such social and physical conditions as access to parks and safe sidewalks for exercise, education (associated with health promoting behaviors), discrimination or unfair treatment (related to self-efficacy), connection with social support system and resources, and healthy food access and choices, as affecting a range of outcomes for individuals and families.

Moreover, statistics have shown that a health gradient exists in which the higher one's social position, the better their health (Marmot, 2006). This social gradient in health is a complex phenomenon which can inform policies that are needed to address the disparity problem. However, the social gradient in health is not solely a function of poverty. Healthcare professionals working among various community populations have become increasingly concerned with health literacy as a key factor in improving and maintaining health. In the following section I provide an in-depth exploration of the research on health literacy to define its function as a determinant of health.

### **Health Literacy as a Determinant of Health**

Peoples' ability to effectively manage their health depends in part on how well they can understand and are motivated to follow instructions given them by healthcare providers. Instructions about medications, treatment regimen and follow up, basic care practices at home, and when and where to seek help for illnesses are crucial elements in managing a family's care. 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 (US Department of Health and Human Services, 2010). In addition to basic literacy skills, health literacy requires knowledge of health topics. People with limited health literacy often lack knowledge or have misinformation about the body as well as the nature and causes of disease. Without this knowledge, they may not understand the relationship between lifestyle factors such as diet and exercise and various health outcomes. Health information can overwhelm even those with



advanced literacy skills. Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained.

Health literacy also includes numeracy skills. For example, calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels all require math skills. Choosing between health plans or comparing prescription drug coverage requires calculating premiums, copays, and deductibles. Inadequate health literacy affects an individual's ability to navigate the healthcare system and communicate effectively with providers, often interfering with them engaging in self-care and illness management. While approximately 90 million US adults are thought to have limited health literacy, rates are higher among elderly, minorities, poor persons, and those with less than a high school education (US Department of Health and Human Services Office of Disease Prevention and Health Promotion, 2010).

It has been estimated by the National Patient Safety Foundation (NPSF) that the health of certain populations in the US may be at risk because of the difficulty some patients experience understanding and acting upon health information. Limited health literacy can be associated with disparity in healthcare outcomes among exceptionally vulnerable populations; NPSF statistics support that a disproportionate number of minorities and immigrants are estimated to have health literacy problems: 50 percent of Hispanics, 40 percent of African-Americans, and 33 percent of Asians (National Patient Safety Foundation, 2011). Low health literacy is also a cost burden on the US healthcare system—annual health costs for those with low health literacy average four times as much as those with higher literacy skills (National Patient Safety Foundation, 2011). A

variety of factors can account for this: routine preventive care, effective disease management, appropriate utilization of care versus use of emergency services, and unnecessary hospitalizations will most likely cost less than tertiary care.

Given the complexity of the current US healthcare system, it is not surprising that limited health literacy is associated with poor health. One of the most obvious dangers of limited health literacy is the potential for misunderstanding medical instructions, which could lead to critical events such as medication dosing errors. Studies have found medicinal dosing errors in patients asked to follow directions in preparing oral rehydration solution for children with diarrhea, among those asked to determine the correct dosage from the label on children's cough medicine, and in diabetes patients asked to dose and administer insulin shots (Weiss et al., 2005). Lacking the required health-related knowledge, some parents might bring their children to the emergency department for non-urgent reasons, while others may fail to seek care for potentially serious conditions. Apart from medical information, misunderstanding related to the readability of instructions, such as child safety seat installation, can lead to possible safety consequences. The lack of skill to successfully negotiate the healthcare system, coupled with past negative experiences with care providers might be of particular consequence among minority and immigrant families. If people feel intimidated by a system they cannot decipher, or face an ethnocentric, unaccommodating attitude when seeking care, it is likely that rather than persist, they will pursue the easiest, most familiar ways to deal with health issues.

Excerpts from medical, public health, and government research study findings support the relationship between health literacy and health outcomes in the following key areas:

**Use of preventive services.** According to research studies, persons with limited health literacy skills are more likely to skip important preventive measures such as mammograms, Pap smears, and flu shots. When compared to those with adequate health literacy skills, studies have shown that patients with limited health literacy skills enter the healthcare system when they are sicker (Scott, Gazmararian, Williams, & Baker, 2002).

**Knowledge about medical conditions and treatment.** Persons with limited health literacy skills are more likely to have chronic conditions and are less able to manage them effectively. Studies have found that patients with high blood pressure, diabetes, asthma, or HIV/AIDS who have limited health literacy skills have less knowledge of their illness and its management (US Department of Health and Human Services Office of Disease Prevention and Health Promotion, 2010).

**Rates of hospitalization.** Limited health literacy skills are associated with an increase in preventable hospital visits and admissions. Studies have demonstrated a higher rate of hospitalization and use of emergency services among patients with limited literacy skills (Baker, et al., 2002).

**Health status.** Studies demonstrate that persons with limited health literacy skills are significantly more likely than persons with adequate health literacy skills to report their health as poor (National Center for Education Statistics, 2006).

**Healthcare costs.** Persons with limited health literacy skills make greater use of services designed to treat complications of disease and less use of services designed to prevent complications. Studies demonstrate a higher rate of hospitalization and use of emergency services among patients with limited health literacy skills. This higher use is associated with higher healthcare costs (Howard, Gazmararian, & Parker, 2005).

**Stigma and shame.** Low health literacy may also have negative psychological effects. One study found that those with limited health literacy skills reported a sense of shame about their skill level. As a result, they may hide their reading or vocabulary inadequacies to maintain their dignity (Parikh, Parker, Nurss, Baker, & Williams, 1996).

A systematic review of research articles from 2009-2011 evaluated 96 studies on health literacy, which contributors rated as being of good or fair quality (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011). Results of the studies supported a relationship between health literacy and outcomes and were grouped by the variables of interest and related findings. The following excerpted correlations are of particular relevance to my proposed study. They are a summary of findings meant to infer possible health-related behaviors associated with low health literacy; the authors' original article can be searched for more specific information on the studies such as health literacy measurement, study methodologies, etc.

### **Use of Healthcare Services and Access to Care**

**Inappropriate use of emergency services.** Nine studies examining the risk of emergency care use and six examining the risk for hospitalization provided moderate

evidence showing increased use of both services among people with lower health literacy (Berkman et al., 2011).

**Preventive services.** Four studies provided moderate evidence of a lower probability of mammography screening and influenza immunizations in low health literacy groups (Berkman et al., 2011). Such findings might reasonably infer that people with limited understanding of the significance of disease protection and early detection would often forego other types of primary and secondary prevention services, leading to a greater burden of morbidity.

### **Healthcare-Related Skills**

**Taking medications appropriately.** Six studies provided moderate evidence that low health literacy is related to poorer skills in taking medications. Three studies directly observed whether participants took prescription medications appropriately and generally found more errors among those with limited health literacy. Three studies examined other measures of taking medications properly—self-reported use of non-standardized dosing instruments (such as kitchen spoons) and observation of participants' use of common dosing instruments. Findings again revealed poorer performance among persons with low health literacy (Berkman et al., 2011).

**Interpreting labels and health messages.** Studies provided moderate evidence that low health literacy is associated with poorer interpretation of labels (prescription medications and nutrition) and health messages. Adult patients with low health literacy in primary care clinics were less able to describe how they would take medications and had a greater probability of misunderstanding directions on one or more labels, and were less

likely to look at auxiliary labels. Additional studies in this category found that persons with low health literacy were less likely to understand nutrition labels, and that mothers with low health literacy were less able to give an organized health narrative for their children (Berkman et al., 2011).

Mayer and Villaire described a scenario that might be seen through the eyes of a low health-literate patient which puts a real face on the range of literacy-related skills needed just to make a routine visit to the doctor:

First, the patient must use a calendar or some other means for remembering the date and time of the appointment.... Then the patient must secure transportation to the appointment—this could mean planning around bus schedules...if the patient is driving, he or she may be faced with dozens of road signs, some signaling one-way streets, others explaining detours and construction.... Once the patient arrives at the destination, he or she will need to interpret signage, including parking signs, building identification signs, and directories.... Inside the waiting room the patient may be asked to fill out patient information and consent forms and to read and acknowledge receipt of the Notice of Privacy Practices, no doubt written several grade levels above his or her ability.... With a waiting room full of people and the potential for embarrassment if he or she seems confused, the patient may decide that the path of least resistance is simply to pretend to understand everything he or she is told.... Once inside the exam room, the patient will likely be interviewed by a nurse practitioner, which means having to articulate something about his or her symptoms and probably establishing a reason for the visit. A patient who does not speak English may have the option of communicating through an interpreter, which adds another layer of complexity to the clinical encounter.... Use of jargon, even in posters on a wall, already has set in motion a process of bewilderment... (Mayer & Villaire, 2007, pp. 11-12).

Virtually all of these activities require some degree of reading proficiency, facility with language, and effective communication skills. Each also calls for informed decision-making.

According to the American Medical Association report, *Health Literacy and Patient Safety: Help Patients Understand*, poor health literacy is a stronger predictor of a person's health than age, income, employment status, or race (Weiss, 2007). Limited health literacy is recognized as contributing to racial/ethnic and other health disparities by way of poor understanding and adherence, as well as limited access to health care.

Evidence of low health literacy as a problem has emerged in the media. Mayer and Villaire (2007) suggest that advertisers, like those doing public relations for multimillion-dollar health benefits companies, have a vested interest in recognizing trends and needs in the marketplace. They cite an advertisement from Blue Cross and Blue Shield which featured a blue and white bookmark with a collegiate type tassel hanging down. The text on the bookmark began "We Could Save Billions in Healthcare Costs if We Could Just Get Kids to Read," then touted a mentoring program that the organization sponsored with the Department of Health Care Policy at Harvard Medical School. The program used "health related children's books to raise health awareness," and the ad explained that "some consumers aren't able to read basic health information...which compromises the quality of health care and adds billions to America's annual healthcare costs" (Mayer & Villaire, 2007, p. 8). Efforts like the Blue Cross/Harvard University cosponsored mentoring program can save healthcare costs in the long run, perhaps preventing unnecessary use of emergency services, for example. However, while the goal of controlling cost and spending less money on health care is worthwhile and will raise the interest of many Americans, such cost-focused campaigns

do little to make people aware of other equally critical consequences of low health literacy among diverse groups.

Literature reviews reveal increasing awareness among researchers as well. In January 2000, Rudd and colleagues published an annotated bibliography of medical and public health literature addressing health literacy issues that appeared between 1990 and 1999 (Rudd, Colton, & Schacht, 2000). While their review suggested a growing recognition of literacy and communication barriers within the health fields, follow-up reviews in succeeding years document a continually rising trend. In their 2003 bibliography of health literacy research published between January and December 2002, Zobel, Rowe, and Gomex-Mandic note that the most significant difference in 2002's bibliography is a marked increase in the body of literature addressing literacy and health. In fact, the number of articles published in medical and public health journals had almost doubled from 2001 (Zobel, Rowe, & Gomez-Mandic, 2003).

While such research has been done through institutions of higher learning, and the evidence identifies literacy as a health issue, few curricula in schools of medicine, public health, nursing, dentistry, or pharmacy have traditionally addressed health literacy (Mayer & Villaire, 2007). Early courses and curricula touching on health literacy were offered at the Harvard School of Public Health, the University of Colorado Medical School, and the University of Virginia School of Medicine (Institute of Medicine, 2004). As educators and providers have developed a better understanding of the relationship between literacy and health, such content must be included in healthcare education in an effort to effectively improve outcomes.



### **Historical Perspectives on Health Literacy: NALS and NAAL**

My review of the literature on defining and measuring health literacy and its impact on the health status of populations draws largely from three of the predominant sources of data in the field of inquiry into health literacy: results from the National Adult Literacy and National Assessment of Adult Literacy surveys; the investigations of Dr. Rima Rudd, a widely recognized leader in health literacy, and colleagues in the Harvard School of Public Health; and the extensive research and systematic reviews done by the Committee on Health Literacy of the Institute of Medicine, culminating in the 2004 report *A Prescription to End Confusion* which examines the body of knowledge in the field of health literacy, and recommends actions to promote a health-literate society.

Early identification of the health literacy concept emerged from the National Adult Literacy Survey (NALS) of 1992 and the National Assessment of Adult Literacy (NAAL) of 2003, both nationally representative surveys of literacy among adults. Although the 1992 NALS did not specifically test knowledge of health-related concepts, the NAAL study expanded the number of background questions about health. The inclusion of health-related tasks as part of the item pool provided considerable insight into the relationship between health and literacy (Comings & Kirsch, 2005). A more in-depth description of the instruments' measures will help the reader clarify this association.

Both the NALS and the NAAL presented participants with everyday tasks such as totaling entries on a bank deposit slip, identifying a piece of information in a news article, determining the difference in price between two items, and other tasks that involve the use of written documents varying from relatively simple to complex. Sixty-five of the

152 tasks on the NAAL were taken from the earlier NALS in order to measure changes in literacy that might have occurred over the previous decade (National Center for Health Education Statistics (NCES), 2005). The 2003 NAAL household background questionnaire was used to collect data about various demographic and background characteristics of adults, administered before the actual assessment with questions asked orally in either English or Spanish. This questionnaire included a section of questions specifically related to health status, preventive health practices, and sources of information about health issues. For example, respondents were asked to rate their overall health in general and were given the response options of excellent, very good, good, fair, or poor. Household respondents were also asked how much information about health issues such as diet, exercise, and disease prevention, they got from newspapers, magazines, the Internet, or other media sources; family members, friends or co-workers; or talking to doctors, nurses, or other healthcare providers. They were given the following response options: a lot, some, a little, none (Kutner, Greenberg, Jin, & Paulsen, 2006). Excerpts of the interpretation of responses to the demographic and background questionnaire are reported below:

- Adults who spoke only English before starting school had higher average health literacy than adults who spoke other languages alone or other languages and English.
- Hispanic adults had lower average health literacy than any other racial/ethnic group.

- At every increasing level of self-reported health, adults had higher average health literacy than adults in the next lower level.
- A lower percentage of adults with below basic health literacy than adults with basic or intermediate health literacy got information on health issues from any written sources or the Internet (National Center for Education Statistics, 2006).

Three literacy scales—prose literacy, document literacy, and quantitative literacy—were used in the 2003 assessment:

- *Prose literacy*. The knowledge and skills needed to perform prose tasks (such as to search, comprehend and use information from texts). Examples include news stories, brochures and instructional materials.
- *Document literacy*. The knowledge and skills needed to perform document tasks. Examples include job applications, transportation schedules, drug and food labels.
- *Quantitative literacy*. The knowledge and skills needed to perform quantitative tasks. Such tasks include balancing a checkbook, figuring out a tip, or completing an order form (Kutner, Greenberg, Jin, & Paulsen, 2006).

The assessment included a health literacy scale that consisted of 12 prose, 12 document, and 4 quantitative items. Tasks used to measure health literacy were organized around three domains: *clinical*, *prevention*, and *navigation of the healthcare system*. The domains are defined in the following way:

- The *clinical* domain includes those activities associated with the healthcare provider-patient interaction, clinical encounters, diagnosis and treatment, and medication. Clinical domain tasks are: filling out an information form, understanding dosing instructions for a medication, and following a physician's directions for a diagnostic procedure.
- The *prevention* domain encompasses activities associated with maintaining and improving health, preventing disease, early intervention for symptoms, and engaging in self-care and management of illness. Examples are: following guidelines for age-appropriate preventive services, identifying signs and symptoms that should be addressed with a health professional, and understanding how diet and exercise decrease health risks.
- The *navigation of the healthcare system* domain is comprised of activities related to how the healthcare system works. Examples are: understanding what insurance will cover, negotiating eligibility for public assistance, and being able to give informed consent for a service (National Center for Education Statistics, 2006).

Twenty-eight health literacy tasks were designed to elicit respondents' skills for locating and understanding health-related information and services; materials were selected to represent real-world, health-related situations such as interpreting insurance information, medicine directions and preventive care information. Of the twenty-eight health literacy tasks, 3 represented the clinical domain, 14 represented the prevention domain and 11 represented the navigation of the healthcare system domain.

Instead of using the same reporting levels used for the 1992 NALS, the US Department of Education reported the NAAL results for the prose, document and quantitative scales by using four literacy levels for each scale: *Below Basic*, *Basic*, *Intermediate*, and *Proficient*. Table 1 summarizes the knowledge, skills and capabilities that adults needed to be classified into one of the four levels on the prose, document, and quantitative scales.

Table 1

*Overview of Literacy Levels*

<b>Level and definition</b>	<b>Associated abilities</b>
<b><i>Below Basic</i></b> indicates no more than the most simple and concrete literacy skills	Adults at the <i>Below Basic</i> level range from being non-literate in English to having the abilities listed below: <ul style="list-style-type: none"> <li>• Locating easily identifiable information in short commonplace <i>prose</i> texts</li> <li>• Following written instructions in simple <i>documents</i></li> <li>• locating numbers and using them to perform simple <i>quantitative</i> operations (primarily addition) when the mathematical information is concrete and familiar</li> </ul>
<b><i>Basic</i></b> indicates skills needed to perform simple and everyday literacy activities	<ul style="list-style-type: none"> <li>• reading and understanding information in short, commonplace <i>prose</i> texts</li> <li>• reading and understanding information in simple <i>documents</i></li> <li>• locating easily identifiable <i>quantitative</i> information and using it to solve simple one-step problems when the arithmetic operation is specified</li> </ul>

Table 1. *Overview of Literacy Levels* (continued)

Level and definition	Associated abilities
<i>Intermediate</i> indicates skills necessary to perform moderately challenging literacy activities	<ul style="list-style-type: none"> <li>• reading and understanding moderately dense, less commonplace <i>prose</i> texts as well as summarizing, determining cause and effect, and recognizing the author's purpose</li> <li>• locating information in dense, complex <i>documents</i> and making simple inferences about the information</li> <li>• locating less familiar <i>quantitative</i> information and using it to solve problems when the arithmetic operation is not specified</li> </ul>
<i>Proficient</i> indicates skills needed to perform more complex and challenging literacy activities	<ul style="list-style-type: none"> <li>• reading lengthy, abstract, complex <i>prose</i> texts as well as synthesizing information</li> <li>• integrating, synthesizing, and analyzing multiple pieces of information located in complex <i>documents</i></li> <li>• locating more abstract <i>quantitative</i> information and using it to solve multi-step problems when arithmetic processes are not inferred</li> </ul>

SOURCE: Hauser, R. M. Edley, C. F. Jr., Koenig, J. A., and Elliott, S. W. (Eds.). (2005). *Measuring Literacy: Performance Levels for Adults Interim Report*. Washington, DC: National Academies Press; White, S. and Dillow, S. (2005). *Key Concepts and Features of the 2003 National Assessment of Adult Literacy* (NCES 2006-471). US Department of Education. Washington, DC: National Center for Education Statistics.

The complete study details and methodology can be accessed at:

<http://nces.ed.gov/pubs2006/2006483.pdf>. I will summarize the findings of the study so that the reader can easily appreciate the correlation of demographic characteristics of populations and their health literacy. Results in the following categories are relevant to this association:

**Gender.** The average health literacy score for women was 6 points higher than that of men. A higher percentage of men than women had Below Basic health literacy (by 4 points); the percentage of women with Intermediate health literacy was 4 points higher than that of men; there were no significant differences in men and women with Basic or Proficient health literacy (National Center for Education Statistics, 2006).

**Race and ethnicity.** White and Asian/Pacific Islander adults had higher average health literacy than Black, Hispanic, American Indian/Alaskan Native, and Multiracial adults. Hispanic adults had lower health literacy than adults in other ethnic groups. The percentages of White and Asian/Pacific Islander adults with Proficient health literacy were higher than all other racial/ethnic groups. 58 percent of White, 52 percent of Asian/Pacific Islander, and 59 percent of Multiracial adults had Intermediate health literacy, compared with 41 percent Black and 31 percent Hispanic adults. Higher percentages of Black and Hispanic adults than White, Asian/Pacific Islander and Multiracial adults had Below Basic health literacy (National Center for Education Statistics, 2006).

**Language spoken before starting school.** Adults who spoke only English before starting school had higher average health literacy than those who spoke a language other than English. The average health literacy score for adults who spoke only English before starting school was at the Intermediate level, as were scores of those who spoke both English and Spanish or English and another language. Adults who spoke only Spanish prior to starting school had the lowest average health literacy scores—Below Basic (National Center for Education Statistics, 2006).

**Highest level of educational attainment.** Starting with adults who had graduated high school, health literacy increased with each higher level of educational attainment. Adults who had not attended or completed school, or were not currently enrolled in school had a lower average health literacy; a higher percentage of these adults had Below Basic health literacy than adults in any other educational group. These same adults were also less likely than all other adults (except those with a GED or equivalency certificate) to have Proficient health literacy (National Center for Education Statistics, 2006).

**Poverty threshold.** Adults living below the poverty level had an average health literacy score of 205, while those living at or up to 125 percent of the poverty level had an average score of 222. Both of these average scores are at the Basic level. Average health literacy was highest for adults who were above 175 percent of the poverty threshold; in this group, average health literacy was in the Intermediate range (National Center for Education Statistics, 2006).

**Employment status.** The ability to complete literacy tasks may impact employability. Of adults with Below Basic prose literacy, 51 percent were not in the labor force while 35 percent were employed full-time. Sixty-four percent of adults with Proficient prose literacy and 54 percent of adults with Intermediate prose literacy were employed full-time. Three percent of adults with Proficient prose literacy and 5 percent of adults with Intermediate prose literacy were unemployed (National Center for Education Statistics, 2006).

It appears evident from this data that health literacy is not independent of social factors and that population groups generally considered to be at risk for health issues—



the poor, minority populations, those without a high school degree, and those with limited or inadequate social resources—are also more likely to have limited health literacy proficiency. Because of studies such as the NALS and NAAL, investigators began to recognize that literacy is likely one of the major pathways linking health and education and may be a contributing factor to the wide disparities in the quality of health care that many in these groups receive.

### **Harvard School of Public Health**

Dr. Rima Rudd is a Senior Lecturer and Principal Investigator on Society, Human Development, and Health at the Harvard School of Public Health. Her work centers on health communication and the design and evaluation of public health programs. She teaches courses on innovative strategies in health education, program planning, and health literacy. Dr. Rudd is globally recognized as a leader in health literacy through her contributions in both the research and practice agendas in the United States, Canada, and Europe. She works closely with the adult education, public health, and medical sectors. Dr. Rudd's extensive research examines literacy-related health disparities, and literacy-related barriers to health programs and services. Her Harvard website on health literacy serves scholars and practitioners (Harvard School of Public Health, 2014).

One of the first analyses of population-based health literacy skills among adults came out of the 2004 work of Dr. Rudd and co-investigators, Irwin Kirsch and Kentaro Yamamoto. Recurring themes surrounding the inefficient and cost-burdened US healthcare system served as the backdrop for their literacy study: First, that access to good health has been unevenly distributed in this country, and that the poor, people of

color, and those with limited English language skills are less likely to receive basic preventive medical care; and second, that public health professionals have long been aware of the link between years of schooling and health outcomes that include morbidity and mortality. Rudd and her colleagues cited that those adults with fewer years of schooling are more likely to die of a chronic disease, and have higher rates of suicide, homicide, cigarette smoking, and heavy alcohol use than those with higher levels of education. They further noted that individuals make (and do not make) decisions that affect their health and the health of their families with varying levels of information and corresponding effectiveness (Rudd, Kirsch, & Yamamoto, 2004). Rudd developed a typology of health activities and coded all health-related items and tasks on adult literacy surveys. She used tasks from the same large-scale literacy assessments (NALS, NAAL) that were judged to involve health-related materials about such topics as drugs and alcohol, disease prevention, safety and accident prevention, emergencies, and staying healthy. She and the investigators identified 191 tasks which they used to create the Health Activities Literacy Scale (HALS). The examination of data collected through the HALS comprise the report *Literacy and Health in America* (Rudd, et al., 2004).

Among the contributions made by this report to the then-growing field of health literacy, the framework used by the authors for organizing health activities proved useful in understanding the broad range of everyday activities associated with public health, and directed health researchers' focus beyond the scope of medical or hospital settings into the community. Perhaps more importantly, *Literacy and Health in America* also characterized the health-related literacy skills of adults in the United States, including at-

risk or vulnerable sub-populations, and showed the disparities existing within our population (Rudd, Kirsch, & Yamamoto, Literacy and Health in America, 2004).

The HALS is a 0 to 500 scale that reflects a progression of health-related literacy skills from low (level 1) to high (level 5). In addition to using the HALS scale to estimate the distribution of health literacy skills among US adults, Rudd et al. also demonstrated how health-related literacy is connected to health status, wealth, and civic engagement. A review of the constructs of the HALS will serve to help the reader make meaning of the population data generated.

Rudd and her colleagues considered a variety of health-related activities undertaken by adults in daily life and categorized them as follows for coding tasks and materials:

**Health promotion:** emphasis is placed on activities that people carry out for their own health, and include behaviors related to nutrition, physical activity, and other “healthy habits.”

**Health protection:** actions taken in everyday life to preserve and protect health, including the health of groups (such as workers, or people living in specific geographic locations), and the public at large (such as those who purchase food or drink water).

**Disease prevention:** actions taken to prevent the onset of illness or to detect a disease at early stages. Prevention includes immunizations (for children, adults, and elderly), routine screenings, from hearing and vision to prostate and breast cancer testing, and health education.

**Health care and maintenance:** learning about an illness or disease, taking action to seek care, complying with medical regimen, including managing medications, and participating in discussions with healthcare providers. In order to understand a disease, engage in self-care, or manage a chronic illness, individuals must use and understand informational brochures, medication labels, and written directions for care.

**Systems navigation:** barriers to programs, services, and care have shaped a health literacy activity referred to as “navigation.” Navigation of the healthcare system can also be impacted by language, culture, literacy of patients, and a generally ethnocentric care environment. Table 2 summarizes the five categories with examples.

Table 2

*Five Categories of Health Activities*

<b>Health Activities</b>	<b>Focus</b>	<b>Examples of Materials</b>	<b>Examples of Tasks</b>
Health Promotion	Enhance and maintain health	Articles in newspapers, magazines, booklets and brochures Charts, graphs, lists Food and product labels	Purchase food Plan exercise regimen
Health Protection	Safeguard health of individuals and communities	Articles in newspapers, magazines Postings for health and safety warnings Air and water quality reports	Decide among product options Use products correctly

Table 2. *Five Categories of Health Activities* (continued)

<b>Health Activities</b>	<b>Focus</b>	<b>Examples of Materials</b>	<b>Examples of Tasks</b>
Disease Prevention	Take preventive measures and engage in early detection	Postings for immunizations and screenings Letters re: test results Graphs and charts	Determine risk Engage in screening or diagnostic tests Follow up
Health Care and Maintenance	Seek care and form a partnership with health providers	Health history forms Medicine labels Discharge instructions	Describe and measure symptoms Follow directions on medicine labels Calculate timing for medicine
Systems Navigation	Access needed services Understand rights	Application forms Health benefits information Statements of rights/responsibilities, informed consent	Locate facilities Apply for benefits Offer informed consent

SOURCE: Rudd, R., Kirsch, I., Yamamoto, K. (2004). *Literacy and Health in America*. Educational Testing Service: Princeton.

This description of the five categories of health activities and subsequent coding of all materials and tasks were used across assessments of adult literacy skills by Rudd and colleagues, and the results were designated as the Health Activities Literacy Scale. Thus the authors used the HALS to define health literacy proficiency in their report. They spread the 0-500 score scale across five levels of proficiency: Score 0-175 = <Level 1;

Score 176-225 = Level 1; Score 226-275 = Level 2; Score 276-325 = Level 3; Score 326-375 = Level 4; Score 376-500 = Level 5 (Rudd et al., 2004). The reader may access the original report in its entirety for an in-depth description of the assessment coding and methodology; I will present a summary of the HALS results which proved useful in the planning of my own program.

In reporting their results, Rudd et al. (2004) reiterate why it is important to understand the distribution of health-related literacy skills in adults by referring to the 2002 Department of Health and Human Services (DHHS) report *Health, United States 2002*, for background information on trends and disparities among US population groups. The authors propose that the results of health literacy assessments of these groups are consistent across multiple studies and are inextricably linked to the identified disparate health outcomes. The DHHS report cited changing demographics, including increasing racial and ethnic diversity, and growing differences in education and poverty rates among subgroups, as contributing to national health trends. Disparities in the use of preventive services by age, race and ethnicity, and family income were constant. For example, racial minorities, the poor, and near poor were identified as much more likely than others to be uninsured and less likely to have had a dental visit in the past year. The DHHS placed these groups at the highest risk of negative health outcomes, and in greatest need of access to appropriate care (Pastor, Makuc, Reuben, & Xia, 2002).

Rudd's summary also referenced the Healthy People 2010 statement of national health goals and objectives which noted high priority health issues and identified populations most at risk. Among the key population groups defined as "at risk" were

people with lower incomes and less education, people from ethnic and racial minority groups, and older adults. Healthy People 2010 noted that inequalities in income and education were at the root of many health disparities in this country. Additionally, at the time of the report, more than one-quarter of Black and Hispanic children lived in poor families, while among people aged 25-64 years, the overall death rate for those with less than 12 years of education was more than twice of those with 13 years or more (US Department of Health and Human Services, 2000).

Of particular interest, Rudd's HALS scores speak to health literacy problems of previously identified at risk groups and are summarized as follows:

**Adults with less than a high school degree.** Adults who had not completed high school or earned a GED had an average score of 220 (0-500 scale), or at the upper end of Level 1. Those who either graduated from high school or earned their GED achieved an average score of 271, and those who continued their education beyond high school obtained an average of 306. More significantly, among those adults who did not complete high school, nearly 22 percent performed below Level 1 on the HALS, 26 percent reached Level 1, and 33 percent Level 2; almost half did not score above Level 1 and slightly more than 80 percent did not score above Level 2. At the time of the assessment, an estimated 52 million US adults had not graduated high school or earned a GED. It follows that large percentages of adults with limited education would have a difficult time performing a broad range of health-related literacy activities (Rudd et al., 2004).

**Adults from minority population groups.** The report discusses the growing ethnic diversity of the population, noting that racial minorities were less likely to have

health insurance, and may have experienced bias and discrimination which affected their perceptions of and responses to the healthcare system. The authors also examined minority population groups in relation to the increase in immigration over the previous decades, noting the need for awareness of health-related literacy issues among the foreign born and opportunities for individuals to achieve health literacy in their native languages and culture. The reported average proficiency score of White adults on the HALS (285) was significantly higher than that of Black (239) and Hispanic (217). With the exception of White adults, more than 10 percent of the other racial/ethnic groups were reported to be below Level 1; among Hispanic adults, nearly 30 percent performed below Level 1. The authors identified variables such as education, resources, and immigrant status as potentially contributing to observed differences among racial/ethnic groups, citing for example, differential access to education for disadvantaged populations based on race/ethnicity. HALS scores were shown to increase in both Black and Hispanic groups with increases in educational attainment, health status (measured by not having a condition that limits participation in activity), and income (access to financial resources) (Rudd et al., 2004).

**Results by country of birth/language group.** The 2000 Census reported that approximately 18 percent of the US population spoke a language other than English at home, with 23 percent of that group reporting that they spoke English “not well” or “not at all.” About 70 percent of the non-English speakers were native speakers of Spanish (Rudd et al., 2004). The average HALS proficiency scores among non-native born adults are significantly below those of the native population. Adults who were born in Spanish-



speaking countries had an average HALS proficiency of 170—more than 100 points below the average proficiency of adults born in the United States. Furthermore, foreign-born adults from European and Asian countries had an average HALS proficiency in the middle of Level 2, while adults who were born in Spanish-speaking countries averaged below Level 1. Nearly all of the White and Black adults assessed reported being born in the United States, but only about half of Hispanic adults were American-born. Interestingly, the 100 point difference in HALS score between White and Hispanic adults was reduced to 30 points when comparison was made between US native-born Whites and Hispanics (Rudd et al., 2004).

The strength of the relationship between education and health literacy proficiency is illustrated by examining results across the three levels of education used in this report: Adults born in the US performed significantly higher than those born in other countries; the differences between those born in the US and those from other countries were smallest among those who pursued their education beyond the high school level; and largest among those who did not have a high school diploma or GED. From the vast amount of data and comprehensive analyses of health-related literacy proficiency assessment in this nearly fifty-page report, the reader can extract a portrait of groups of adults who are at risk for limited health literacy:

- Those who have not completed high school or obtained a GED,
- Those who have health-related restrictions on their ability to attend school or work,
- Those who are members of minority populations, and

- Those who have emigrated from other countries, particularly Spanish-speaking countries.

Moreover, compared with adults who have strong health literacy proficiencies, those with limited proficiencies are:

- More likely to report living in poverty or near-poverty,
- Less likely to report reading prose and documents, and
- Less engaged in civic activities. They are less likely to vote, use a library, and they rely on television as a primary source of information.

Rudd and her co-researchers conclude their report by discussing implications for their findings in the areas of health outcomes, health disparities, research, and education. An awareness of the importance of literacy to health outcomes has provided a basis for developing measures of health literacy that go beyond word recognition and reading comprehension to examine prose and document literacy, oral communication, and quantitative skills. Adults apply prose reading skills to gather information, and document skills to understand charts and labels on food, products, and medicine. Writing skills are needed for individuals to complete forms such as benefit application or informed consent, while math skills help them determine timing, measure medicines, and calculate readings on instruments such as thermometers. Patients need oral presentation skills with descriptive vocabulary to provide a narrative of illness, symptoms, and feelings to healthcare providers. The HALS findings that large percentages of at-risk populations in

this country lack the skills needed to navigate the healthcare system point to a disconnect which may indeed jeopardize the status of their health.

It has been suggested by Rudd and other sources cited throughout this paper that racial and ethnic minorities tend to receive a lower quality of health care than that of non-minorities and are less likely to receive routine preventive and medical procedures. Attention to the impact of provider and institutional contributions to racial and ethnic disparities in care (discrimination, ethnocentrism, cultural incompetence) will improve understanding and facilitate the reduction of unequal burdens of poor health among minority populations. The findings from the HALS analysis which show that minorities who are poor, lack resources, and have less than a high school education are likely to lack health literacy skills may compound already existing disparities in health care. An institutional, educational, and policy focus is therefore necessary to identify needed change for improved outcomes.

Prior to the HALS study, the authors note that the majority of the literacy-related studies in the health field were narrowly focused on adults as patients in healthcare settings and on their ability to read patient education and health related materials (Rudd et al., 2004). The HALS creation of a health activities framework allowed researchers to examine health activities of adults within a broader range of contexts and settings, including home, work, and community. The health activities framework categorized activities undertaken to promote health, protect health, prevent disease, engage in health maintenance, and navigate the healthcare system. This model provides ways to measure specific health-related skills such as purchasing food and products, interpreting

instructions and information, using medicine, applying for insurance, and offering informed consent. The authors also point to the need for continued development of tools to measure health literacy, moving beyond common literacy assessment tools.

Lastly, the HALS analysis implies that better health might be linked to improvements in education, particularly in poor and disadvantaged communities. Instructional objectives and action plans need to be implemented related to skills needed for the previously identified health activities. Adults trying to apply health information would benefit from clearer written and oral communication, and even more so from materials designed to provide information from the user's perspective. To this end, educational opportunities need to be extended to health professionals, administrators and communicators, for a clear understanding of health literacy issues and the impact of poor proficiencies on populations and the system at large.

The findings of the HALS and Rudd's analysis of the science on health literacy are noteworthy because they go beyond mere measures of literacy, and incorporate those existing measures into a broader framework which apply peoples' reading, comprehension, oral presentation, and numeracy skills to their performance on health-related activities necessary to achieve and maintain good health. We are again presented with a profile of who among us are likely to bear a disproportionate burden of poor outcomes resulting from a web of causality which includes low health literacy. The report also charges public health professionals, educators and healthcare providers to design and implement strategies in their respective arenas to generate more health literate

communities. As both a public health nurse and educator, my community health education program has been informed by such conclusions.

### **Institute of Medicine**

The Institute of Medicine (IOM) is an independent, nonprofit organization that works outside of government to provide unbiased and authoritative advice to decision makers and the public. Established in 1970, the IOM is the health arm of the National Academy of Sciences, which was chartered under President Abraham Lincoln, in 1863. The National Academy of Sciences has expanded into what is collectively known as the National Academies, which comprises the National Academy of Sciences, the National Academy of Engineering, the National Research Council, and the IOM (National Academy of Sciences, 2014).

As declared on its website, “The IOM asks and answers the nation’s most pressing questions about health and health care.” The following summary further defines the work of the Institute:

Our aim is to help those in government and the private sector make informed health decisions by providing evidence upon which they can rely. Each year, more than 2,000 individuals, members, and nonmembers volunteer their time, knowledge, and expertise to advance the nation’s health through the work of the IOM. Many of the studies that the IOM undertakes begin as specific mandates from Congress; still others are requested by federal agencies and independent organizations. While our expert, consensus committees are vital to our advisory role, the IOM also convenes a series of forums, roundtables, and standing committees, as well as other activities, to facilitate discussion, discovery, and critical, cross-disciplinary thinking (National Academy of Sciences, 2014).

In April 2004, the IOM released its landmark report on Health Literacy: A Prescription to End Confusion. The work for this report was undertaken by the

Committee on Health Literacy whose members were chosen for their specific competencies. They included health professionals and scholars across disciplines such as public health, medicine, nursing, academia, neuroscience and behavioral health. The report was independently reviewed in draft form by individuals chosen by the National Research Council's (NRC) Report Review Committee, based on their diverse perspectives and technical expertise. The review was meant to assist the IOM in making its report as sound as possible, meeting standards for objectivity, evidence, and responsiveness to the study purpose (Institute of Medicine, 2004).

To guide the investigation, the committee was charged with the following:

- Define the scope of the problem of health literacy, with the intent to identify root problems which contribute to health illiteracy; to identify affected populations and estimate costs to society; to develop a basic set of indicators of health literacy for assessment of the extent of the problem at the individual, community and national levels (Institute of Medicine, 2004).
- Identify the obstacles to creating a health-literate public; these may include the complexity of our healthcare system, many and often contradictory health messages, advancing technologies, and limits within public education to promote literacy (Institute of Medicine, 2004).
- Assess the approaches that have attempted to increase health literacy; identify gaps in research and programs; focus on public health interventions to increase literacy of the public rather than improving health provider/primary care interactions (Institute of Medicine, 2004).
- Identify goals for health literacy efforts and suggest approaches to overcome obstacles to reaching these goals; these include research or policy initiatives, interventions, or collaborations that would promote health literacy (Institute of Medicine, 2004).

The committee accepted the definition of health literacy presented by the National Library of Medicine: "The degree to which individuals have the capacity to

obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Ratzan & Parker, 2000, p. 2).

They began by developing a framework for health literacy identifying three areas for potential intervention. The model proposed that health literacy is influenced as individuals interact with educational systems, health systems, and social and cultural factors. This conceptual model suggested that these factors ultimately contributed to health outcomes and costs, but available research at the time supported only limited conclusions about causality. Thus the need to build on the existing body of knowledge was identified.

The value of the IOM report is that it provided a systematic review of the multitude of studies on health literacy that existed at the time. The committee reviewed the strength and limitations of available measures of literacy and health literacy and concluded, like Rudd and others, that while health literacy involved a range of social and individual factors, many of the tools being used to measure health literacy primarily measured reading skills but no other critical skills. The reading skills of adults were often estimated with a “grade level” measure, which the committee felt was imprecise at best (Institute of Medicine, 2004). To advance the field of health literacy, the authors called for, among other things, continuing research into the development of new measures to accurately establish baseline levels of health literacy, which could be monitored for change over time.

The organizing principle of the report was to ultimately recommend strategies on systematic and individual levels to confront barriers to health literacy. The proposals

were directed at government, education, health, and socio-cultural systems, and were consistent with the report's initial objectives that established a blueprint for health literacy.

The report's summary of findings echoed that of the NALS, NAAL, and Rudd's HALS surveys, including:

- Links between education and health outcomes were strongly established.
- Health literacy included a variety of components beyond reading and writing, including numeracy, listening and speaking.
- Reliable assessment tools must consider lack of knowledge in health-related domains, lack of familiarity with language and types of materials, and cultural differences in approaches to health and health care.
- Limited health literacy was a greater problem among older adults, people with limited education and income, and those with limited English-speaking proficiency.
- Health literacy was strongly associated with health behaviors and outcomes; those with low health literacy were less able to manage illness than those with higher literacy.
- Health literacy had an impact over time on healthcare utilization and increased healthcare costs; patients with limited health literacy had higher rates of unnecessary hospitalization than those with adequate health literacy.
- Shame and stigma experienced by those with poor literacy skills, as well as negative experiences with the healthcare system, may create a barrier to improving health literacy (Institute of Medicine, 2004).

The committee added findings relevant to the three contexts for intervention identified in their theoretical framework of health literacy: the health system, educational system, and culture and society. The healthcare system in the United States is described as complex and confusing, owing to the nature of health care itself, the mix of public and private financing, and variations across delivery settings. An adult's difficulty in



navigating this system would be compounded by inadequate literacy skill levels. Directions, signs, documents and forms, medical instructions and health education may use jargon and technical language that is not user-friendly. So, the demands for reading, writing, and numeracy skills have increased with the complexity and technological advancement of the healthcare system. As noted in the IOM's Quality Chasm Report, health literacy relates to three of the six aims of quality improvement: safety, patient-centered care, and equitable treatment. The readability levels of informed consent documents for both research and clinical practice exceed the documented average reading levels of adults in the United States, which has important ethical and legal implications on care (Institute of Medicine, 2001).

The report cites that adult education is a vital resource for individuals with limited literacy or limited English proficiency. National programs like Adult Basic Education and Literacy (ABEL) provide classes on topics that support health literacy, such as basic literacy and math skills, English language and high school equivalence, but serve far fewer of the millions of adults who need them. In 1995, the Joint Commission on National Health Standards published the *National Health Education Standards* with the subtitle *Achieving Health Literacy*. The standards described the knowledge and skills needed for health literacy and what students should know by the end of grades 4, 8, and 11, providing a framework for curriculum development. Unfortunately, at the time of the IOM report, most of the standards were not widely met (Institute of Medicine, 2004). The IOM also reiterated what Rudd had found: that education professionals and staff had

limited training, continuing education, and practice opportunities to gain skills in teaching health literacy.

The report affirmed that culture gives meaning to health communication and that health literacy must be addressed in the context of culture and language. Social factors such as increasingly competing sources of health information (national media, Internet, product marketing) posed a challenge for those with limited literacy, and research findings in social and commercial marketing did not contribute to health literacy efforts (Institute of Medicine, 2004).

Upon concluding its examination of scores of studies and text the IOM Committee declared a health-literate American an achievable future goal, with health and educational systems structures taking responsibility for providing clear communication and adequate support to enhance health-promoting actions. They envisioned a health-literate society as one in which:

- Everyone has the opportunity to improve their health literacy; access to reliable, understandable information to improve their overall well-being.
- Health content would be basic parts of K-12 as well as adult learning curricula.
- People are able to assess the credibility of health information from a variety of media sources.
- The cultural contexts of diverse populations and non-English-speaking people are integrated into all health information.
- Health practitioners communicate clearly using everyday language in their interactions with patients.
- Patients feel free and comfortable to ask questions in the patient-provider relationship.

- Medical instructions, rights and responsibilities are presented in clear, everyday terms so that people can take needed action; informed consent documents are developed so that all people can give or withhold consent based on information they understand (Institute of Medicine, 2004, pp. 13-14).

Arguably the most prominent contribution of this 300-some page report to advancing health literacy and equalizing health outcomes across populations, are the recommendations for interventions to be made over the coming years by a variety of government, public health, academic, social, and political entities that the Committee emphasized as critical to success. To provide the reader insight into the breadth and depth of the labor put into this undertaking by the IOM, I have excerpted a summary of those recommendations from the report below.

### **IOM Recommendations for a Health-Literate America**

**Recommendation 2-1.** The Department of Health and Human Services and other government and private funders should support research leading to the development of causal models explaining the relationships among health literacy, the education system, the health system, and relevant social and cultural systems.

**Recommendation 2-2.** The Department of Health and Human Services and public and private funders should support the development, testing, and use of culturally appropriate new measures of health literacy. Such measures should be developed for large ongoing population surveys, such as the National Assessment of Adult Literacy Survey, Medical Expenditure Panel Survey, and Behavioral Risk Factor Surveillance System, and the Medicare Beneficiaries Survey, as well as for institutional accreditation and quality assessment activities such as those carried out by the Joint Commission on Accreditation of Healthcare Organizations and the National Committee for Quality Assurance. Initially, the National Institutes of Health should convene a national consensus conference to initiate the development of operational measures of health literacy which would include contextual measures.

**Recommendation 3-1.** Given the compelling evidence noted above, funding for health literacy research is urgently needed. The Department of Health and Human Services, especially the National Institutes of Health, Agency for Healthcare Research and Quality, Health Resources and Services Administration, the Centers

for Disease Control and Prevention, Department of Defense, Veterans Administration, and other public and private funding agencies should support multidisciplinary research on the extent, associations, and consequences of limited health literacy, including studies on health service utilization and expenditures.

**Recommendation 4-1.** Federal agencies responsible for addressing disparities should support the development of conceptual frameworks on the intersection of culture and health literacy to direct in-depth theoretical explorations and formulate the conceptual underpinnings that can guide interventions.

**4-1.a.** The National Institutes of Health should convene a consensus conference, including stakeholders, to develop methodology for the incorporation of health literacy improvement into approaches to health disparities.

**4-1.b.** The Office of Minority Health and Agency for Healthcare Research and Quality should develop measures of the relationships between culture, language, cultural competency, and health literacy to be used in studies of the relationship between health literacy and health outcomes.

**Recommendation 4-2.** The Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the Indian Health Service, the Health Resources and Services Administration, and the Substance Abuse and Mental Health Services Administration should develop and test approaches to improve health communication that foster healing relationships across culturally diverse populations. This includes investigations that explore the effect of existing and innovative communication approaches on health behaviors, and studies that examine the impact of participatory action and empowerment research strategies for effective penetration of health information at the community level.

**Recommendation 5-1.** Accreditation requirements for all public and private educational institutions should require the implementation of the National Health Education Standards.

**Recommendation 5-2.** Educators should take advantage of the opportunity provided by existing reading, writing, reading, oral language skills, and mathematics curricula to incorporate health-related tasks, materials, and examples into existing lesson plans.

**Recommendation 5-3.** The Health Resources and Services Administration and the Centers for Disease Control and Prevention, in collaboration with the Department of Education, should fund demonstration projects in each state to

attain the National Health Education Standards and to meet basic literacy requirements as they apply to health literacy.

**Recommendation 5-4.** The Department of Education in association with the Department of Health and Human Services should convene task forces comprised of appropriate education, health, and public policy experts to delineate specific, feasible, and effective actions relevant agencies could take to improve health literacy through the nation's K-12 schools, 2-year and 4-year colleges and universities, and adult and vocational education.

**Recommendation 5-5.** The National Science Foundation, the Department of Education, and the National Institute of Child Health and Human Development should fund research designed to assess the effectiveness of different models of combining health literacy with basic literacy and instruction. The Interagency Education Research Initiative, a federal partnership of these three agencies, should lead this effort to the fullest extent possible.

**Recommendation 5-6.** Professional schools and professional continuing education programs in health and related fields, including medicine, dentistry, pharmacy, social work, anthropology, nursing, public health, and journalism, should incorporate health literacy into their curricula and areas of competence.

**Recommendation 6-1.** Health care systems, including private systems, Medicare, Medicaid, the Department of Defense, and the Veterans Administration should develop and support demonstration programs to establish the most effective approaches to reducing the negative effects of limited health literacy. To accomplish this, these organizations should:

- Engage consumers in the development of health communications and infuse insights gained from them into health messages.
- Explore creative approaches to communicate health information using printed and electronic materials and media in appropriate and clear language. Messages must be appropriately translated and interpreted for diverse audiences.
- Establish methods for creating health information content in appropriate and clear language using relevant translations of health information.
- Include cultural and linguistic competency as an essential measure of quality of care.

**Recommendation 6-2.** The Department of Health and Human Services should fund research to define the needed health literacy tasks and skills for each of the priority areas for improvement in health care quality. Funding priorities should include participatory research which engages the intended populations.

**Recommendation 6-3.** Health literacy assessment should be a part of healthcare information systems and quality data collection. Public and private accreditation bodies, including Medicare, the National Committee for Quality Assurance, and the Joint Commission on Accreditation of Healthcare Organizations should clearly incorporate health literacy into their accreditation standards.

**Recommendation 6-4.** The Department of Health and Human Services should take the lead in developing uniform standards for addressing health literacy in research applications. This includes addressing the appropriateness of research design and methods and the match among the readability of instruments, the literacy level, and the cultural and linguistic needs of study participants. In order to achieve meaningful research outcomes in all fields:

- Investigators should involve patients (or subjects) in the research process to ensure that methods and instrumentation are valid and reliable and in a language easily understood.
- The National Institutes of Health should collaborate with appropriate federal agencies and institutional review boards to formulate the policies and criteria to ensure that appropriate consideration of literacy is an integral part of the approval of research involving human subjects.
- The National Institutes of Health should take literacy levels into account when considering informed consent in human subjects research. Institutional Review Boards should meet existing standards related to the readability of informed consent documents (Institute of Medicine, 2004, pp. 14-16).

These recommendations, born of exhaustive compilation and investigation of the preeminent sources of information on health literacy, represent a call to action and direction for challenging barriers to the health-literate society envisioned by the IOM. They provide a foundation on which to develop programs, policies, and related activities, for those who engage in health, educational, and social interactions with low health-literate populations.

From the broader perspective of health literacy as a determinant of health, in the next chapter I will narrow the focus of discussion to health literacy as a minority health issue, exploring the role culture and motivation play in the process of promoting healthful change.

## Chapter 2

### Health Literacy as a Minority Health Issue

My review of the literature uncovered the interrelationship of health literacy, culture and language in the discussion of addressing health disparities among diverse populations (Andrulis & Brach, 2007). In its report *Health Literacy: A Prescription to End Confusion*, the Institute of Medicine contends that health literacy must be viewed in the context of language and culture and calls for further investigation into the relationship between cultural diversity and health literacy (Institute of Medicine, 2004). Cultural differences between individuals and service providers, if not addressed, have also been shown to contribute to poor health outcomes through misunderstanding, value conflicts, and disparate concepts of health and illness (Carter-Pokras, Lie, Braun, & Coleman, 2012). There exists then, a dual challenge of limited health literacy and cultural differences for providers working with socioeconomically disadvantaged ethnic minority populations.

Culturally diverse individuals with limited literacy and limited English proficiency (LEP) are among the most vulnerable patients. According to the 2003 NAAL, nearly 40 percent of American adults—90 million people—have limited health literacy. Of these, almost 32 million are nonwhite and/or Hispanic. Andrulis and Brach (2007) compiled and calculated NAAL data to estimate the percentage of adults with limited health literacy (defined as scoring in the Basic or Below-Basic levels of the NAAL) by race and ethnicity. Results showed that less than a quarter of White adults had limited



health literacy, compared to almost half of the Alaskan Native/Native Americans population, well over half of Black Americans, and two thirds of Hispanic Americans (Andrulis & Brach, 2007). The fact that a majority of minority Americans have limited health literacy must be considered in the discussion of population-based health disparities.

Confronted by statistics that continually uncovered a glaring discrepancy between the health and care of racial minority groups and non-Hispanic Whites, the government began to take the lead in policy development aimed at improving equity. The Office of Minority Health (OMH) was created by the USDHHS in 1986 following the Secretary's Task Force Report of Black and Minority Health. The stated mission of the OMH is to "improve the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities" (US Department of Health and Human Services, Office of Minority Health, 2014, para 2). The OMH Resource Center, which began in 1987, is the nation's largest repository of information on health disparity issues; a "one-stop shop" for minority health research and referrals. The Center provides assistance to healthcare agencies and organizations, and conducts health education and awareness campaigns that address disease prevention, health promotion, and healthier lifestyle choices (US Department of Health and Human Services, Office of Minority Health, 2014). In 2000, the OMH developed the National Culturally and Linguistically Appropriate Services (CLAS) Standards, in response to healthcare disparities, changing demographics, and policy requirements. The standards were intended to advance health equity by establishing a blueprint for individuals and organizations to implement culturally and linguistically appropriate services. The OMH

drew an early connection between health outcomes and culture/ethnicity in the following way:

Health inequities in our nation are well documented, and the provision of culturally and linguistically appropriate services (CLAS) is one strategy to help eliminate health inequities. By tailoring services to an individual's culture and language preference, health professionals can help bring about positive health outcomes for diverse populations. The provision of health care services that are respectful of and responsive to the health beliefs, practices and needs of diverse patients can help close the gap in health care outcomes. The pursuit of health equity must remain at the forefront of our efforts; we must always remember that dignity and quality of care are rights of all and not the privileges of a few (Office of Minority Health, 2014, p. 2).

The fifteen standards are arranged under the headings of Governance, Leadership, and Workforce; Communication and Language Assistance; Engagement, Continuous Improvement, and Accountability; addressing spheres where opportunities to advance cultural competence and decrease disparities might exist. CLAS proposed such actions as organizational policy, programs, and workforce developed in response to the literacy needs of diverse cultures, utilizing easy-to-understand print and multimedia materials in the languages commonly used by those groups (Office of Minority Health, 2014). In the fall of 2010, an OMH Enhancement initiative revised the standards to expand their scope, and improve their clarity to ensure implementation. The full list of Enhanced CLAS Standards can be accessed at: <https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedNationalCLASStandards.pdf>.

The OMH envisioned the standards continuing over the next decade as a framework for healthcare organizations which serve ethnically diverse communities. Since that time, several states, including New Jersey, have proposed or passed legislation

regarding cultural diversity education for health professionals. Evidence that the ability of people to read and understand health information, carry out instructions, and access culturally sensitive care is crucial to improving and maintaining health is threaded throughout such proposals in both government and private sectors. The core aims of guidelines such as the CLAS standards, and state policy on culturally competent healthcare providers contribute to a paradigm of care from which both my professional practice and health education program derive: that in order to improve the health outcomes of minority populations, education as well as health service programs must be designed and implemented in a manner that is both literacy and culturally appropriate to their recipients.

Sentell and Halpin conducted a study to determine whether the traditionally viewed importance of education and race in explaining health disparities was diminished when literacy was considered. They expanded on a few prior studies in which literacy was in fact shown to be a more powerful predictor of health status, health knowledge, and health-related behaviors than either education or race. They also found that including literacy in predictive health status models removed the predictive power of both education and race. They concluded that inadequate literacy was both an important contributing factor in health disparities and a possible avenue for interventions which had mistakenly been attributed to other factors, such as race alone (Sentell & Halpin, 2006, August). The significance of these findings was that literacy could be an effective area on which to focus the fight against health disparities; adult literacy could be potentially be improved, and the literacy-related demands of the healthcare system could be targeted,

with implications for both system-level and individual encounters. Thus the rationale for the development of education programs designed for low health-literate adults as a strategy to improve health equities among racial/ethnic groups is supported.

Relevant to this discussion, the 2003 IOM report *Unequal Treatment* noted that many adults from racial/ethnic minority groups find that language barriers and cultural misperceptions are problematic in their efforts to access health care. In addition, non-native speakers of English face issues related to informed consent and shared decision-making, as well as their ability to follow a medical regimen, keep appointments, or obtain information about illness and medicines (Smedley et al., 2003). Complicating the problem of low literacy within minority populations even further is the recognition that recent immigrants, besides having trouble understanding English, actually have trouble reading and comprehending their native language; Hispanics often have low literacy in both English and Spanish (Bennett, McCollum, Culhane, Mathew, & Elo, 2007). As the Hispanic population in this country continues to grow, this is of noted concern for health outcomes in this group. In the following section, I will more closely examine the concept of culture as a context in which educators and healthcare providers must consider their approach to individuals and families.

### **The Role of Culture**

Recognizing that culture plays an important role in communication helps us better understand its impact on health literacy. For people from different cultural backgrounds, health literacy is affected by belief systems, communication styles, and understanding and response to health information. Even though culture is only one part of health literacy,

it is a very important piece of this complicated topic. The United States Department of Health and Human Services recognizes that “culture affects how people communicate, understand and respond to health information” (US Department of Health and Human Services Office of Disease Prevention and Health Promotion, 2010, p. 1).

Defining culture is a challenging task. A review of the literature reveals numerous descriptions. My preferred definition is that of Madeline Leininger (2002), a noted transcultural nursing theorist, who described culture as a set of beliefs, values, and assumptions about life widely held among a group of people and transmitted across generations (p. 47). Culture develops over time and is resistant to change, and is the context in which groups operate. Culture is important to a discussion of health literacy because it is the lens through which people view and attach meaning to health communication (Institute of Medicine, 2004). It follows then, that culture exerts a considerable influence on the quality of health of its members. Providers who interact with ethnically diverse populations must first be aware of the impact of health literacy on health practices and compliance, and take into account the influence of culture in order to maximize their patients’ outcomes. Understanding a person’s culture and its potential effect on his or her understanding, beliefs, and comfort level will allow a provider to connect to that person in a way that is more likely to result in competent care and compliance with instructions. Developing cultural competence is a pathway for providers to achieve such aims.

Cultural competence can be defined as “effective, equitable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices,

preferred languages, health literacy, and other communication needs” (US Department of Health and Human Services, 2014, p. 1). The IOM notes that a deliberate, cognitive process of recognizing cultural beliefs and practices is necessary for all providers who wish to work with and be sensitive to the needs of their clients (Institute of Medicine, 2002). Cultural competence demands that systems tailor the delivery of services to meet clients’ social, cultural, and linguistic needs with the goal of providing quality care equally across populations regardless of race, ethnicity, cultural background, or English proficiency.

Joseph Betancourt, a researcher at the Harvard Medical School, reported on a number of factors which lead to disparities in health among racial and ethnic groups, including social determinants as previously defined. He added that cultural differences among patients, providers, and the healthcare system were also potential contributors to disparities. These differences might influence providers’ decision-making and patient interactions and include: variations in patients’ abilities to recognize and describe symptoms, thresholds for seeking care (including the impact of racism and mistrust); expectations of care (such as preferences for or against certain treatments); and the ability to understand prescribed treatment and directions (Betancourt, Green, & Carrillo, 2002). These findings substantiate that people from different cultures may have difficulty getting appropriate, timely and quality care because of language barriers, and that they might have different perspectives on health, medical care, and expectations about diagnosis and treatment; the development of culturally sensitive healthcare practices would help remove these barriers and create a system more responsive to the needs of an increasingly diverse

population. The emergence of cultural competence in health and social systems can be seen as an approach to reduce factors that contribute to racial and ethnic disparities.

Betancourt and his research colleagues published a field report in 2002 on cultural competence in health care which was supported by the Massachusetts Commonwealth Fund. The researchers focused their literature review on studies of racial/ethnic disparities in health care and cultural competence. They also selected experts who had presented at national conferences on these topics or who were members of national expert cultural competence advisory panels. The researchers then conducted interviews with these experts representing academia, government, managed care and community health care. Those interviewed were asked to define cultural competence in their domain of health care, identify actionable components of cultural competence, identify links to racial and ethnic disparities in health care, and suggest models of culturally competent care (Betancourt et al., 2002). As to the benefits of cultural competence, the experts drew clear associations among cultural competence, quality improvement, and reduction of racial and ethnic disparities in health outcomes. While acknowledging many causes for such disparities, they regarded efforts to improve quality care through greater cultural competence at multiple levels to be among the primary interventions toward equitable care across populations. Further, these experts spoke of the need to use tools and benchmarks to evaluate outcomes, creating standards for the evaluation of care; they saw a need to translate cultural competence into quality indicators or outcomes that can be measured and as such, a means by which to eliminate barriers and disparities.

Betancourt's team visited programs identified by experts as models of culturally competent care. They assessed the development, structure, strengths, challenges and impact of cultural competence interventions in academia, government, managed care, and community health care. The academic setting was a family practice residency program at White Memorial Medical Center in Los Angeles. The area served by this facility is predominantly Mexican-American and half the population speaks mostly Spanish. The facility formalized its cross-cultural curriculum in the late 1990s; several faculty members, a director of behavioral science, a manager of cross-cultural training, and a director of research and evaluation devote time specifically to cultural competence training of new physicians. The doctors spend nearly 30 hours of orientation on issues related to cultural competence, including traditional healers and community-oriented care, and hold small group discussions, readings, and self-reflective exercises. A yearly faculty development retreat integrates cultural competence into all of the teaching at White Memorial. An evaluation of the outcomes of these interventions yielded key lessons for success such as: conduct a needs assessment of residents before curriculum development; create a multi-disciplinary teaching team; carve out time for faculty development; include both minority and non-minority staff as faculty; and integrate cultural competence into many different aspects of the curriculum so that the effort is not viewed as an added burden, but sets the tone for the entire program (Betancourt et al., 2002). Program evaluators also spoke to the means of gaining organizational consensus for this type of program, such as modifying the hospital to reflect the demographics of the community,



performing public relations, securing federal funding and grants, and meeting regulatory requirements.

The community cultural competence model appraised by Betancourt and colleagues was that of the Sunset Park Family Health Center (SPFHC) in Brooklyn, New York. Funded over thirty years ago as a federally qualified community health center, SPFHC consists of a network of primary care sites, family support and literacy programs, health education and wellness centers, and other community-sited supportive programs. Sunset Park has attracted immigrants for decades; at first Scandinavian workers, followed by Puerto Ricans in the 1940s. Today the community includes many of the long-settled ethnic groups as well as newer Chinese, Mexican, Central and South American, Dominican, and Middle Eastern population groups (Lutheran Health Care, 2014). In the early 1990s SPFHC began efforts to expand access to care for recent Chinese immigrants to the area. This Asian Initiative became its first experience in creating culturally competent health care. The initiative focused at first on reducing barriers to care—offering flexible hours of service, translation services and translated signage, and training Chinese-educated nurses in upgraded clinical skills so they could pass state licensing exams in English. This last effort addressed the shortage of linguistically and culturally appropriate staff as a barrier to access for many ethnic immigrant groups.

Continuing these efforts, SPFHC has made cultural competence a constant goal, funding regular staff training programs, expanding its relationships with community groups, and creating an environment that celebrates diversity (displaying multicultural art work, offering an array of ethnic foods, and creating prayer rooms). The Mexican Health

Project is one of several recent primary care sites targeting a growing immigrant community. The project provides an assessment of community health needs and recommends various interventions for communication in clinical settings and patient education (Lutheran Health Care, 2014). Lessons identified by Betancourt from this model include: form partnerships with community-based organizations to help establish culturally appropriate primary care; look for creative use of available resources internally (staff) and externally (websites); and measure success by high patient satisfaction, good clinical outcomes, fewer barriers to access, and collaborative relationships with community groups (Betancourt et al., 2002).

To achieve cultural competence providers need to develop an awareness of their own feelings, thoughts, and environment without letting them have undue influence with how they perceive those from different backgrounds. Healthcare professionals cannot assume that their beliefs and values are the same as their patients' and must consciously resist judgmental attitudes such as "different is not good." By being open to learning about the cultures of their patients, culturally competent providers will have a better understanding of a patient's health-related needs and culturally specific meanings of health and illness; accepting and respecting cultural differences will facilitate their patients' and families' abilities to make decisions which meet their needs and beliefs. One of the best ways for a provider to build skills in dealing with diverse groups is through cultural encounters, or interpersonal interactions and experiences with members of cultures different from one's own. Successful cross-cultural encounters are those in which providers can comfortably engage in effective communication, use appropriate

language and literacy level, and learn directly from patients about their life experiences and the significance of their experiences for health. The encounter can be evaluated on the basis of four aspects: the provider feels successful about the relationship with the patient; the patient feels that interactions are cordial, respectful and cooperative; tasks are done efficiently; and the provider and patient experience little or no stress (Leininger, 2002).

When first coming into contact with individuals who are culturally different from themselves, providers may adapt general cultural concepts to the situation until they are able to learn directly from the individuals about their culture. Providers must assume a professional responsibility for their education in cultural competence by attending conferences, reading professional literature, and observing cultural practices. In compliance with accreditation standards, transcultural care has become a mandated competency across healthcare settings, health science educational curriculums, and private sector organizations. The federal government requires any organization that receives Medicare funds to provide annual training and competency evaluation in transcultural care. A beginning practitioner can access any number of resources to increase cultural knowledge and skill, from general theoretical concepts and models discussed below, to experience in practice with specific ethnic cultures such as Hispanic communities, which will be presented as the target population for my education program.

Many different elements inform culture and there is a variety of ways in which culture might affect health care. In order for providers to better understand those effects

and optimize culturally competent care for diverse groups, they will need to focus on the elements of culture that are most likely to influence the patient-provider relationship:

**Language:** the most obvious component of culture, serves as a connection to others and a way to transmit beliefs, values, and information. Although health literacy issues are not solely related to language, providers need to be aware of the challenges that language poses, for example, that patients' literacy levels may be low even in their native language. Merely translating the words of the healthcare provider into the language of the patient does not guarantee that the patient will understand their meaning.

**Family relationships and experiences:** shared experiences, family structure and roles, and relationships among family members all influence the patient. In some cultures, patients may have a whole network of people on whom they rely in times of illness and they may feel more comfortable in that support system. Inviting family members to participate in care may not only be culturally appropriate, but more effective based on their roles. For instance, if dietary changes are necessary to improve health, the importance of those changes must be understood and accepted by the person who prepares the family meals. Another culturally competent approach to care is an understanding by the provider of the family's past experiences with the healthcare system, which can reveal insight into patients' attitudes toward seeking and complying with care instructions.

**Race and ethnicity:** while one might consider that the United States has made significant advances in the area of racial equality over the years, it has been well-noted that health care is one area in which marked racial inequalities persist. A disproportionate

number of minorities are afflicted with diabetes and cardiovascular disease. They also have higher infant mortality rates and lower rates of childhood immunizations than Whites. A Commonwealth Fund 2001 Health Care Quality Survey focusing on patient perceptions revealed that Blacks, Hispanics, and Asians were more likely than Whites to believe that they would receive better health care if they belonged to a different race. Members of these groups also felt that healthcare providers judged them unfairly or treated them disrespectfully because of their race (Mayer and Villaire, 2007). Culture can impact patient-provider communication in other ways; Latino patients may have a tendency to be more forthcoming and emotionally demonstrative, and accepting of medical treatment, while Asians may be more closed about their symptoms and reluctant to divulge information if they feel uncomfortable with the provider (based on provider's age, gender, tone of voice, etc.). Communication not only with providers but within families is similarly influenced by ethnic culture. Directly informing a patient of a cancer diagnosis is seen as cruel in some Asian cultures. Filipinos may feel that discussion about end-of-life care with family members denigrates the belief that God determines each person's fate, and the Navajo believe that talking about illness or death is dangerous because words can become reality (Mayer and Villaire, 2007). As previously noted, ethnicity shapes the role that family plays in health, and how much input from the family is expected.

**Traditional remedies and alternative health care:** the use of traditional folk remedies and medications often considered unconventional and impractical by mainstream allopathic medicine is prevalent among many cultures outside of the United

States. Providers may lack knowledge or be unaware of the existence and use of such culturally-based practices and treatments among their patients. While many of these remedies (such as herbs), or treatments (such as cupping and coining), may not be dangerous, there may be other types of products which do pose a threat to health when combined with prescribed medications or used in place of potentially effective treatment. Mayer and Villaire (2007) found that although some patients reported they do not avoid mainstream medicine, they tend to use herbal remedies in conjunction with conventional treatment, often without consulting their providers about possible interactions between the therapies. Culturally congruent care entails an effort by healthcare providers to learn about the various folk remedies that are a part of their patients' health and illness traditions and make attempts to either accommodate them into their prescribed regimen or re-pattern as needed.

**Spiritual beliefs and values:** in the past, patients' beliefs about the spiritual or supernatural dimension of illness were considered irrelevant by many health providers. Increasingly, US medical education has included classes on medical ethics and the beliefs of various non-Western faiths, but this does not necessarily make physicians and other providers experts on religion, nor ensure the consideration of these beliefs in the design of care. It must be taken into account that religion and spirituality permeate all aspects of life for those patients who are observant, and that quite often their beliefs will affect their healthcare decisions and practices. Providers also need the emotional intelligence to be aware of how their own religious beliefs might influence their acceptance of the patients' value system.

Larry Purnell, Professor Emeritus at the University of Delaware College of Health Sciences and widely regarded as a leader in transcultural nursing, developed domains of cultural assessment to provide a resource for providers to gain insights into the cultural beliefs of patients, to simplify health assessments and interventions quickly and accurately, and to enable culturally relevant care. His domains both incorporate and go beyond those elements of culture listed above to construct an organizing framework that can be used by providers for patient encounters in all practice settings. The Purnell Model for Cultural Competence (2013) is based on explicit assumptions which include:

- Culture has a powerful influence on one's interpretation of and response to health care.
- Caregivers who can assess, plan, and intervene in a culturally competent manner will improve the care of their patients.
- When patients are co-participants in their care and have a choice in health-related goals and interventions, their compliance and health outcomes will be improved.
- Learning culture is an ongoing process that develops in different ways though primarily through cultural encounters.
- Prejudices and biases can be minimized with cultural understanding.

Purnell describes twelve domains of cultural assessment with related concepts:

- overview and heritage-country of origin and effects on health, economics, education, etc.

- communication-dominant language, dialects, contextual use and paralanguage (non-verbal) variations
- family roles and organization—head of household, gender roles, extended family, acceptance of non-traditional family lifestyles
- workforce issues—autonomy, acculturation, assimilation
- biocultural ecology—biological and physiological variations among ethnic and racial groups, genetic, hereditary, and genetic diseases
- nutrition—the meaning of food, common foods and rituals, nutritional deficiencies and food limitations
- high-risk health behaviors—use of substances, lack of physical activity, non-use of safety measures, attitudes toward sexual practices and measures to prevent sexually transmitted disease
- pregnancy and childbearing practices—culturally sanctioned and non-sanctioned fertility practices, practices related to pregnancy, birthing, and postpartum period
- death rituals—views on death and euthanasia, death rituals, burial practices, bereavement behaviors
- spirituality—formal religious beliefs, use of prayer, meaning of life, sources of strength



- healthcare practices—focus of care (acute vs. preventive), traditional beliefs and practices, views on mental illness, experiences with the healthcare system
- healthcare practitioners—use of traditional, magico-religious, and biomedical healthcare providers, gender of providers (Purnell, 2013).

With each domain Purnell suggests questions for providers to ask and observations to make when assessing patients from a cultural perspective. The list of questions is extensive and Purnell recognizes that providers are not able to complete a thorough cultural assessment at each patient encounter; thus the provider must determine which questions to ask based on the patient's symptoms, teaching needs, and potential impact of culture on the treatment. Examples of questions in the Family Roles and Organization Domain include:

- Who makes most of the decisions in your family?
- What are the duties of the women/men in your family?
- Are there extended family members in the household?
- Who is mainly responsible for taking care of the children?

Under the Health Care Practices domain, a provider might ask:

- What prevention activities do you use to keep yourself healthy?
- Who takes responsibility for the health of the family?
- What do you do when you/your children are sick?
- Are healthcare services easy for you to obtain?
- Do you feel welcome when you see a healthcare professional? (Purnell, 2013, pp. 14, 20).

Gathering this type of information would be useful, for example, for a provider to plan the most effective health teaching approach for an individual or family. It might also indicate how compliant the family might be with the follow up, based on their comfort level with and access to the healthcare system. While various conceptual models for cultural competence exist in the literature, there are commonalities among them in the description of the basic organizing factors of culture.

In another theoretical framework, Giger and Davidhizar (2002) have identified six cultural phenomena that vary among groups and affect their encounters with health care. These phenomena are used to present the diversity that exists between cultural groups and call attention to details that culturally diverse providers need to apply to their assessment and planning of care.

**Communication.** If providers fail to understand verbal and non-verbal patterns and cultural rules of communication, a patient's acceptance of a treatment plan may be threatened. Patients who do speak the dominant language or misinterpret the provider's verbal or non-verbal communication in an unfamiliar environment, may react by withdrawing, becoming angry, or uncooperative. An assessment of communication should consider dialect, style, volume (including silence), touch, context of speech or emotional tone, and kinesics (gestures, stances, eye behavior).

**Space.** Communication occurs within the context of space, which is the distance between individuals when they interact. Zones of interpersonal space may range from intimate to public space, and rules concerning personal distance vary from culture to culture. Extreme modesty practiced by some cultures might even prevent members from

seeking preventive measures such as breast or gynecological screening. An individual's comfort with personal space, proximity to others, body movement, and touch must be evaluated in the context of a therapeutic encounter.

**Social organization.** Similar to Purnell, Giger and Davidhizar maintain that the social environment in which people grow up and live plays an essential role in their development. Social organization refers to the social group structure with which individuals and families of various cultures identify, including family roles, extended family and kinship networks. Giger and Davidhizar also propose exploration of social barriers such as unemployment, homelessness, lack of insurance, legal status, stigma or disenfranchisement, which may prevent people from entering the healthcare system.

**Time orientation.** Some cultures are considered future oriented, others present oriented, and still others past oriented (Giger & Davidhizar, 2002). People who are future oriented are concerned with long-range goals, and with healthcare measures in the present to prevent future illness; they prefer to plan, make schedules, and set appointments. Others are oriented more to the present than the future and may be late for appointments because they are less concerned about planning to be on time. Such differences in time orientation may influence healthcare measures such as long-term planning and explanation of medication schedules. Past oriented cultures are concerned with traditional values and ways of doing things; any attempt to interfere with that tradition may cause mistrust. Those that are past oriented tend to be conservative and slow to change those things that are tied to the past. They look to the past for motivation, guidance and direction. Examples of such cultures are Latin Americans and Native

Americans, who may seek out traditional remedies and courses of action before agreeing to allopathic medical interventions, if at all.

**Environmental control.** This refers to the ability of an individual to control nature and to plan and direct factors in the environment. Some groups perceive man as having mastery over nature; others perceive humans to be dominated by nature; while others see a harmonious relationship between humans and nature. This particular phenomenon plays an important role in the way patients respond to health-related experiences, including the ways in which they define illness and seek and use healthcare resources. As an example, Asians or Native Americans may perceive illness as a disharmony with other natural forces and medicine can only relieve symptoms, rather than cure the disease. They may likely look to naturalistic solutions to resolve a condition.

**Biological variations.** These are traits such as body structure, skin color or other visible physical characteristics, enzymatic and genetic variations, susceptibility to disease, nutritional preferences and deficiencies, and psychological characteristics. A note here: providers must take care to distinguish culture from race; assuming that all persons of a particular race or possessing similar racial characteristics are members of the same ethnic culture, not only displays stereotypical thinking, but can jeopardize the effectiveness of a culturally appropriate provider-patient encounter.

A provider can utilize frameworks such as Purnell's domains, and Giger's cultural phenomena as the basis for assessment, clinical encounters, and care planning with patients of different cultures. By asking questions related to these categories of cultural variation and observing patients' behaviors and responses within a cultural context,

health professionals can design care that is patient-centered rather than disease-centered. When providers are sensitive to both health literacy and cultural competency, they increase the likelihood that patients will understand the benefits of preventive care, for example, and act on that understanding. If an increasing number of our diverse population use preventive services, our society should ultimately benefit from reduced healthcare costs as well as improvement in health outcomes.

### **Inhibitors to Culturally Competent Care**

Betancourt elaborated on cultural barriers that might contribute to racial and ethnic disparities in health care, as pathways for interventions directed at patients, providers, and the healthcare system as a whole. Three primary obstacles are described:

**Lack of diversity in healthcare leadership and workforce.** While minorities make up 28 percent of the population (at the time of the report), only 3 percent of medical school faculty, 16 percent of public health school faculty, and 17 percent of all city and county health officers are minorities. It is likely that minority healthcare providers will be more apt to take into account sociocultural factors that impact the provision of care to minority clients. The authors cite studies that point to the link between the racial and ethnic diversity of the healthcare workforce and quality of care; when doctor and patient share the same racial or ethnic background, patient satisfaction and self-rated quality of care are higher. These markers are, in turn, closely related to positive health outcomes and compliance with treatment regimens (Betancourt, 2002). It follows from this data that a culturally competent healthcare encounter or educational program will involve members of that ethnic community in the planning and implementation of services.

**Systems of care poorly designed for diverse patient populations.** In examining complex health systems that are not responsive to the needs of diverse patients, Betancourt found language discordance between patient and provider to be a central issue. Systems lacking interpreter services or culturally and linguistically appropriate health education materials lead to patient dissatisfaction, poor comprehension and adherence and lower quality care (Betancourt et al., 2002). It is also important to distinguish between merely providing interpreter services and considering cultural beliefs and practices when working with clients of diverse backgrounds. In the Hispanic culture for example, the various dialects, meanings and practices between subgroups, such as Cuban, Puerto Rican, or Mexican may differ, and resources must be individually tailored appropriate to these cultural elements.

**Poor cross-cultural communication between providers and patients.**

Linguistic barriers that many ethnic minorities in this country experience range from no or low English proficiency, to limited proficiency in speaking, reading, or comprehending English. In healthcare settings these linguistic barriers can present challenges to both patients and providers. Communication barriers other than language, however, contribute to disparities in care. When providers fail to understand cultural differences between themselves and their patients, the communication and trust between them may suffer, negatively affecting adherence to medications and health promotion strategies. Furthermore, when providers ignore sociocultural factors relating to their patients, they may resort to stereotyping, which can easily affect their behavior and decision-making (Betancourt et al., 2002). In evaluating potential sources of racial and ethnic disparities in

health care, the IOM highlighted the roles of bias, discrimination, and stereotyping at the individual, institution, and health system levels. The committee that authored *Unequal Treatment* proposed cross-cultural education in professional curricula as an intervention to improve responsiveness to cultural differences in health attitudes, behaviors, beliefs, and language between providers and their patients (Smedley et al., 2003).

These findings by Betancourt and the cultural constructs previously described indicate that the insidious functions of racism, ethnocentrism, stereotyping, and discriminatory practices may often shape encounters between minority groups and the healthcare system. Before addressing multicultural backgrounds and perspectives of their patients, healthcare providers must first address their own personal and professional values, beliefs, ethics, and life experiences to optimize their assessment and interactions with those from a culture different than their own. A provider's self-awareness is crucial to their provision of authentic and equitable care and must proceed to an awareness of the experiences various cultural groups may have confronted in seeking care. Lacking this, providers who do not understand transcultural care, or practice in an environment where colleagues are insensitive to cultural variations, or are critical of or offended by these concepts, may express behaviors which inhibit culturally competent encounters.

### **Ethnocentrism in the Healthcare Experience**

In discussing inhibitors to providers developing cultural competence, Sutherland (2002) describes ethnocentrism as a type of cultural prejudice at the population level. Ethnocentrism is the belief that one's own group determines the standards of behavior by which all other groups are to be judged. Ethnocentric providers are typically unfamiliar

and uncomfortable with anything that is different from their culture, believing that the way they provide care is the best (or only) way. From this perspective, providers may judge other groups in relation to their own culture with concern to language, behavior, customs, and religion. Ethnocentrism is in direct contrast with cultural relativism, the idea that all norms, beliefs, and values are dependent on their cultural contexts, and should be treated as such (Sutherland, 2002). Cultural relativism might certainly be difficult to maintain for those with limited cultural knowledge or desire who are confronted with cultures whose practices or beliefs conflict with their own. Ethnocentric attitudes unfortunately continue to exist among healthcare professionals across a variety of settings and encounters; the experience of having the beliefs and opinions of the provider imposed upon an individual, ignoring or undervaluing his or her cultural principles can surely decrease the opportunity for positive care outcomes. Shapiro and colleagues (2002) interviewed patients from different cultures regarding their interactions with healthcare providers and identified dislikes such as providers acting like they know it all, treating patients as ignorant, minimizing patients' complaints, using technical language, being dismissive of patients' efforts to research their own conditions, and telling patients not to use homeopathic remedies.

Stanhope and Lancaster (2009) elaborated on added behaviors that are likely to operate in an ethnocentric healthcare environment:

**Stereotyping:** attributing certain beliefs and behaviors about a group to an individual without giving adequate attention to individual differences.



**Prejudice:** having a deeply held reaction, often negative, about another group or person. A person may be viewed negatively because of race, skin color, religion, ethnicity, or social standing with no regard for the worth of the individual.

**Cultural blindness:** the tendency to ignore all differences among cultures, to act as though these differences don't exist, and as a result to treat all people the same.

**Cultural imposition:** the process of imposing one's values on others. Caregivers impose their values on patients when they forcefully promote Western medical treatments while ignoring or deriding the patients' value of their own cultural traditions.

**Cultural conflict:** a perceived threat that may arise from a misunderstanding of expectations between patients and providers when either group is unfamiliar with cultural differences.

**Cultural shock:** a feeling of discomfort or disorientation experienced by an individual attempting to understand or effectively adapt to another cultural group that differs in practices, values and beliefs; anxiety is caused by unfamiliar sights, sounds, and behaviors.

It is easy to understand how such behaviors might create a less than therapeutic environment in which effective patient-provider interactions can take place, contributing to misunderstanding of care, lack of trust, dissatisfaction and non-compliance by patients. Ultimately, the inability or unwillingness of ethnic minority group members to navigate this healthcare system will put them at an increased risk for poor health outcomes, contributing to racial/ethnic disparities in care. Simply being aware of patients' cultural beliefs and learning about other cultures may help providers to be less judgmental, more

accepting of cultural differences, and less likely to engage in the behaviors that inhibit cultural competence. Those healthcare professionals who embrace the value of culturally competent practice must be willing to establish individual and group approaches that work for patients of diverse cultures.

Mayer and Villaire (2007) suggested guidelines that healthcare professionals can follow as a first step toward developing culturally competent behaviors in patient-provider interactions, ultimately contributing to more successful outcomes. The list of steps includes:

- Conduct a cultural assessment
- Do homework to learn about the cultures your patients come from
- Make your office or care setting culturally comfortable
- Keep language simple
- Ask questions that will help determine your patient's beliefs and behaviors
- Never dismiss or ridicule patients' beliefs
- Do what you can to accommodate the patient's family
- During all interactions with patients, look like you are listening

The central elements which comprise the discussion of cultural competence can be summarized as attitudes, knowledge, and skills. Attitudes regarding cultural sensitivity and awareness can be enhanced by strategies that increase providers' understanding of the impact of sociocultural factors on patient care and outcomes. Providers who engage in exploration and self-reflection on culture, racism, and ethnocentric thinking can analyze

these factors as they relate to the culture of care and what impact they have on clinical decision-making. To foster knowledge of the values, beliefs and behaviors of certain cultural groups, providers can learn about the surrounding community in which they practice, with attention to socioeconomic status, immigration experience, nutritional habits, folk illnesses and healing practices, and disease incidence and prevalence. A cross-cultural focus on skills emphasizes communication and interpersonal interaction skills of providers in a clinical encounter. Skilled providers can develop methods to elicit patients' explanatory models (what patients believe is causing their illness), identify and negotiate different modes of communication, assess the role of family, determine the patient's perception of biomedicine, and be aware of issues of mistrust (Smedley et al., 2003).

Although there are many pieces to the puzzle of healthcare disparities, evidence from the sources I have presented clearly supports that multi-level efforts to advance health literacy and create culturally competent care settings are primary strategies toward improved outcomes. These interventions will need to be comprehensive and ongoing, but raising public and healthcare provider awareness of the problem of disparities is an important first step. Engaging healthcare professionals at the individual level from an attitude, knowledge and skills approach with cultural competence tools such as Purnell's and Giger's is essential before systemic change can occur. Recommendations such as those made by Betancourt in response to cultural barriers to care at the organizational level can lead to changes on a broader scale. The most effective intervention on all levels will be education; a number of public and private organizations have developed

educational campaigns targeted toward healthcare consumers, providers and policy makers. These include: the USDHHS “Closing the Health Gap” campaign to heighten awareness of health disparities; Diversity Rx, which provides a clearinghouse of information on language, culture and improving health services for minorities; and the Henry J. Kaiser Family Foundation which has developed publications on health literacy, and cultural healthcare disparities (Institute of Medicine, 2004). Educational efforts which raise public awareness will also contribute to systemic interventions on the greater scale—changes to healthcare law and policy to promote equality in healthcare outcomes.

### **Advocacy: The Driving Force**

Health literacy and cultural competence stand out as essential forces in the fight to reduce overall health disparities across populations. Boiling down the data from a broad variety of sources presented in this chapter, I am able to distill practical applications to grassroots interventions with specific groups in the community. As the details of my study unfold in the following chapters, the reader will recognize the common themes which thread the research findings in health literacy and cultural competence operating in the development of my health education program. I will draw those connections as I describe each phase of the program from selection of participants through outcomes and implications.

A final note, the force that must underscore such interventions by me or any health or educational professional is that of advocacy. Public health providers working among disparate groups in the community are well-versed in this concept as it is a central component of our practice. The goal of advocacy is to promote self-determination in a

client group. The “client” may be an individual, family, group, or an entire community. The process of advocacy can be defined to include informing, supporting, and affirming (Mallik & Rafferty, 2000). Knowledge is essential to the outcome of decision making, but the interpreting of knowledge is affected by cultural values and the meaning individuals assign to that knowledge. Informing in a cultural context is not a one-way activity by providers; more active participation of clients in conversation with providers has been linked to better treatment compliance and health outcomes. Supporting involves upholding an individual’s right to make a choice and to act on that choice. Affirming is based on the provider’s belief that an individual’s decision is consistent with his or her values and goals. It is not the provider’s role in this process to tell the individual which choice is correct, but rather to: provide the opportunity for information exchange, giving individuals the tools that can empower them in making the best decision from their perspective; enable the individual to make an “informed decision,” a powerful tool for building self-confidence; and empowering individuals with skills that can strengthen their autonomy and confidence in the future. Effective advocacy maintains a balance between “doing for” and “promoting autonomy” (Lancaster & Stanhope, 2014).

Empowerment is a specific advocacy strategy which helps people acquire the skills and information necessary for informed decision-making and ensures that they have the power to take control over their own lives. Health education and health promotion programs are empowering efforts to reach racial and ethnic minorities who are in need of information, risk reduction activities, and guidance in accessing care. Health education and promotion focuses on educating community members about health conditions for

which minority populations experience a disproportionate burden. Specific skills that recipients of health education can develop include: the ability to identify and manage health problems in oneself or family, understanding and attaining preventive services, how to communicate with healthcare providers, knowing what types of healthcare services are available within the community, and recognizing the difference between primary care services versus emergency room services, and how to access each appropriately.

Education is a powerful tool for self-determination and a correlate of health. Public health professionals utilize three levels of prevention—primary, secondary, and tertiary—as a framework to prevent adverse health outcomes and reduce health risks and complications in community populations. *Primary prevention* refers to interventions that promote health and prevent the occurrence of disease; *secondary prevention* is aimed at early detection and prompt treatment of a condition; and *tertiary prevention* efforts limit the effects of disease or disability and enhance rehabilitation to reduce long-term consequences (Lancaster & Stanhope, 2014). Education is the gold standard of primary prevention, and the most commonly used strategy by advocates to empower their clients by increasing their knowledge and motivating them to make healthful change. The most effective education programs will be those designed and implemented in ways that are understood and accepted by learners. Providers who consider health literacy needs and cultural perspectives of community populations in teaching-learning encounters are taking the first steps toward reducing racial and ethnic health disparities at the grassroots level. In the next chapter I will describe the preparation of my educational program,

drawing upon the evidence-based principles which have been presented to the reader thus far.

## **Chapter 3**

### **Preparing for the Program**

At the conclusion of the last chapter, I introduced the concept of empowerment as a tactic to improve health outcomes in ethnic minority populations who may be at a disadvantage due to among other factors, health literacy and cultural barriers to accessing care. In this chapter I will continue to elaborate on empowerment strategies such as health education and health promotion, as well as components of learning and behavioral theory as elemental to the design of my health literacy program.

#### **Empowerment through Health Promotion**

Bailey (2010) defined empowerment at several levels including individual community members, organizations within the community, or the community at large. Individual empowerment is a process of increasing one's power to take action to improve one's own life. Empowered individuals gain new skills and attitudes to influence others and to affect the outcomes of decision-making. At the next level, organizational empowerment involves increasing the power of groups in the community to control decisions related to the health and welfare of those groups. At the community level, the ultimate effects of healthful change generated by community members and groups will improve outcomes for the population as a whole.

Bailey's model conceives empowerment as occurring along a continuum from personal empowerment to group process and eventually to community transformation. It is a prototype to that of my original thesis: by improving the health literacy skills in



individuals and families, the health behaviors and outcomes of those population groups will change for the better and ultimately contribute to the reduction of the larger problem of health disparities, in particular those among ethnic minority populations.

Health promotion can be defined as a process that fosters people's ability to improve their own health by increasing their control of its determining factors. Health promotion involves educating people to change their behavior, thereby increasing healthy life expectancy throughout populations and reducing inequities (World Health Organization, 2005). An added impetus for a national focus on health promotion is that of economic necessity; the US Preventive Services Task Force estimates that increasing the proportion of the population who engage in health promotion and illness prevention services to 90 percent would result in healthcare cost savings of nearly \$22 billion (Maclosek, Coffield, Flottemesch, Edwards, & Solberg, 2010).

At the population level, providers focus health promotion efforts on behavior modification and prevention and/or management of specific health conditions. Community health educator and author Mary Jo Clark noted that before executing their role in health promotion, providers must consider a number of factors that might influence the health promotion situation. In addition to health literacy, these include:

- *Fatalism*, the belief that one's fate is fixed and that personal efforts can do little to affect that fate. Fatalistic beliefs are associated with lower rates of participation in health promotion, prevention, and screening activities
- *Readiness for change*, that is, that people only engage in change when they are good and ready to do so. Change may occur in stages over time,

from when an individual first contemplates the need for change through actually taking and maintaining change. A provider can develop strategies to motivate change based on a conceptual health behavior model, a few of which I will present following this discussion

- *Health professionals' attitudes toward and involvement in health promotion activities*, which also influence health promotion behaviors among individual patients. Healthcare providers may often miss opportunities for health promotion in the care of their patients. Lack of time and reliance on written materials can lead to ineffective health promotion, particularly among population groups with low literacy levels (Clark, 2008). The factors Clark describes not only support, but supplement the ideas and theories applied to improving health literacy and disparities that I derived from the research in my previous chapters, which served to guide my program.

### **Health Education: A Primary Prevention Strategy**

Although population-focused health professionals may use a variety of strategies to foster health promotion at the individual level, health education provides the most direct information and skills development opportunity to assist individuals to make effective health-related decisions. Health education is a participatory learning process that enables people to make informed decisions. The World Health Organization (2014) defines health education as “the use of learning experiences to improve people’s knowledge or change their attitudes for the purpose of fostering health” (para.1). The

primary purpose of health education is to empower patients to make any of three types of health-related decisions: decisions about self-care, decisions about the use of health resources, and decisions about societal health issues (Clark, 2008).

How best to develop a health education program that succeeds in achieving these aims? Different types of learning may be required to facilitate health promotion action by individuals. Types of health learning have been classified into learning domains which drive the learning objectives and teaching activities in a given session. A number of principles of learning also apply to health education and can be grouped as general principles of learning and principles related to the health education message and its delivery in the teaching-learning process. I have defined and detailed how these domains and principles of learning are specifically applied in my health education plan in the following chapters.

### **Theoretical Framework**

A number of conceptual models have also been developed to guide health promotion practice. While no single theory or conceptual framework dominates research or practice in health promotion and education, reviews of journal articles published in the last two decades have revealed the most often-used theories in health behavior research. While many theories have been cited, only a few of them were used in multiple publications and by several authors (Glanz & Bishop, 2010). I have summarized below the central elements of four of the most widely-used theoretical models of health behavior, upon which I drew to guide me in developing behavioral change tactics.

**The Health Belief Model (HBM).** Originally developed to help understand why people did or did not use preventive health services in the 1950s, HBM has evolved to address newer concerns in prevention and detection, and lifestyle behaviors. HBM theorizes that peoples' beliefs about whether or not they are at risk for a health problem, and the benefits of taking action to avoid it, influence their readiness to take action. Core constructs of HBM are: Perceived susceptibility and perceived severity—what are my chances of having this problem and how badly will it affect me?; Perceived benefits and barriers—how will making change help me, what is preventing me from making change?; Cues to action—my mother died from this health condition, my family needs me to stay healthy; and Self-efficacy—I believe I am/am not capable of making this change (Glanz, Rimer, & Viswanath, 2008). HBM has been most often applied for health issues that are prevention-related and asymptomatic, where knowledge and beliefs are more important than overt illness. The success of HBM in motivating individual-level change relies on strategies that raise awareness of the threat of potential health problems, facilitate an appreciation of long-term benefits of change, and build confidence that the participant has the skills and support to achieve their goals.

**The Precaution Adoption Process Model.** This is a “stage” model that describes stages in decisions to adopt or not adopt a health-related behavior (whether or not to make precautionary change). In stage 1, a person is unaware of the health-related issue and the need to adopt any particular new behavior. In stage 2, one may be aware of the issue but is unengaged by it and not considering any action. In stage 3, the person is deciding whether or not to act; he or she has considered the possibility of action, but has

not yet made a decision regarding learning the new behavior. Stage 3 may be followed by either stage 4 or stage 5. In stage 4, the person has decided not to act. Conversely, in stage 5 the person has decided to act, but has not yet taken action. The process may stop at stage 4 for those who decide not to adopt a new behavior. Persons in stage 5 who have decided to adopt the behavior proceed to stage 6 in which they act to engage in the behavior, and hopefully then to stage 7, in which the behavior becomes a routine part of their lifestyle (Weinstein, Sandman, & Blalock, 2008). This process can be simply applied to the adoption or non-adoption of health-related behaviors such as exercise, or dietary changes as learners begin with little knowledge or concern about the health effects of exercise and proper nutrition, then: are motivated by learning and valuing how diet and exercise can improve their health outcomes, find positive reinforcement in feeling better, and ultimately incorporate behaviors such as regular exercise and reading nutrition labels into the daily routines of caring for themselves and their families. The role of the provider is to identify the learner's stage and facilitate their transition through the stages to behavior change by offering information and support best suited to their capabilities. For example, consciousness raising techniques may highlight the need for change in moving learners from stage 1 to 2, while emotional support and tips for making change can lead to the action stage.

**Social Cognitive Theory (SCT).** The cognitive formulation of social learning theory described by Bandura, explains human behavior in terms of a three-way, reciprocal model in which personal factors, environmental influences, and behavior continually interact. SCT combines concepts from cognitive, behavioral, and emotional

models of behavior change, so it can readily be applied to education and counseling interventions for disease prevention and management. A basic premise of SCT is that people learn not only through their own experiences but also by observing the actions of others and the result of those actions (Bandura, 1977). Key constructs of SCT that are relevant to health behavior interventions include observational learning, reinforcement, self-control, and self-efficacy. Interventions such as goal-setting and self-monitoring are useful in promoting reinforcement and self-control. Self-efficacy, a learner's confidence in their ability to take action and overcome obstacles to persist in that action is an important focus for providers attempting to influence health behavior change. By breaking down a large goal of reducing fat intake into small weekly goals that are more easily attainable, a learner is more likely to believe that they are capable of change. The key Social Cognitive construct of reciprocal determinism means that a person can be both an agent for change and a responder to change; changes in the environment, the examples or role models, and reinforcements can be used to promote healthier behavior. This core construct is also central to social ecological models and supports health education, modeling and group learning environments as effective health promotion tactics.

**Social Ecological Model.** Employing elements of SCT, the Social Ecological Model explains factors affecting behavior and also provides guidance for developing successful programs through social environments. Social ecological models emphasize multiple levels of influence (individual, interpersonal, organizational, community) and the idea that behaviors both shape and are shaped by the social environment. The principles of this model that are consistent with SCT suggest that creating an

environment conducive to change is important to making it easier for learners to adopt healthy behaviors (National Institutes of Health, Office of Behavioral and Social Sciences Research, 2014). Example influences based on levels of influence stated above can include: individual—knowledge of cardiovascular disease risk factors; interpersonal—friends or family members affected by cardiovascular disease; organizational—health education and promotion programs on diet, exercise etc.; community—accessibility and affordability of screening and follow-up services.

The theoretical concepts presented above seem to suggest that health behaviors are shaped by a variety of determinants at different levels of intervention. For example, physical activity is influenced by self-efficacy at the individual level, social support from family and friends at the interpersonal level, and perceptions of crime and safety at the community level. In clinical settings, strategies to change health behaviors best focus on individual levels such as knowledge, beliefs, and skills. From an ecological perspective however, individuals can achieve and maintain behavioral changes which contribute to healthier families and communities when intervention strategies are broadened to target factors at other levels of influence such as organizational policies and social determinants of health. Applied to the development of my educational program, this point of view requires that I consider not only the participants' personal characteristics and learning needs, but how the process of health behavior change operates in the context of the family, culture, and social environment in which they exist. To this end, I attended to individual, interpersonal, and community level interventions by providing direct instruction to participants, assisting them to incorporate learned health behaviors into the

care routines of their families, and facilitating their ability to successfully navigate the healthcare system and access community resources.

Deciding on the best interventions from among the most widely used models for targeting behavioral determinants begins with identification of the population of interest combined with the most important and changeable determinants. I chose elements of individual-level theories, primarily the Health Belief Model, to begin the planning of my program. As my target population was primarily Hispanic women of disadvantaged socioeconomic status, with varying levels of language and health literacy, I felt the HBM emphasis on beliefs/knowledge about health problems, susceptibility, and the benefits of learning ways to take action to prevent and/or manage illness provided a good foundation on which to design a basic health teaching plan.

Individual-level intervention strategies that derive from the Social Cognitive Theory (SCT) include: goal setting, behavioral contracting, and tailored health communication. Key constructs of SCT that are relevant to behavior change include observational learning, reinforcement, self-control, and self-efficacy (National Institutes of Health, Office of Behavioral and Social Sciences Research, 2014). To incorporate these elements into my plan and increase learner self-efficacy, I decided that specific format strategies should include: setting small, incremental, and achievable goals with learners; using a specified type of behavioral contracting with learners to clarify expectations and responsibilities; and monitoring and reinforcement, including learners' self-monitoring by completing and assignments and keeping records.



I drew upon the “staging” sequence of The Precaution Adoption Model to initiate the process of interaction between educator and learner; at the start of the proposed change process (via an education program) learners would be assessed as to their level of health literacy (beginning knowledge) and interest in learning how to prevent illness and improve health. The course of effecting behavior change was to proceed over time (4 weeks of the program), with learners achieving progressively higher levels of knowledge toward assimilating health promoting behaviors (driven by weekly learning objectives established for each lesson). With respect to the Precaution Adoption stage 7, ensuring learners’ compliance with and long-term maintenance of new health behaviors, my program would conclude with a one month follow-up evaluation where learners would be asked to describe how they were using the new information they had gained, and in what ways their health behaviors had changed (see Appendix C).

### **Using Groups for Health Education**

Social Cognitive and Ecological theory support teaching and learning in groups as an effective method of health education, by their emphasis on such concepts as observational learning and social environments. Health behavior is influenced by the groups to which people belong, and groups may dictate or support health practices, as has been noted in the context of cultural groups. In addition, group support often helps people make needed changes for health that they are unable to accomplish on their own. For learners with similar background characteristics, the “collective identity” of the group might ease the discomfort of self-consciousness and create a bond among members, particularly with regard to culture, language barrier, and literacy level. Thus, group

teaching fosters positive peer support and feelings of belonging; members share common concerns and receive reinforcement from one another. Several Healthy People 2020 priorities can be addressed in health promotion and education groups in which individuals learn healthy behaviors and gain reinforcement from others in making change in their lifestyle choices.

Through group discussion, learners can exchange information, feelings, and opinions with each other and with the educator. Teaching in groups rather than one-on-one allows the educator to reach a number of learners at the same time. Group discussion as an active instructional method can incorporate specific strategies such as guided learning, collaborative learning, and small-group activities. Benefits of group discussions are that they lead to deeper understanding and longer retention of information, increased social support, greater transfer of learning, more favorable attitudes toward learning, and more active learner participation. This teaching technique is learner centered as well as subject centered and is noted as highly effective in reinforcing previous learning (Bastable, 2014).

As a classroom educator, I favor the value of group discussion for learning in the cognitive and affective domains, a detailed explanation of which I will include in the development of my teaching plan. I am also aware of the challenges that can arise with this instructional method and the tactics I would need to employ for involvement in and control of the process in my learners group. Limitations of group discussion might include one or more members dominating the discussion, while shy learners may refuse to become involved or need a great deal of encouragement to participate. Groups may

easily digress from the topic at hand, interfering with achievement of the objectives. The instructor must be skilled enough to tactfully redirect learners who digress or dominate without losing their trust and that of other group members. Alternatively, if members do not easily interact, the instructor will be challenged to stimulate productive conversation. Group discussion may be more time-consuming for transmission of information than other methods such as lecture; it requires that the instructor be present at all sessions to act as a facilitator and resource person. In addition, group teaching requires the instructor to be able to tolerate less structure and organization than other teaching methods.

While these aspects of using groups for health education might be more challenging for a novice teacher, I have worked extensively with groups in both classroom and community instructional settings. As previously noted, I find it crucial to the success of the discussion that I sustain trust within the group. Everyone must feel safe and comfortable enough to express his or her point of view. Negative responses will break down the relationship between instructor and students, creating a poor learning environment; I am careful to acknowledge all students' answers and ideas, even when incorrect or off track, in a way that positively reinforces their efforts—they are commended for their participation. Respect and tolerance toward others is modeled by me and required of all group members, sending a message that the value of what each member has to say and their right to participate is guaranteed. A helpful approach is that I tell the group at the beginning of the session that my goal is to hear from all members by asking for their input and points of view during the discussion period. I will often ask

learners who digress from that goal to hold questions or comments that can be handled at the end of the discussion.

Cooperative learning, as a strategy of group education, relies on active student participation and is the methodology of choice for transmitting foundational knowledge. Cooperative learning is further distinguished by the instructor's role, in which the instructor is the center of authority in the class, with group tasks usually more closed-ended and often having specific answers (Bastable, 2014). Cooperative learning is a form of group work that focuses on problem-solving that leads to deep learning and critical thinking. According to Millis (2010), cooperative learning includes four key components:

- Structuring of the learning tasks by the teacher
- Interactive student-to-student execution of the tasks
- Immediate debriefing or other assessments to provide the teacher and students with prompt feedback about the success of learning
- Instructional modifications by the teacher based on feedback

Cooperative learning requires that pre-determined behavioral objectives guide the achievement of learning outcomes and should be presented at the beginning of each session. The instructor must adhere to the objectives to keep the discussion focused and prevent wandering ideas or a forum for dominance of individual opinions. An experienced educator is best suited to facilitating group progress and must be well versed in the subject matter to field questions, to move the discussion along in the direction intended, and to give appropriate feedback (Miller & Stoeckel, 2011).

Several theoretical concepts were operational in my decision to provide health education in a group format. Groups are an effective vehicle for initiating and implementing healthful changes. As previously discussed, a learner's self-efficacy is enhanced via group interaction and positive reinforcement of efforts by group members and the instructor. The decision to act and maintain learned behaviors over time might be influenced by a learner's desire to follow group norms, and Social Cognitive features such as observational learning, personal-environmental interaction, and reinforcement via role-modeling are easily integrated into group process. I chose cooperative learning strategies to construct my group learning model: I reviewed specific learning objectives, which students were expected to accomplish for each class, and assessed how successfully students felt they achieved objectives again at the end of class; each lesson consisted of structured learning tasks in specific health promotion subjects such as child care, illness prevention, nutrition, and physical activity; students worked in small groups to share ideas and solve assigned tasks; each student group presented the results of their work to the class, and I would provide feedback and encouragement of student discussion; and as a nurse and health educator, I felt confident in my knowledge of the topic areas and the students perceived me as a credible authority on healthcare matters.

A significant advantage to using groups for my health education project is that it would provide a context in which considerations of literacy level, language obstacles, and cultural influences could be collectively addressed. I chose to initiate a selected membership group, in which participants would have mutual health needs or concerns. I was able to draw participants from an already established group; such groups

theoretically have operating methods that have proved successful. Members are familiar with each other's preferred styles of interaction and may be comfortable working with and able to influence one another. The strength of common ties and interests can balance dissimilar traits (Lancaster & Stanhope, 2014). The homogenous group composition benefitted my program goals in a number of ways. Individuals are attracted to others from similar backgrounds, with similar experiences, and with common interests and abilities. My group participants shared common attributes such as gender, language, culture, socioeconomic and literacy status. As a predominantly Hispanic group of women, they were exposed to the same health risks and disease prevalence of that population, and upheld the same traditional and familial health practices, diet, and lifestyle behaviors. They also shared the common role of caretaker for their children and families, with the responsibilities and challenges that duty entails. Group process is most effective when members agree on a common focus, and clear and achievable objectives. Thus I chose the educational content of my classes with input from the group, so as to target topics that would be of most interest to them and enhance participation.

The similarities in the women's backgrounds and socio-cultural characteristics made it possible for me to examine the interplay among cultural factors, literacy status, and health outcomes in an ethnic minority, disadvantaged population sample. This group composition also provided a context from which I could design program components to target the central issues of my thesis; health literacy assessment, and linguistic and culturally appropriate teaching strategies to facilitate healthful change in populations at risk for disparate health outcomes. In the following chapters, I will describe the specific

design and implementation of my health education program, beginning with health literacy screening tools (Appendix A), course outline and lesson plans, and description of my sample, setting, and instructional methods.

## **Chapter 4**

### **Designing the Program**

#### **Measuring Health Literacy**

In order to design an effective education program, I first needed to assess the basic health literacy level of my participants as well as determine what content areas were most needed. I searched the literature for existing health literacy screening tools and found no shortage of information on available tested instruments. I needed a tool however, that would be appropriate for my study population in terms of both culture and language proficiency. The students participating in the program were predominantly Hispanic female family caregivers, ranging in age from twenties through mid-forties, with a maximum of high school education level, and varying levels of English proficiency (as described by Oasis program staff).

Although several literacy assessment tools are published, the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) and Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995) were developed specifically to measure patients' health literacy skills. I chose to examine these tools in more detail as they were favorably referenced as reliable and valid. The REALM is a medical-word recognition and pronunciation test comprising 66 medical terms, arranged in order of complexity by the number of syllables and pronunciation difficulty. The test starts with simple one-syllable words (e.g., pill, eye) and ends with multi-syllable words (e.g., antibiotics, potassium). Patients read down the list, pronouncing aloud as many words as



they can while the tester scores the number of words pronounced correctly using standard dictionary pronunciation as the scoring standard. Scores on the REALM vary from 0 (no words pronounced correctly) to 66 (all words pronounced correctly.) The score assigns health literacy skills into four categories of grade-equivalent reading level: 0-18 (3<sup>rd</sup> grade), 19-44 (4<sup>th</sup> to 6<sup>th</sup> grade), 45-60 (7<sup>th</sup> to 8<sup>th</sup> grade) and 61-66 (9<sup>th</sup> grade). It can be administered and scored by personnel with minimal training, making it easy to use in clinical settings (Columbia University, n.d.).

The TOFHLA measures the functional literacy level of patients, using real-to-life health care materials. These materials include patient education information, prescription bottle labels, registration forms, and instructions for diagnostic tests. The TOFHLA assesses two main constructs, numeracy and reading comprehension; it has a total of 67 items. The numeracy scale, used to measure the ability to read and understand numbers, includes 17 items; the reading comprehension scale, used to measure the patient's ability to read and understand healthcare-related passages, contains 50 items. In the reading comprehension sections, patients are asked to select the correct response from a list of four possible choices. Responses are reviewed for accuracy, and each item answered correctly is assigned a score of one. Incorrect items are given a score of zero. To interpret the total score, participants receiving a score of 59 or below are considered to have inadequate functional health literacy; those scoring 60-74 have marginal functional health literacy and subjects scoring 75 and above have adequate functional health literacy. There are two additional versions of the TOFHLA: TOFHLA-S, a validated Spanish translation, and the S-TOFHLA, a shortened Spanish form that requires up to 12 minutes to

administer. The short form is composed of 4 numeracy items and 36 reading comprehension items (Columbia University, n.d.).

As my intended study population was predominantly Spanish-speaking with varying levels of proficiency in reading and/or speaking English, I narrowed my search to instruments which were developed specifically for such populations. Lee et al. (2006) conducted a psychometric study intended to develop and validate a health literacy test, termed the Short Assessment of Health Literacy for Spanish-speaking Adults (SAHLSA), for the Spanish-speaking population. The authors' note the design of SAHLSA was based on the REALM; in addition to the word recognition test in REALM, SAHLSA incorporates a comprehension test using multiple-choice questions designed by an expert panel. Lee and his colleagues tested and compared the tool with other health literacy instruments in a sample of 201 Spanish-speaking and 202 English-speaking subjects recruited from an ambulatory healthcare center. They found that with only the word recognition test, REALM could not differentiate the level of health literacy in Spanish. The SAHLSA significantly improved the differentiation. Also, when correlated with the TOFHLA, the SAHLSA score was significantly and positively associated with the physical health status of Spanish-speaking subjects holding constant age and years of education, supporting its validity and reliability (Lee, Bender, Ruiz, & Cho, 2006).

I noted several limitations in the review of the SAHLSA. The instrument was developed based on standard, "dictionary" Spanish and English. The instrument might be less useful in different Spanish- and English-speaking subpopulations who are accustomed to using different idiomatic expressions. As with other health literacy

instruments such as TOFHLA and REALM, SAHL-S&E is a reading test. It assesses an individual's reading skill in the healthcare context. The design is based on the assumption that reading ability is a basic literacy skill, without which patients would have difficulty functioning in and negotiating the healthcare system. Furthermore, the instrument does not capture other skills such as numeracy and interpersonal communication that may also be important in health care. The study by Lee did not utilize a random, representative sample of Spanish speakers and English speakers in the community. The clinic-based participants recruited for the study might be more receptive to a health literacy test, but less representative of my target sample.

Although these instruments appeared to accurately measure the constructs they were designed for, they are both primarily indicators of reading skills (word recognition or reading comprehension and numeracy). I was interested in evaluating a broader range of skills related to health literacy; cultural and conceptual knowledge, listening and speaking, as well as numeracy, writing and reading. I needed assessment data to inform the language, types of educational materials, and cultural differences in approaches to health and health care as aspects of my program. I was also concerned that the comprehensive and lengthy format of the tools might prove overly burdensome to my sample learners. I reviewed the literature for research that might identify questions that could best indicate that a learner may have low or marginal health literacy. I sought evidence to determine whether short screening questions and demographic information might help predict a patient's literacy status.

I found various studies suggesting that providers could use a few questions to identify patients with limited health literacy. Chew, et al. (2004) sought to develop a practical method for identifying patients with low health literacy. They completed in-person interviews of patients in an outpatient clinic that included 16 health literacy screening questions using a 5-point Likert scale, followed by the validated health literacy tool, the Short Test of Functional Health Literacy in Adults, or STOFHLA, a shortened version of the TOFHLA. Based on the STOFHLA data, patients were classified as having either inadequate, marginal, or adequate health literacy. Each of the 16 screening questions was evaluated and compared to two comparison standards: inadequate health literacy, and marginal health literacy on the STOFHLA. Results of the study determined that 4.5 percent of participants had inadequate health literacy, and 7.5 percent had marginal health literacy on the STOFHLA. Three of the screening questions, “How often do you have someone help you read hospital materials?” “How confident are you filling out medical forms by yourself?” and “How often do you have problems understanding your medical condition?” were effective in detecting inadequate health literacy, although weaker in identifying patients with marginal health literacy. The study concluded that these three questions were each effective screening tests for inadequate health literacy in their population (Chew, Bradley, & Boyko, 2004, pp. 591-2).

To further evaluate the accuracy of Chew’s three candidate questions in identifying patients with limited or marginal health literacy, Wallace and colleagues (2006) designed a variation of that study which utilized demographic data, health literacy questions, and the REALM, rather than STOFHLA, to screen participants. They

hypothesized that providers were often unable to identify patients with limited health literacy skills during routine clinical interactions, and such patients were often reluctant to reveal this limitation. Determining a patient's literacy level would alert the provider to the need for special approaches in communicating health information, such as using non-medical (plain) language, drawing pictures, giving small amounts of information at a time, and using a teach-back approach (Wallace, Rogers, Roskos, Holiday, & Weiss, 2006). The authors maintained that asking questions such as "Can you read?" or "How many years of school did you complete?" did not accurately predict a patient's literacy level (p. 875), but despite the availability of reliable and valid instruments such as REALM or TOFHLA, most providers did not screen further for limited understanding due to time constraints and/or potential for embarrassing patients. The aim of Wallace's study was to identify screening items that could be easily implemented in a clinical setting, accurately estimate health literacy, and be non-threatening to patients.

Wallace's investigators interviewed participants face-to-face and began with collecting demographic information using five items (sex, age, race/ethnicity, educational attainment, and health insurance coverage). Next, patients were asked each of Chew's three health literacy screening questions, each with a range of five possible response options: 1) "How often do you have problems understanding your medical condition?" (always, often, sometimes, occasionally, or never); 2) "How often do you have someone help you read health information?" (always, often, sometimes, occasionally, or never); and 3) "How confident are you filling out medical forms by yourself?" (extremely, quite a bit, somewhat, a little bit, or not at all). Lastly, patients' health literacy skills were

measured with the REALM, as the reference standard. Interestingly, in all analyses, “How confident are you in filling out medical forms by yourself?” was statistically more predictive of limited and marginal health literacy than the other two questions; a combination of two or more screening items did not significantly improve this value. Of the demographic items explored, educational attainment was the most significant predictor of patients’ health literacy (Wallace et al., 2006, p. 877).

While differing from Chew’s findings on which question most effectively measured patients’ health literacy level (Chew identified: “How often do you have someone help you read health information?”), Wallace’s conclusions reaffirmed that combinations of multiple questions were no more effective in identifying those with limited or marginal health literacy skills than one single question. The results of both studies concurred that a single question could be useful in assessing health literacy more accurately than demographic information alone.

Results of another study were further refined to produce the Single-Item Literacy Screener (SILS), a one-question test for adequate literacy (Morris, MacLean, Chew, & Littenberg, 2006). Morris and colleagues noted, like others, that while instruments that measure reading ability were used in research studies, the time required to administer these tools (from three minutes on average for the REALM-R to 12 minutes for the TOFHLA) limited their usefulness in the practice environment.

Referring to Chew’s 16 question study which identified three questions as effective for detecting inadequate health literacy, Morris modified that format to develop a single-question literacy screener that would efficiently identify patients who have

difficulty with a central aspect of health literacy, understanding health related materials. The aim of this instrument was to identify patients who need help understanding printed material and verbal instruction regardless of the etiology (limited education, language barrier, low literacy).

Morris and colleagues assessed the diagnostic accuracy of the SILS as an indicator of limited health literacy compared with a diagnostic strategy using the S-TOFHLA. Their SILS used the question: “How often do you need to have someone help you when you read instructions, pamphlets, or other information from your doctor or pharmacy?” Possible responses were 1-Never, 2-Rarely, 3-Sometimes, 4-Often, 5-Always (Morris, et al., 2006, p. 9). Scores greater than two were considered positive, indicating some difficulty with reading and understanding health-related information. The SILS was administered by investigators in written format, as part of a questionnaire, and was always done prior to the S-TOFHLA. Their results showed that the SILS had better performance in the subset of patients with the lowest reading ability. The authors further determined that statistically the SILS performed moderately well in ruling out limited reading ability, thus allowing providers to target additional assessment to those most in need. They concluded that in contrast with the S-TOFHLA, which took roughly seven minutes to administer, the SILS was brief and practical for use in clinical settings with the potential to improve outcomes and care processes for individuals with limited health literacy. In their discussion, Morris and colleagues noted that as education and ethnicity have been reported to be significantly associated with health literacy, those factors might also prove useful in identifying patients in need of alternative communication strategies,

complementing SILS, which is a more direct assessment of a need (Morris et al., 2006). Among their conclusions was a recommendation that further study of the use of SILS in settings with more diverse populations was warranted; such an implication weighed in favor of my inclination toward using brief health literacy screening questions with my Hispanic study population (see Appendix A).

The findings of these studies provided a theoretical basis from which to design the screening tool I would use with my program participants. I found a final study by Jeppesen et al., (2009) that largely influenced the development of my own instrument. The authors' objective was to identify which screening questions and demographics independently predicted limited health literacy, allowing providers to then individualize their patient education. They argued against universal screening for literacy difficulties, in favor of providers in a given setting taking responsibility for assessing how well their individual patients understand health information; knowing what questions to ask about patients' learning styles would help them to personalize teaching strategies.

Jeppesen and colleagues built upon the results of studies which suggested that a few questions could be used to identify patients with limited health literacy. They wondered whether the questions were in fact superior to other proxies, such as highest educational level, or self-rated reading ability, which they were intended to replace. The authors noted that the latter factors, though not perfect predictors of literacy, were felt to be strongly associated with literacy level, and therefore merited study as risk factors for potential problems with health literacy. The hypothesis of this study was that short screening questions along with demographic information would help predict a patient's



literacy status. Further, they sought to discover which questions and demographic data were superior predictors (Jeppesen, Coyle, & Miser, 2009).

From their statistical analyses, the researchers developed a final logistic regression model for predicting limited health literacy (Table 1, p. 27) which determined that lower self-rated reading ability, lower educational attainment, and more frequent need for help with written health materials were all independently associated with limited health literacy. Male sex and nonwhite race were independently associated with this outcome as well. The authors recommended that providers who wish to screen for limited health literacy ask about self-rated reading ability, highest education level attained, and use the SILS-type format as part of a social history. To help providers remember what specific questions to ask and which answers may be considered predictive of a health literacy problem, they proposed the mnemonic “SOS,” as illustrated in the table below.

Table 3

*SOS Mnemonic for Screening Patients for Limited Health Literacy*

<b>Question Topic</b>	<b>Letter</b>	<b>Category</b>	<b>Threshold<sup>a</sup></b>
Educational attainment	S	The person’s <b>S</b> chooling is ...	... <b>S</b> ub-Secondary.
Self-rated reading ability	O	The person’s <b>O</b> pinion of his or her reading ability is that ...	... he or she is <b>O</b> nly an <b>O</b> kay reader.
Help needed when reading <sup>b</sup>	S	When the person reads health-related materials, <b>S</b> upport is ...	... <b>S</b> ometimes <b>S</b> olicited.

<sup>a</sup>Answers that may indicate a problem with health literacy. <sup>b</sup>Single-Item Literacy Screener. (Jeppesen, Coyle, & Miser, 2009, Jan-Feb, p. 29).

According to this mnemonic, an educational attainment of high school or less, a self-rated reading ability of “okay” or worse, and asking for help with reading health materials at least “sometimes” are all associated with a higher likelihood of limited health literacy and can be used by providers as a framework for discussing their patients’ potential barriers to learning.

A strength of this study was that it combined several different screening questions and demographic information into one predictive model. The fact that self-rated reading ability, SILS-type result, highest education level attained, gender, and race were all significant predictors of limited health literacy (even after adjustment for one another) clarified that they were independently helpful at predicting health literacy problems, and that the use of all of these questions and demographics would be superior to the use of any one of them. Another strong point was that this study was clinically based; participants were recruited at an urban family practice center which served an ethnically diverse population. And whereas many literacy screening tools might determine whether or not a patient has limited health literacy, they are less effective at defining etiology and helping providers design care. This study supported the assumption that asking specific questions about how an individual understands health information would better clarify intervention strategies; for example, a positive result on needing help with health information and instructions indicates the need for a family member to be present during education sessions. At the very least, it seemed to me that asking these questions could prompt a conversation about an individual’s learning styles and needs.

After consideration of the various study results, I decided that elements from both Chew's and Jeppesen's instruments were best suited for use with my program objectives and target population. I constructed a tool that would capture demographic data that I considered relevant to a health literacy profile based on my earlier literature review: gender, age, race/ethnicity, highest grade level, and primary language. I felt more comfortable using a combination of questions rather than a single-item, thinking that consistent levels of response to questions of a similar nature would reinforce the results. Since I chose to use screening items that had been previously tested in primary research studies, the validity and reliability of the questions for the purpose of evaluating health literacy had already been established. I believed that the questions transcended race or language and could be translated into Spanish and still capture accurate data. I utilized self-rated reading ability as well as four additional questions: "How often do you have trouble learning about your medical condition because of difficulty understanding information from your doctor?" (always, often, sometimes, never); "How confident are you at filling out medical forms by yourself?" (very, somewhat, a little bit, not at all); "How confident do you feel you are able to follow directions to take medication correctly?" (very, somewhat, a little bit, not at all); and "How often do you have someone help you read health materials?" (always, often, sometimes, never). As with the study by Morris, I would consider a response beyond the midpoint option for the given question (always, often or a little bit, not at all) indicative of health literacy deficiency. Responses of "just OK" or "not good" regarding reading ability would be similar indicators. My health literacy screening form is attached as Appendix A.

I was satisfied that the information yielded by asking participants these questions could constitute a reasonable assessment of oral, written, and numeracy literacy, and social markers such as family involvement and use of healthcare resources. This screening data would allow me to tailor my instructional methods around learners' capacities, for example, use of visual graphics and demonstration with feedback. By evaluating the participants' self-rated reading ability in both their primary language and English, I determined the extent to which my materials would need to be translated, and in the case of manufactured resources such as books and PowerPoint slides, how many I would need in English and in Spanish.

### **Health Literacy Educational Resources**

Prior to the beginning of the study, I made several visits to the Oasis program site to speak informally with both staff and students to brainstorm ideas for the program. I attended during lunchtime in order to have access to volunteers (for translation as necessary) and students in a casual and comfortable atmosphere and in fact, I participated as a volunteer serving lunch. My aim was to find out what subject matter would be of most interest and benefit to the women, and how motivated they might be to attend four weekly sessions. Not surprisingly, the most frequent topics of conversation among the women revolved around the care of their children. I was also aware, through my public health experience, that obesity and type-2 diabetes are predominant health risks among Hispanic populations. Statistics from the CDC corroborate my impressions: The prevalence of obesity among female Hispanic American adults during 2007-2010 was larger than the prevalence among White, non-Hispanic female adults during the same

years, and in 2010, the largest prevalence of diabetes was among Hispanic and non-Hispanic African-American adults compared with prevalence among White, non-Hispanic adults (Centers for Disease Control and Prevention, 2015). The data on childhood obesity are further distressing: Prevalence of obesity in Hispanic boys aged 2-19 in 2011-2012 was 24.1 percent, and 20.6 percent for Hispanic girls in the same age group; the rates for non-Hispanic Whites in the same age groups were 12.6 percent for boys, and 15.6 percent for girls (Centers for Disease Control and Prevention, 2014).

I informally surveyed the women on which topics related to reducing these health risks they would be most interested in learning about. The two most identified topics were nutrition (healthy eating) and physical activity (exercise). Based on my discussions with the women, I chose three topics on which to tailor teaching-learning interventions and mechanisms for reinforcement and maintenance of new behaviors: caring for a sick child and preventing illness and injuries; improving skills to create and maintain a healthy diet; and ways to incorporate physical activity into the daily routine of family members (see Appendix D). A format of sixty to ninety-minute sessions would provide adequate time for the presentation of information in various formats and group activities for participatory learning, while hopefully keeping participants engaged over a manageable four week span of time. I planned to devote two weeks to child care as this stood out as the common concern among the women, and one week each to nutrition and physical activity. Although I had a “captive audience” in the sense that the learners were already participants in Oasis programs, my sessions would need to be held on Saturdays, outside of the regularly scheduled classes for the week. Attendance for the program was

encouraged but voluntary, and required that the women commit to at least one hour on Saturday morning for four weeks (see Appendix D). This presented challenges not only to populate the classes, but also to motivate continuous attendance and investment by the participants.

To my advantage, the familiar and culturally accommodating Oasis environment provided a comfortable setting for interaction among the students and volunteers who felt at ease with one another. I chose to utilize only two volunteers who worked regularly with the students to assist me in implementing the program, so as to reduce potential variation in the interventions and threats to internal consistency of the study. Social cognitive and ecological theoretical constructs explain human behavior in terms of a three-way reciprocal model in which personal factors, environmental influences, and behavior continually interact (National Institutes of Health, Office of Behavioral and Social Sciences Research, 2014); the idea that behaviors are shaped by the social environment suggested to me that creating a user-friendly environment conducive to change might be the first step to making it easier for learners to adopt healthy behaviors. To complement the learning environment, my aim was to offer an easy-to-read publication highlighted with visual graphics, and provide a copy to each participant as a “takeaway” resource that could subsequently be used as a reference after the program ended. Also of paramount importance was the need to adapt instruction to the language and cultural needs of the participants.

**Institute for Healthcare Advancement  
What to Do When Your Child Gets Sick**

I first learned about the Institute for Healthcare Advancement (IHA) while attending the National Conference to End Health Disparities sponsored by the Center of Excellence for the Elimination of Health Disparities (CEED) at Winston-Salem State University, in 2009. Located in La Habra, California, the IHA is a not-for-profit public benefit charity which, as per its website is “dedicated to empowering people to better health by providing health care and improving health literacy at the national level” (Institute for Healthcare Advancement, 2015). As part of its services, the IHA provides direct healthcare delivery in its community clinic, the Friends of Children Health Center (FOC). Outreach and social services are delivered to the community through its La Habra Family Resource Center (FRC), including counseling, home visits, insurance assistance, case management, referrals, and education. The IHA is also a national leader in health literacy issues. Its “What to Do for Health” book series features easy-to-read and easy-to-use healthcare information. The IHA has also mounted efforts to combat low health literacy by producing health literacy educational activities for providers, including an annual conference (UCLA, 2014).

The “What to Do for Health” series features seven books written at a third to fifth grade reading level. All books are available in English or Spanish; some are also in Vietnamese, Chinese, or Korean. The books are intended to help consumers with health problems, wellness tips, and sound guidance on topics such as parenting children and teens, and caring for an elderly loved one. Over four million copies of the series have

been sold and utilized by health plans, state governments, community groups, hospitals, and educational organizations across the United States (Institute for Healthcare Advancement, 2015). The books offer features that I sought to incorporate into my teaching format: written and designed to be easy-to-read and easy-to-use, with plain language and no medical jargon; simple illustrations to support teaching content; short and to-the-point chapters that are well organized for easy navigation. The “What to Do When Your Child Gets Sick” book provides easy-to-understand information on more than fifty common childhood medical problems, from fevers, infections, and pinkeye to heat rash, broken bones, bites, and poisoning (Mayer & Kuklierus, 2004).

The IHA site summarizes data from the results of several organizations across the country which utilized books in the series for patient education:

Parents were given a copy of *What to Do When Your Child Gets Sick* and taught how to use it. Independent studies found:

- 57-61 percent fewer visits to the emergency room
- 39-56 percent fewer visits to doctors/clinics
- 43-60 percent fewer school days missed by children due to illness or injury
- 41-47 percent fewer work days missed by parents due to children’s illness (Institute for Healthcare Advancement, 2015).

I tracked the results of a nation-wide program sponsored jointly by the University of California at Los Angeles (UCLA) Anderson School of Management and Johnson & Johnson. The Johnson & Johnson Family of Companies Contribution Fund supported an initiative which partnered UCLA and Johnson & Johnson in the establishment of the Health Care Institute (HCI) in 2001. The mission of the UCLA/Johnson & Johnson



Health Care Institute is to better prepare parents to address the health needs of their children (UCLA, 2014). A survey conducted by Dr. Ariella Herman, an educator at UCLA Anderson School of Management and Research Director for the HCI, suggested that many parents are uneducated or misinformed on several dimensions of their children's health. She noted that many parents often don't have time to become better educated about the health needs of their children, contributing to soaring healthcare costs, inappropriate use of emergency rooms, and generally less effective health outcomes (Herman & Jackson, 2010). In a later article focused on the health literacy of low-income and minority populations as a national public health priority, Herman cited that compared with children from high-income families, children from low-income families in the United States face disproportionate health challenges; they have worse reported child health status and health risks, including higher than average rates of childhood obesity and dental cavities. She noted that while effective health promotion and disease prevention strategies have the potential to reduce the health burdens of vulnerable children, families most vulnerable to child health risks may also have the lowest levels of literacy and health literacy (Herman, Nelson, Teutsch, & Chung, 2013).

In response to these risks, the HCI designated families of children enrolled in Head Start programs across the country as the target population for their training initiative. Head Start (HS), a national early childhood program for low income families, was created in 1964 as part of the War on Poverty. HS and Early Head Start (EHS) programs annually serve approximately one million children aged 0 to 5 years. Recognizing the relationship between health and school readiness, HS has required its

grantees to coordinate health-related services such as basic screenings, health education, and referrals to healthcare providers (US Department of Health and Human Services, Administration for Children and Families, Office of Head Start, 2009). Results of the nation-wide survey of HS directors in 2001 made clear that although grantees had access to health materials and resources to conduct health education trainings, these sessions were often poorly attended and the materials were not well understood by participants (Herman et al., 2013).

The HCI subsequently developed a structured health promotion training program for HS grantees, and since its inception has trained more than 1,400 HS leaders from programs across the US. In turn, trained HS staffs have implemented health promotion programs for their families using culturally adapted, low-literacy materials on various prevention topics. Family education programs include experiential group learning activities and hands-on skill building, which the trainers found to be a powerful way to motivate family participation and engagement. Since 2001, HCI-trained staff from 240 HS programs have reached 60,000 families nation-wide (Herman et al., 2013).

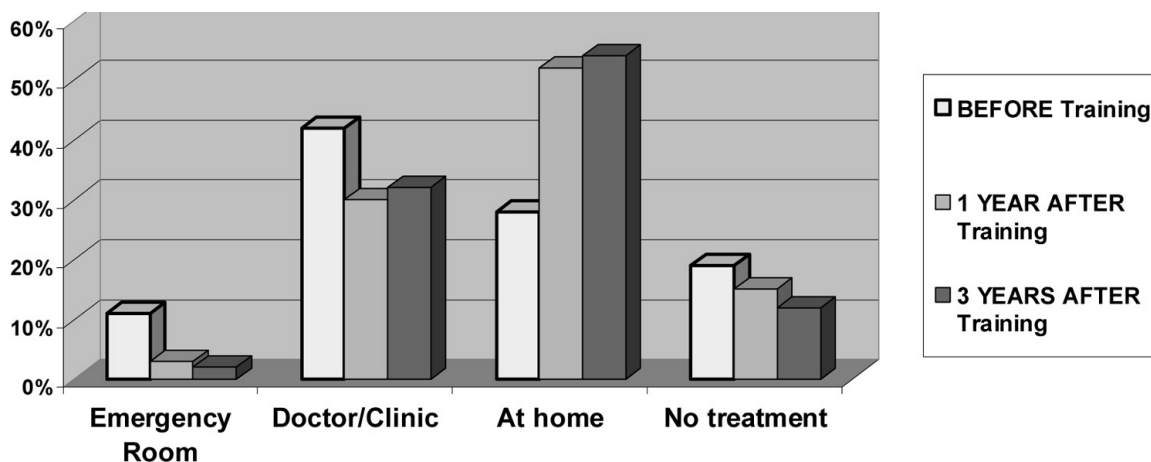
A brochure developed by UCLA Anderson School of Management provides detailed information about the HCI Head Start Health literacy program. Regarding program content it states:

Parent training sessions are tailored to the demographic, language, and cultural needs of the families at each participating program. During the sessions, parents receive basic health care and medical information and learn to use *What to Do When Your Child Gets Sick*, by Gloria Mayer RN, and Ann Kuklierus RN, a low-literacy guide covering more than 50 common childhood illnesses. Parents also receive hands-on instruction in

key actions, such as taking temperatures and measuring medicine (UCLA Anderson School of Management, n.d., p. 5).

I noted that the HCI training technique blends many educational techniques: audio, visual, hands-on, group with peer-to-peer teaching, and handouts for home use and reinforcement of learning. The learning environment also provides the opportunity for social interaction and networking among parents. I assessed such elements of the HCI training design as a fit with the objectives, population considerations, and theoretical framework of my program. For each of their implemented health promotion modules, HCI collected pre-intervention and post-intervention data from parents. The baseline parent measurements were done at the initial training session using written questionnaires to determine topic-specific health knowledge and self-reported behaviors which were translated into the parent's native language. The same questionnaires were given again at the completion of the program to measure changes in knowledge and behaviors. If literacy limitations posed problems for families to complete these written questionnaires independently, they were administered orally by staff. Post-training interventions occurred monthly for six months with home visits by HS staff to reinforce training, track behavior change, and collect data from parents on variables related to the child's illness in the previous month: days the child was absent from school; days the primary caretaker was absent from work due to their child's illness; number of times the child was treated at home, at a doctor's office, clinic or in the ER; and last, the number of times the primary caretaker referred to the book and did not need to seek treatment for the illness (Herman & Jackson, 2010).

The results of successful HS program implementation at various agencies nationwide are numerous and published in press releases on the UCLA Anderson School of Management site (<http://www.anderson.ucla.edu/programs-and-outreach/uclajohnson-and-johnson-health-care-institute/resources/press-releases>). Herman and Jackson (2010) analyzed data collected from 55 HCI trained HS agencies in 35 states spanning the continental US between 2003 and 2006. Comparison of data from pre- and post-intervention parent questionnaires showed a significant decrease in the reported number of missed school and work days, and significant decreases in reported numbers of emergency department and doctor visits. The qualitative impacts of the program were significant as well. Parents reported that they were better able to determine whether they could treat their child at home, or needed the advice of a health care professional. Benefits from the training included increased parental awareness of symptoms related to common illnesses, earlier and improved treatment, fewer days of missed school for children, and a reduction in work absences for parents (Herman & Jackson, 2010). An informal assessment of the long-term effects of the intervention was performed on a subsample of 581 parents who volunteered to be tracked annually for three years after the training. The results indicated persistent use of the health book by these participants over the three-year follow-up period; self-reported responses regarding their first source of help in the past three months for common childhood illnesses showed that the change in behavior was consistent over time. The graph below plots responses to the query: “What was your FIRST source of help for common childhood illnesses in the past three months?”



*Figure 1.* Responses to the query: “What was your FIRST source of help for common childhood illnesses in the past three months?” Source: Herman, A. and Jackson, P. (2010). Empowering Low-Income Parents with Skills to Reduce Excess Pediatric Emergency Room and Clinic Visits through a Tailored Low Literacy Training Intervention, *Journal of Health Communication*, 15: 8, p. 906.

Both articles cited with Dr. Herman as principal investigator drew the conclusion that the HCI training approach to health promotion for low-income families represents a valuable and potentially cost-effective way to increase prevention and reduce health disparities in vulnerable populations. The researchers also noted that the HCI programs have demonstrated consistent outcomes in diverse settings and cultures, suggesting both scalability and sustainability (Herman et al., 2013). The persistence of these trends over time implies the potential for the program to be replicated successfully in a variety of settings, as highlighted in the HCI brochure:

While Head Start families have been an initial focus of the Health Care Institute, the model can be easily and efficiently replicated in all states and with other community groups and partners...it is the Health Care Institute’s goal to develop partnerships with health care institutions, community based groups, educational organizations, and others who can utilize and advance this hands-on training model, enabling millions of children and families to benefit from new found health care knowledge (UCLA Anderson School of Management, n.d., p. 2).

The body of evidence available on the effectiveness of the HCI trainings, and the well-defined narrative of the purpose, theoretical framework, and elements of the program influenced my choices in designing a health literacy educational curriculum. The HCI approach recognizes the multiple levels of influence on health behavior and outcomes (from organization-level to social interactions within and among families), with the ultimate goal of affecting individual-level health behaviors of parents and children, consistent with a social ecology-type model. While it was not my aim to entirely replicate the HCI training, I recognized that the congruence between the HCI program elements and my own objectives could prove a valuable resource to my endeavor, particularly regarding instructional setting and methods. Such was the basis of my decision to use *What to Do When Your Child Gets Sick* as the teaching tool for the two classes on child health maintenance and sick care.

### **The Newest Vital Sign**

In 2005, the Pfizer Corporation sponsored health literacy research through its Health Literacy/Clear Health Communication Initiative. Although definitions of health literacy generally related to individual abilities, the Pfizer initiative emphasized the interactions between individuals and the healthcare environment as determinants of health literacy. Pfizer assumed a leadership role in promoting clear health communication, assigning healthcare professionals the responsibility to communicate in a way that is readily understood by the average consumer (Pfizer, 2008).

With research support and honoraria from the Pfizer Initiative, Dr. Barry Weiss, at the University of Arizona's College of Medicine, worked to develop a quick and

accurate screening test for health literacy available in English and Spanish. Weiss and colleagues administered candidate items for the new instrument and also the TOFHLA to English-speaking and Spanish-speaking primary care patients. By statistically measuring correlations between the new instrument and TOFHLA scores, they formulated a final instrument, the Newest Vital Sign (NVS), a bi-lingual screening test for general literacy, numeracy, and comprehension skills applied to health information, which quickly emerged as the cornerstone of the Pfizer Clear Health Communication campaign. NVS is a nutrition label that is accompanied by six questions and requires three minutes for administration. Patients read the label while the provider asks six questions about how they would act on the information (see Appendix E). A scoring sheet, with the correct answers is used to record the responses. Patients with fewer than four correct answers suggest the possibility of low health literacy (Weiss, et al., 2005 November).

I found the idea of using a nutrition label to assess health literacy appealing because nutrition labels are familiar items that are important parts of health management for many chronic diseases, including the diabetes and obesity concerns of my program participants. They are pertinent to health promotion in that many healthy people use information on nutrition labels to help achieve healthy eating habits. Patients' ability to understand and use the information on nutrition labels is likely the first step in the process of making healthy eating decisions and dietary changes. Mastering the task of deciphering nutrition labels would not only build reading, but numeracy and document skills as well; the same skills that are needed to understand and follow a provider's medical instructions.

Another benefit of the NVS as a teaching tool was its availability in both English and Spanish. Weiss et al. documented good reliability, validity, and accuracy scores in their testing of both versions of the tool by enrolling 250 English-speaking patients to validate the English version of the NVS (NVS-E), and 250 Spanish-speaking patients to validate the Spanish version (NVS-S). Since its inception the NVS has been cited in over 33 peer-reviewed studies. The authors note the limitation that the psychometric properties of the NVS-S, although adequate to predict limited health literacy, were not as good as those of the English version. They speculate that this result may stem from a heterogeneity of language and culture among the population of Spanish-speaking patients (Weiss et al., 2005). I hoped to counteract such dialectic discrepancies in bilingually prepared teaching resources by using the Oasis volunteers who were members of the same community and worked on a daily basis with the women attending my program, to assist with reading of visual displays.

The characteristics of the NVS seemed to be a fit for my program needs. It is a research-tested tool that is accurate, yet relatively quick and simple to administer in both English and Spanish-speaking groups. Results are instantaneous and useful for feedback and teach-back strategies. It centers on developing literacy skills in the context of simple nutritional information and so its use might be an effective way to introduce learners to basic concepts required for healthy dietary change. I envisioned beginning the class on nutrition with a visual display of the NVS-E and NVS-S (read aloud by volunteers as necessary) and completion of the six question exercise by participants who would then share and talk about their answers in a guided discussion. The USDHHS Health



Resources and Services Administration provides a toolkit for the use of NVS and links to nutritional teaching resources that can be used with low health literate learners which I reviewed for inclusion in my class content (US Department of Health and Human Services, Health Resources and Services Administration, n.d.). The English version of both the NVS and Score Sheet for Questions and Answers are displayed below:

<b>Nutrition Facts</b>			
Serving Size		½ cup	
Servings per container		4	
Amount per serving			
Calories	250	Fat Cal	120
		%DV	
<b>Total Fat</b>	13g		20%
Sat Fat	9g		40%
<b>Cholesterol</b>	28mg		12%
<b>Sodium</b>	55mg		2%
<b>Total Carbohydrate</b>	30g		12%
Dietary Fiber	2g		
Sugars	23g		
<b>Protein</b>	4g		8%
*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.			
<b>Ingredients:</b> Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.			

Figure 2. Nutrition Label. Source: Weiss, B., et al. (2005, November). Quick assessment of literacy in primary care: the newest vital sign. *Annals of Family Medicine*; 3(6): p. 516.

## Score Sheet for the Newest Vital Sign Questions and Answers

**READ TO SUBJECT: This information is on the back of a container of a pint of ice cream.**

		ANSWER CORRECT?	
		yes	no
1.	If you eat the entire container, how many calories will you eat? <i>Answer: 1,000 is the only correct answer</i>		
2.	If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have? <i>Answer: Any of the following is correct: 1 cup (or any amount up to 1 cup), Half the container Note: If patient answers "two servings," ask "How much ice cream would that be if you were to measure it into a bowl."</i>		
3.	Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day? <i>Answer: 33 is the only correct answer</i>		
4.	If you usually eat 2500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving? <i>Answer: 10% is the only correct answer</i>		
<b>READ TO SUBJECT: Pretend that you are allergic to the following substances: Penicillin, peanuts, latex gloves, and bee stings.</b>			
5.	Is it safe for you to eat this ice cream? <i>Answer: No</i>		
6.	(Ask only if the patient responds "no" to question 5): Why not? <i>Answer: Because it has peanut oil.</i>		
<b>Interpretation</b>		Number of correct answers:	
Score of 0-1 suggests high likelihood (50% or more) of limited literacy			
Score of 2-3 indicates the possibility of limited literacy.			
Score of 4-6 almost always indicates adequate literacy.			

Figure 3. NVS Score Sheet for Questions and Answers. Source: Weiss, B., et al. (2005, November). Quick assessment of literacy in primary care: the newest vital sign. *Annals of Family Medicine*; 3(6): p. 516.

### **The National Library of Medicine: Medline Plus**

The United States National Library of Medicine (NLM), located in Bethesda, Maryland, is a division of the National Institutes of Health, and is the world's largest medical library. A description of its functions is excerpted from the NLM website:

The NLM has been a center of information innovation since its founding in 1836. The world's largest biomedical library, NLM maintains and makes available a vast print collection and produces electronic information resources on a wide range of topics that are searched billions of times each year by millions of people around the globe. It also supports and conducts research, development, and training in biomedical informatics and health information technology. In addition, the Library coordinates a 6,000-member National Network of Libraries of Medicine that promotes and provides access to health information in communities across the United States (U. S. National Library of Medicine, National Institutes of Health, 2015, p. 1).

The Library offers extensive health information resources for scientists, health professionals, historians, and the general public. Of its numerous databases, the Library's main portal for consumer health information is Medline Plus, which is available in both English and Spanish. Medline Plus contains comprehensive, updated information on approximately 900 health topics. It also provides interactive health tutorials which are narrated programs that use animated graphics to explain conditions and procedures in plain language, and a collection of videos (U. S. National Library of Medicine, National Institutes of Health, 2015).

As a resource for consumers, Medline Plus provides a webpage "Health Literacy" which discusses the importance of patients understanding and using health information correctly, as well as obstacles to good health posed by low health literacy, including trouble filling out forms, following medical instructions, and understanding how to take

medicines correctly. The page also provides links to other government (NIH, CDC, USDHHS) and non-government medical sites (American Medical Association, Harvard Medical School) that inform readers about health literacy issues, and offer resources such as Health Check Tools, tutorials on understanding medical words, and health concerns for children, teenagers, and seniors, among others (US National Library of Medicine, 2014).

As a resource for providers, the Medline Plus web page “How to Write Easy-to-Read Health Materials” organizes guidelines to create low health literacy easy-to-read (ETR) materials into four steps:

- Step 1. Plan and Research: Determine and know your target audience; consider reading level, cultural background and attitudes, and language proficiency. Determine objectives and outcomes; what you want your target audience to do as a result of your teaching.
- Step 2. Organize and Write: Consider language and writing style, visual presentation and representation.
- Step 3. Evaluate and Improve: Test materials on a few individuals or sample group from your target audience. Evaluate feedback and revise material as necessary.
- Step 4. Inform and Stay Informed: Label created ETR materials as “easy-to-read,” Medline Plus will display materials as ETR if the sponsoring organization labels them and evaluates for reading level (US National Library of Medicine, 2013, p. 1).

The Medline Plus Easy-to-Read page provides links to ETR materials from a variety of sources on “Health Topics” arranged alphabetically from A through Z. A link to “Drugs and Supplements” makes ETR information available on generic and brand name drugs as well as vitamin supplements and herbal medicines. Complementing the vast amount of printed health information, the page also links to interactive tutorials which offer audiovisual content in either a timed or self-paced format, accompanied by ETR text. The tutorials are offered in English and Spanish, and cover a variety of health topics, surgical and treatment procedures, and lifestyle activities. My final class topic, exercise and physical activity (see Appendix F), required cognitive and psychomotor learning skills; I believed an audiovisual tutorial format might be an effectual instructional technique and provide a change of pace from the first three classes for the learners. I reviewed the “Prevention and Wellness” topics and chose “Exercising for a Healthy Life,” an animated slide show with voice over and graphics, focusing on the benefits of physical activity on health, types of beneficial activities, and tips for starting (US National Library of Medicine, 2012). One of the recommendations in the tutorial was the use of a pedometer to count the number of steps and set daily activity goals. It occurred to me that giving each learner a pedometer as a take-away could serve the dual purpose of motivating the class to pay attention to exercise as well as to attend the last class.

Satisfied that my selection of information and teaching materials from these three sources comprised a sound basis for planning a program to improve health knowledge

with attention to cultural congruence and limited language proficiency, I proceeded to the design and presentation stages of the project continued in Chapter 5.

## Chapter 5

### The Study

#### Participant Selection

Paterson is one of the most densely populated cities in NJ and the US; the poverty rate is significantly above the national average. It is a city facing harsh adversity with 28 percent of its people living below the poverty line, nearly double the 15 percent national average. Approximately 89 percent of children in Paterson qualify for free or reduced school lunch programs and only 11 percent of adult residents hold a Bachelors or higher degree. In fact, only 59 percent of Paterson teens graduate from high school and only 1 percent of all NJ college bound seniors are from Paterson (Robert Wood Johnson Foundation, 2014).

I chose the Oasis Program in Paterson as the setting for my health education program. *Oasis- A Haven for Women and Children*, posts the following mission statement on its website:

Oasis is dedicated to feeding and clothing needy women and children and to offering them educational resources and skills to obtain meaningful employment and to break the cycle of poverty. Oasis offers these services in a safe, compassionate and nurturing environment. We are committed to fostering healthy family relationships, and we seek to preserve the dignity of people and their cultures (Oasis - A Haven for Women and Children, n.d.).

A non-profit organization, Oasis offers its services to local women and children living below the poverty line. Oasis' clients are economically and financially distressed with various health issues, living in overcrowded multi-generational family dwellings. Most are mothers with school aged children, exhibiting low levels of self-esteem. The

ethnicity demographics of clients are 61 percent Hispanic, 25 percent Middle Eastern, 10 percent Black, 2 percent White, and 2 percent Asian (Oasis - A Haven for Women and Children, n.d.).

Many of the women at Oasis have become disenfranchised as a result of poverty, addiction, violence, incarceration or other life circumstances which have put them at risk for vulnerability. Programs are designed to prepare the women to re-enter their social environment and pursue economic and personal recovery. Classes are offered for GED attainment, English as a second language, computer training, workplace readiness, and certificate programs. Workshops on health/wellness, self-esteem, and parenting are also offered (Oasis - A Haven for Women and Children, n.d.). In addition to classes, hot lunches are served Monday through Friday, a food pantry, donated clothing, diapers and child-care items are available to program participants. There is also a daycare center and after-school program for children while their mothers attend class. The services are free of charge to the women and their children as long as the women regularly attend classes and complete the program.

Oasis is governed by a voluntary board of directors which is composed of community representatives, local business leaders, and members of several non-profit organizations which serve the area. At the time of my program, the newly appointed executive director was Sister Gloria Perez. My contact and liaison for the health education program was Chief Operating Officer Jim Walsh, who directed the Women and Children's programs (Oasis - A Haven for Women and Children, n.d.). I had been acquainted with Mr. Walsh for several years as I had provided Baccalaureate nursing



students for health fairs at Oasis in my capacity as a faculty member at Felician College in Lodi, New Jersey. There is no Institutional Review Board at Oasis; both Mr. Walsh as women's program director, and Sister Angela as executive director approved the plans and documents for the program. They were enthusiastic about the idea of health education classes designed specifically for the women at Oasis, and offered their support in sponsoring the program and providing the facility. The Institutional Review Board of Drew University, chaired by Dr. Allan Dawson, conducted an expedited review and approved my research study, its corresponding documents, and the process I had planned for protecting the confidentiality of participants. All respondents were assigned a code number which corresponded with their Informed Consent signatures (see Appendix G) and was the identifying marker on class question forms. The master list of participants' names was kept by me in a three-ring binder in my home office.

I met with Mr. Walsh, the staff social worker, and volunteers who work in the after-school program to discuss how best to inform the women about the health education program and motivate them to attend. We printed a flyer that would be displayed in the classrooms and lunch area, describing the program and indicating that participants would receive a book to use for classes and keep for use at home (Appendix D). The Oasis instructors and volunteers encouraged the women to attend classes, and were able to provide basic information in English and Spanish. The program was open to any of the women who were enrolled in classes and participated in the after-school program.

After three weeks of advertising the program, 41 women responded indicating they would like to attend. I was pleased with the response rate as I assumed an attrition of

participants would occur over the four classes. These women were asked to complete a Health Literacy Screening form and Informed Consent form (Appendices A & G) prior to the start of classes. Two volunteers assisted me in communicating with the women, translating conversation about the program to instructions for completing the forms, and translation of the actual documents and class materials into Spanish. While I have moderate facility with written and spoken Spanish, the Oasis volunteers lived in the same neighborhoods as many of the women and were familiar with the regional dialects and forms of conversational dialogue of the group. This is an important consideration for linguistic competence as not all Hispanics speak the same Spanish and even subtle differences across dialects might alter accurate communication. To ensure the validity of the translation, I reviewed all forms and class materials with my two volunteers, Evelyn and Maria. We read the information together in English, they translated the information into Spanish and read it back in English. They were given copies of the book and slides for class in English and Spanish ahead of time, so they could familiarize themselves with the concepts being taught and fine tune how they might need to clarify the commercially translated resources. We paid close attention to health and medical terminology, including colloquial terms for various illnesses and parts of the body. By limiting the participation in translation to these volunteers, I felt that the meaning of my information could be reliably communicated to and understood by the women in the program.

### **Survey Results**

The 41 women who completed the Health Literacy Screening form ranged in age from 25 to 46, with the majority being in their 30s. The highest grade in school

completed by the respondents ranged from fourth to twelfth grades, and one with an Associates Degree in college. Twenty out of the 41 women indicated they had partially or fully completed high school. The women were given the choice of which language version of the survey to complete; 33 of the respondents filled out the Spanish version of the survey, while 8 completed the English form. Five respondents identified English or Spanish/English as their primary language for reading/writing and speaking; the remainder (36) indicated that they read, wrote, and spoke Spanish as their primary language. I provided verbal information and materials in both English and Spanish, and allowed the women to choose in which language they preferred to learn for a purpose related to evaluating my study outcomes; could a health literacy program offered bilingually to the same group of learners be successful regardless of the primary language of the instructor and students? The women's responses to the health literacy questions are summarized below:

**1. How do you rate your reading ability?**

**First Language:** Very Good: 12 Good: 14 Just OK: 12 Not Good: 3

**English:** Very Good: 4 Good: 8 Just OK: 15 Not Good: 14

**2. How often do you have trouble learning about your medical condition**

**because of difficulty understanding written information or instructions from your doctor?**

Always: 2 Often: 11 Sometimes: 10 Never: 18

**3. How confident are you filling out medical forms by yourself?**

Very Much: 10 Somewhat: 12 A Little Bit: 14 Not at All: 5

**4. How confident do you feel you are able to follow directions to take medications correctly?**

Very Much: 24 Somewhat: 8 A Little Bit: 5 Not at All: 4

**5. How often do you have someone help you read medical information?**

Always: 2 Often: 10 Sometimes: 14 Never: 15

I made several observations in examining the womens' individual responses on the Health Literacy Screening form. There was not a clear connection between educational level and self-rated reading ability; i.e., the respondents who rated their reading ability as less than very good or good were high school graduates. There was a significant difference between how the women felt they could read in Spanish versus English; while 63 percent rated their reading ability as very good or good in their primary language, that rate dropped to 29 percent in English, with 29 out of 41 rating their ability as just OK or not good. I concluded that any written information that was not provided in their primary language could likely be misunderstood by 70 percent of these women, supporting the need for linguistically appropriate instruction materials. Although more than half of the respondents felt confident in their Spanish reading ability, that still left 37 percent ranking in the lower two categories, at risk for misunderstanding written information in their primary language. The question itself was a broad assessment of reading ability, and did not necessarily evaluate any degree of facility with health, illness, or medical jargon.

The question in which the women rated most highly was the ability to follow directions taking medication correctly. I mistakenly assumed these answers would

correlate with reading ability. This difference might actually be due to the now prevalent trend of bi- or multi-lingual labeling on over-the-counter medications (although, I am not aware that this is the case with prescription drugs, unless the pharmacy itself serves predominantly Hispanic patients). This again, is a general question about one's confidence in taking medication, and not an evaluation of actual competence.

The questions that asked about difficulty understanding medical information from the doctor (#2), and needing help reading medical information (#5) rated comparably. Twenty-three of 41 respondents identified some degree of difficulty learning about medical conditions due to misunderstanding information from the doctor (56 percent), while 26 of 41 needed some degree of help reading medical information (63 percent). These questions were related in that they both evaluated prose literacy; I expected that individuals who had trouble understanding the doctor's information might also need help reading medical literature. More than half the women (29) scored themselves below the highest level in these areas, and of those, 32 percent were below level two in understanding information about their condition, and 29 percent below level two in needing help reading medical instructions. I had previously determined that scores below the midpoint option of any question would indicate a significant deficiency in health literacy. I speculated that these deficits were related not only to literacy (reading) level, but also to linguistic and cultural barriers in the healthcare encounter when providers do not alter their approach to information relative to the population they serve.

The question on which the women scored lowest was #3: "How confident are you filling out medical forms by yourself?" Thirty-one of the 41 respondents (76 percent)

were less than confident filling out forms, with 46 percent of those scoring below the midpoint and therefore significantly deficient in this task. This question evaluated competency in both document and quantitative (numerical) literacy, but would also require prose skills for individuals to succeed in the task. The implications of deficits in such skills cut across a range of healthcare-related aspects; individuals having difficulty reading and understanding about their health conditions, and information provided by their doctor would most likely be ill-equipped to make adequate decisions about improving their health, including when and how to seek care. Further, feeling confused or unable to complete forms and documents could surely impede their navigation of the healthcare system and access to resources. The women in the class were by and large the primary caregivers for their family and children, so it is reasonable to assume that these obstacles would impact health outcomes of entire families in the community.

The results yielded by the Health Literacy Screening of my participants helped me to determine how best to proceed with teaching class. The screening was the first step in my audience assessment, which continued throughout the teaching/learning encounter. Of the 41 women who completed the screening form, 61 percent rated themselves as having some degree of difficulty in the areas of evaluation, and 33 percent scored below the midpoint on the overall scores of the screening tool, indicating health literacy deficiency in reading, understanding, writing, and communicating about medical information. I am confident that the women scored the questions accurately and comprehended all aspects of the Informed Consent form they signed; the face-to-face encounter between myself

and the women during the process allowed me to clarify meaning and explore any queries from either side in depth with linguistic and cultural authenticity.

The designated setting for the classes was the lunch room and general purpose area of the Oasis building at 59 Mill Street in Paterson; the space was large, open and bright, and could comfortably accommodate up to 100 people. Seating was arranged around tables that would provide space for participants to use their class materials and the opportunity to work in groups. An ample sized screen across the front wall of the room was easily visible from all vantage points and would create a focal point for the students and an area from which I could address them. With the number of attendees anticipated to be over 40, the classrooms were not big enough to allow a comfortable arrangement that would facilitate the women interrelating in groups. I wanted to be able to walk among the students as I spoke with them to integrate myself into the group and engage them in the process. This area was also a comfortable space for the students; they shared meals together and participated in various social events in the lunch room. I thought that such a setting would be less intimidating than a formal classroom, and would put the women at ease to converse. Creating a comfortable learning environment is an essential step in the instructional process, and this room was physically accommodating, with good visual and acoustic qualities, and familiar to the participants as a venue for positive social interaction.

### **Lesson Planning**

I began by developing an outline of the components needed to design my health education program. My intent was to provide a framework in which the learners could

gain knowledge about health issues through participatory methods. I believed that a group-based problem-solving approach would encourage the learners to be critical thinkers about health issues, facilitating ongoing learner participation and input. The elements of my program are described and summarized below.

### **Participants of the Program**

An assessment of the intended learners should be the first step in designing an education program. Assessment of the learner focuses on four determinants of learning (Haggard, 1989):

1. Characteristics of learners' - demographics, traits, including cultural considerations
2. Learning needs - what the learner needs and wants to learn
3. Readiness to learn - when the learner is receptive to learning
4. Learning style - how the learner best learns

Assessment of learning needs starts with identifying the learner's demographic data such as age and gender, socioeconomic, and cultural characteristics. Participant data were collected prior to the actual planning of the program to paint a picture of the population that I would be working with. Education and income, termed "correlates of health" by public health researchers Stanhope and Lancaster (2009, p. 405), were found to have a direct effect on an individual's ability to maintain optimal health, either through issues of access, or knowledge and awareness. Cultural characteristics of a population are relevant, not just in terms of primary language spoken, but also of health beliefs and



practices, and health issues and risks prevalent in a given ethnic group, as discussed in Chapter 2.

In addition to collecting data about the learners, I sought to generate data from the learners themselves, as they are usually the best source of needs assessment information about themselves. Elements of social cognitive and group learning theory (Chapter 3) suggest that engaging learners in defining their own health issues and learning needs should motivate their participation by investing them in planning for a program specific to their interests. Also, the learner can be a valuable source of information about cultural health perceptions and beliefs. Haggard (1989) described various methods used either singly or in combination to yield reliable information on learning needs. The methods I chose were interview, questionnaire, and pre- and post-testing. I used the information obtained from my pre-class screening and question forms to prepare linguistic and literacy appropriate teaching resources. Through informal conversations with the women in my early visits prior to starting the program, I explored topics they wanted to learn about, and their cultural attitudes about health and illness, traditional practices, and healthcare system experience.

I considered that collecting socio-cultural data from the women themselves was necessary to identify factors which might mediate the relationship between health literacy and optimal health outcomes. Depending on the specific health behavior and outcome of interest, numerous other mediators could potentially influence how learning new information might stimulate health behaviors on the part of the women. Perceived

effectiveness of the behavior, motivation, self-efficacy, fatalism, and decision-making skills were learner attributes I would need to assess.

It quickly became clear to me that family, religion, and health beliefs were important cultural influences for these women. Valuing the family over the individual was a consistent theme among them. Although many of the women lived in a traditional patriarchal family structure, they described their role as being responsible for the health and care needs of their husband and children. Family relations emerged as a framework in which I might motivate behavior change; I presented the idea that developing better health habits would benefit the family and provide a better example for their children. Thus, the women might be persuaded to alter a high-fat diet or increase their level of physical activity out of a sense of duty to their children. The extended family was often involved in assisting with health decisions and care, so I was careful to reference all extended family caregivers in my class discussions and encouraged the women to share the information from class with them, for their benefit and approval. The collectivistic culture of the participants emphasized shared responsibility, harmony and cooperation within the group and created an ideal context in which the women could succeed in class learning activities.

The women in this group were predominantly Hispanic-Catholic, and as such, their health beliefs and practices were shaped by deep-seated spiritual tradition. They regularly petitioned iconic figures such as Jesus and the Blessed Mother with prayer, and followed various Catholic rituals that they believed would bestow God's favor upon them and their families. A few of the women described actual altars to Jesus and the Saints that

they kept at home; shrines with figures of deity and candles to light in seeking God's help or blessing. This external locus of control, the belief that higher powers, as opposed to the individual, control life events and destiny, necessitated that I explore with the women how they might attribute lifestyle behaviors and situational factors to the state of their health. I also employed a "God helps those who help themselves," or "God has provided the opportunity for you to learn so that you can help your family" approach in an attempt to motivate them towards achieving self-efficacy. Although the women routinely sought care in the mainstream healthcare system, many also embraced traditional cultural beliefs such as illness resulting from an imbalance of humors within the body, requiring either hot or cold, and dry or wet remedies to correct the balance. For example, to correct an imbalance, one would consume food or herbs with the opposite quality of the illness; "cold" conditions are treated with "hot" food or medications. Empacho, a form of upset stomach, was explained to me by one woman to be caused by eating the wrong food at the wrong time of day. The most common treatment for empacho is to rub the stomach or back gently with cooking oil and sometimes pinch the spine. Through conversation with the women I also learned about the role that emotions played in the development of certain illnesses. Envidia, or envy, can cause illness or bad luck, while Susto, (translated as fright sickness) can happen after a traumatic experience, resulting in anxiety, depression or insomnia. By recognizing the cultural context of the illness beliefs and practices of my audience, I could accommodate their traditions into my teaching and proposed interventions. While endorsing their traditional remedies for various infectious illnesses, I could encourage them to combine appropriate medications with the treatment

to strengthen the curative effect. I believe that understanding the broader context of their everyday life experiences, informed my culturally relative encounters with these women and promoted their trust and acceptance of me. It became my goal to have the women feel as though I developed my teaching program with them and their families in mind.

Lichtenthal (1990) stressed that no matter how much an instructor feels the learner needs the information being provided, if the learner is not ready, then the information will not be absorbed. He used the acronym PEEK to identify elements of four types of readiness to learn:

1. **P** - Physical readiness: ability, complexity of the task, environmental effects, health status, gender.
2. **E** - Emotional readiness: anxiety level, motivation, frame of mind, developmental stage.
3. **E** - Experiential readiness: past failures and successes, cultural background, locus of control, orientation.
4. **K** - Knowledge readiness: present knowledge base, cognitive ability, learning and reading disability (including literacy level), and learning style.

Once I collected and reviewed data about my audience of learners, I could apply that information to make decisions related to their readiness to learn. For example, length of classes and nature of assignments, grade-level of content, stress-reducing and positive reinforcement strategies, set-up of the room, cultural sensitivity and presentation of information in the primary language spoken were planned to stimulate the optimal level of readiness in participants.

Understanding how someone likes to learn and learns best helps the instructor select appropriate teaching approaches. Through observation, questionnaires, or just asking a question such as “how do you learn best?” I could ascertain how the learners would comprehend and retain information. My review of the literacy screening forms as well as my conversation with participants and volunteers during the informed consent process led me to believe that visual and aural styles of instruction would enhance interpretation and retention of written material by learners, and that group activities would stimulate them to participate in class and share information with each other. Thus the crucial first step of assessing my audience proved essential to developing the framework of my project.

### **Objectives**

As opposed to educational or instructional objectives, I chose to focus on *behavioral objectives* to guide the development of my program. With behavioral objectives, also known as *learning objectives*, the modifiers “behavioral” or “learning” indicate that this type of objective is action-oriented rather than content-oriented, learner-centered rather than teacher-centered, and short-term outcome focused rather than process focused (Morrison, Ross, & Kemp, 2004). In short, behavioral objectives describe exactly what the learner will be able to do after a learning experience. In contrast with a broad or long-term goal, an objective is a single, specific, unidimensional behavior. A behavioral objective is the intended result of instruction, not the process or means of instruction itself. Anderson et al. (2001) stated, “When we teach, we want our students to learn. What we want them to learn as a result of our teaching are our objectives” (p. 3).

For learning success, objectives need to be clearly written, realistic, and learner centered. If objectives are unrealistic, or too difficult to achieve, the learner can become discouraged which interferes with motivation and ability to comply. Another important characteristic of objectives is measurability; there must be a specific way to determine whether the desired behavior has been achieved.

I wrote each week's lesson plan with three simple objectives on which the class content and methods were devised. The program was based on using *What to Do When Your Child Gets Sick* for the first two classes (Mayer & Kuklierus, 2004). An example follows for week one:

At the end of this session the learners will:

- Demonstrate two ways to find topics in the book
- State three topics they can find in the book
- Demonstrate how to use the book to find information they need to know

Upon completing class activities and discussion, participants were asked to demonstrate use of the book, and complete a simple post-test that asked questions about topics covered in class. In this way, their achievement of the learning objectives could be measured.

Behavioral objectives are written relative to a specific domain of learning: cognitive affective and/or psychomotor. The cognitive domain is known as the "thinking" domain; learning in this domain involves the acquiring of information and addresses the learner's intellectual abilities and thinking processes (Eggen & Kauchak, 2012). Teaching methods most often used to stimulate thinking in the cognitive domain include: lecture,

verbal, written and visual tools. The resources I used for learning in the cognitive domain included the IHA books, PowerPoint slides, and interactive tutorials.

The affective domain is known as the “feeling” domain. Learning in this domain increases internalization and commitment to attitudes, beliefs and values. Objectives will involve the learner changing attitudes about certain unhealthy practices or behaviors and an effective strategy to accomplish this is group discussion, and the sharing of ideas and beliefs (Eggen & Kauchak, 2012). I sought to accomplish affective learning through group discussions, where the women would share personal experiences and concerns, and talk about potential barriers to changing health behaviors. The group process itself would also allow the women to encourage and support each other to succeed.

Finally, the psychomotor domain, or “skills” domain involves acquiring fine and gross motor abilities to carry out physical movement, including manipulation of equipment or performing a procedure. According to Eggen and Kauchak (2012), “while intellectual abilities enter into psychomotor learning, the primary focus is on the development of manipulative skills rather than on the growth of intellectual capability” (p. 17). Demonstration by the instructor and reciprocal demonstration by learners is the most common form of psychomotor teaching. Class activities in this domain included practicing how to take a person’s temperature and read a thermometer, as well as completing the interactive tutorial on exercise and learning to use a pedometer. For my program I wrote objectives in all three domains of learning to allow for a variety of experiences best suited to participants’ learning styles.

## Teaching Plan

Once learning objectives were written it was necessary to make clear what the learner was to learn and what the instructor was to teach. The overall goal of improving learners' ability to care for their families and related behavioral objectives were the basis for the development of my teaching plan. Teaching plans can be presented in a number of different formats, but educators Ryan and Marinelli (1990) assert that a complete teaching plan should incorporate the following eight basic elements:

1. The purpose
2. Statement of the overall goal
3. List of objectives
4. Outline of the content
5. Instructional methods used for teaching the content
6. Time allotted for teaching of each objective
7. Instructional resources (materials, equipment, etc.) needed
8. Methods used to evaluate learning

I developed a lesson plan for each week's class using the above format which I reviewed with participants at the beginning of the class. Content was drawn from the previously identified IHA publication *What to Do When Your Child Gets Sick* by Mayer and Kuklierus (2004), and objectives and activities were designed to promote learning in all three domains. The plan for the Week 1 class is displayed below:



## **Lesson Plan: What to Do When Your Child Gets Sick - Week 1**

### **Introduction to Book**

**Time allotted:** 40 minutes teaching time, 20 minutes evaluation and discussion

**Learning Objectives:** At the end of this session the learners will:

- Demonstrate two ways to find topics in the book
- State three topics they can find in the book
- Demonstrate how to use the book to find information they need to know

### **Methods/Materials**

- Lecture, demonstration, interactive class participation, group discussion
- Copies of *What to do When Your Child Gets Sick*
- PowerPoint presentation to accompany information in the book
- Handouts to emphasize teaching points
- Written questions/answers to measure learning
- Written, visual resources provided in English and Spanish
- Verbal instruction provided in Spanish via translator as needed

### **Content**

- Introduce book, purpose of book (*Slide 1*)

- Take a look at what's in the book - review sections and brief explanations

**Activity:** have learners turn to “What’s in the Book” and look at topics. Ask learners to place a check mark next to two topics they want to read when they get home

- Ways to find information in the book (*Slide 2*)
- How to use book to find information on topics you need to know (*Slide3*)

**Activity:** Have learners find following topics - Earache (pg. 46), Sore throat (pg. 63), Sunburn (pg. 134), Head lice (pg. 121).

- Special features that make book easy to use (*Slide 4*)

### **Assessment of Learning**

Learners will write the answer to the following question in class: List four things you would do if your child brought home a note from school stating that some of the children in the class have head lice.

### **Evaluation**

The process of evaluation is described as “...gathering, summarizing, interpreting, and using data to determine the extent to which an action was successful” (Worral, 2012, p. 604). I devised methods to achieve both content and outcome evaluations of my program. *Content evaluation* determines whether the learners actually acquired the knowledge or skills taught to them (Worral, 2012);

my content evaluation methods were related to each specific learning objective and were meant to measure the degree to which the learners achieved those objectives. Referring back to the objectives of Week 1 lesson plan:

At the end of this session the learners will:

- Demonstrate two ways to find topics in the book
- State three topics they can find in the book
- Demonstrate how to use the book to find information they need to know

The content evaluation for this class required students to answer questions by looking up a certain topic in the book and internalizing that information in a way that enabled them to describe the correct action to take in a given situation. If the students were able to answer the questions successfully, they would have achieved the stated objectives by doing so.

Given the nature and amount of new material the learners would be presented, I needed strategies to prevent them from becoming overwhelmed as well as a way to verify that they could both comprehend and retain the information accurately. I was aware not to assume that learners understand just because they don't ask questions, particularly among low-literate and various cultural groups. An often used patient-centered communication approach known as the teach-back method is exceptionally well suited for use with low-literate learners. Also called "closing the loop" or the "show me" method, teach-back confirms that the instructor has explained to the patient what they need to know in a way that they understand. In addition, teach-back also provides an

opportunity for the instructor to correct any misunderstandings and reiterate critical information that was not remembered by the student (Xu, March, 2012).

During a teach-back session, the instructor teaches a concept and then confirms the learners' understanding by asking them to accurately explain the concept back. Based on the response, the instructor can determine how well the learners comprehend and recall the content that has been taught. If a learner has trouble explaining or recalling the material, the instructor will need to repeat, clarify or modify the instruction. With my population of learners, this strategy would also provide the opportunity for me to evaluate the effectiveness of my teaching plan and refine it as needed, simultaneous with the teaching/learning experience rather than later. In addition to having the women respond aloud to the class evaluation questions, I planned to ask open-ended recall questions that might stimulate new behaviors; after the first two classes which were devoted to learning how to use the *What to Do When Your Child Gets Sick* book, I would question the women on what they would do when they got home (where would they keep the book, when would they use it), and who they might show and discuss the book with (family members, caregivers).

The purpose of *outcome* or *summative evaluation* is to determine the effects or outcomes of teaching by summarizing what happened as a result of the education (Worral, 2012). For example, did the student who gained new knowledge or learned a new skill use that information correctly once they went home? My outcome evaluation sought to measure long-term change that would continue after the learning experience, which is related to my general goal of increasing learners' ability to manage and improve health

for their families. I determined that this step would require a follow-up with the learners after an interval of time to evaluate their perceptions of how their behaviors changed as a result of their new knowledge.

### **The Program Week by Week**

In the following sections, I have summarized highlights of the weekly class sessions, noting attendance, participation and interaction of the women, their attention, motivation, and overall state of mind during class activities. I have also described lesson content and teaching/learning methods for each week. The women who signed Informed Consent for the program and completed the Health Literacy Screening Form were given a pre-class questionnaire that they were to complete and bring to the first class (Appendix B), which was intended to identify their health knowledge and behaviors, and topics of greatest concern regarding their children's health. I hoped that beginning our first encounter with a group discussion of what the women had written would serve to "break the ice" and put them at ease sharing ideas about a highly important commonality of their lives—the care of their children. This information would also provide a baseline by which to measure how well they internalized class teaching and developed new behaviors as a result of completing the program. Observing this initial interaction would help me distinguish participant characteristics such as the talkative versus reticent group members, those who were seemingly quick to grasp information as opposed to those who would require repeated reinforcement, and those who displayed confidence and engagement in interactions, compared to those who sat alone somewhat cautiously regarding the goings on around them. I would direct the women into working groups of no more than six,

purposely choosing members who would provide a balance among the traits I observed; talkative mixed with quiet, confident with anxious, hoping that members could build upon each other's abilities for motivation and success.

On our first day of class, volunteers Maria, Evelyn, and I were prepared thirty minutes in advance of the ten o'clock starting time with PowerPoint set up on the screen, seats arranged at the tables facing the screen, with pencil and paper at each seat. We had a pre-printed attendance sheet at the entrance door (names with assigned codes) on a table with copies of *What to Do When Your Child Gets Sick* as well as slide handouts and post-class questions in both English and Spanish. By 10:15 a.m. no one had arrived, and I questioned whether or not our information about class times had been accurately communicated. Maria did not seem at all concerned and smiled, saying "don't worry—that's how we are—always late!" It occurred to me that this cultural domain of time orientation would need to be accommodated and might require that I vary class length to allow for an extra twenty to thirty minutes as needed.

By 10:20 the women had started to file in, some alone and some a few at a time. Not knowing what to expect, many of them looked at the room set up, and me, somewhat hesitantly. I asked Maria and Evelyn, with whom they were familiar, to greet the women at the door as they entered, sign them in and distribute the books and class materials. By 10:30 no one else had arrived, so I decided to start informal discussions to get things underway. Not unexpectedly, the final class attendance when we began was twenty-eight. This represented a 33 percent mortality rate to the initial study population of forty-one, and while disappointing, a 67 percent attendance rate from the initial sample would be

adequate to determine learning and behavior change in those completing the classes.

While I made a point of reinforcing the importance of continuing to come to class to the women, I debated whether or not to give them the books to take home after class as I had originally planned. My fear was that if they got the book to keep after the first class, their motivation to attend subsequent classes might wane. I decided on an approach that might boost self-efficacy, appeal to a sense of community, and recognize the dedication of the women working to meet their duty of caring for their families, which would create a shared vision among them and promote participation in a social learning theory-based process. To accomplish this, we advised the women that those who attended the classes on child care and satisfactorily completed the evaluation questions would receive a certificate of completion and a free copy of the child care book. For the sake of those who might be intimidated by having to be alone in the spotlight, the women would be assigned to groups for discussion and response to the presentation. Working in a group with members of varying degrees of skill could help the less knowledgeable learn from others and achieve a sense of collective success.

The women at first took random seats while I welcomed them and briefly reviewed what would happen over the next four weeks. Maria was the primary translator with me at the front of the room. I asked if anyone had questions, but no one replied. We then started the conversation about what they had written on their pre-class questionnaires again, no immediate response. I called upon one of the women who I had noticed to be more sociable and talkative than the others coming into the class, to share with the rest of the group what she had written about her concerns for her children. She

actually seemed flattered and reacted cheerfully to being picked, giggling to those around her and standing up without hesitation. She told the class that her children were nine and ten, and that her daughter suffered from asthma. This prompted a response from a few others whose children also had asthma, and some of the women began to talk among themselves though not to the class. I was nonetheless encouraged that the women began to feel at ease enough to chat in response to a health issue their children had in common. As the woman standing continued to talk, others became less intimidated by their surroundings and three or four joined the discussion while remaining seated. The women spoke Spanish in a 3:1 ratio to English; they were encouraged to use the language they felt most comfortable with, and Maria ensured that the points of conversation were communicated to those who needed translation.

The discussion of the pre-class questionnaire continued for about ten minutes by which time slightly more than half of the women participated. My strategy to begin our initial encounter with an informal group sharing to establish common objectives proved successful, underscoring the usefulness of social learning theory as a framework for my group process. One of the questions asked the women to tell when and for what reason they last called the doctor and took their child to the emergency room, as well as how confident they felt about finding information and resources to care for their children at home. I collected the completed questionnaires from the women for later evaluation, but from the group discussion I estimated the responses to range between one week and three months for the last visit to the doctor or emergency room. Allergies, red eyes, vomiting, fever, stomach ache, and the flu were described by the women as reasons for the visits.



The majority of the women who spoke said they felt confident about caring for their sick children at home; slightly less so about finding resources to learn more about health. A summary of the responses to the pre-class questionnaire are listed below:

**Ages of Children:** 6 months to 12 years; median age 7.5

**Most Important Health Concerns for Children:** Asthma and allergies, nutrition, high cholesterol, diabetes, high blood pressure, skin problems, weight, eye problems (vision), speech problems, getting hurt, seeing a doctor for a physical

**Last Time You Called Doctor (and Why):** One week to three months ago; average three to four weeks. **Those who gave reasons:** Asthma (2), allergies, vaccine, blood tests, child sick (cold), skin rash on back, fever (4), car accident, physical check-up (4), ear infection, surgery for hernia, red eyes.


**Last Time You Took Your Child to Emergency Room (and Why):** Two weeks to two years ago; average six months. **Those who gave reasons:** Allergies (3), asthma, stomach virus (2), diarrhea (2), broken arm, vomiting (2), flu, fever (5), chest pain, stomach pain, hard stomach.

After I was satisfied that we had established a rapport, I explained to the women that we would help them to get into groups to discuss class information. With the help of Maria and Evelyn who were familiar with the women, I attempted to mix the groups to achieve a balance of varied learner characteristics that I had observed. I explained to the women that in the first class they would be learning how to use the *What to Do When Your Child Gets Sick* book by watching the slides and then finding specific content in the book as a group. I reviewed the learning objectives, what they would be expected to do

after the presentation and approximately how long the class would run. I encouraged them to discuss the information from the slideshow in their group, and ask any questions or offer ideas from their own experience to share with the class. The slideshow was presented in Spanish, as all the women could speak Spanish, even though nine out of the twenty-eight women elected to use the English version of the book. Maria also assisted me in communicating my instructions in colloquial Spanish.

## Three Ways to Find Things in the Book

- **Picture of the body**
- **What's in this book**
- **What's in this book from A to Z**



The figure displays three sample pages from a book. The top page is a body diagram with labels for various parts of the body. The middle page is a table of contents titled 'What's in This Book' with a list of chapters and page numbers. The bottom page is an alphabetical index titled 'What's in this Book from A to Z' with a list of terms and page numbers.

*Figure 4.* Three Ways to Find Things in the Book. Source: The Institute for Healthcare Advancement, La Habra, CA. © 2013.

The slideshow consisted of a total of eighteen illustrated PowerPoint slides which corresponded with the lesson plan and learning objectives for the first class. I divided the presentation into two parts to span the first two weeks. Slides 1 through 10 introduced the book and how it would help the learners, then how to use the book, including how information was organized, and how to find specific topics. This instructional format presented the women with verbal, visual, and tactile stimuli within a social learning setting. A sample of a slide (English version for the reader) is shown below.

The women were attentive throughout the slide presentation; I paused the slides after a topic was covered, such as how to find content in the book, and allowed the women to practice and demonstrate finding a random topic, and recite to the group information on what they had found (teach-back). The women appeared exceptionally engaged in this group activity, even those who had been less outgoing at the start of class; the room was filled with the sounds of voices and laughter as many of the women went through the book and pointed out pages to each other. My volunteers and I circulated throughout the tables to observe and reinforce the demonstration. I sensed that this teaching/learning design was particularly well suited to my audience and offered a context in which the women could gain an increased self-efficacy through a participatory learning process.

Due to the late start time, the class was running over an hour by the time we had reviewed the first nine slides, with accompanying group activities. A few of the women were getting ready to leave, there was a general restlessness in the room and it was obvious that the women's capacities to attend were depleted. As a closing task, I asked

the women to fill out the information page on the inside cover of their books (name, address, emergency contacts and numbers, doctor or clinic number, etc.), and think about where they might keep the book at home. A few volunteered, “near the phone,” “in the bedroom,” but the majority of the women were quick to gather up and file out, returning their books to the table at the front door. As they were leaving I thanked them for their attention and good work and reminded them that we would finish up lesson two next week at which time they would receive a book to take home.

The lesson plan for Week 2 followed through with the rest of the slides on sick child care, safety, and what to do for accidents and injuries.

### **Lesson Plan: What To Do When Your Child Gets Sick- Week 2**

#### **Caring for a Sick Child**

**Time allotted:** 20 minutes teaching, 15 minutes evaluation and discussion

**Learning Objectives:** At the end of this session the learners will:

- List three things they can do to prevent illness in children
- State three signs that a child is sick
- When given an illness, state two things they can do to care for their child at home, and two reasons to call the doctor or nurse

#### **Content**

- What the book will tell you about caring for a sick child (*Slide 5*)
- What you can do to prevent sickness (*Slide 6*)
- Signs that a child is sick (*Slides 7, 8*)

**Activity:** Have learners find section in the book on How to Tell if Your Child has a Fever. Review steps for taking a temperature under the arm with a glass thermometer, then ask learners to read the temperature on the thermometer.

- Important points about over-the-counter medicines (*Slide 9*)

### **Evaluation**

Learners will write the answer to the following questions: Using the book, list two things you can do if your child has a fever. Find the section in the book on diarrhea, and list two reasons to call the doctor or nurse

### **Child Safety**

**Time allotted:** 15 minutes teaching, 15 minutes evaluation and discussion

**Learning Objectives:** At the end of this lesson the learners will:

- State what is the leading cause of injury and death for children over nine months old
- State three common accidents that happen to children
- Identify three safety measures to reduce the risk of accidents for children
- Use the book to find information on what to do for accidents and emergencies

**Content**

- What the book will tell you (*Slide 10*)
- Accidents and children (*Slide 11*)
- Common accidents that happen to children (*Slide 12*)
- Safety tips (*Chapter 1*)
- How to prepare yourself to handle accidents or injury (*Slides 13, 14*)

**Assessment of Learning**

Learners will write the answer to the following:

- Using the book, list two safety tips to prevent burns, and list two safety tips to prevent choking
- What is the first thing you should do if a child spills a cup of hot coffee on his arm?
- What are some signs you see when a cut becomes infected?
- What is the first thing you should do if a child swallows a poison?

**Conclusion**

- Review what was learned in class (*Slide 16*)
- Review what learners should do when they get home (*Slide 17*)
- Review how to find a doctor for your children (*Slide 18*)

Class 2 began much the same way as the previous class, with the women filing in between 10:10 and 10:20 a.m. Compared to the first week, I noticed that most of them

seemed more at ease, interacting with each other and the volunteers as they walked in. I was pleasantly surprised to find that all but one of the women from Class 1 had returned. As they took their seats in their groups, I reviewed what we would be doing in class that day, and asked whether anyone had a question or comment about last week's class or something that may have happened at home. A few women spoke among themselves but seemed reluctant to address the class, so I reassured them that if they had any questions they wanted to ask me or the volunteers, we would be happy to talk with them after class.

We followed the same format as our first class, but since there was no need for introduction time, we were able to follow the lesson plan activities in a timely fashion. The women watched the second half of the slides, with points emphasized by Maria or myself, and we paused after a topic was covered to complete the group discussions. One of the topics covered on the slides was how to take a temperature and read a thermometer. I thought that this would provide a good psychomotor teach-back opportunity for the women, and paused the slides for the exercise. As we went through the steps in the book, I noticed that several of the women were not engaged in the process or paying much attention. I explored what the women knew about reading thermometers and was surprised to hear that the majority of them used "the ones from the drugstore that show the temperature" (digital, or color coded disposables, I assumed). One woman indicated that she was able to tell if her child had a fever by touching him, and a few more agreed. I assessed that regardless of my initial objective, this was clearly not a task the women were interested in learning and moved on.

I expected an increase in class participation this week as the women now knew what to expect in the sessions, but only a handful more were responsive to my questions and comments than in the first class. What I did notice was that even among the quietest women who had not spoken out at all during class, there was considerably more discussion within the groups themselves, largely in Spanish. I was satisfied that while not everyone would participate in at-large class dialogue, my goals for the group learning process were being achieved.

After we finished the slide show and our discussions, I ended by reviewing our learning objectives and asked the women for responses to show whether they had been accomplished. Again, the few verbal students replied, answering questions about how to tell whether a child is sick, when to call the doctor, and common causes of injury to children. I initiated a conversation about how the women felt they would use the book, and who they would share it with; but receiving limited response from the class, I instead directed the women to talk about it with each other, and share ideas about what they had learned. In order to evaluate individual learning, we broke up the groups and distributed the post-class questionnaire (Appendix C) to the women to complete individually, using the book as a reference. This would reinforce how to use the book to look up information on common health issues they might encounter at home; their correct answers would confirm that they had correctly found and understood the content.

This class ran close to ninety minutes and as restlessness began to take hold, we reminded the women that they would receive their copy of the book to take home on the way out when they handed in their completed questions. The women completed the



questions in varying lengths of time and filed out as they finished, handing in their questions to Evelyn at the door, carrying their books with them. Evelyn reminded them to put the book in a handy place at home, to practice looking up topics, and share information with family and other caregivers. About six or seven women remained after the others had left, and Maria and I checked with each of them to make sure they understood the questions and to offer guidance. The women appeared to be having difficulty writing the answers to the questions, though they were able to repeat the questions verbally. To compensate for their deficient writing skills, I asked Evelyn and Maria to help me question the women individually and transcribe their answers as they explained what they looked up in their books. Even though they had trouble with written language, they were able to follow verbal directions and demonstrate how to use the book to answer questions. It occurred to me that recognizing their impaired writing ability and taking the time to assist them to acquire new knowledge in an alternative format might not be a routine practice of providers in a hectic clinical encounter. Twenty-seven women completed the post-class evaluation exercise on the first two classes with the *What to Do When Your Child Gets Sick* book and PowerPoint slides; the results of their learning will be presented in the Findings chapter at the conclusion of this paper.

The learning topic for Week 3 was nutrition; our teaching materials included the NVS label with accompanying questions developed by Pfizer, as previously displayed in Chapter 4 (see Figures 2 & 3). We also presented a slideshow developed by the United States Department of Agriculture (USDA) about reading nutritional labels titled *Read It*

*Before You Eat It*. Although provided in both English and Spanish, a sample slide from the presentation is displayed below in English as Figure 4, for the reader:



*Figure 5. Read It Before You Eat It.* Source: United States Department of Agriculture. (2003, March). *Read It Before You Eat It*. Retrieved from Food and Nutrition Service: <http://www.fns.usda.gov/tn/read-it-you-eat-it>

The most significant feature of Class 3 was the dramatic drop in attendance from the previous two weeks; only fifteen on the twenty-seven women who attended Class 2 came back for Class 3. While disappointed, I was not completely surprised, as Maria had predicted that a lower turnout might occur after the child care classes. She explained that many of the women may have likely perceived an obligation to take part in the program

as well as a curiosity to see what they would do in class. After completing the child care classes, and the novelty of using the book ended, they were satisfied that they had accomplished what they came for and received the book as promised. They were also influenced by the culture of the group and may have decided collectively that it was not necessary to return for the last two classes.

Those women who did attend Class 3 were attentive to the slideshow, but offered little response in the way of questions or comments about the information. They were each given a copy of the slides as handouts to keep and refer back to as needed. We had asked the women the week before to bring in some of their favorite recipes that they made for their families. A few of them had done so and we encouraged them to share and discuss what they thought the health benefits of the meals might be in light of what they had learned from the slideshow. The women seemed more at ease talking among themselves about recipes and preparing meals for their families; this was an area in which they had much self-confidence and cultural familiarity, and I felt this group activity could promote affective and psychomotor transfer of knowledge along with self-efficacy in the learners. Beans were a predominant dietary staple for most of the families, and the women concurred that they were a good source of nutrition (iron, protein, and fiber). A variety of meats were used in cooking, including beef, chicken, and pork. We discussed lean versus fattier meats and asked the women to identify ways of preparing the meats that might reduce calories and excess amounts of fat, sugar or salt to the meal. Although one woman who responded seemed to be aware of the health risks of ingredients such as lard, cream, and sugar cane, she maintained that these recipes were central to traditional

family meals down through the generations. The fundamental significance of food in Hispanic tradition, which permeates the celebration of life events, religious rituals, and remedies for illness, would prove a formidable obstacle to any suggestions for changing authentic recipes. I again enlisted Maria's help to engage the women in casual conversation about her own favorite meals and talk about ways they might substitute healthier ingredients (such as olive oil and spices) that could still add flavor to the dishes while allowing fats and sugar to be removed. The women could identify with Maria and I hoped that they would be more likely to accept new suggestions from someone who understood the cultural significance of traditional cooking. We asked that the women try one of their recipes substituting one of the ingredients they discussed and let the class know how they liked it next week. I was not convinced that all of the women would follow through, but if one or two of them made a healthful menu change that their families enjoyed, the others might consider the possible benefits of trying to do the same.

With the image of the Newest Vital Sign (NVS) food label displayed on the screen large enough to be easily seen by everyone, we started asking the six questions which accompany the NVS (Figure 3). The women were given question forms on which to write their answers (Appendix E). Again, Maria was available to assist those with limited writing skills by listening to their answers to the questions. We put no time limit on answering the questions, but assumed that if any of the women were still struggling with a question after two or three minutes, we would move ahead without prompting so as not to jeopardize the accuracy of the test. We asked the questions in sequence and did not indicate to the women that they had answered correctly or not. According to the NVS

instructions, scoring one point for each correct answer: four or more correct answers would indicate adequate health literacy, a score of two or three would indicate the possibility of limited literacy, while a one or none score suggests a high likelihood (50 percent) of poor literacy (Pfizer, 2008).

All but a few of the women were able to complete the questions within ten to twelve minutes. We collected the forms and reviewed the answers so that the women could verify what they had gotten correct, and understand what they had gotten wrong. The results of their responses are being reported in chapter 6, Findings. When we asked the women how they felt about this exercise, most of them nodded, smiled or offered positive comments; there were three or four women who had not been able to complete the questions, either in writing or verbally, who appeared upset. I did not address any particular individual concerns, but addressed the class as a whole and reassured them that this was not a test that they could pass or fail, but a way of learning new information, and it was not uncommon for students to find the exercise difficult. We ended by providing information about websites in Spanish that they could visit to learn more about healthy foods. The women had mixed demeanors as they left, and we reminded them that the next class on physical activity would be important to attend as it would add to what they had learned about nutrition and help lower their risk for illnesses such as diabetes, which they had identified as a concern. We also told them that they would receive free pedometers and learn how to use them to count their steps each day. I had been informed earlier in the day by Mr. Walsh that our next class would need to be in two weeks, as the agency was using the space for another event the following Saturday. I felt that this might hinder

our continuity but had no recourse, so I stressed that the women make note of the schedule change, and asked Maria and Evelyn to follow up with them over the course of the week.

The fourth class was exceptionally disappointing in that only four women returned from Class 3. I had optimistically purchased twenty pedometers and joked to myself that I most likely jinxed the class by doing so. I couldn't help but think that the two week break between classes contributed to the poor showing, but in reality I had noticed a gradual decline in interest by many of the women since Class 2. It was notable that the women who returned were in fact the most engaged, responsive, and successful students in the program; they had rated well on the Health Literacy Screening form, and scored highly on their post-class evaluation questions in addition to leading group participation. Although data from a class of four would not be quantitatively supportive to my assessment of learning in the original target population, nonetheless my observations about these women supported the theoretical correlation of health literacy, self-efficacy, and an internal locus of control with successful learning outcomes.

We continued on with the class as planned after waiting twenty minutes for more students. Since there were so few of us, I moved to a conventional classroom upstairs which was equipped with audiovisual equipment and Internet access. There was little to note this day in comparison to the previous three classes; the atmosphere in the room was decidedly different, as these women showed no signs of the stress or pressure to succeed that had perturbed many of their classmates in previous weeks. We proceeded through the interactive tutorial on physical activity from Medline Plus in English, as the women

expressed that they were literate in English and felt comfortable with this version. These women had chosen English versions of the book, screening and question forms throughout the program, and had no difficulty with the tutorial or the post-class evaluation (Appendix F). I ended class earlier than usual, as the students were able to complete the work quickly. I distributed the pedometers and we went through the instructions for using them. We set a goal that the women would reach 10,000 steps per day by the end of one month (3,000 is average), and record their steps so that we could evaluate their progress at the one month follow up meeting I had planned for the program.

I had advised the women at the beginning of the program that I would come back to visit them one month after the program and follow up on how and when they were able to use the book and the other new information they had learned. I was also interested to identify any behavior changes they might have adopted as a result of the classes. I reminded the four women who were present for the last class and asked Evelyn and Maria to advise the rest of the women when they saw them during the week. Since there were so few at the last class, I couldn't adequately wrap up and debrief the group as a whole regarding their experiences with the program, so I planned to make that a part of the one month follow-up. As the women left, one or two asked if they could take pedometers home for family members to use, and it occurred to me that these women could also role model behavior for the rest of the group who had not attended. I gave them extra pedometers to take home and asked them if they would assume the task of teaching the rest of the women how to use them when they were next together at lunch or in class. Being assigned this responsibility seemed to please these four students; they

were clearly internally motivated individuals for whom such recognition was in itself a reward. I asked Evelyn and Maria to distribute the rest of the pedometers to the women during the week with every confidence that these few could generate enthusiasm in their fellow learners about the pedometers, hopefully reaching objectives in affective and psychomotor domains that I had been unable to achieve.

In the next and final chapter I will present the findings of the evaluation of learning and my conclusions about the program and follow up with respect to its feasibility for use in other settings.



## Chapter 6

### Findings and Conclusion

#### Evaluating Learning

For the content evaluation of the program, I calculated the results of the post-class questionnaires following each weekly session to determine how effectively the women were able to interpret and internalize the information presented to them that day. The questions on the post-class forms of the first two lessons on child care (Appendix C), correlated with the learning objectives established for those classes; by answering the questions correctly, the women would demonstrate that they were able to use the book to find specific topics; to identify signs of illness in their children, and know how to care for them versus calling the doctor; and to prevent common injuries, and how to respond appropriately to emergencies. With the help of my translators, I reviewed the forms for completeness and accuracy of the answers to the eight questions, which were formulated directly from the content of *What to Do When Your Child Gets Sick*. I set the passing rate at six or more out of eight completely and correctly answered questions (75%).

Twenty-seven women completed the post-class questionnaire with the breakdown of scores as follows:

Eight questions complete and correct: 15 (56%)

Seven questions complete and correct: 6 (22%)

Six questions complete and correct: 4 (15%)

Five or less questions complete and correct: 2 (7%)

Based on these results, I concluded that learning outcomes had been met for 93% of the women in the classes on child care, with 56% of those achieving a perfect score.

Although Maria and I made ourselves available to interpret and clarify the questions as needed, we provided no assistance to the women in finding the actual answers to the questions. Since the questions were somewhat open-ended, requiring the women to write short answers as opposed to a multiple choice format, I considered an answer correct if it satisfied the intent of the question, and was clearly obtained from the book content. For example, in response to the question “What are some signs that a cut has become infected?” I construed that a reply of “it has white on it and hurts if you touch it” referred to the description of purulent discharge (pus) and painful inflammation found in the book. While it was not clear why two of the women were unsuccessful in correctly answering at least six questions, I suspected that they had difficulty with writing the answers, as several of the answers were incomplete, trailing off after a few words or left blank.

The post-class evaluation questions for the class on nutrition were taken directly from the worksheet developed by Pfizer to accompany the NVS (Appendix E) to meet the learning objectives for the exercise. Fifteen students completed the six-question form with the following results:

Score of six questions complete and correct: 1 student (7%)

Score of five questions complete and correct: 4 students (27%)

Score of four questions complete and correct: 5 students (33%)

Score of three questions complete and correct: 5 students (33%)

According to the thresholds set by Pfizer, 33% of the women's scores fell into the category of limited literacy, while 67% achieved passing scores, indicating adequate literacy and successful content mastery. Since only one student correctly answered all six questions, I looked for a pattern in the responses. All of the remaining students, including those with adequate literacy scores of four and five, incorrectly answered question four, which asked what percentage of a daily caloric intake of 2500 would be consumed with one labeled serving of 250 calories (answer: 10%). The question was either left blank, or answered as 2.5%, 25%, and 250%. I took this finding to indicate that numeracy literacy, within the broader context of literacy adequacy in interpreting and applying health information, still posed a challenge for many of the women.

I decided that the findings from the final class on physical activity would not contribute to a valid content evaluation of the program since the sample in this exercise was extremely small and consisted of the best students, not representative of the entire group. All four women successfully completed the Medline Plus tutorial and answered the evaluation questions correctly. Interestingly, these were the same four women who had high self-rated English literacy proficiency and utilized the English versions of the childcare book and all class materials and evaluation forms.

### **One Month Follow-up**

I planned the post-program follow-up visit for several purposes. I wished to conduct an outcome (summative) evaluation of the health education program by examining what ultimately happened as a result of the teaching. My aim in implementing the program was to help the women gain new knowledge about health behaviors and

apply that information to the care of their families at home. Identifying behavior changes that the women adopted and maintained for at least a month after the learning experience would support my original proposal that culturally congruent education programs designed for learners with low or limited literacy could effectively improve their ability to manage their family's health.

I sought to test the Precaution Adoption Process Model as a paradigm for the learning and behavior processes that learners in similar programs might undergo. The model, explained in detail in Chapter 3, describes stages in which an individual decides to adopt or not adopt a health-related behavior, or whether or not to make precautionary change (Weinstein, Sandman, & Blalock, 2008). I examined each of the seven stages of change in relation to the behaviors of the learners that I observed during the course of the program. Most all of the women began the program at stages 1 and 2; unaware of the need to adopt any new health behaviors, or unengaged by any particular health issue and not considering any action. I identified stage 3 as the point the women had reached as they began the program; they had considered the possibility of action, or learning a new behavior, by consenting to participate in the program, although they had not all demonstrated a firm commitment to learning and acting on new health information.

Stage 3 of the model may be followed by either stage 4 or 5; in stage 4 the learner has decided not to act, while in stage 5, the learner had decided to act, but has not yet taken action. For several of the women in the class, the process had clearly stopped at stage 4, namely those who did not return to all four classes, although all but one did attend and complete the requirements for the childcare classes. It is difficult to know

whether, aside from the desire to learn, the women were motivated by the actual class topics, the promise of a free book, or simply peer pressure to attend these two classes. In any event, those who did attend can be seen as moving to stage 6 in which they acted to engage in the behavior (complete the classes and answer the evaluation questions). Following up with the women after one month would allow me to evaluate how many had proceeded to stage 7, and whether the model would fit as a framework for other similar programs.

My impression is that stage 7, where a new health behavior becomes part of the learner's routine lifestyle, is not only a function of their motivation and ability to act, but also on the interventions of the provider (or educator) during the learning process. By identifying the learner's stage, and offering information and support consistent with their capabilities to help them move through stages, or determining where they needed extra encouragement, I presented a realistic chance for the women to succeed. In particular, using positive reinforcement techniques to raise self-efficacy, and employing social cognitive strategies such as utilizing confident and successful students to help others, did appear to facilitate learning in my classes and would be elemental to an instructor's role in this type of program.

Finally, I felt that meeting with the women a month after the program would provide a good opportunity to debrief, or get feedback from the women on their perceptions of the program, and whether or not it helped them feel better about their ability to improve their health and that of their families. I arranged to meet with them in the lunch room where we had our original conversations and three of the four classes. My

volunteers had advised the women to stay at the end of lunch before afternoon classes so we would hopefully get the majority of the program participants. We were able to have twenty-one of the original students meet with us. I decided that in order to get valid and candid feedback from the women, I would avoid re-creating a “testing” type interaction in which they were given a formal written questionnaire, which might generate the pressure of “right” and “wrong” answers being evaluated, and result in socially desirable responses. Instead, I asked the women if we could talk informally about their thoughts and feelings, a conversational exercise in which they might feel more at ease. I also asked whether they would write in their own words any stories or instances in which they used the book or new information at home (I provided paper and pens). When I asked them to share their feelings about the book and the classes, I made note of some of their comments (translated):

“It is easier to look up things in the book before I called the doctor.”

“I can understand most of it...for watching my grandchild, it has been a lot of years since I had to do this.”

“The pictures make it easy to understand.”

“I wish I had this book before.”

“I remember to look at the food labels now.”

Six of the women volunteered that they had used the book on a regular basis, and checked it first before automatically calling the doctor. Of the women who responded verbally or wrote down their information, the chapters on fever, eyes, ears, nose, stomach,

and skin were most frequently viewed. When asked specifically whether they had read the “When to Call the Doctor” section, eleven confirmed that they had.

I asked the women whether they felt the class on nutrition had been useful, and how they were using that information now. More than half, thirteen women, answered that they have read food labels more consistently, while seven acknowledged that they learned to be more concerned about getting the appropriate amounts of fat, proteins, and carbohydrates into daily meals. I concluded that without having the women record a daily or weekly diet recall, it wouldn’t be possible to determine actual improvements in their nutritional intake, but only which behaviors they had adopted as a result of the class (e.g., reading food labels).

Only two of the women in our follow-up group had attended the last class on physical activity, but since other class members also received pedometers with instructions on daily step goals, I asked the group using the pedometers whether they were counting their steps. Only six women reported that they had tried the pedometers, and none of them indicated they were using them consistently.

I summarized the results of the outcome evaluation with the women’s responses to the following inquiries one month after the program:

1. Did you have a health book at home before starting the class?

Yes: 4 No: 8

2. Have you used the book at home to look up health information?

Yes: 14 No: 7 (5 wrote comments that their children had not been sick)

3. Were you able to use the book instead of calling the doctor?  
Yes: 7 No (called doctor): 5 Other (problem resolved): 2
4. Were you able to use the book instead of going to the emergency room?  
Yes: 4 No (went to ER): 2 Other (not an emergency): 8
5. Do you feel more confident about caring for your child/family's health after the classes?  
Yes: 11 No: 3
6. Have you shared information from the book or class with other family members or friends?  
Yes: 9 No: 5

I interpreted these results as generally favorable regarding the usefulness of the book and the potential impact of the classes on the women's future health behaviors. As opposed to simply handing out the books to the women, I felt that the introduction of health information by an instructor in an interactional setting contributed appreciably to the positive outcome measures, and would be the preferred format for the replication of future programs. The findings of both the content and outcome evaluations of the program led me to conclude that health education similarly designed for at-risk populations could indeed empower individuals in healthcare decision-making for improved outcomes on a personal, family, and even community level as the students are motivated to share that information with others in their social groups.



## **Conclusion and Recommendations**

Throughout this paper, I have examined health literacy as one determining factor of population health outcomes, and in particular, within a cultural context of ethnic minority, limited English proficiency (LEP) group. Comprehensive research findings from government, healthcare, and education sources have consistently pointed to the need to improve the health and literacy of socioeconomically disadvantaged families as a national public health priority. These discussions have also revealed that low or limited health literacy may indeed contribute to the larger concern of health disparities among populations in this country. A social gradient, in which those groups on the lower end of the scale bear a disproportionate burden of poor health outcomes, has been identified to result from a complex web of causality which includes factors such as education, income, race and ethnicity, and knowledge of and access to adequate healthcare resources.

I have also presented culture and language as factors which critically influence the quality and effectiveness of the healthcare individuals receive. Culturally and linguistically incompetent healthcare encounters compound other challenges that ethnic minority and LEP groups might face navigating through the US healthcare system and thus create a formidable barrier to good health for these families.

The aim of my dissertation project was to implement a health education program which I designed specifically to meet the assessed needs of a Hispanic, largely LEP, limited health literacy group of women who I considered to be representative of a larger target population with similar characteristics. I developed my curriculum based on established educational and behavioral theoretical frameworks, while also incorporating

elements gleaned from the literature on health literacy and cultural competence as determinants of successful health outcomes across populations.

Believing that effective interventions to improve health literacy must be targeted not only at the individual, but also group, and system or community levels as well, I planned my program as a first step, small scale effort to achieve individual learning and behavior change that could ultimately be disseminated throughout families and neighborhoods, and at the same time transform health education for those groups similarly disadvantaged. My professional tenets of advocacy and empowerment of vulnerable populations underscored my mission and motivation to achieve successful results.

As described above, my evaluation findings were generally positive; the group of learners, although varied in their pre-screened health literacy and language proficiency levels, largely achieved scores on post-class questionnaires (see above) which demonstrated internalization of new information, and upon the one-month follow-up evaluation reported some degree of maintaining newly learned behaviors.

### **Lessons Learned**

Several factors emerged during the implementation of the program which shaped the basis for a critique of its effectiveness and potential for replication:

- Culture and language proficiency are common determinants among population groups who experience less than satisfactory health outcomes.
- Barriers to successful healthcare interventions in these groups may be due to practical factors such as access, but may also include social factors such as

mistrust due to prior negative experiences or perceived exclusion because of linguistic or cultural differences with providers.

- Education programs specifically designed for low or limited literacy individuals within a culturally appropriate context can facilitate successful learning on basic healthcare issues by creating a connection between the instructor and learners.
- Providers and health educators need not necessarily be bilingually fluent to present such culturally competent programs, provided that they seek out and utilize resources that meet the needs of their learner audience.
- Incorporation of elements of learning and behavioral theory, such as social cognitive theory and group process into program objectives and methods, may also facilitate motivation among learners.

Prior to the program, many of the women in the study indicated that they felt confident caring for their sick children, yet their responses to pre-class screening showed that they did make trips to the emergency room for common health issues such as fever. One month after completion of the education program, more than fifty percent of the women surveyed indicated that they had used the book and information from class to take care of their children, either in place of or prior to calling the doctor or using the emergency room (see findings above). Over sixty percent of the participants also shared the information with family and friends, with the potential for a ripple effect of change beyond the original group of learners.

Another important conclusion is that increasing healthcare knowledge and skill in literacy challenged populations can be best achieved with a combination of learning resources and face-to-face interaction between the instructor and learning group. Herman et al. (2013) cited a Head Start grantee provider who elected not to participate in an educational program and simply distributed the training book and resources to families and staff; measurements of pre- and post-intervention knowledge and behavior for this group showed no change, suggesting that simply distributing written information, even in one's primary language, is likely ineffective.

### **Limitations of the Program**

My ability to evaluate the overall effectiveness of the program was clearly hampered by the attrition of the participants over the last two classes. The critical measurements of pre- and post-class learning and maintenance behaviors is restricted to the first two classes on the care of children at home based on the *What to Do When Your Child Gets Sick* publication, with some useful data from a sample nearly half the size of the original group, from the third class on nutrition. The final class on physical activity was attended by only four, which would provide no statistically significant results.

I considered that the two week gap between the third and last classes may have contributed to an already dwindling interest in the program after the childcare sessions; perhaps I could have requested a change in venue to an upstairs classroom to avoid a break in continuity? It is more likely, however, that as noted, the women seemed less motivated to return after completing the first two classes and receiving their book; their attention span for learning tasks was best suited to two sixty to ninety minute classes with

a consistent theme. While the topics of nutrition and exercise are related to identified health needs for this population, they might be best covered in a separate set of classes, not tagged on to the predominant program topic of child care. As I found in my research, there is no shortage of available resources for low literacy and culturally competent health education; a careful audience assessment should be done to determine an effective format and appropriate length and duration for the classes.

### **Future Study**

This study primarily looked at how empowering parents with new knowledge might ultimately lead to better health outcomes for their families and improved skills in utilizing healthcare resources as one piece towards solving the puzzle of health disparities in our society. Much of the literature also identified the financial impact of poor health literacy on the cost-burdened US healthcare system. Future studies of health literacy education programs which examine cost savings via reduced unnecessary usage of emergency services for routine care would strengthen the cause for the development and implementation of such programs across healthcare settings. Replication of a program such as the one I have presented could be done simply and cost-efficiently with the same resources and personnel so long as there is administrative support from a provider institution and a commitment to improving healthcare outcomes across populations.

To adequately measure the success of achieving cost and quality outcomes of health literacy programs, follow-up evaluations need to be done over time; looking at cost reduction through appropriate use of primary care services, or whether health-related behavior changes have persisted over time might take a year or more to determine. Such

studies would provide even stronger evidence to support the need for culturally competent health literacy education.

While not the sole answer to solving the problem of health disparities in economically disadvantaged, ethnic minority populations in this country, providers who recognize the literacy needs and cultural attributes of their clients can empower them to improve their health by designing specific individual-level interventions which may ultimately contribute to larger scale system and community-level health change.

## Appendix A

### Health Literacy Screening Forms

Respondent Code: \_\_\_\_\_

Age: \_\_\_\_\_

Gender: M \_\_\_\_\_ F \_\_\_\_\_

Race: Latino \_\_\_\_\_ African-American \_\_\_\_\_ White \_\_\_\_\_ Other \_\_\_\_\_

Highest grade in school completed: \_\_\_\_\_

Primary Language: Reading/Writing \_\_\_\_\_ Spoken \_\_\_\_\_

Please check answers below:

1. How do you rate your reading ability?  
In your first language: Very Good \_\_\_\_\_ Good \_\_\_\_\_ Just Ok \_\_\_\_\_ Not Good \_\_\_\_\_  
In English: Very Good \_\_\_\_\_ Good \_\_\_\_\_ Just Ok \_\_\_\_\_ Not Good \_\_\_\_\_
2. How often do you have trouble learning about your medical condition because of difficulty understanding written information or instructions from your doctor?  
Always \_\_\_\_\_ Often \_\_\_\_\_ Sometimes \_\_\_\_\_ Never \_\_\_\_\_
3. How confident are you filling out medical forms by yourself?  
Very Much \_\_\_\_\_ Somewhat \_\_\_\_\_ A Little Bit \_\_\_\_\_ Not At All \_\_\_\_\_
4. How confident do you feel you are able to follow directions to take medication correctly?  
Very Much \_\_\_\_\_ Somewhat \_\_\_\_\_ A Little Bit \_\_\_\_\_ Not At All \_\_\_\_\_
5. How often do you have someone help you read health/medical materials?  
Always \_\_\_\_\_ Often \_\_\_\_\_ Sometimes \_\_\_\_\_ Never \_\_\_\_\_

## ENCUESTA DE SALUD DE ALFABETIZACION

*Respondent Code:* \_\_\_\_\_

Edad: \_\_\_\_\_

Genero: \_\_\_\_\_

Raza: Latino \_\_\_ African-American \_\_\_ White \_\_\_ Otro \_\_\_

Nivel mas alto de educacion terminado: \_\_\_\_\_

Idioma Principal: Lectura/Escritura \_\_\_\_\_ Habla \_\_\_\_\_

Por favor cheque las respuestas abajo:

1. Como usted califica su habilidad para leer?  
Muy bien \_\_\_ Bien \_\_\_ Mas o menos \_\_\_ No muy bien \_\_\_
2. Cada cuanto usted se encuentra con dificultad de entender su condicion medica porque le es dificil entender la informacion escrita o instruida por su doctor?  
Siempre \_\_\_ A menudo \_\_\_ A veces \_\_\_ Nunca \_\_\_
3. Que tan confidente es usted para llenar formularios medicos por su propia cuenta?  
Confidente \_\_\_ Mas a menos \_\_\_ Un poco \_\_\_ Para nada \_\_\_
4. Que tan confidente usted se siente de poder seguir las direcciones para tomar su medicamento correctamente?  
Confidente \_\_\_ Mas o menos \_\_\_ Un poco \_\_\_ Para nada \_\_\_
5. Cada cuanto usted tiene a alguien que le ayude a leer su historia medica o materiales medicos?  
Siempre \_\_\_ A menudo \_\_\_ A veces \_\_\_ Nunca \_\_\_



**Appendix B**  
**Pre-Class Questionnaire**

*Respondent Code:* \_\_\_\_\_

1. What are the ages of your children?

---

2. What are your most important health concerns for your children?

---

---

3. When is the last time you called the doctor about your child? For what reason?

---

---

4. When is the last time you took your child to the emergency room? For what reason?

---

---

5. How confident do you feel about caring for an illness or injury for your child at home?

Very Much \_\_\_\_\_ Somewhat \_\_\_\_\_ A Little Bit \_\_\_\_\_ Not Enough \_\_\_\_\_

6. How well do you know what services in the community you can use to get information or help for your children's health?

Very Well \_\_\_\_\_ Somewhat \_\_\_\_\_ A Little Bit \_\_\_\_\_ Not Enough \_\_\_\_\_

**Cuestionario de la Pre-Clase**

*Respondedor code:* \_\_\_\_\_

1. ¿cuáles son las edades de sus niños?

\_\_\_\_\_

2. ¿cuáles son sus preocupaciones más importantes de la salud por sus niños?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. ¿cuándo es el último tiempo usted llamado el doctor about your child (por qué razón)?

\_\_\_\_\_  
\_\_\_\_\_

4. ¿cuándo es el último tiempo que usted llevó a su niño al cuarto de emergencia (por qué razón)?

\_\_\_\_\_  
\_\_\_\_\_

5. ¿cómo confidente usted se siente sobre cuidar para una enfermedad o lesión para su niño en el hogar?

Mismo Much \_\_\_\_\_ Somewhat \_\_\_\_\_ Un Pequeño Bit \_\_\_\_\_ No Enough \_\_\_\_\_

6. ¿usted sabe cómo bien qué servicios en la comunidad usted puede utilizar para conseguir la información o para ayudar para salud de s de sus niños'?

Mismo Well \_\_\_\_\_ Somewhat \_\_\_\_\_ A Little Bit \_\_\_\_\_ No Enough \_\_\_\_\_

## Appendix C

### Post-Class Evaluation

*Respondent Code:* \_\_\_\_\_

1. List four things you would do if your child brought home a note from school stating that some of the children in the class have head lice.

---

---

2. Using the book, list two things you can do if your child has a fever.

---

---

3. Find the section in the book on Diarrhea and list two reasons to call the doctor or nurse.

---

---

4. Using the book, list two safety tips to prevent burns.

---

---

5. List two safety tips to prevent choking.

---

---

6. What is the first thing to do if a child spills a cup of hot coffee on his arm?

---

---

7. What are some signs you see when a cut becomes infected?

---

---

8. What should you do if your child swallows a poison?

---

---

**Cuestionario de la Poste-Clase**

*Respondedor Code:* \_\_\_\_\_

1. Cosas de la lista cuatro que usted haría si su niño trajo a hogar una nota de la escuela que indicaba que algunos de los niños en la clase tienen piojos principales.

---

---

2. Con el libro, enumere dos cosas que usted puede hacer si su niño tiene una fiebre

---

---

3. Encuentre la sección en el libro en razones de la diarrea y de la lista dos de llamar al doctor o a la enfermera

---

---

4. Con el libro, enumere dos extremidades de seguridad para prevenir quemaduras

---

---

5. Extremidades de la seguridad de la lista dos a evitar el estrangular

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6. ¿Cuál es la primera cosa a hacer si un niño derrama una taza de café caliente en su brazo?

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7. ¿Cuáles son algunas muestras que usted ve cuando un corte se infecta?

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8. ¿Qué debe usted hacer si su niño traga un veneno?

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## Appendix D

### Course Advertising Flyers

# Important Notice of Health Program

A Health Literacy Workshop will be held at Oasis on Saturdays beginning in March (schedule to be determined)

There will be four classes, from 10:00 - 11:30 AM.

Topics will include:

- How to care for your children when they are sick, and how to prevent illness
- Good nutrition and how to read food labels
- Physical activity and exercise

Classes will be taught by Elizabeth Stallings RN

All participants will receive a free copy of a book on child care—books and class information will be provided in English and Spanish

Please notify Mr. Walsh if you would like to attend so we can buy the books we need

## **AVISO IMPORTANTE DEL PROGRAMA DE LA SALUD**

Un taller de la instrucción de la salud será sostenido en el oasis el sábado que comienza en marcha (el horario que se determinará)

Habrán cuatro clases, de 10:00 - 11:30 AM.

Los asuntos incluirán:

- Cómo cuidar para sus niños cuando son enfermos, y cómo prevenir enfermedad
- Buena nutrición y cómo leer etiquetas del alimento
- Actividad y ejercicio físicos

Las clases serán enseñadas por Elizabeth Stallings RN

Todos los participantes recibirán una copia libre de un libro en los libros del cuidado de niño y la información de la clase será proporcionada en inglés y español

Notifique por favor a Sr. Walsh si usted quisiera atender así que nosotros podemos comprar los libros que necesitamos

## Appendix E

### Newest Vital Sign

#### Nutrition Evaluation Form Ice Cream Food Label Activity/

*Respondent Code:* \_\_\_\_\_

Directions: This information is on the back of a container of ice cream. Use the ice cream food label on the previous page to answer the following questions.

This paper will be collected after you have answered the questions. Thank you!

1. If you eat the entire container, how many calories will you have eaten?

Answer: \_\_\_\_\_ calories

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how many cups of ice cream could you have?

Answer: \_\_\_\_\_ cups

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer: \_\_\_\_\_ grams of saturated fat

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer: \_\_\_\_\_ percent

5. Pretend that you are allergic to the following substances: Penicillin, Peanuts, Latex Gloves, and Bee stings.

Is it safe for you to eat this ice cream? Circle: YES / NO

Answer: Why it is or is not safe to eat this ice cream?

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**Formulario De Evaluación Nutricional  
Actividad De Etiqueta Nutricional De Helado**

*Respondent Code:* \_\_\_\_\_

Intrucciones: Esta información está en la parte de atrás del recipiente del helado. Utilice la etiqueta del helado en la página anterior para que pueda responder las siguientes preguntas. Este papel se recogerá después de contestar las preguntas. ¡Gracias!

1. Si usted se come todo el contenido de helado, Cuantas calorías se va a comer?  
Respuesta: \_\_\_\_\_ calorías
  
2. Si se les permite comer 60 gramos de carbohidratos cuando se sirva, cuantas tazas de helado usted puede comer?  
Respuesta: \_\_\_\_\_ tazas
  
3. Su doctor le recomienda que reduzca la cantidad de grasas saturadas en su dieta. Usted usualmente tiene en sus alimentos 42 gramos de grasa saturada cada día, cual incluye una porción de helado. Si usted para de comer helado, cuantos gramos de grasa saturada usted va a consumir cada día?  
Respuesta: \_\_\_\_\_ Gramos de grasa saturada
  
4. Si usted por lo normal se come 2,500 calorías al día, que porcentaje de su valor diario de calorías usted se va a comer en una porcion ?  
Respuesta: \_\_\_\_\_ porcentaje
  
5. Haga de cuenta que usted es alérgica(o) a las siguientes sustancias: Penicilina, Maní, Guantes de Látex, y las picaduras de abeja.  
Usted cree que es sano comerse este helado?      Circule: SI / NO  
Responda por que es o no es sano comerse este helado?

\_\_\_\_\_  
\_\_\_\_\_



## Appendix F

### Physical Activity Questionnaire

Respondent Code: \_\_\_\_\_

1. How many minutes of physical activity should adults get every day?

\_\_\_\_\_

2. Exercise that increases your heart rate is called (circle one):

- Aerobic
- Weight training

3. State 3 examples of aerobic exercise:

\_\_\_\_\_  
\_\_\_\_\_

4. State 3 ways you can become more physically active during your day:

\_\_\_\_\_  
\_\_\_\_\_

5. What kinds of daily exercise activities will you start after learning this information?

\_\_\_\_\_  
\_\_\_\_\_

6. State 2 reasons that children may become overweight:

\_\_\_\_\_  
\_\_\_\_\_

7. State 2 health problems overweight children can develop in their lives:

\_\_\_\_\_  
\_\_\_\_\_

8. State 3 ways you will help your child keep a healthy weight:

\_\_\_\_\_  
\_\_\_\_\_

## Preguntas De Actividad Fisica

*Respondent Code:* \_\_\_\_\_

1. Cuantos minutos de actividad fisica deben los adultos conseguir diarios?

\_\_\_\_\_

2. Ejercicio que aumenta su ritmo cardiac (circulo uno):

- Aerobio
- Eentrenamiento de pesa

3. Indique tres ejemplos de ejercicio aerobio:

\_\_\_\_\_  
\_\_\_\_\_

4. Indique tres maneras que usted puede hacer mas fisicamente activo durante su dia:

\_\_\_\_\_  
\_\_\_\_\_

5. Que clases de actividades diarias de ejercicio usted va a comenzar despues de aprender esta informacion?

\_\_\_\_\_  
\_\_\_\_\_

6. Indique dos razones que los ninos pueden hacer gordos:

\_\_\_\_\_  
\_\_\_\_\_

7. Indique dos problemas de salud en que ninos gordos pueden tener en sus vidas:

\_\_\_\_\_  
\_\_\_\_\_

8. Indique tres maneras que usted ayudara a su nino a mantener un peso sano:

\_\_\_\_\_  
\_\_\_\_\_

## Appendix G

### Health Education Program Consent Form

*Respondent Code:* \_\_\_\_\_

Principal Investigator:  
ELIZABETH STALLINGS  
XXX-XXX-XXXX

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#### INTRODUCTION

You are invited to take part in a research study which involves an education program on various topics related to you and your children's health. The purpose of the research is to find out whether this program increases your knowledge about health issues and improves your family's health now and in the future. We are also interested in knowing what concerns you have about improving your family's health. We ask that you read this form and ask any questions you may have before agreeing to attend the program. The program and all materials will be provided in both English and Spanish.

#### DURATION

The program will consist of four one-hour classes. All classes are on Saturday mornings at 10:00-11:00 a.m. and will be held in the dining room at Oasis.

#### PROCEDURES

If you participate in this program, we will ask you to complete a short questionnaire before the classes begin. We may also ask you to provide information after the program finishes to see whether it helped you learn new information.

#### CONFIDENTIALITY

All information you provide will be kept confidential. Your identifying information will not be used for any purposes outside the program. If the results of this program are published or presented, no information will make it possible to identify participants.

#### RISKS/BENEFITS

This program poses few or minimal foreseeable risks to the mental or physical well-being of participants.

The benefits of participation include learning new information that will help you keep your children healthy and safe, and care for them at home when they are sick, as well as knowing when to call the doctor and seek medical care.

#### VOLUNTARY NATURE OF THE STUDY

If you decide to participate in this program, you are free to withdraw at any time without penalty. However if you do participate in the program, we hope that you will attend all sessions, arrive on time, and follow up with any instructions given in the classes.

If you have questions or concerns regarding this program and would like to speak with someone, you may contact the program instructor Elizabeth Stallings at xxx-xxx-xxxx or researcher@hotmail.com.

If you have questions or concerns regarding this study and would like to speak with someone other than the instructor, you may contact Dr. William Rogers of the Drew University Institutional Review Board at IRB@drew.edu or by phone at xxx-xxx-xxxx.

#### STATEMENT OF CONSENT

This program has been explained to me and my questions have been addressed. I understand that my participation is voluntary and that I may withdraw at any time without penalty.

Participant signature \_\_\_\_\_ Date \_\_\_\_\_

## Forma Del Consentimiento Del Programa De La Educación De Salud

*Introducción Code:* \_\_\_\_\_

Investigador Principal:  
ELIZABETH STALLINGS  
XXX-XXX-XXXX

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A le invitan que participe en un estudio de la investigación que implique un programa de la educación sobre los varios asuntos relacionados con usted y su salud de niños. El propósito de la investigación es descubrir si este programa aumenta su conocimiento sobre ediciones de la salud y mejora la salud de su familia ahora y en el futuro. También estamos interesados en saber qué preocupaciones usted tiene sobre mejorar la salud de su familia. Preguntamos que usted lee esta forma y hacemos cualquier pregunta que usted pueda tener antes de acordar atender al programa. El programa y todos los materiales serán proporcionados en inglés y español.

### DURACIÓN

El programa consistirá en cuatro clases de una hora. Todas las clases son el las mañanas en 10:00 - 11 de sábado: 30, y serán sostenidos en el cuarto que cena en el oasis.

### PROCEDIMIENTOS

Si usted participa en este programa, pediremos que usted termine un cuestionario corto antes de que las clases comiencen. Podemos también pedir que usted proporcione la información después de que el programa acabe para considerar si le ayudó a aprender la nueva información.

### SECRETO

Toda la información que usted proporciona será mantenida confidencial. Su información que identifica no será utilizada para ninguna propósitos fuera del programa. Si los resultados de este programa se publican o se presentan, ninguna información permitirá identificar a participantes.

### RIESGOS/BENEFICIOS

Este programa plantea pocos o riesgos previsibles mínimos al bienestar mental o físico de participantes.

Las ventajas de la participación incluyen la nueva información que aprende que le ayudará a mantener a sus niños sanos y seguros, y el cuidado para ellos en el país cuando son enfermas, así como saber cuándo llamar al doctor y buscar asistencia médica.

#### NATURALEZA VOLUNTARIA DEL ESTUDIO

Si usted decide participar en este programa, usted está libre retirarse en cualquier momento sin pena. Sin embargo si usted participa en el programa que esperamos que usted atienda a todas las sesiones, llegue en tiempo, y carta recordativa con cualquier instrucción dada en las clases.

Si usted tiene preguntas o preocupaciones con respecto a este programa y los quisiera hablar con alguien, usted puede entrar en contacto con los Elizabeth Stallings del instructor del programa en xxx-xxx-xxxx o researcher@hotmail.com.

Si usted tiene preguntas o preocupaciones con respecto a este estudio y los quisiera hablar con alguien con excepción del instructor, usted puede entrar en contacto con a Dr. Guillermo Rogers del dibujo a comité examinador institucional de la universidad en IRB@drew.edu o por el teléfono en xxx-xxx-xxxx.

#### DECLARACIÓN DEL CONSENTIMIENTO

Este programa se ha explicado a mí y cualesquiera de mis preguntas se han tratado. Entiendo que mi participación es voluntaria y que puedo retirarme en cualquier momento sin pena.

Signatura del participante: \_\_\_\_\_ Fecha: \_\_\_\_\_

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