6-2016

Effect of an Internet-Based Education Program on Self-Care Agency in People Living with Human Immunodeficiency Virus

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EFFECT OF AN INTERNET-BASED EDUCATION PROGRAM ON SELF-CARE AGENCY IN PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS

by

Darcel Maria Reyes

A dissertation submitted to the Graduate Faculty in Nursing Science in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York 2016
EFFECT OF AN INTERNET-BASED EDUCATION PROGRAM ON SELF-CARE AGENCY IN PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS

By
Darcel Maria Reyes

This manuscript has been read and accepted by the Graduate Faculty in Nursing in satisfaction of the dissertation requirement for the Degree of Doctor of Philosophy

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THE CITY UNIVERSITY OF NEW YORK
Abstract

EFFECT OF AN INTERNET-BASED HEALTH EDUCATION PROGRAM ON SELF-CARE AGENCY IN PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS

by Darcel M. Reyes

Advisor: Dr. Kathleen M. Nokes

Both low health literacy and insufficient electronic health literacy (ehealth) impede access to reliable internet health information for people living with chronic illnesses such as HIV/AIDS. Use of reliable internet health information has been shown to improve self-care through increased understanding of symptoms, disease processes, and improvements in adherence with treatment plans.

This study examined the effectiveness of two interventions that taught people living with HIV/AIDS (PLWH) how to recognize reliable internet based HIV health information. Orem’s Self-Care Theory was the framework for this quasi-experimental study that used a non-equivalent two-group design with two experimental interventions (MEDLINE and E-HELP). Participants (N=100) in both interventions watched the NLM video, Evaluating Internet Health Information, and completed an at-home assignment that consisted of navigating to an HIV health information website and identifying the six criteria of a reliable internet health information website as described on the video. The E-HELP group (n=50) received a teach-back session averaging about 12 minutes with an expert clinician. Participants in both groups returned one week later to demonstrate their ehealth. HIV health literacy, electronic health literacy, and ability to identify reliable internet health information were measured before and after the interventions and one week later; self-care agency was measured before the interventions and one week later.
The mixed model procedure, a Generalized Linear Modeling technique, was used to account for the longitudinal nature of the data. The mixed procedure allows for the modeling of the covariance structure to account for this correlation of the same subject responses. A restricted maximum likelihood approach (REML) was used and the covariance type was unstructured since we were not imposing any constraints on the values. A full model was fitted first for all study variables and included the basic conditioning factors of age, gender, race, ethnicity, education, and AIDS diagnosis. Model fitting was repeated eliminating the non-significant variables with the exception of time and the interaction of time and group. The independent variables (HIV health literacy, ehealth, and ability to identify reliable internet health information) were loaded to determine the effect of the intervention on the dependent variable, self-care agency.

Some differences were found in basic conditioning factors. Non-Hispanics had significantly more self-care agency compared with Hispanics (207.98 vs. 183.36, \( p = .000 \)); this may be related to English proficiency, acculturation, and cultural factors. Younger age was significant for HIV health literacy \( (p = .020) \), ehealth \( (p = .001) \), and ability to identify reliable internet health information \( (p = .024) \) which is consistent with previous research. Women had significantly better HIV health literacy compared to men \( (p = .039) \).

No significant within group differences for self-care agency were found for either the MEDLINE group \( (p = .780) \) or the E-HELP group \( (p = .631) \). Participants may have needed more than one session of either intervention to produce an increase in self-care agency, or there may not have been adequate time between the two sessions of either intervention to produce increases in self-care agency. Results of this study did not provide sufficient evidence that, within the scope of Orem’s theory of self-care agency, health literacy is a foundational capability or that
EHealth and ability to identify reliable internet health information are constituents of power component #7.

There were no significant differences in scores between groups for HIV health literacy ($p=.748$), eHealth literacy ($p=.308$), ability to identify reliable internet health information ($p=.259$), and self-care agency ($p=.887$). Possible reasons for the lack of significant difference between the two intervention groups include the short time between sessions, participants’ limited access to computers, and a preference for information from healthcare providers. In addition, the interventions may not have been sufficiently different to produce significantly different results.

There were, however, significant within group improvements from baseline to the final session in HIV health literacy (MEDLINE: $p=.005$; E-HELP: $p=.045$), eHealth (MEDLINE: $p=.003$; E-HELP: $p=.000$), and ability to identify reliable internet health information (MEDLINE: $p=.000$; E-HELP: $p=.000$), which indicates that some components of the interventions made a difference.

Participants’ demonstration of eHealth skills belied the lack of difference between groups on electronic health literacy and ability to identify reliable internet health information. Scores on the at home assignment, which required participants to navigate to an HIV health-related website, then find and identify the six website reliability criteria, were higher for the E-HELP group (received the teach-back session) compared with the MEDLINE group that just watched the video. When the investigator observed the participant find an HIV health-related website and identify the six website reliability criteria, there was an increase in eHealth for the E-HELP group compared to a decrease in eHealth for the MEDLINE group. Although further testing and refinement of the interventions are needed, evidence from this study indicates that either
intervention may be a low cost and effective means to teach people how to identify reliable internet health information for self-care.

Keywords: People living with HIV, HIV, health literacy, electronic health literacy, internet health information, reliable internet health information, self-care agency
I would like to thank those who walked with me on this journey. It is because of their love, support, and encouragement that I have made it to this final destination.

To my husband, Francisco (Ray) Reyes, thanks for always believing in me even when I did not believe in myself. Your wisdom always sustains me. To my daughters, Amy and Clara, who motivate me to work each day to leave them a better world. Ray, Amy, and Clara, you are my greatest treasures.

I owe a debt of gratitude to my parents. My father, who told me stories when I was a little girl about Miss Leta, a nurse and the only healthcare professional for an entire community in Guanaja, Honduras. Those stories taught me that nurses made a difference in the lives of people and communities. My mother, who gave me the time, space, and place to complete this dissertation and who also reminded me of the importance of the nursing profession.

Thanks to my patients, whose struggles have taught me about courage and perseverance and whose experience inspired this work. I hope my work in health literacy makes a difference in your lives.

There were two organizations that provided scholarship assistance during this journey that I would like to acknowledge. Thank you Barbara and Donald Jonas, founders of the Jonas Center for Nursing and Veterans Healthcare for giving me the opportunity to be Jonas Nurse Scholar Leader during this journey. This wonderful opportunity helped me grow as a scholar. Thank you, Alpha Phi Chapter of Sigma Theta Tau for a research grant to support this study.

I want to thank my committee members for providing guidance during this process. Dr. Farren, your input on the theoretical foundation of this study was invaluable, thank you. Dr. Plichta, thank you guiding me in the development of hypotheses to test the theory. Dr. Zarcadoolas, thank you for being a “health literacy role model,” ensuring that participants would
understand instructions for the instruments used to test the interventions. Dr. Wilson, thank you for your suggestions about the study design and setting an example for the use of nursing theory to test health literacy interventions.

To Dr. Nickitas, thank you for the Herman Biggs Policy Fellowship, an opportunity to think about the policy implications of research.

To Dr. Ray Ownby, thank you for the use of the HIV-HL instrument.

Finally, my deepest appreciation and gratitude goes to Dr. Kathleen Nokes. Years ago, Ray told me that when I was ready, the right mentor would appear. I believe Dr. Nokes is the mentor for whom I was meant to wait. As my teacher at Hunter College, Dr. Nokes inspired me to think beyond the clinical setting to the policy and political aspects of healthcare. She gave me my first teaching appointment and asked in return that I pursue doctoral studies. That was the beginning of this journey. Throughout this journey, Dr. Nokes has given me an appreciation of rigorous scholarship, introduced me to a community of nurse scholars, and pushed me to go beyond what I thought of as my limitations. None of this would have been possible without her support and guidance. Dr. Nokes, thank you for being a mentor and a friend.
Dedication

This dissertation is dedicated to immigrant children, especially girls, who journey from the Center of the Americas to this great country with dreams and hopes of achieving something great for themselves and their families.

Kofi Annan,
Secretary General, United Nations
September 8, 1997
# Table of Contents

**ABSTRACT** iv  
**ACKNOWLEDGEMENTS** viii  
**DEDICATION** x  
List of Tables xiv  
List of Figures xv  

## CHAPTER I: RESEARCH OBJECTIVE 1  
- The Need for Self-Care Agency in Persons Living with HIV 3  
- Problem Statement 13  
- Theoretical Framework: Orem’s Self-Care Theory 14  
- Purpose of Study 16  
- Research Questions 17  
- Chapter I Summary 18  

## CHAPTER II LITERATURE REVIEW 19  
- Orem’s Theory of Self-Care Agency as a Theoretical Framework 19  
- Orem’s Theory of Self-Care Agency and Health Literacy 21  
- Health Literacy in People Living with HIV 23  
- Health Literacy Interventional Studies 30  
- eHealth and People Living with HIV 31  
- eHealth Interventional Studies 37  
- Evaluation of the NLM Tutorial 40
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Implications for Research, Practice, Policy, and Theory</td>
<td>101</td>
</tr>
<tr>
<td>Chapter V Summary</td>
<td>105</td>
</tr>
<tr>
<td>Appendix A: Tables</td>
<td>107</td>
</tr>
<tr>
<td>Appendix B: Approvals from HELP/PSI and Hunter IRB</td>
<td>128</td>
</tr>
<tr>
<td>Appendix C Scripts for Recruiting Potential Participants</td>
<td>130</td>
</tr>
<tr>
<td>Appendix D Measurement Instruments</td>
<td>140</td>
</tr>
<tr>
<td>Appendix E Scripts for E-HELP and MEDLINE Protocols</td>
<td>159</td>
</tr>
<tr>
<td>Appendix F: At Home Assignment</td>
<td>162</td>
</tr>
<tr>
<td>Appendix G: Figures</td>
<td>163</td>
</tr>
<tr>
<td>References</td>
<td>166</td>
</tr>
</tbody>
</table>
List of Tables

Table A1: Website Evaluation Criteria 107
Table A2: Evaluation of AIDS Denialist Websites 108
Table A3: Conceptual-Theoretical-Empirical Structure of Study 109
Table A4: Definition of Study Variables 110
Table A5: Administration of Measurement Instruments for E-HELP and MEDLINE 111
Table A6: Procedure Used for Study Implementation 112
Table A7: Demographic Comparison of Populations at Research Sites 113
Table A8: Treatment Fidelity Strategies 114
Table A9: List of Abbreviations 115
Table A10: Phase 1 Sample Characteristics 116
Table A11: Demographic and HIV-related Variables 117
Table A12: Tests of Fixed Effects on Self-Care Agency 118
Table A13: Tests of Fixed Effects on HIV Health Literacy 119
Table A14: Tests of Fixed Effects on eHealth 120
Table A15: Tests of Fixed Effects on Identification of Internet Health Information 121
Table A16: Within Group Differences for Self-Care Agency 122
Table A17: Within Group Differences for HIV Health Literacy 123
Table A18: Within Group Differences for eHealth 124
Table A19: Within Group Differences for Identification of Internet Health Information 125
Table A20: Percentage of Correct and Incorrect Responses on At-Home Assignment 126
Table A21: Percentage of Correct and Incorrect Responses during Skills Testing-Second Session 127
List of Figures

Figure 1: Relationships Among Health Literacy, eHealth, Ability to identify reliable internet health information, and Self-Care Agency 163

Figure 2: Relationship between Intervention and Study Variables 164

Figure 3: Participant Recruitment in the MEDLINE and E-HELP Groups 165
Chapter I

Research Objective

Scholars initially described health literacy as the ability to perform the basic reading and numerical tasks required to function in a healthcare environment (American Medical Association, 1999). Over time, the definition of health literacy evolved to include the wide range of skills and competencies needed to seek out, comprehend, evaluate, and use health information resources to make informed health decisions, reduce health risks, and increase quality of life (Zarcadoolas, Pleasant, & Greer, 2006). People seek health information from a variety of resources including television, newspapers, books, magazine articles, healthcare providers, and the internet. Health literacy related to living with HIV/AIDS (HIV health literacy) is the ability to use reliable health information from a multitude of sources to make decisions about self-care, understand disease processes, adhere to medication regimens, decrease the risk of opportunistic infections, and manage the symptoms of HIV and co-morbidities.

The internet, a vast computer-based network of commercial, educational, governmental, and social media websites linked together through electronic communication technology, is a relatively new source of health information that requires a new set of health literacy skills. Electronic health literacy (ehealth) is the ability to use electronic communication technology to access, understand, and use internet based health information for self-care (Eng, 2001; Norman & Skinner, 2006b; Norman, 2011). Internet-based health information is only useful to the person living with HIV (PLWH) if it is reliable. Ineffective or detrimental health choices may result from the inability to recognize unreliable internet based health information. The ability to recognize reliable internet-based health information is a fundamental skill of ehealth.
Self-care agency is the ability to engage in activities or behaviors that maintain health and wellbeing; self-care deficits occur when a person experiences limitations in their ability to perform self-care activities (Orem, 2001). Limited ehealth may be an unrecognized factor in self-care deficits in PLWH. HIV infection rates are increasing among people with health disparities (CDC, 2015). This places a higher demand for HIV self-care knowledge on individuals who are more likely to have low HIV health literacy, impaired self-care agency, and limited access to sources of reliable health information (Chou & Holzemer, 2004; Hicks, Barragan, Franco-Paredes, Williams, del Rio, 2006; Denning, DiNenno, & Wiegard, 2011; Warwrzynia, et al., 2013). PLWH who lack ehealth skills have poorer control over their infection, manifested by lower CD4 cell counts and higher HIV viral loads which is consistent with less adherence to treatment regimens and a poorer understanding of disease processes (Drainoni, et al., 2008; Kalichman, et al., 2008; Kalichman, et al., 2010; Kalichman, et al., 2012). There is a need for interventions that improve ehealth skills, including the ability to recognize reliable internet health information.

The two ehealth interventions tested in this study, MEDLINE and E-HELP (Electronic HIV Education and Learning Program), are designed to teach PLWH how to recognize reliable internet health information. The theoretical basis of this interventional study is Orem’s Self-Care Theory, which proposes that people use self-care agency to transform health information from a variety of sources into knowledge that can be used to make decisions about the behavior and actions needed to improve or maintain health. The purpose of this study was to test the effectiveness of the interventions in teaching PLWH how to identify reliable internet health information in order to increase HIV self-care agency.
The Need for Self-Care Agency in People Living with HIV

PLWH require frequent visits to healthcare providers to promote adherence, identify signs of treatment failure, address complications arising from HIV, and treat comorbidities. The pill burden of HIV treatment remains for a person’s lifetime. Although antiretroviral medications extend the life of the PLWH, the treatment also places them at risk for other co-morbid conditions such as renal failure, heart disease, lipodystrophy, and hyperlipidemia (HHS, 2015). The complexity of HIV disease and its treatment make self-care knowledge crucial to the optimum health of PLWH. Inability to provide self-care may result in the development of AIDS (Acquired Immunodeficiency Syndrome), the final stage of HIV disease when the CD4 cells fall below 200 cells per cubic millimeter of blood (200 cells/mm3) and the immune system becomes vulnerable to opportunistic infections. Self-care knowledge may be increased through access to health information and the person’s ability to make judgments about the information’s reliability and usefulness for self-care.

Many factors adversely affect the self-care in PLWH. These factors include low-income, which results in delayed care, limited access to non-publicly funded healthcare settings, and increased sexual risk behaviors (CDC, 2015). In addition, PLWH experience higher rates of incarceration, substance abuse, poverty, and unstable housing, which are associated with disruptions in HIV care and limit opportunities for health education. HIV health literacy and ehealth skills can play an important role in mitigating the barriers to self-care experienced by PLWH by increasing HIV self-care agency.

Effects of Limited Health Literacy

Limited health literacy results in poorer health outcomes, less use of preventative services, increased hospitalizations, higher mortality, less adherence to medication and treatment
plans, more medication errors, and less self-care skills (Berkman, DeWalt, Pignone, 2004; Berkman, et al., 2011; Bostock & Steptoe, 2012). Although health literacy has a stronger effect on health than race, ethnicity and income, persons most likely to have low health literacy are African American or Hispanic/Latino, living with chronic diseases, have less than a high school education, lower income, and older age (Berkman, et al., 2004; Berkman, et al., 2011).

In addition to poorer health outcomes, the financial cost of low health literacy is a substantial burden on the health care system. Estimates of the cost of low health literacy ranges from $143 million to $172 billion annually, with some estimates as high as 238 billion (Vernon, Trujillo, Rosenbaum, & DeBuono, 2007; Echler, Wieser, & Brugger, 2009; Haun, et al., 2015; Rasu, Bawa, Suminski, Snella, & Warady, 2015). Additional expenditures for low health literacy range from $143.00 to $7,798.00 per person (Eichler, Wieser, & Brugger, 2009). In a study of veterans, the average cost of care for those with inadequate health literacy was $31,581, compared to $17,033 for a veteran with adequate health literacy; the estimated three-year cost increase for caring for veterans with inadequate health literacy was $143 million (Haun, et al., 2015). An analysis of Medical Expenditure Panel Survey data from 2005 to 2008 estimated the annual cost of primary care office visits at $1284.00/year for people with low literacy compared to $719.00/year for people with adequate literacy (Rasu, et al., 2015). Prescription drug costs were estimated at $3362.00/per year for people with low health literacy compared with $910.00/year for people with adequate literacy; investigators projected that annual prescription costs for adults with low health literacy could potentially reach $172 billion (Rasu, et al., 2015).

Factors associated with Low Health Literacy

Results of the 1993 National Adult Literacy Survey (NALS) and the 2003 National Assessment of Adult Literacy (NAAL) indicated that people who needed accurate health
information the most were the least able to access sources of health information (Kutner, Greenberg, Jin, & Paulsen, 2006). Both surveys found that limited health literacy was associated with lack of a high school diploma, being African American race or Hispanic/Latino, and poverty. Results of the NAAL indicated that only 12% of Americans had a level of health literacy sufficient to understand medication instructions or navigate to a clinic appointment. A review of 85 U.S. studies with a total of 31,129 participants spanning the years 1963 to 2004 supported the findings of the NALS and NAAL surveys with regard to the relationship between health literacy and race, ethnicity, poverty status, and educational level (Paache-Orlow, Parker, Gazmararian, Neilsen-Bohlman, & Rudd, 2005). Subsequent surveys of people using hospitals, emergency rooms, and outpatient services found similar results; poverty, less than a high school education, older age, health disabilities, and membership in a racial or ethnic group were significantly associated with lower levels of health literacy (Rudd, Kirsch, & Yamamato, 2007; Downey & Zun, 2008; Walker, Pepa, & Gerard, 2010; Olives, Patel, Patel, Hottinger, & Miner, 2011; Kobayashi, Wardle, Wolf, & von Wagner, 2014; Kobayashi, Wardle, Wolf, & von Wagner, 2016). The Program for the International Assessment of Adult Competencies (PIAAC), the most recent assessment of literacy in the United States, also found that 12% of adults had proficient reading literacy and only 9% had proficient numerical literacy (Goodman, Finnegar, Mohadjer, Krenzke, & Hogan, 2013).

**Internet Access in the General Population**

Availability of the internet has increased over time, but demographic disparities in access still exist. Between 1997 and 2011, the number of U.S. households with internet connection increased from 19% to 75% of all U.S. households (Blanking & Strickling, 2011; File, 2013). Of the 75% of households that have internet access, 58% use a personal computer (desktop, laptop,
or notebook), 31% also own a hand held device that is internet capable, and 7% of Americans own only a handheld device (Blanking & Strickling, 2011). The public library is also a source of access to internet technology; 73% of Americans ages 16 and older access the internet on a library computer and 47% of them use library computers to get health information (Zichuhr, et al., 2013). In spite of increased internet availability, only 27% of Americans have the ability to access the internet from multiple sites and multiple modalities; 16% of Americans have no access to the internet (File, 2013). Americans without access to the internet are disproportionately older, African American, Hispanic/Latino, have low income, and less education (File, 2013).

Age and education are factors in internet use. Eighty-three percent of people 18 to 34 years of age and 82% of people age 35 and 44 years of age access the internet compared with 61.7% of persons over the age of 55 and 45% of people over 65 years of age (File, 2013). As educational attainment increases, internet access increases; 31.5% of non-high school graduates reported internet use compared with 90.0 percent of individuals with at least a bachelor’s degree (File, 2013).

Income affects internet access. Internet use among people with incomes of between $15,000 and $25,000 grew from 35% in 2009 to 57% in 2013 while internet use among those with incomes greater than $100,000 increased by only 1% during the same time period (Blanking & Strickling, 2011; File 2013). However, 96% of households with incomes greater than $100,000 had internet access, while only 57% of households with incomes of $25,000 or less had internet access (File, 2013).

Over time, internet access has increased in ethnic and racial groups, but inequalities still exist (File, 2013). In 2000, 46.1 % of White households reported internet use at home, compared
with 76.2% in 2011. In 2000, in both Hispanic/Latino and African American households, only 23.6% reported internet, these rates increased to 58.3% and 56.9% respectively in 2011.

Smartphones are another way people are accessing the internet. Race and ethnicity do not seem to be a factor in terms of smartphone use. Some sources report greater smartphone use for internet access among African Americans and Hispanic/Latino, but the most recent census data suggests there is little difference by race and ethnicity (File, 2013). The rate of smartphone use for White and African Americans is 48%, slightly higher than Hispanic/Latinos (45.4 %), but the differences among the three groups are not statistically significant (File, 2013).

**Internet Use and eHealth in the General Population**

In terms of use of the internet, the NAAL survey indicated that only 19% of people with below basic health literacy used the internet for health information (Kutner, et al., 2006). Although there are no recent national assessments of ehealth, the PIAAC survey assessed problem solving using electronic technology and found that only 6% of U.S. adults had proficient levels (Goodman, et al., 2013). This latest data may be an indicator of people’s limited ability to navigate the internet and recognize reliable web-based information.

**Internet Use for Health Information and eHealth**

While the internet might be used for access to information about a variety of things including social media, its use as a source of health information is more complex. Large scale surveys conducted by governmental agencies and research organizations provide a demographic picture of the various ways Americans are accessing the internet for health information (Blank & Strickling, 2011; Couper, et al., 2010; Weaver, et al., 2009; Fox, 2010; Fox & Purcell, 2010; Fox, 2011; Fox & Duggan, 2012; Zickuhr, Raine Purcell, 2013; Fox & Duggan, 2013). Most research about ehealth mirror health literacy and internet access; people who are older, of
African American or Hispanic/Latino descent, have less education, lower incomes, and/or limited health literacy also have less ehealth skills and are less likely to search for health information on the internet (Fox & Duggan, 2012; Kim, 2015). While it appears that a larger percentage of White Americans seek internet health information (60%) compared with African Americans (51%) and Hispanic/Latinos (48%), when college education is factored in, all three groups have similar or insignificant differences in rates of on-line health information seeking (Fox, 2011; Rooks, et al, 2012; Kontos, Blake, Chou, & Prestin, 2014). Among all groups, women are 1.4 to 2 times more likely than men to look for internet health information (Weaver, et al., 2009; Fox & Duggan, 2013; Haun, Conrad, Hon, et al., 2013; Kontos, et al., 2014; Mannierre, 2015).

Educational level is a factor in searching for internet-based health information. The Pew Internet & American Life survey ($N=3,014$ households) indicated that only 24% of people with a high school diploma seek internet health information; in comparison, 81% of those with a college degree seek internet health information (Fox, 2011). The Health Information National Trends Survey data ($N=2,358$) found that those with less than a college education are more likely to use social media to find health information rather than health websites (OR 1.59, 95% CI 1.06-2.39) (Kontos, et al., 2014).

Age is factor in internet use for health information; 29 to 32% of people over 65 years of age look for health information on the internet compared with 71% of those ages 18-29 (Fox, 2011; Kontos, et al., 2014; Choi, N., 2011; Tennant, Stellefson, Dodd, et al., 2015). Evidence indicates that the reduced use of internet health information in older adults is related to low income, less education, ethnic or racial origin, difficulty using computers and accessing internet information, low health literacy, and lack of understanding how internet health information can
improve self-care knowledge (Peterson, Dwyer, Mulvaney, 2009; Choi, 2011; Choi & DiNitto, 2013).

Health status affects the ability to search the internet for health information. Less than half of adults with chronic health conditions use online health information, reporting a strong reliance on healthcare providers as the primary source of health information (Fox & Purcell, 2010). Factors that account for reduced rates of internet health seeking among people with chronic diseases include older age, less income, and less than a high school education (Fox & Purcell, 2010). Other barriers to seeking internet health information for those with chronic illness include difficulty operating the computer, navigating the internet, constructing search strategies using browsers, fears about lack of privacy, and inability to evaluate a website as a source of credible information (Lustria, Smith, & Hinnant, 2011; van Deursen, 2012; van der Vaart, Drossaert, de Heus, Taal, & van de Laar; 2013).

Mobile Health and Access to Internet Health Information

Mobile health, or mhealth, is the use of cell phones or smartphones to access internet health information. The majority of Americans, 85%, own a cell phone; half of all cell phone owners have smartphones and approximately 31% to 52% have used mobile phones to access internet health information (File, 2013; Fox & Duggan, 2012; Fox & Duggan, 2013). People who use mhealth are typically between the ages of 18 and 49, employed, have higher incomes, and have a college education (File, 2013). Men are greater users of mhealth (Hung, Conrad, Hon, et al., 2013). Pew Internet and American Life surveys (Fox & Duggan, 2013) report lower rates of mhealth use among low-income people when compared to those with higher incomes (28% vs. 37%). Those with less than a high school education (17%) use mhealth less than those with a high school degree (26%) or those with a college education (38%). Only 19% of people 50 years
of age or older use mhealth technology compared with a mhealth usage rate of 40% in younger groups (Fox & Duggan, 2012). In addition, people who have had a recent medical crisis or a significant change in their health are more likely to use mhealth (Fox & Duggan, 2013; Huang, et al, 2013).

**Beneficial Effect of eHealth on Self-Care**

The benefits of using internet information for self-care include: (1) improved communication with healthcare providers about treatment decisions, (2) more control over health decisions, (3) increased participation in care, and (4) changes in self-care activities (Jimson, et al., 2008; Iverson, Howard, & Penney, 2008; Neter & Branin, 2012). African American and Hispanic/Latino internet users, compared to White Americans, were significantly more likely to use internet health information to change their approach to self-care, diet and exercise, and reported that internet use improved their understanding of symptoms and treatment plans (Cohall, et al., 2011; Rooks, et al., 2012).

**Internet Access among People Living with HIV (PLWH)**

PLWH who use the internet for health information are generally better educated and have higher incomes (Samal, et al., 2011; Chander, et al., 2012; Shacham, Stamm, & Overton, 2009). Internet use had a positive effect on health status regardless of the modality used for access; PLWH who used the internet for health information had lower viral loads and higher CD4 counts (Saberi & Johnson, 2015). However, racial/ethnic minorities, those with low income, less education, and history of incarceration were less likely to use the internet for health information (Samal, et al., 2009; Saberi & Johnson, 2015).
Website Characteristics and Access to Health Information

According to a report from a National Academy of Science health literacy workshop, health literacy is fundamental to ehealth (Marchibroda, 2009). Factors such as reading level of the text, presentation format, and the volume of sources of health information effect the ehealth skill set of locating, understanding, and discerning the reliability of online health information (Marchibroda, 2009; Ye, 2010). For PLWH who have low health literacy, this means access to health information may be limited to non-internet sources.

Internet-based health information is often presented at an 11th grade reading level, far above the average reading level of U.S. citizens, which is 5th to 8th grade (Bauer & Kanaan, 2006). Many health information websites use complex scientific language or medical jargon, making websites difficult to understand for persons without an “advanced” level of health literacy (Bauer, 2008; Cashen, 2009; Egbert & Nanna, 2009). For PLWH who have low health literacy, this may mean difficulty accessing, understanding and applying internet based health information as they make self-care decisions.

Websites may present online health information in a format meant to influence the behavior of people or reflect the bias of the website’s sponsor (Zarcadoolas, Pleasant, & Greer, 2006). Websites cluttered with advertisements make it difficult for people to distinguish reliable health information from messages meant to influence consumer spending (Eisenach & Kohler, 2002; Dubowitz & Schlutz, 2015). People with less education found social media and commercial websites more or as equally trustworthy as websites sponsored by academic research institutions or government agencies (Dutta-Bergman, 2003; Peterson, Asiani, & Williams, 2003; Robertson-Lang, Major, & Henning, 2011; van der Vaart, Drossaert, deHeuss, et al., 2013). Focus group research conducted by Reyes, Nokes, & Hickey (2013) found that for PLWH who
had low literacy, trust of commercial websites may result in the purchase of bogus health products.

Less reliable websites may present personal anecdotes as health information without citing supporting medical evidence. This is a threat to the provision of safe health information for internet users regardless of health literacy level because people become engaged in personal anecdotes and suspend the health literacy skill of evaluating the reliability of the information (Rains, 2007). Ability to differentiate between anecdotal evidence and scientific evidence is particularly important when considering the proliferation of WIKIs and BLOGs, which allow the presentation of inaccurate health information, personal experience, or opinions as facts (Eng, 2000; Marchibroda, 2009; Handel, 2011). For PWLH and limited health literacy, this may result in the avoidance of effective HIV medication or the use of medications that do not have scientific proof of efficacy (Kalichman, et al., 2002; Kalichman, et al., 2012).

In addition to presenting questionable health-related advice, the volume of information on a particular topic may be overwhelming. A query (February 23, 2016) using the term “HIV” in the Google search engine produced 171,000,000 websites, the Yahoo search engine produced 15,000,000 websites, and Bing produced 15,000,000 websites. This is significant, because the majority (84%) of people who search the internet for health information began with a search engine; 13% start at a health website, 2% at a general site like Wikipedia, and 1% start their health information search at a social network (Fox & Duggan, 2013). The volume of HIV websites increases the difficulty of distinguishing between reliable and fraudulent health information, regardless of health literacy level.

The quality of internet health information makes the ability to identify the reliability of a health information website a crucial ehealth skill. The Agency for Health Research and
Quality, the Medical Library Association, the National Institute of Cancer, the National Center for Complementary and Alternative Medicine, and Health on the Net recommend six criteria to evaluate the reliability of a website, specifically: (1) Sponsorship (2) Financial disclosure, (3) Quality, (4) Privacy, (5) Currency, and (6) Advertising policy (Hanif, Read, Goodacre, Chaudhry, Gibb, 2009; Monheit, 2011; Medical Library Association, 2012; Laversin, Baujard, Gaudinet, Simonet, Boyer, 2011) (Table A1).

HIV-related Internet Health Information

The proliferation of AIDS denialism websites, which promote the idea that HIV is harmless, does not cause AIDS, and rejects antiretroviral treatment (ART) as poison is another deterrent to accessing reliable health information (Kalichman, et al., 2010; Kalichman, et al., 2012). For example, the ReThinking AIDS website has a privacy policy that indicates it would share viewer information with similar websites, eliminating confidentiality. The website sponsors have healthcare credentials, but none has conducted research in HIV since the introduction of ART for HIV treatment. This is significant because ART changed the course of HIV disease progression. A newly diagnosed PLWH who uses the ReThinking AIDS website may not be aware of the timing and effect of ART on HIV disease. This may lead to no HIV treatment or deferred treatment, resulting in increased HIV transmission, opportunistic infections, and poorer health outcomes. Table A2, which evaluates three websites sponsored by AIDS denialists using the six evaluation criteria, reveals significant gaps.

Problem Statement

PLWH are susceptible to misinformation from internet sources, resulting in less than adequate self-care agency. There is insufficient research evaluating the effect of ehealth interventions on the HIV health literacy and self-care of PLWH. In order to improve self-care
agency in PLWH, nurses need evidence based ehealth interventions that address gaps created by the inability to identify reliable internet health information.

**Theoretical Framework: Orem’s Self-Care Theory**

Most health literacy and ehealth studies are not framed by an educational, behavioral, or social science theory or model (Wallace, Vaughn, Rogers, et al., 2012; Mackert, Champlin, Honton, Munoz, Demasio, 2014). There are many health literacy theories and ecological models of health literacy suitable frameworks for studies of population based health literacy interventions (Berkman & McCormack, 2010; Sorensen, et al., 2011; Haun, Valerio, McCormack, Sorenson, Paasche-Orlow, 2014). However, literacy theories do not comprehensively frame studies of nursing interventions that target the patient-nurse dyad. The holistic nature of Orem’s Self-Care Theory makes it a strong framework for nursing research (Taylor & Renpenning, 2011).

The Self-Care Deficit Theory of Nursing created by Orem consists of three separate but articulating theories: the theory of self-care agency, the theory of self-care deficit, and the theory of nursing system (Hartweg, 1991; Taylor & Renpenning, 2011). Because this research tests an intervention to improve self-care agency in PLWH, Orem’s theory of self-care agency is used. Orem defines Self Care Agency as the “complex acquired capability to meet one’s continuing needs for care of self that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes wellbeing” (Orem, 2001, p. 254). Self-care agency is a three-part construct consisting of (1) five foundational capabilities, influenced by basic conditioning factors, that in conjunction with (2) ten power components determine the (3) capacity to perform self-care operations (Orem, 2001). Self-care operations includes self-care knowledge.
Basic conditioning factors as described by Orem (2001) are demographic characteristics that are innate to the individual (race, ethnicity, culture, gender), occur as life progresses (age, developmental stage, health status), or are acquired (income, education, available resources). Basic conditioning factors have a direct effect on foundational capabilities, which are comprised of verbal, perceptual, manual, reading, and reasoning abilities (Orem, 2001). Power components arise from foundational capabilities (Orem, 2001; personal communication, Peters, 2012). The power component of interest in this study is #7: *The ability to acquire technical knowledge about self-care from authoritative sources, to retain it, and to operationalize it* (Orem, 2001, pg. 265). Power components enable self-care operations (personal communication, Peters, 2012).

The capacity to perform self-care operations, the third component of self-care agency, requires knowledge to perform behaviors or engage in activities that promote or maintain health promotion. Self-care operations for PLWH are on two levels; generic self-care for health promotion and maintenance that all people must perform, and the specific self-care required to manage the complications of treatment, the symptoms, and the co-morbidities of HIV disease (Chou & Holzemer, 2004). Thus, self-care is multidimensional, requiring both general knowledge needed for self-care decisions and HIV specific knowledge, strategies, and behaviors needed to manage symptoms and complications of the disease (Chou & Holzemer, 2004).

When basic conditioning factors are optimal and foundational capabilities, power components, and self-care operations are integrated and adequate within self-care agency, the person can initiate self-care practices that promote and maintain health (Orem, 2001; Taylor & Renpenning, 2011). People who have less than adequate income, lower educational levels, poor health status, or are members of a disadvantaged group may have impaired self-care agency because of the effect of less than optimal basic conditioning factors on foundational capabilities.
and power components. Thus, people who experience health disparities, such as PLWH, may not have adequate HIV-related self-care agency.

**Health Literacy, eHealth, and the Theory of Self-care Agency**

There is mutuality between the concepts of health literacy, ehealth and self-care agency. The health literacy skills of reading and comprehension are also part of the knowing and doing foundational capabilities of Orem’s theory. Power component #7 denotes the need for technological skills to obtain health information, which encompasses ehealth skills, including the ability to discern the reliability of health information. Self-care agency includes the use of health information from various sources to make self-care decisions, which, with the advances in electronic communication technology, now include internet sources. These relationships among health literacy, ehealth, and self-care agency suggest that ehealth interventions, such as the ones proposed in this research, will result in improved self-care agency. Figure 1.1 illustrates the relationships between the study variables using Orem’s theory of self-care agency and the conceptual-theoretical-empirical-structure of the study is presented on Table A3 and definitions of study variables are presented on Table A4.

**Purpose of Study**

The purpose of this quasi-experimental study was to measure the effectiveness of ehealth interventions in increasing HIV-health literacy, ehealth, ability to identify reliable internet health information, and self-care agency in PLWH, thus expanding Orem’s Self-care Agency Theory to include health literacy as a foundational capability and ehealth as a power component. Figure 2 illustrates these proposed relationships.
Research Questions

Research questions to test the interventions applying Orem’s theory were:

1. Does the E-HELP, compared to the MEDLINE intervention, significantly increase HIV health literacy, e-health literacy, the ability to identify reliable internet health information, and self-care agency?

2. Does participation in either the E-HELP or MEDLINE intervention increase HIV health literacy, e-health, the ability to identify reliable internet health information and self-care agency?

Intervention Groups

Both intervention groups (MEDLINE and E-HELP) participated in brief educational programs that taught how to identify reliable internet health information sources using the Medline tutorial, *Evaluating Internet Health Information*, along with an at-home assignment (homework). Only the E-HELP intervention included an individualized teach-back session with an expert clinician. Either intervention is applicable to internet-based health-related information that is accessed through any format.

Assumptions

This study is based on the assumption that PLWH need to be able to identify reliable internet-based information about health promotion, health maintenance, chronic disease management, treatments, and medication purpose and administration in order to maintain health and well-being, make informed decisions about their health, and improve self-care agency.

Significance

With the widespread use of the internet by people for health-related information, nurses need an expanded understanding of Orem’s theory that addresses advances in information
technology. Testing an ehealth intervention provides evidence of the need to expand the theory of self-care agency to include health literacy as part of foundational capabilities, and ehealth and the recognition of reliable health information as part of power component #7.

Chapter I Summary

In spite of increased internet availability, barriers to reliable internet health information still exist for PWLH including low health literacy, lack of ehealth skills, difficulty identifying reliable health information, and the continued proliferation of fraudulent or inaccurate HIV health information websites. Research suggests that use of reliable internet health information improves health outcomes. However, there is limited theory based research that tests interventions designed to improve the ability of PLWH to evaluate reliable internet based health information sites.

This quasi-experimental study uses Orem’s self-care theory as the theoretical framework to test whether ehealth interventions improve self-care agency by increasing HIV-health literacy, ehealth, and the ability to recognize reliable health information in a sample of low income PLWH. Table A9 provides definitions of all abbreviations used in the text.

Chapter two reviews the limited body of literature that used Orem’s Theory of Self-Care Agency to frame health literacy research. The literature about health literacy in general and HIV health literacy specifically is discussed, including reports of health literacy and ehealth skills-based interventions targeting PLWH. Findings from surveys of internet health information seeking and use by PLWH are discussed.
CHAPTER II

LITERATURE REVIEW

This literature review explored the relationships among health literacy, ehealth, ability to identify reliable internet health information, and self-care agency. Because no articles were found that used Orem’s self-care theory to frame research about health literacy and ehealth in PLWH, the literature search was expanded to include research that used Orem’s theory to explore health literacy in populations with chronic disease or health disparities. In addition, articles that described the effects of health literacy and/or ehealth interventions on self-care in populations of PLWH or that used the Medline video were reviewed.

Orem’s Theory of Self-Care Agency as a Theoretical Framework

Two studies that used Orem’s theory in a population of PLWH focused on the relationship of basic conditioning factors to self-care agency (Holstad, Pace, De, & Ura, 2006; Hurst, Montgomery, Davis, Killon, & Baker, 2005). Holstad, et al., (2006) found that high levels of self-care agency were positively related to the amount of self-care practiced ($r=0.44$, $p<0.01$), health status ($r=0.33$, $p<0.01$), interpersonal aspects of care ($r=0.40$, $p<0.01$), perceived utility of medications ($r=-0.32$, $p<0.01$), support or barriers to care ($r=-0.38$, $p<0.01$), and perceived susceptibility to illness ($r=0.29$, $p<0.01$) in a sample of PLWH ($N=120$). Hurst, et al., (2005), in a sample of HIV positive African American women ($N=62$), found that while age, annual income, and level of education were not related to self-care agency, health status was significantly related to both self-care agency and self-care behaviors ($p=0.01$).

Other studies in populations with chronic disease also found significant positive relationships among self-care agency and the basic conditioning factors of health status, age,
education, disease knowledge, and income (Token, Durmaz, & Argon, 2007; Ovayolu, Ovayolu, & Karadag, 2011; McDonnell, Turner, & Weaver, 2001; Callaghan, 2005). Two cross-sectional studies found self-care agency was positively related to degree of disability (health status), education, and income in people with rheumatoid arthritis (Token, et al., 2007; Ovayolu, et al., 2011). Investigators in both studies found that increased disability was associated with poorer self-care agency ($p=0.001$). Higher education was associated with better self-care agency ($p=0.001$) in that participants with a university education had better self-care compared with junior high school or primary school graduates. Although not statistically significant, participants with higher incomes had better self-care agency compared to those who had low incomes or were unemployed. Similarly, in a study of people infected with tuberculosis, McDonnell et al., (2001) found a significant correlation between self-care agency and better adherence to treatment in participants with higher incomes ($p=0.004$) and education beyond high school ($p=0.005$).

Data from a study that investigated the relationship of selected basic conditioning factors to self-care agency and self-care behaviors in a sample of adults aged 65 to 98 ($N=235$) found statistically significant relations among education, income, race, ethnicity, medical problems (health status), and gender (Callaghan, 2005). Participants who had a college education had greater self-care agency compared with those with only a high school diploma ($p=.000$) and adequate income was correlated with greater self-care agency ($p=.05$). Race or ethnicity was also a significant factor; self-care agency was significantly higher in Whites compared with African Americans ($p=.03$) or Hispanic/Latinos ($p=.04$). Participants with a health problem had greater self-care agency compared to those without ($p=.04$).
Orem’s Theory of Self-Care Agency and Health Literacy

Four research studies used Orem’s theory as the conceptual framework in studies of health literacy. The researchers explored the proposition derived from Orem’s theory that literacy is part of the basic conditioning factor of education and therefore, health literacy is a foundational capability. Findings provide evidence that limitations in either literacy or health literacy resulted in less than adequate self-care agency specific to the person’s health condition (Wilson, Brown, & Stephens-Ferris; 2006; Wilson, Baker, Nordstrom, & Legwand, 2008; Wilson, Mood, & Nordstrom, 2010; Wilson, Mood, Nordstrom, & Risk, 2010).

In an experimental study of childhood immunization knowledge in young urban mothers (N=37), Wilson et al., (2006) explored the effect of health literacy on self-care knowledge. The experimental group (n=19) received easy-to-read version of a pamphlet about childhood vaccines and the control group (n=18) received the standard Centers for Disease Control and Prevention (CDC) vaccine pamphlet with an 11th grade reading level. All participants completed high school; however, 51% read at 8th grade or lower as scored by the Rapid Estimate of Adult Literacy in Medicine (REALM) and 46% of participants did not understand the information presented in the pamphlet (Wilson, et al., 2006). Although the experimental group showed a greater increase in immunization knowledge compared with the control group, differences in scores were not significant.

The relationship between health literacy and reading level of health information was explored in a sample of young, low income, urban mothers (N=30) with a mean age of 26. The mixed methods study investigated participants’ ability to teach-back the risks, benefits, and safety of childhood vaccines and assessed the relationships among health literacy, income, and
age (Wilson, et al., 2008). The study used two CDC vaccine pamphlets, one about inactivated poliovirus vaccine written at a 9th grade reading level and the other pamphlet about the pneumococcal conjugate vaccine written at a 10th grade reading level. Participants’ mean REALM scores of 54 indicated reading levels were between 7th and 8th grade for the sample (Wilson, et al., 2008). The only statistically significant relationship was between health literacy and the benefits of the polio vaccine. Participants with REALM scores of 58 to 61 gave completely correct responses about polio vaccine benefits; participants with lower scores ranging from 49 to 56 gave incorrect responses ($F = 4.70$, $p = 0.02$). Reading level is a possible explanation for this finding because there was less discrepancy between the lower reading level of the polio vaccine pamphlet and the participants’ health literacy level, which is supportive of the relationship between literacy as a basic conditioning factor and health literacy as a foundational capability.

A non-experimental study tested the radiation side-effect knowledge in a convenience sample of people undergoing radiation therapy ($N = 47$). The researchers used the Knowledge of Radiation Side Effects (KORSET) to measure radiation side effects knowledge and the REALM to measure health literacy. Scores on the KORSET significantly increased with health literacy ($p < 0.01$). Participants with health literacy levels below third grade scored an average of 45 on the KORSET, those with 7th to 8th grade health literacy levels scored 83, and those with health literacy levels above 9th grade scored 96.

An experimental study explored the effect of health literacy and behavioral contracting on an audiovisual education program to improve self-care agency related to radiation therapy (Wilson, et al., 2010). The control group received usual care ($n = 23$); one treatment group received the audio-visual program only ($n = 24$), and an enhanced treatment group received the
program plus behavioral contracting \((n=23)\). The REALM scores for the total sample \((N=70)\) ranged from 0 to 66, with a mean score of 60 (SD=12.2) or an average reading level of 7th to 8th grade. A repeated measures ANOVA showed that when accounting for the health literacy of participants, changes in the use of radiation self-care were statistically different among the three groups \((F=3.55; p<0.03)\). Scores on the radiation self-care techniques checklist for participants with low health literacy in the control group decreased over 6 months from 17 to 5, whereas self-care scores for participants at all health literacy levels in both treatment groups increased, indicating that interventions can sustainably improve self-care in people with lower health literacy.

**Health Literacy in People Living with HIV**

This section discusses research that did not use Orem’s Theory of Self-Care Agency as a theoretical foundation. Health literacy effects HIV disease knowledge and self-care including the ability to adhere to treatment regimens (Drainoni, et al., 2008; Kalichman & Rompa, 2006; Nelsen, et al., 2013; Mooss, Brock-Getz, Ladner, Fiaño, 2013). PLWH who have lower health literacy may not understand HIV-specific disease concepts such as CD4 count and viral load, have difficulty understanding treatment instructions, need more healthcare visits and hospitalizations, and are greater risk for treatment failure (Kalichman & Rompa, 2000; Kalichman, Pellowski, & Chen, 2013).

**Health Literacy and HIV Disease Knowledge**

Drainoni, et al., (2008) explored the relationships between disease knowledge and levels of health literacy in a sample of PLWH \((N=231)\); 28% of the sample had inadequate health literacy determined by a score of \(\leq 80\%\) on the Test of Functional Health Literacy in Adults (TOFHLA). Participants with lower health literacy were more likely to be a member of a racial
or ethnic group and have less than a high school diploma. Participants who discussed laboratory results and treatment plans with healthcare provider were twice as likely to have adequate health literacy compared with participants who did not ($p=0.03$, $p=0.02$ respectively) indicating that health literacy is associated with better HIV disease knowledge.

A descriptive study examined the relationships between health literacy, knowledge of health status, and HIV/AIDS transmission beliefs in a sample of 694 PLWH (Mooss, et al., 2013) The REALM was used to measure health literacy, beliefs about transmission were measured using a 5 item true or false survey, and the demographic survey contained questions about CD4 count and viral load count as a measure of health status. Participants who had a high school health literacy level or greater knew their health status in terms of CD4 ($p=0.01$) and viral load count ($p=0.01$) and also understood how HIV was transmitted ($p=0.01$). High health literacy was the only predictor of whether or not clients held correct HIV-related transmission beliefs ($\text{OR} = 1.67$ $(1.15, 2.43)$, $p =0.01$).

A survey of HIV positive veterans ($N=244$) found no association between treatment adherence and self-assessed HIV knowledge measured by questions about HIV transmission, managing HIV symptoms, medication treatment with antiretroviral medications (ART), and side-effects (Nelsen, et al., 2013). Initial results showed a relationship between high confidence answering Chew’s single item health literacy screen, “How confident are you filling out medical forms by yourself?” (Morris, MacLean, Chew, & Littenberg, 2006: Chew, Griffin, Partin, et al., 2008) and aspects of self-care; those with higher health literacy had better treatment adherence ($p=0.04$), knowledge of viral load results ($p=0.0001$), and blood tests showed that their HIV levels were undetectable ($p<.00001$). However, this relationship was not maintained in multivariate analysis. Loss of these relationships may indicate that Chew’s single-item screener
is an inadequate measure of the complexity of HIV health literacy rather than the lack of a relationship between health literacy, HIV knowledge, and health status (Wawrzyniak et al., 2014).

**Health Literacy and Basic Conditioning Factors in PLWH**

Two studies by Kalischman & Rompa (2000 & 2006) explored the effect of health literacy on the ability of PLWH to understand HIV disease concepts. Both studies measured health literacy using the TOFHLA; a cut point of $\geq 80\%$ defined inadequate or adequate health literacy. In the first study Kalichman and Rompa (2000) used a two group quasi-experimental design ($N=294$); controlling for years of education, they found that higher health literacy was associated with undetectable viral loads, knowledge of CD4 cell count, and ability to explain the meaning of both these HIV disease markers ($p<0.01$). In contrast, lower health literacy was associated with lack of knowledge about CD4 and viral load counts, less engagement in care, more visits to healthcare providers, less understanding of self-care instructions, ($p=0.05$), and a higher risk of engaging in unsafe sex ($p<0.01$). Health literacy was significantly related to education (OR=4.9, 95% CI=2.5-9.5); 46% of those with lower health literacy had less than a high school diploma compared with 15% of the participants with higher health literacy.

In the second study, Kalichman & Rompa (2006) administered a 14-item survey of HIV treatment knowledge and asked participants ($N=339$) about HIV-related lab values and health status. Results were similar to the first study; participants with lower health literacy were significantly less likely to know HIV-related lab values ($p<0.05$), or understand the meaning of either ($p<0.01$), were more likely to perceive their health as poor ($p<0.03$), have more hospitalizations ($p<.05$), lower CD4 counts ($p<0.05$), and higher viral loads ($p<0.01$). Participants with low health literacy felt less involved in their HIV care and felt that healthcare
providers did not explained treatments in an understandable manner, although they were more likely to visit healthcare providers on a monthly basis (F = 3, 87, p<0.05).

**Health Literacy and HIV Self-Care Information**

Findings of two non-theory based studies indicated that low health literacy, as measured by the REALM, impairs PLWH’s ability to identify HIV medications and limits their sources of self-care information (Wolf, et al., 2004; Wolf, et al., 2005). Researchers conducted structured interviews about HIV medications with low income diverse PLWH (N=157) (Wolf, et al, 2004) and found that an inability to name HIV medications (p<0.01) and a reliance on healthcare providers as the sole source of HIV treatment information was associated with a health literacy level below ninth grade (p< 0.005). In the second study, health literacy was a significant factor in the ability of PLWH (N=204) to identify HIV medications (Wolf, et al., 2005). As the number of medications increased, the ability to identify them decreased regardless of health literacy level. All of the participants with high health literacy who were taking 1 to 2 medications could correctly identify their medications, but only 35% of participants with high health literacy taking more than 3 medications could correctly identify medications (p=0.05). Only 65% percent of participants with low health literacy taking 1 to 2 medications could correctly identify medications; when the number of medications increased to 3 or more, none of the participants with lower health literacy could correctly identify medications (p=0.05). This has clinical significance because many PLWH have treatment regimens consisting of more than one antiretroviral medication; opportunistic infections or co-morbidities require additional medications. In both studies, lack of understanding of CD4 count and viral load was associated with poorer treatment adherence.
Several studies investigated the relationship between health literacy and medication adherence. A study of the relationship between health literacy and HIV medication adherence in a sample of 145 PLWH used the TOFHLA with a cutoff point of 90% to determine adequate or inadequate health literacy (Kalichman, et al., 2008). Adherence was measured by unannounced pill counts at 21 and 35 day intervals and calculation of the percentage of pills counted to pills prescribed. The median adherence rate was 71%. Lower health literacy was associated with not achieving an adherence rate of at least an 80% (OR=3.94, 95% CI=1.63 to 9.5) or 90% adherence rate (OR=4.96, 95% CD=1.55 to 15.88). In a sample of 204 PLWH, health literacy was the significant independent predictor of non-adherence to medication regimens irrespective of race (AOR=2.12, 95%, CI=1.93-2.32). Investigators used the REALM and measured medication adherence with the Patient Medication Adherence Questionnaire (Osborn, Paasche-Orlow, Davis, & Wolf, 2007). Statistical analyses confirmed a significant relationship between African American race and low health literacy (adjusted odds ratio [AOR] =7.4, 95% CI=1.49-10.9). However, the effect of African American race on non-adherence to medication regimens was reduced by 25% and became non-significant when health literacy was included in the analysis (AO=1.80, 95%, CI=0.51 -5.85; C statistic=0.72).

In a cross sectional study of PLWH of Puerto Rican descent (N=200), 47% of the sample had marginal or inadequate health literacy (Rivero-Mendez, Suarez-Perez, & Solis-Baez, 2015). The study used the Spanish version of the TOFHLA with scores of ≤59% indicating inadequate health literacy, 60 to 74% indicating marginal health literacy, and ≥75% indicating adequate health literacy. Demographic factors such as years of education beyond high school, employment, higher income ($p=0.01$), and younger age ($p=0.00069$) were significantly correlated with higher health literacy. Health literacy was correlated to participants’ ability to
recall their CD4 count and viral load \( (p=0.05) \). Significant interactions were found between health literacy and adherence; people with marginal or adequate health literacy had better adherence compared with those with inadequate literacy level \( (p=0.00069) \).

**Measurement Instruments and HIV Health Literacy**

The REALM and TOFHLA may not provide an accurate picture of health literacy in PLWH (Nokes, et al., 2007; Mayben, et al., 2007). Results of a study that examined the effect of health literacy measured by the REALM on other aspects of self-care such as body change distress, depressive symptoms, and HIV symptoms in a sample of 489 PLWH found an association between higher health literacy in Hispanic/Latino participants and poorer health outcomes \( (p=0.05) \). Participants with higher health literacy scores rated physical health more poorly \( (p=0.02) \), psychological support as lower \( (p=0.026) \), and reported less social support \( (p=0.009) \), results that were inconsistent with prior research studies (Nokes, et al., 2007). Nokes et al., (2007) proposed that the reason for the unexpected results was that the REALM was a test of reading skill rather than health literacy and suggested that people with higher reading levels may be better able to describe symptoms and articulate their health status.

Health literacy, as measured by the TOFHLA, was not a factor in delayed diagnosis of HIV in a sample \( (N=119) \) of recently diagnosed low income PLWH (Mayben, et al., 2007). Instead, gender \( (p=0.005) \), reason for testing \( (p=0.001) \), and marijuana use \( (p=0.04) \) were all factors affecting delayed diagnosis. There may be several explanations for this finding. In this sample, the percentage of participants who did not finish high school and those that had some college were almost equal \( (28\% \text{ vs. } 29\%) \) and may have contributed to equalizing the scores on the TOFHLA. Similar to the conclusions of Nokes et al., (2007), researchers in this study
suggested that the TOFHLA was not an accurate measure of health literacy tests but a test of literacy.

However, lower health literacy might be an indicator of poorer health status and a risk factor for HIV infection. Participants with lower health literacy also had a mean CD4 count of 175 at diagnosis compared with a mean CD4 count of 247 for those with adequate health literacy (Mayben et al., 2007). Participants with less HIV knowledge had lower CD4 counts compared with those who had greater HIV knowledge (191 vs. 260). Although these associations were not statistically significant, they are clinically significant because the CDC associates a CD4 blood count below 200 as a criterion for an AIDS diagnosis.

Colbert, Sereika, and Erlen (2012) used the TOFHLA and found results that were dissimilar to previous studies of health literacy in PLWH. Bivariate analyses and stepwise regression controlled for the effect of race, income, and level of education to examine the associations among functional health literacy, medication-taking self-efficacy and HIV treatment adherence in a sample of 302 PLWH and found that health literacy had no effect on adherence. Only 9.9% of the sample (n=30) had inadequate health literacy based on the short form TOFHLA with a mean of ≤75% to differentiate inadequate from adequate health literacy. There was no difference in adherence levels between patients having the inadequate and adequate health literacy (U = 3845.50, Z = -0.521, p = 0.602); however self-efficacy was associated with greater medication adherence, (b= 0.21; 95% CI = 0.08, 0.35). There are several differences in this study compared to other studies of health literacy in PLWH. Overall, a larger percentage (91%) of this sample had adequate health literacy compared to previous studies; this may be because the study used a lower cut point (75%) to determine adequate health literacy.
Health Literacy Interventional Studies

Only three studies of health literacy interventions in populations of PLWH were found and all found a relationship between adherence, self-care knowledge, and health literacy. A pilot study that tested a health literacy intervention in 91 Hispanic/Latinos randomized participants to a control group (n=40) that received standard care or the intervention group (n=41) that received the educational intervention (van Servellen, et al., 2003). Health literacy was measured with a modified REALM that contained 24 HIV-related terms; outcomes were measured at 6 weeks and 6 months. At six weeks the intervention group showed improvement in knowledge (t = 2.22; p = 0.03), recognition (t = -2.97, p < 0.0001), and understanding of HIV terms (t = -3.52, p < 0.0001). At six months, recognition (t = -3.16, p < 0.0001), and understanding of terms (t = -3.93; p < 0.0001) improved in the intervention group, as did communications with healthcare staff and HIV providers (p < 0.001).

A nurse led intervention to improve HIV self-care was tested in a sample of PLWH (N=30) with a mean TOFHLA score of 66% indicating inadequate health literacy (Kalichman, Cherry, & Cain, 2005). The intervention applied Doak’s health literacy principles (Doak, Doak, & Root, 1996) in two 90 interactive minute sessions and one 60-minute booster session. Three months later the researchers found significant increases in HIV knowledge (p <0.01), participants’ knowledge of their CD4 count and HIV viral load (p<0.05), and intention and ability to take ART (p<0.05).

Based on the findings of the nurse led study, a randomized control study was developed (Kalichman, et al., 2013). A sample of PLWH (N= 446) who scored < 90% correct on the TOFHLA were divided into marginal (≥85 to 90) and lower literacy (≤85) groups and randomly allocated to 1 of 3 adherence education conditions: pictograph-guided adherence education (n =
148), standard adherence education \((n = 157)\), or general health improvement education \((n = 141)\). Participants were followed for nine months. Participants with marginal health literacy in the pictograph-guided and standard education groups demonstrated greater adherence and undetectable HIV viral loads compared with those in the general health education group \((\text{Wald } x^2 (2) = 5.93, p < 0.05)\). Findings indicate that using pictographs and targeted messages resulted in better self-care and health outcomes.

**eHealth and People Living with HIV**

Health literacy contributes to ehealth. There are lower rates of internet use among PLWH (Hogan & Palmer, 2005; Thomas & Shuter, 2010; Samal, et al., 2011). A nationwide survey \((N=662)\) that explored the information preferences of PLWH found that only 14% selected the internet as a source of health information (Hogan & Palmer, 2005). In addition, internet-based information was not rated as highly as information from healthcare providers in terms of usefulness (15% vs. 51%), trustworthiness (12% vs. 55%), availability (36% vs. 53%), and ease of understanding (20% vs. 48%). Selection of the internet as a source of information was associated with educational level. Twenty-five percent of college graduates choose the internet, 15% of those with some college education compared with 8% of those who completed high school, and 5% of those with some high school used the internet for health information.

A survey of internet use by urban dwelling PLWH \((N=435)\) found that less than half (45%) of the sample used the internet for health information (Samal, et al., 2011). Internet users had greater medication adherence \((p=0.001)\) even after adjusting for age, gender, race, and education \((OR=2.91, 95\% CI 1.22-6.95)\). In a survey conducted in a New York City hospital based HIV clinic where 94% of the patients were African American or Hispanic/Latino and 81% had household incomes below the poverty line, almost 70% of the participants \((N=208)\) accessed
the internet, but only 48.8% used it for health information (Thomas & Shuter, 2010). In both
surveys, participants who reported high internet health seeking behavior were significantly
younger ($p=0.001$) and had higher levels of education ($p<0.001$).

Higher levels of health literacy (Kalichman, et al., 2002; Kalichman, et al., 2005) are
associated with Internet use among PLWH. In one study ($N=228$), only 30% of participants used
the internet (Kalichman, et al., 2002). Participants who used the internet had better educations,
higher incomes, were significantly more likely to know their CD4 counts and viral loads, and
adhere to their medication regimens ($p=0.05$). In another study, ($N=147$) 15% of participants
with less than a high school education used the internet compared with 34% of high school
graduates and 50% of persons with some college (Kalichman, et al., 2005). Income was the only
significant predictor of internet use for minorities ($OR=2.9$, $p=0.01$), whereas education
($OR=101.1$, $p<0.01$) and income ($OR=207.9$, $p<0.05$) predicted internet use among non-
minorities. In both studies, internet use was not associated with age, gender, ethnicity, HIV
related hospitalizations, or HIV symptoms (Kalichman, et al. 2002; Kalichman, et al., 2005).

The need for internet navigation instruction may explain the reason for lower rates of
seeking internet health information among PLWH (Mayben & Giordano, 2007). In a sample of
PLWH ($N=128$), 89% wanted to use the internet to get HIV health information and 66% of the
participants expressed the need for instruction (Mayben & Giordano, 2007). Health literacy was
an independent predictor of needing internet use instruction ($OR=0.39; p=0.04$); 37% of those
who reported needing instruction had inadequate health literacy compared with 12% of those
who did not need assistance ($p=0.002$).

Age, race, and education were associated with needing instruction on how to use the
internet. Fifty-nine percent of participants needing assistance were over 40 years of age,
compared with 31% not needing assistance ($p=0.02$). In terms of race, 23% of participants who needed assistance were White Americans, compared with 57% of African American who needed assistance ($p=0.01$). Lower education affected participants’ need for instruction, 33% of those with less than a high school education needed assistance compared with 17% of those who did not ($p=0.05$). Gender and ethnicity did not significantly affect participants’ need for instruction.

**Internet Use and Health Outcomes in PLWH**

PLWH who use the internet for health information have greater HIV knowledge, greater confidence in their ability to adhere to medications, more active coping, more social support, higher CD4 counts, and undetectable viral loads (Kalichman, et al., 2003; Kalichman, Cain, et al., 2005; Saberi & Johnson, 2015). Results of a correlational study of PLWH ($N=147$) showed that PLWH who used the internet had significantly more education ($OR=1.32$, $p=0.01$), higher incomes ($OR=3.72$, $p=0.01$), and were less likely to be African American than PWLH who did not use the internet ($OR=0.32$, $p=0.010$) (Kalichman, 2003). Findings of a descriptive study of PLWH ($N=419$) who used the internet found almost half ($n=199$, 47%) of the sample used internet-based health information (Kalichman, et al., 2005). Again, PLWH who used internet-based health information were more likely to have higher incomes, more education, less likely to use injection drugs, less likely to miss doses of medication, and less likely to have CD4 counts less than 200 ($p=0.001$). Internet users also sought information from a variety of sources in addition to internet ($p=0.001$).

A survey conducted by Saberi & Johnson (2015) demonstrated that PLWH ($N=1,494$) who accessed the internet for health information through various platforms, including mhealth, had higher odds of having excellent medication adherence ($OR=1.49$, 95% CI [1.17, 1.91], $p=.001$) and a suppressed viral load ($OR=1.52$, 95% CI [1.11, 2.09], $p=.009$). Participants who
were African American, Hispanic/Latino, had less than a high school education, a history of incarceration, or did not know their CD4 count were less likely to engage in internet health searches; neither health literacy or ehealth literacy were measured.

A study of ehealth in HIV positive women in New York City found that higher ehealth literacy was associated with increased risk behavior (Blackstock, Cunningham, Haughton, et al., 2016). Women reporting sexual risk behaviors had higher ehealth (61.1% vs. 38.9%, \( p = .11 \)), were older (50.5 vs. 46 years old, \( p = .03 \)), and less likely to report fair or poor health status (33.3% vs. 17.1%, \( p = .15 \)). Several issues are of concern with these results. First, neither ehealth or health status was significant at the .05 level. Second, the eHEALs score was dichotomized into lower or higher ehealth literacy using a median split and not a mean value. Third, the eHEALs measures confidence using the internet to find health information, not the actual ability to find internet information and this study did not appraise the participants’ skills navigating the internet, evaluating health information, or use of health information.

**Susceptibility to Fraudulent Information**

Earlier research about internet use in PLWH indicated that income, education, HIV knowledge in addition to health literacy affected PLWH’s ability to identify reliable internet health information (Benotsch, Kalichman, & Weinhardt, 2004; Kalichman, Cherry, Cain, et al., 2006). Researchers evaluated participants’ (\( N=324 \)) ability to determine the trustworthiness of the *Journal of the American Medical Association* (JAMA website) and an unreliable website about a cure for AIDS using goat’s blood (Benotsch, et al, 2004). Health literacy was determined using the TOFHLA and a 16 item test evaluated participants’ HIV treatment knowledge. Participants with lower health literacy, fewer years of education, lower income, and less HIV treatment knowledge gave more credibility to the AIDS cure website compared with participants
with higher health literacy, more education, and more treatment knowledge ($p<0.01$). Another group of researchers used the same websites to examined the association between health information seeking as a coping skill and the ability to evaluate the quality of internet health information in a sample of 419 PLWH (Kalichman, et al., 2006). Participants’ assigned quality ratings to the websites based on trustworthiness, relevance, level of detail, accuracy, and usefulness of the information. Higher education, more frequent internet use, and higher scores on the information-seeking coping scale were significantly related to quality ratings of the JAMA website ($p=0.01$). In contrast, participants with lower incomes and less education, and who coped by avoiding health information assigned higher credibility to the fraudulent AIDS cure website ($p<0.01$).

But higher health literacy does not prevent vulnerability to false internet-based health information or improve the ability to detect an unreliable health information website (Kalichman, Eaton, & Cherry, 2010; Kalichman, Cherry, White, et al., 2012). In two studies, participants who scored 80% or above on the TOFHLA, indicating high health literacy, had difficulty identifying reliable internet health information. A study of AIDS denialism beliefs in PLWH ($N=343$) found that frequent internet use was associated with the belief that there is no proof that HIV causes AIDS, scientists continue to debate the cause of AIDS, herbal or natural remedies can cure AIDS, and HIV is treatable using natural immune boosters ($p=0.01$; Kalishman, et al., 2010). Participants who endorsed the AIDS denialist websites had more HIV symptoms, less adherence to medication, and were less likely to have an undetectable viral load ($p<0.05$).

Another study of PLWH ($N=344$) who used the internet for health information found that dietary supplement users were significantly more inclined to believe and trust the information the false claims of two websites that endorsed treating and curing AIDS with vitamins or natural remedies


(p<0.05) compared to information on a reliable health information website sponsored by Tufts University HIV health information website (p<0.05; Kalichman, et al., 2012).

Reliability of HIV Health Information Websites

Distinguishing the difference between AIDS denialist websites, questionable HIV health information websites, and reliable internet health information sources may be difficult because many HIV health information websites do not meet the criteria of website reliability. Researchers evaluated 137 HIV health information websites using criteria based on the six criteria of a reliable website described in chapter one, Table A1 (Horvath, et al., 2011). Results of the survey showed that 35% of the websites did not have dates current within the year of the survey, only 7% of the websites had information reviewed by an expert, and only 4% had information that was journal referenced. One website in the sample actively promoted the avoidance of HIV medications and provided personal stories about successful treatment of HIV without antiretroviral medication.

PLWHs’ Perceptions of Internet Health Information Websites

Difficulty identifying reliable health information may a reason for the lower rates of internet health seeking behavior among PWLH regardless of health literacy level. A mixed method study used semi-structured interviews and a survey to solicit newly diagnosed PLWH’s perceptions of HIV-related health information websites (Courtenay-Quirk, et al., 2010). Participants (N=63) indicated a preference for websites that were easy to navigate, used simple language, had information provided by an expert, and avoided the use of medical jargon. Participants expressed a desire for greater access to website contact information. Many of the participants noted that internet information could be misleading, biased, or outdated.
A qualitative study investigated the perceptions of HIV care clinicians and PLWH ($N=13$) about an HIV information website developed by the investigators (Dixon & Kaneshiro, 2012). Participants spoke out loud while performing tasks associated with searching for HIV related internet health information on the website. Although participants who were clinicians found the information accurate, participants who were PLWH found the website overwhelming and difficult to navigate. They requested simpler content about testing, treatment, and self-management.

A mixed methods study using surveys and focus groups found that participants ($N=23$) expressed mistrust of internet-based health information because of difficulty determining credibility of websites, information overload, and inability to identify the authority of website information (O’Grady, 2008). Participants were also concerned about privacy and confidentiality when posting personal information on a website; participants felt that revealing their HIV status via internet websites could be stigmatizing. Another qualitative study of 27 HIV positive women’s willingness to use the internet found that lack of ehealth skills and concerns about privacy prevented participants from using the internet for health information (Blackstock, Shah, Haughton, Horvath, & Cunningham, 2015).

**eHealth Interventional Studies in PLWH**

Interventions that teach PLWH how to identify reliable internet health information can be effective and result in improved medication adherence (Kalichman, Cherry, Cain, Weinhardt, & Benotsch, 2006; Kalichman, Cherry, Cain, Pope, et al., 2006; Robinson & Graham, 2010; McInnes, Solomon, Shimada, et al., 2013; Ownby, Waldrop-Valverde, Caballero, & Jacobs, 2013). Researchers randomized participants to a control group or an experimental group that matched participants based on gender, race, age, education, TOFHLA scores, income, years with
HIV, and HIV risk factors (Kalichman, et al., 2006; Kalichman, et al., 2006b). The control group received educational sessions about HIV disease. The experimental group learned a website evaluation schema, searched for health websites, and used the schema to evaluate the website’s reliability. Both groups had access to computers at an AIDS service agency and evaluated the previously mentioned JAMA and AIDS cure website on accuracy, amount of detail, credibility, relevance, and usefulness. Initially, there was no difference in the control and experimental groups’ ability to discriminate between the two websites. As the study progressed, the experimental group demonstrated increased website evaluation skills. At the three-month mark, the experimental group rated the AIDS cure website as having lower quality than the JAMA website ($p<0.005$). The experimental group also demonstrated greater internet use at the six-month follow-up, including searching for internet information and clinical trials ($p<0.01$), using e-mail, and bringing internet information to providers ($p<0.05$). Self-efficacy was also greater in the experimental group at 3, 6, and 9 months ($p<0.05$). Although internet use was greater in the experimental group as the study progressed, the difference between groups was not significant. However, outside of the AIDS service center, 43% the experimental group accessed the internet compared with 23% of the control group.

An intervention to teach PLWH ($N=18$) how to find reliable internet health information had limited success (Robinson & Graham, 2010). Instructors taught computer skills, internet navigation skills, and identification of reliable internet health information in a single fifty-minute session using a PowerPoint format (Robinson & Graham 2010). The PowerPoint format is not conducive to teaching manual computer skills. Consequently, a significant portion of the session was devoted to instruction of computer skill and not website evaluation skills. Investigators used the eHEALs to measure perceived confidence in using the internet before the intervention,
immediately after the intervention, and 3 months after the intervention. Results indicated a significant increase in perceived confidence in using the internet immediately post-intervention \((p<0.05)\). The increase in confidence was not retained at the 3-month mark; only knowledge of available health information resources \((p=0.04)\) and how to find the health information resources \((p=0.01)\) was retained. A possible reason participants’ retained this knowledge could be handouts given at the end of the intervention, which recommended ehealth websites and instructions for access. The ability to evaluate health information \((p=0.30)\) and identify the quality of the information \((p=0.92)\) was not retained at the 3-month follow-up.

A four session weekly program taught HIV positive veterans with low ehealth skills how to find and identify reliable HIV and HCV health information. Investigators hypothesized that increasing the veterans’ ehealth skills would increase their knowledge and engagement in care (McInnes, Solomon, Shimada, et al., 2013). The program taught three of the six reliability criteria (sponsorship, quality, and currency). There was a statistically significant increase from baseline to immediately after the intervention in use of the internet \((p=0.0009)\), searching for internet health information \((p=0.03)\), disease knowledge \((p=0.05)\), and confidence in using the internet \((p=0.009)\). The increase in internet use, searching for internet information, or disease knowledge were not sustained at the three-month follow-up. No change occurred in patient engagement immediately after the intervention, however, three months later, patient engagement increased significantly \((p=0.03)\) as did confidence in using the internet \((p=0.004)\). This program was expensive \($300/per participant, excluding compensation for participation\) and time consuming but the results indicate that interventions that teach PLWH how to use the internet can have a beneficial effect on self-care.
An intervention targeting HIV-related health literacy that consisted of a one-hour touchscreen computer program with content about medication adherence and HIV-related coping strategies was developed by a multidisciplinary team and tested in a sample of 114 PLWH (Ownby, et al., 2012). Health literacy was measured with the TOFHLA; six participants had scores of ≤59% indicating inadequate literacy, ten had scores of 60%-74% indicating marginal health literacy, and 108 had scores ≥75% indicating adequate health literacy. Over the course of the study, HIV knowledge ($F=4.25, p=0.02$) and adherence skills ($F=4.17, p=.02$) improved in participants with lower health literacy; this may have been a function of improved numeracy ($F=4.17, p=0.2$), a necessary component of adherence, which measured by the TOFHLA.

**Evaluation of the NLM Tutorial**

Creators of the NLM video did not evaluate its effectiveness (personal communication, 2010). A search of the databases revealed only one randomized control group study that evaluated the NLM video as an ehealth intervention in a healthy sample of older adults. The study compared collaborative learning with individualistic learning (Xie, 2011). Participants ($N=124$) who had limited experience accessing online information were randomized into groups that viewed the video alone or in a group. Delivery method made no difference in participants’ learning. Multivariate repeated analyses found time of measurement had a significant main effect ($p=0.001$). Univariate repeated measures analyses revealed the main effects of time of measurement were on ehealth efficacy, perceived usefulness of ehealth skills, and ehealth skills ($p<0.001$). These results suggest that the NLM video is an effective intervention for teaching people how to evaluate the credibility of internet-based health information regardless of learning format.
Viewing the NLM video alone may not be sufficient to develop adequate ehealth skills in PLWH. Reyes, Nokes, & Hickey (2013) conducted three focus groups in a population of low-income PLWH (N=19) who attended adult day healthcare programs (ADHC) sponsored by an AIDS service organization. Participants watched the NLM 16-minute video in a group and answered a series of questions aimed at soliciting their perceptions of the effectiveness of the video. The mean score on of 62.87 (SD 23.6) on a measure of reliable internet health information indicated that participants continued to have difficulty identifying the characteristics of a reliable health information website after watching the video. Confirming these findings, participants reported that they would have liked “real life websites” instead of mock-up examples of websites and an opportunity to practice the skills taught in the video with an instructor.

**Discussion of Literature Review: The Need for the Study**

Gaps in knowledge exist about the relationship between health literacy, ehealth literacy, and self-care agency in PLWH and concepts in Orem’s Self-Care Theory can assist to explain those relationships. The body of knowledge about the effectiveness of ehealth interventions on self-care is limited and none of the research thus far has been framed using a nursing theory. Promoting self-care has long been a key function of nursing practice.

This review confirmed the consensus of Orem scholars that few studies have expanded concepts within Orem’s Theory of Self-Care (Taylor, Geden, Isaramalai, & Wongvatunyu, 2000; Moore & Pichler, 2000; Fawcett, 2005). In the studies of chronic illness framed by Orem’s theory, the basic conditioning factor of education was linked to better health status. This may be because people with better education have higher levels of literacy and are better able to use self-care information, possibly reflecting health literacy as a foundational capability. Wilson et al.,
found evidence of this relationship in several studies, but more evidence is needed in groups with chronic illnesses and health disparities.

No studies could be found that tested ehealth or use of reliable internet health information as part of power component (PC) #7. When Orem first developed her theory, the internet was not accessible and computers were not in common use. Using Orem’s theory to encompass existing technology would enhance the theory’s usefulness for practice and research. By framing the intervention in this study using Orem’s theory, we will add to the body of evidence about the relationships between health literacy, ehealth, identification of reliable internet sites, and self-care agency.

**Effectiveness of Health Literacy and eHealth Interventions**

This review confirms the findings of other systematic reviews: there are a limited number of interventions that directly target health literacy and ehealth in PLWH (Perazzo, Reyes, & Webel, 2016). The interventional studies reviewed demonstrate that health literacy and ehealth skills increase use of the internet, HIV knowledge, and adherence. However, commonly used measures may not reflect the information and self-care needs of PLWH.

Researchers have noted that the REALM and the TOFHLA have limitations as measures of health literacy in general and in PLWH specifically (Nokes, et al, 2007; Mayben, 2006; Collins, Curry, Bakken, et al., 2012). In general, the instruments are not direct measures of literacy, but may reflect educational level rather than health literacy. Neither of these instruments translates well to a computer based format or measures ehealth (Collins, et al., 2012). The REALM may have an unintentional bias against African Americans and the TOFHLA against Hispanic/ Latino (Collins, et al., 2012), populations most effected by HIV disease. The TOFHLA cut points for adequate, inadequate, or marginal health literacy were
inconsistent in the studies reviewed, indicating a lack of standardization of health literacy measures and consensus among researchers about markers of low health literacy in PLWH. An HIV specific health literacy instrument would contribute to the body of knowledge about health literacy in PLWH by focusing the self-care content on information needed to live with HIV/AIDS. To date, the HIV-HL is only computer based instrument available that test HIV specific knowledge. It has only been tested during its development and scored a reliability of 0.69. This study provides additional testing to validate the HIV-HL.

**Evaluation of eHealth Interventions**

eHealth was directly measured using the eHEALs in only one study, most of the studies measured ehealth skills indirectly with the TOFHLA, a health literacy measurement. By using a tool that measures ehealth and an HIV specific health literacy tool that reflects internet health information seeking, a direct measure of ehealth and a more accurate assessment of HIV health literacy can be obtained.

The ehealth interventions reviewed in this chapter did not have a theoretical basis (Watkins & Xie, 2014; Mackert, Chapin, Holton, Munoz, & Damasio, 2014). Using theory could enhance ehealth interventional research by providing a framework to explain and generalize findings and also inform the creation of interventions. Using Orem’s theory allows the researcher to explain the results of the interventions in terms of PLWH’s self-care agency.

The ehealth interventions described in this review were, for the most part, effective in increasing participants’ health literacy and ehealth skills. However, all the interventions required a substantial commitment of time from the participants and financial investment by clinicians who would implement them. In addition, the interventions are administered in a classroom
setting. Studies of brief, low cost, easily administered interventions that can be used in the clinical setting are needed.

The E-HELP intervention reflects a “real world” experience of health education with a nurse or other healthcare provider in a clinical setting. The E-HELP intervention capitalizes on PLWH’s preference for obtaining health information from a trusted healthcare provider by using the teach-back strategy. In the clinical setting, teach-back is the recommended approach for improving a patient’s health literacy (Brega, Mabachi, Weiss, et al., 2015; Joint Commission, 2007). Several studies reviewed provided evidence that teach-back made a difference in participants’ health literacy (Wilson, et al., 2006; Wilson, et al., 2008; Kalichman, Cherry, & Cain, 2005; McInnes, Solomon, Shimada, 2013). This study tests the effectiveness of the teach-back strategy coupled with an opportunity for independent practice in improving participants’ ehealth skills and ability to identify reliable internet health information in order to improve self-care agency.

If the E-HELP intervention is effective, nurses in a variety of clinical settings can use it to teach chronically ill people how to find reliable internet health information. Review of the literature indicates that this is the first time an intervention combining the NLM video, teach-back, and independent practice has been tested in this population.

Chapter II Summary

Nurse researchers testing Orem’s theory have concentrated on the relationship between basic conditioning factors and self-care agency. Wilson extended foundational capabilities to include health literacy, however, there is no research that explores ehealth as a power component of self-care agency. Because of the increased availability of internet-based health information, it is necessary to test health literacy and ehealth skills as elements of Orem’s Self-Care Theory.
PLWH and low health literacy have poorer health outcomes but those who use reliable internet health information have better health outcomes. Regardless of health literacy level, many PLWH cannot recognize reliable internet health information because numerous HIV websites do not adhere to recommendations that ensure credibility. The health literacy of PLWH may be difficult to evaluate because the most commonly used instruments are not specific to the HIV self-care information needs. There is a limited number of ehealth interventional studies in PLWH; these studies indicate for more theory based interventional research. The third chapter presents the methodology, protocols, and instruments used in the study to test the relationships among basic conditioning factors, health literacy, ehealth, and self-care agency.
Chapter III

Methodology

This quasi-experimental study used Orem’s Self-Care Theory to determine if either ehealth intervention (MEDLINE or E-HELP) made a significant difference in health literacy, ehealth, ability to identify reliable internet health information, and self-care agency of PLWH. The study used a non-equivalent two group design recommended by Campbell & Stanley (1963) when groups are similar but researchers are not able to randomize participants. During Phase 1, the instrument packet was piloted with seven PLWH at another agency site for usability before Phase 2 data were collected. During Phase 2, participants received either the MEDLINE or E-HELP intervention. Data were collected at baseline, immediately after the intervention, and one week later (Table A5).

Methodology

Population and Study Sample

Population Characteristics

The setting for this study was a multi-site Adult Day Health Care Center (ADHC) program administered by a non-profit agency. The ADHC program provides healthcare, social services, and nutrition for PLWH and histories of substance abuse in the New York City boroughs of Brooklyn, Queens, and the Bronx. All three ADHC program sites have the same New York State Department of Health, AIDS Institute mandated program admission criteria. The study sample was drawn from the client population of this agency. Table A7 provides a comparison of demographics in the populations of the two study sites based on data published by the ADHC program in its annual report and provided for this study by an official of the program (personal communication, B. Zeller, 2014).
Sample Size

This study had a total sample size of 100 participants in two intervention groups. Sample size was determined using the G Power 3.1.2 statistical power program with an $\alpha$ of 0.05 and an effect size of 0.3 (http://www.psycho.uniduesseldorf.de/abteilungen/aap/gpower3)

Study Inclusion and Exclusion Criteria

Potential participants were accepted for the study if they were members of the ADHC program; 18 years of age or older; HIV-positive; had the ability to provide informed consent to be a research participant, and spoke English. There was no educational requirement, although data was collected on this variable. Because the measurement instruments were not validated in other languages and the NLM video was only available in English, potential participants who could not speak or understand English were excluded from the study.

Setting

Each ADHC program site has an educational room that is equipped with computers that are used by the participants. The Brooklyn and Queens sites were chosen because the demographic characteristics of the clientele of these two sites are the most similar. Using a computer random selection program, Queens was designated the E-HELP site and Brooklyn was designated as the MEDLINE site. During the day, there are many opportunities for clients to interact during programmatic activities. Geographic randomization rather than randomization of participants within the same location reduced the risk of study protocol contamination that would occur through the exchange of information between participants in different treatment groups at the same location.
Human Subjects Protection

There were two separate consenting processes: one for Phase 1 or the instrument testing and one for the intervention. The HIV/AIDS clinical agency that served the participants supported the research. The study was approved by the Institutional Review Board (IRB) at Hunter College (Appendix B). The required IRB standard consent form was used to obtain written consent from all participants prior to participation. Potential participants were informed that anxiety related to learning a new skill was a possible risk associated with the study and that if this occurred, a referral would be made to a healthcare provider. No participant expressed or exhibited anxiety at any point in the study. All signed consent documents were secured in a locked cabinet separate from data collection instruments.

The measurement instruments did not contain identifiable personal information and only the PI, research assistant (RA), and committee chair had access to that data. The RA was trained by the PI; all tasks and responsibilities associated with obtaining informed consent, reading and discussing study protocols, and human subject research ethics were reviewed. All members of the research team completed the Collaborative Institutional Training Initiative program.

A unique identifier was used for each participant that linked their individual scores at the three data collections points. The unique identifier was a combination of the first 2 letters of the borough and a number, e.g., BK1 for Brooklyn 1, QU2 for Queens 2. The key with the unique identifier was stored separately from the consents and the instrument packets.

Informed Consent Procedure

All participants gave written informed consent prior to participation in the research. The RA read the informed consent document with the potential participant and answered all questions. If the participant could explain in his or her own words the purpose and protocols of
the study, it was assumed the potential participant was able to give informed consent. The RA asked for a verbal indication from the potential participant that he or she understood the study and was interested in participating, then witnessed the participant signing the consent. Two potential participants, one in the E-HELP group and one in the MEDLINE group were not consented because they could not read the consent form. All participants were informed that they could withdraw from the study at any time without penalty and each participant was informed of the right to withdraw from the study prior to each treatment session. The RA followed a script when obtaining consent to ensure that potential participants were fully informed about study procedures, potential risks, and right to withdraw from the study (Appendix C)

**Recruitment**

The investigator posted flyers with a study description and contact information on the public information boards in the ADHC. Staff members of the ADHC programs referred potential study participants to the principal investigator (PI). Volunteers distributed flyers with information about the study in the client dining rooms of the ADHC sites two weeks prior to the study and regularly until recruitment targets were achieved. Announcements about the study were made in the ADHC program community meetings. Participants were provided a small thank you for their time with $10.00 at the end of each of the two sessions.

**Measurement Instruments**

The independent variables, health literacy, ehealth, and identification of reliable internet health information were measured with the HIV Related Health Literacy Scale (HIV-HL), the eHealth Scale (eHEALs), and the Identifying Reliable Internet Health Information Scale (IRIHIS) respectively. The dependent variable, self-care agency was measured with the Self-As-Carer Inventory (SCI). A demographic questionnaire collected descriptive information about
the samples’ basic conditioning factors and HIV related information. Appendix D (D1 through D5) contains the instrument packet.

**The HIV-Health Literacy Scale**

Health literacy was measured by the HIV Health Literacy Instrument (HIV-HL) which is a 20-item scale administered via a computer with a touchscreen or a mouse that uses multiple formats to present the items (Ownby, et al., 2012). Presentation formats include a picture with questions and several possible response choices related to the picture. Items presented in an audiovisual format test the respondent’s ability to listen and understand health information. Other items are presented in standard written form with a question and several possible responses test the respondent’s ability to read and understand instructions. The instrument can be self-administered and is self-scoring; it takes 10 to 15 minutes to complete. Reading level of this instrument could not be calculated because of the questions are presented in varying formats.

Quantitative analysis showed a strong correlation with the TOFHLA, a widely used test of health literacy (Ownby, et al. 2012). The instrument developers used receiver operating characteristic curve analysis to determine if the HIV-HL could predict if a respondent had low literacy on the TOFHLA. Results showed that a score of 15 on the HIV-HL predicted low literacy (area under the curve=0.77; z=2.57; p=0.01) on the TOFHLA. The HIV-HL was significantly correlated with the total score on the TOFHLA (0.58, p<0.05), and both the numeracy (0.54, p<0.05) and reading (0.53, p<0.05) subscales.

The HIV-HL was also significantly correlated with the information subscale of the LifeWindows Scale (0.39, p<0.05), a self-report measure of participants’ understanding and recall of medication instructions. The HIV-HL correlated with the immediate (0.37, p<0.05) and delayed recall (0.29, p<0.05) scales of the Wechsler Memory Scale. These correlations are
important because the HIV-HL requires respondents to remember and use what they heard in the audiovisual portions of the instrument, necessary health literacy and self-care skills.

The HIV-HL was administered in a study of the effectiveness of a computer administered health literacy intervention tailored for PLWH (N=120). Participant scores on the HIV-HL ranged from 8 to 20, out of a possible range of scores of 0-20, with a mean score of 16.38 and a standard deviation of 2.46. The Cronbach’s α was 0.69; the minimum acceptable value is 0.70 (Bland & Altman, 1997). The developers of the HIV-HL scale believe that the diverse format and content of the questions may be the reason for the borderline Cronbach’s α.

This instrument was selected for this study for several reasons: (1) the HIV-HL provides a comprehensive evaluation of the health literacy of PLWH by testing the application of prose, document, oral, listening, quantitative, and ehealth skills tailored to HIV self-care; (2) the computer-based format of the HIV-HL is consistent with the study’s intervention; (3) Ownby et al., developed the HIV-HL for a study that tests a computer delivered health literacy intervention as does this study, an indication of its suitability for this study and (4) there is no other instrument that tests HIV specific health literacy. Cronbach alpha was computed for baseline results for this sample as .691.

The eHealth Literacy Scale (eHEALs)

Electronic health literacy was measured with the eHealth Literacy Scale (e-HEALs) which is an 8 item Likert scale self-report tool that measures the individual’s perceived skill using internet technology for health information (Norman & Skinner, 2006a; Norman & Skinner, 2006b). The e-HEALs is comprised of six core skills or literacies, specifically: (1) traditional (2) health (3) information (4) scientific (5) media (6) computer; a total score is computed (Norman
& Skinner, 2006). The eHEALs is a paper and pen test and takes approximately 7 minutes to complete. The reading level of this instrument is 6th grade.

The eHEALs developers conducted reviews of the literature for each core literacy in Medline, PsycInfo, ERIC, Sociological Abstracts, and Web of Science. The literature review resulted in the decision to develop survey items based on a theoretical model of ehealth literacy because there are few ehealth literacy tools in the literature. Norman & Skinner (2006a) developed an initial bank of items and submitted them for review by experts in ehealth literacy. Instrument developers conducted small group item testing with adolescents ranging in age from 12-19 years to determine readability, item wording, and relevance. Adolescents were chosen to pilot test the items because they are a group with developing traditional and internet literacy skills. The final 8-item set was tested in a sample of students in grades 7-10 (N=230). The mean score was 3.0, indicating a moderately high level of confidence in using the internet for health information.

Internal reliability of the eHEALs with the alpha coefficient was 0.88. Item scale correlations between items ranged from $r=0.51$ to $0.76$. A principal components analysis produced a single factor solution with an eigenvalue=4.479, and explained 56% of the total variance. Factor loadings ranged from 0.60 to 0.84. Test-retest reliability of the e-Heals was calculated using a standard regression model and ranged from $r=0.49$ to $0.68$, showing modest stability over a six-month time period (Norman & Skinner, 2006a). Cronbach alpha was computed for baseline results for this sample as 0.945.

**Identifying Reliable Internet Health Information Scale**

The Identifying Reliable Internet Health Information Scale (IRIHIS) was created specifically for this study by the investigator using the format suggested by Bandura (1986). The
IRIHIS is a 6-item Likert type self-efficacy scale that measures the participants’ confidence in identifying reliable internet health information. The specific items were derived from the six criteria for a reliable website (Table A1.) which is explained in the Medline video, “Evaluating Internet Health Information.” The main stem of each item states, “When I look at a health information website I am confident I can identify…” and is followed by one of the six criteria. The IRIHIS item responses range from 1 indicating no confidence, to 5, indicating high confidence in the ability to find reliable internet health information. The respondents’ task is to select a response that reflects their confidence in their ability to identify a reliable health website. It takes approximately 5 minutes to complete the IRIHIS. Possible scores on the IRIHIS range from 6 to 30. The reading level is 8th grade for this scale. Cronbach alpha was computed for baseline results for this sample was .927. This is the first time the IRIHIS was used in a quantitative study.

**Self-As-Carer Inventory (SCI)**

The SCI is a 40-item paper and pencil self-report of perceived capacity to care for oneself (Geden & Taylor, 1991). Either a total score or subscales can be computed. The SCI is comprised of a six-point equal interval scale, with anchors of 1 for very accurate and 6 for very inaccurate. The lowest score is 40 and the highest possible score is 240, therefore, the higher the score, the better the self-care (Geden & Taylor 1991). The reading level of this instrument is 6th grade.

Three experts in Orem’s Self-Care Deficit Theory (Geden & Taylor, 1991) established content validity. Each expert was asked to judge the items for content validity and rate the item for clarity (1=clear to 3=unclear). Revisions were made on items that lacked content validity or were scored greater than 1 on clarity. The revised instrument was tested on 10 English speaking
adults in a public clinic. A second content analysis was undertaken to assess the relevancy of each item to self-care agency (the capacity for self-care) using a scale ranging from “not relevant=1” to “very relevant” =4. The content validity index was 94% (Geden & Taylor, 1991).

The SCI was piloted in a sample of 589 college students (Geden & Taylor, 1991). The test-retest reliability correlation coefficient for the whole instrument was 0.85. The subscale test-retest coefficients ranged from 0.83 on the judgment scale and 0.54 on the physical skills scale (Geden & Taylor, 1991). Cronbach’s coefficient alpha for the total inventory was 0.96. The Cronbach’s alpha for each of the subscales is as follows: knowledge of self, 0.92; judgments affecting self-care, 0.89; self-monitoring, 0.83; and physical skills and satisfaction with self-care, 0.87 (Geden & Taylor, 1991).

The research studies reviewed in Chapter Two also indicate that the SCI is a reliable and valid tool for the measurement of self-care agency in people with chronic illness (Token, Durmaz, & Argon, 2007; Ovayolu, Ovayolu, & Karadag, 2011; McDonnell, Turner, & Weaver, 2001). Participants in all studies scored within the moderate to high range for self-care agency (68 to 118 out of a possible range of score from 40 to 240) and had similar standard deviation scores (24 to 28). The alpha coefficients in the studies ranged from 0.94 to 0.97, comparable with Geden & Taylor’s alpha of 0.96. Cronbach alpha was computed for baseline results for this sample as .975.

**Demographic and HIV-related Questionnaire**

This questionnaire collected information on the basic conditioning factors of age, gender, race, ethnicity, educational level, and diagnosis of AIDS at a 5th grade reading level.
Interventions

The PI administered the interventions in two different formats to two groups designated as “E-HELP” or “MEDLINE” as described on Table A6. Both groups watched the NLM video, *Evaluating Internet Health Information* during the first session. The difference between the two interventions was the addition of a teach-back session in the E-HELP intervention. Scripts for the E-HELP and MEDLINE interventions are located in Appendix E (Appendix E1 and E2).

Data collection

Data were collected from July, 2013 through November, 2014. After ensuring that the participant understood and consented to participate in the study, the research assistant (RA) helped participants complete the demographic questionnaire and the four research instruments. The RA administered the instruments at each testing point in the study but was not involved in the intervention. Table A5 outlines the points in the study when the RA administered the measurement instruments. The equipment needed for this study included a computer with internet access and audio. Table A6 describes the specific tasks, time allotted, and personnel assigned to each intervention protocol.

The NLM Tutorial, *Evaluating Internet Health Information*

The United States National Library of Medicine and the National Institute of Medicine (Medline) 16-minute video, *Evaluating Health Information: A Tutorial from the National Institute of Health* (US Department of Health and Human Services 2009; US National Library of Medicine 2009) is located on the Medline Plus website. The video was selected for the accuracy and reliability of the information. Because it a government sponsored website, it is free of commercial sponsorship. The video explains how to evaluate a health information website using the criteria described on Table A1 and presents the information in visual, text, and audio formats.
The text is written at a 5th grade level. Because the Medline tutorial is in the public domain, participants were able to access the tutorial at other locations through the following link: http://www.nlm.nih.gov/medlineplus/webeval/webeval.html.

E-HELP Intervention

After viewing the NLM video, a 15-minute ehealth skills and teach-back session was conducted by the PI who guided participants as they navigated to an HIV health information website. During the teach-back session, the PI prompted participants to identify each of the six criteria of a reliable website. For example, the PI asked, “Can you show me how you would identify the sponsors of the website?” and the correct response was locating the “About Us” page. The script for the teach-back session can be found in Appendix E (Appendix E 1). After the teach-back session, the PI gave verbal instructions for the “At-Home Assignment,” (Appendix F) that was completed during the week between sessions. The PI instructed participants to look for HIV health information websites, evaluate them using the six criteria, and record their findings on the At-Home Assignment (Appendix F). Participants were encouraged to do the “at home” activity without help from family, friends, or ADHC staff. In the second session, participants reviewed the at-home assignment with the PI and then demonstrated their ehealth skills by independently finding an HIV health information website and identifying the six criteria of that reliable website (Table 1 A).

The MEDLINE Intervention

After watching the video, the PI gave the same verbal instructions for the at-home assignment as was given in the E-HELP intervention. A teach-back session was not conducted. The “at home” assignment was explained and the PI (Appendix E 2) answered any questions participants had about the at-home instructions (Appendix E 2). Participants returned in a week
for the second session. In the second session the At Home Assignment (Appendix F) was collected and the participant was asked to independently demonstrate the ehealth skill of finding an HIV health information website and identifying the six criteria of a reliable website.

**Quality Control Procedures**

Quality control measures ensured to the greatest degree possible that the interventions made the difference in the scores rather than outlying events (Table A8). Campbell & Stanley (1963) suggest that in order to reduce the threats to internal validity posed by history, maturation, testing, and instrumentation the groups should be as similar as possible. The first step in controlling for history and maturation is the selection of participants from similar populations. A high degree of similarity between the groups because of the similarities in the ADHC population demographics in terms of gender, age, socioeconomic status, educational level, race, ethnicity, and years with HIV was anticipated. To ensure that the histories and maturation processes of the groups were as similar as possible, the RA used the same recruitment script (Appendix B, Appendices B 1 and B 2) with each potential participant to ensure that the same information about the study was disseminated to all and that potential participants would have a similar understanding of the study.

Possible threats to internal validity posed by the interaction of history and maturation include the interaction between participants and non-participants, study fatigue, maturation of participants related to repeat testing, drifts in protocol for participant recruitment, instrument administration, intervention implementation, participant attrition, and extraneous environmental variables (Burns & Grove, 2009). To control for the possible effect on study outcomes of interactions between study participants and non-participating ADHC program clientele, the PI and the RA asked study participants not to request help finding reliable internet health
information from ADHC staff, clientele, friends, family, or other possible educators such as librarians or healthcare providers. In the second follow-up session, the PI asked study participants if they had received assistance, and their responses are reported in chapter 4.

Scheduling the intervention sessions in the early afternoon after lunch reduced the maturation threats of hunger and fatigue. The PI attempted to limit threats to internal validity caused by repeat testing by asking the participant to record his or her responses based on their perceptions and knowledge at that point in time and not previous experience. Study participants were informed that there was no “right” or “expected” answer to the questions and that an honest answer about their knowledge at that moment is the most helpful and accurate information.

The threat to internal validity posed by participant attrition was addressed by ascertaining, if possible, the reasons participants chose to drop out (Burns & Grove, 2009). Most attrition occurred after the first session in the MEDLINE group and was related to loss of follow-up because the participant dropped out of the ADHC program and could not be contacted by phone. In both groups, there were a number of participants (5 in MEDLINE and 4 in E-HELP) who were not interested in taking part in the second session and did not give a reason. However, potential participants were recruited to ensure a sample size of 50 was maintained for each group.

To reduce the effect of extraneous environmental variables, a specific time for the study was arranged at each study site. During that time, the education room was reserved and only study participants and researchers were allowed into that space. The computer was checked for working order prior to the study to prevent disruptions in protocol. The rooms at each ADHC program were inspected prior to each intervention point of the study to ensure that temperature,
lighting, furniture arrangement were as similar as possible to each other and at each data
collection point in the study.

**Treatment Fidelity**

Treatment fidelity refers to the methodological strategies used to monitor and enhance the
reliability of behavioral health interventions (Eaton, Doorenbos, Schimitz, Carpenter, &
McGregor, 2011; Bellg, et al., 2004). The five elements of treatment fidelity are (a) study
design, (b) interventionist training, (c) treatment delivery, (d) treatment receipt, (e) enactment of
treatment skills (Bellg, et al., 2004). Table A8 in explains the strategies used to promote
treatment fidelity.

**Research Hypotheses and Questions**

The research hypotheses tested relationships between the independent variables, health
literacy, ehealth, ability to identify reliable health information, and the dependent variable, self-
care agency.

**Research Question 1:** Does the E-HELP, compared to the MEDLINE intervention, significantly
increase HIV health literacy, ehealth literacy, the ability to identify reliable internet health
information, and self-care agency?

**Hypothesis 1:** E-HELP, compared to the MEDLINE intervention, makes significant
positive differences in the HIV health literacy, ehealth literacy, ability to identify reliable internet
health information, and self-care agency controlling for basic conditioning factors.

**Sub-hypothesis 1a:** The E-HELP intervention compared to the MEDLINE intervention
makes significant positive differences in HIV-health literacy.

**Sub-hypothesis 1 b:** The E-HELP intervention compared to the MEDLINE intervention
makes significant positive differences in electronic health literacy.
**Sub-hypothesis 1c:** The E-HELP intervention compared to the MEDLINE intervention makes significant positive differences on Ability to Identify Reliable Health Information.

**Research Question 2:** Does participation in either the E-HELP or MEDLINE intervention significantly increase HIV health literacy, ehealth, the ability to identify reliable internet health information and self-care agency?

**Hypothesis 2:** There are significant positive differences in HIV health literacy, ehealth literacy, the ability to identify reliable internet health information and self-care agency through participation in either E-HELP or MEDLINE.

**Sub-hypothesis 2a:** Participation in an ehealth intervention makes significant positive differences in HIV-health literacy.

**Sub-hypothesis 2 b:** Participation in an ehealth intervention makes significant positive differences in electronic health literacy.

**Sub-hypothesis 2c:** Participation in an ehealth intervention makes significant positive differences in Ability to Identify Reliable Health Information.

**Data Analysis**

Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 22 software (IBM Corporation, Armonk, New York). Data were cleaned and there were no missing data (Kellar & Kelvin, 2013). Prior to data analysis, instruments were reviewed to ensure all data were accurately recorded. Frequency tables were created and examined to locate missing data, and identify incorrectly coded data, out of range data, and skewness of data. If a variables had a skewness of less than + or -1, the variable was considered normal.
Cronbach’s alpha was calculated for each of the instruments used in the baseline data collection period in this sample in order to determine the reliability of the instruments. A reliability coefficient of .70 or higher is acceptable (Bland & Altman, 1997).

Descriptive statistics summarized the demographic and HIV-related findings for both MEDLINE and E-HELP groups and the total sample (Table A 11). Univariate statistical analyses used chi square or t-tests to determine if there were any significant differences on the basic conditioning factors between the E-HELP and MEDLINE groups (Table A 11).

Multivariate statistical analyses were undertaken to determine if the data supported or rejected the study hypotheses. Generalized linear models, specifically the mixed models procedure, was used in order to account for the longitudinal nature of the data. Because longitudinal assessments are obtained from the same subject it is necessary to account for the correlation of these repeated measurements. The mixed procedure allows for the modeling of the covariance structure to account for this correlation of the same subject responses (Singer & Willet, 2003).

**Chapter III Summary**

This study explored the relationship between the independent and dependent variables using a non-equivalent two-group design with two experimental conditions, and repeated measures before the intervention, immediately after the intervention, and one week later. Statistical analysis explored the effect of the interventions on the study variables. Quality control measures prevented drift from the data collection protocol. The study was conducted according to accepted ethical standards of research. All abbreviations used in the text were defined (Table A9).
Chapter IV

The Results

This chapter presents the results of Phase 1 and Phase 2 of the study. Phase 1 presents the results of the cognitive interviews conducted about the instrument packet and is presented in two main sections: (a) the sample characteristics of the interviewees and (b) the results of the cognitive interviews for each instrument. Phase 2 reports on the results of the implementation of the two ehealth interventions. Statistical findings of Phase 2 of the study are presented in two main sections: (a) descriptive statistics of sample characteristics and study variables and (b) multivariate statistical analyses of the data in order to test the hypotheses.

Phase 1: Piloting the Instrument Packet

The cognitive interviews in Phase 1 provided insight into issues related to participant instructions, instrument format, and the item choices on the self-report instruments. During Phase 1, participants are referred to as “interviewees” in order to avoid confusion between the two different samples. The purpose of the cognitive interviews was to determine how potential participants would interpret the data collection instruments and identify possible misperceptions in order to provide clear instructions to the participants during phase 2 of the study.

Description of Phase 1 Sample

Seven interviewees were included; the majority of whom were (Table A10) African American (6), female (5), and had a high school education (5). Three participants had an AIDS diagnosis for an average of 15 years. Two interviewees did not use computers or access the internet, one had a computer at home, one used the computer at the library, and the rest accessed the internet through multiple sources; only one interviewee searched for health information using a cell phone.
Results of Cognitive Interviews

In general, interviewees answered questions based on previous knowledge and past experience, which included living with HIV, experience with computers and the internet, and previous participation in research studies. One interviewee reported that the reason she was experiencing difficulty completing the instruments was that she needed glasses and did not wear them on the day she was interviewed. People with low literacy often use the excuse “I forgot my glasses” as an explanation for why they have not completed forms or read health information (Cutili & Bennet, 2006). Because the ‘forgot my glasses’ explanation could be expected in Phase 2, it was decided to give participants the option of having the instruments read to them.

Demographic and HIV-related Questionnaire

For the most part, interviewees felt that the questions were clear, did not need explanations and were self-explanatory. Interviewees found the questions easy to answer because, as one person said, the questions “related to self and I can relate to self.” Interviewees felt that potential participants would understand the questions if their ability to read was adequate. However, interviewees found question 2 about age, question 3 about race, and question 4 about ethnicity challenging to answer. Interviewees also commented that participants may have confusion about HIV status versus AIDS diagnosis.

Interviewees identified a problem with question 2, which asked “age at last birthday.” As one interviewee said, “The question about birthdays was tricky; I had to think about it for a while.” Another interviewee said, “Age at last birthday, that’s a funny way to say it.” One interviewee interpreted this phrase to refer to his age the previous year (2013), not his age the year of the cognitive interview (2014). For example, he was 51 in 2014, but reported his age as
50 because that is how old he was on his birthday in 2013. This was corrected in phase 2 by instructing participants to provide their age at their “most recent birthday.”

Racial/ethnic identification posed a challenge for an interviewee who picked the “other” choice in question 3 about race and for question 4 about ethnicity said, “No, I am not Hispanic.” This person identified herself as Puerto Rican. Persons whose country of origin is the Caribbean, Central or South America, might self-identify from a cultural or national perspective rather than the ethnic perspective of Hispanic/Latino or a racial perspective of African American/Black or White (Gennaro, 2013). This issue was resolved in Phase 2 by requesting that the participants check “Hispanic/Latino” if they identified as themselves as coming from any country where Spanish was the main language. In terms of race, any choice picked by the participant was accepted, including “other.”

Barriers to answering the demographic questions identified by the Phase 1 interviewees included feeling ashamed of their HIV status or not accepting their HIV positive status. Interviewees felt these barriers would prevent a participant from understanding the difference between HIV and AIDS. Another interviewee mentioned that some PLWH do not develop AIDS and that there was no choice for potential participants who fell into that category. In Phase 2, participants were instructed to answer questions related to HIV status to the best of their personal knowledge, and write “I don’t know” if they did not know their HIV status.

**HIV Health Literacy Instrument (HIV-HL)**

The HIV-HL uses a computer and some items require an answer before a respondent can proceed to the next screen. To illustrate, demographic items were asked and the interviewee could not proceed to the HIV health literacy questions until the demographic data was completed. As in the demographic survey, the interviewees of Hispanic/Latino descent did not
want to choose this option or select a racial category and wanted to be identified by their country of origin. To address this issue, participants in Phase 2 who expressed this sentiment were instructed to select the “choose not to answer” response because ethnicity was already selected on the demographic survey and not needed again on the HIV-HL for this study. Responses to HIV-HL demographic questions were not used in the data analysis, only the information collected on the demographic questionnaire.

Interviewees thought the HIV-HL instructions were clear. Those interviewees who experienced difficulty reading the text reported that hearing the instructions at the same time increased their comprehension. In contrast, those interviewees with proficient reading skills were frustrated with the slow pace of speech used by the narrator and felt it disrupted their concentration. One interviewee requested that the sound be muted, except for the video question. We allowed this option in Phase 2 for those participants who requested it.

For all of the interviewees, taking a test on the computer was a new experience and most of them said that using the computer to take an HIV literacy test was fun because they were learning a new skill while answering the questions. There was great variation in interviewees’ ability to use the internet. Interviewees with computer or internet experience were more comfortable navigating through the HIV-HL. Interviewees with limited internet experience appeared to have difficulty with eye-hand coordination when using the mouse to select answers to questions in the HIV-HL. The touch screen worked better with these interviewees because of the decreased need for hand-eye coordination. In Phase 2, a touch screen was used.

The interviewees enjoyed taking the HIV-HL because they were familiar with multiple choice questions and the subject matter gave them an opportunity to test their knowledge about HIV. The HIV-HL allowed the interviewees to use the knowledge they had accumulated about
being HIV positive from their own experience and education received from the clinical setting to answer the questions. One interviewee, who admitted to low literacy and cognitive deficits, said that the HIV-HL made him feel smart because he was not limited by having to read the questions.

Interviewees answered the questions about medication self-management from personal experience. For example, in question 12, about how many pills to take in the morning and evening, an interviewee responded “1 in the morning and 1 in the evening” because that was how he took his medication. When the interviewee answered the question this way and realized it was the wrong answer, he said, “Then I would take 2 in the evening to keep my doses even.” The correct answer was “2 in the morning and 1 in the evening.” On question 8 which asked the interviewee to figure out how many 100 mg tablets were needed, the correct answer was “take 3 pills 3 times a day,” an interviewee answered “take 3 one time because that is what I do.” Another interviewee said that taking 3 pills at a time was overdosing and that it should not be done. This statement in itself may be an indication of health literacy because it implies an awareness of safe medication self-administration. An interviewee interpreted the response choices “three pills three times a day” or “three at a time” as incomplete because the responses did not include the words “every day.” The interviewee concluded that without those phrases, there was no right answer among the responses. If this comment was made by a phase 2 participant, he or she was instructed to assume that the response meant that the medication was to be taken every day.

HIV provider practice protocols in the clinical setting influenced the way interviewees answered questions. For example, interviewees consistently answered “30” to question 6 about how long the prescription would last if they took 2 tablets twice a day if the bottle contained a
total of 60 tablets. The correct answer is 15 days because 4 tablets needed to be taken daily but all interviewees answered 30 days. This may be because the interviewees usually received prescriptions for a 30-day supply of medications prescribed for chronic health problems. Interviewees also had a problem with question 24, which asked the percentage of time PLWH had to take medication to prevent HIV drug resistance. The correct answer was 95%, but because there was not a “100%” choice included, interviewees felt that there was not a correct answer to this question. To address these issues in Phase 2, participants were instructed to answer the questions based on the information given in the question and not their personal experience.

**Electronic Health Literacy Scale (eHEALs)**

Interviewees found this the easiest paper and pencil test because the instructions at the beginning of the survey were simple. Interviewees stated that they knew how to answer the questions based on the instructions. Each numeric value on the scale had a description that participants were familiar with from other surveys. Selections were made based on the definitions associated with each numeric value. Interviewees liked the 1=strongly disagree to 5=strongly agree format. The instructions for taking the eHEALs were not modified in Phase 2. However, proficiency and using the internet and beliefs about internet information influenced answers. Interviewees who used computers based their answers on knowledge of the internet and past experience browsing and “googling.” One interviewee who used the internet likened the term “internet health information resources” to a “health library.” Another interviewee who used the internet had difficulty answering the questions because “you can’t believe everything on the internet.” An internet user was challenged by the eHEALs items about how to use the internet to find information (item 4), differentiating between high and low quality information (item 7), and
confidence in using the internet for health decisions (item10). This interviewee said, “Sometimes the internet may not have all the information, I would second guess or ask my primary care provider.”

Self-perception of computer literacy influenced interviewees’ response choices on the eHEALS. Those interviewees who did not use the internet described themselves as “computer illiterate” and tended to select the “strongly disagree” response choice to items on the eHEALs. When one interviewee was asked about her choices, she stated “I gave a lot of ‘strongly disagree’ answers because I don’t know about the internet. I was thinking as I answered the questions that I really needed the computer and I could use it to better my health. It opened me up to the possibilities of what I need to learn. I need to advance my technology skills to advance my health.” Another interviewee who described himself computer illiterate answered “strongly disagree” to question #3 about knowledge of internet resources. But his reasoning for this choice indicated a degree of computer ability, “If I wanted to learn I would type in ‘neuropathy’ and follow the instructions.” This response indicates that electronic health literacy, the concept measured by the eHEALs, may be viewed by this population as a dichotomy: a person is either a computer expert or computer illiterate, instead of a skill that is achieved along a learning curve. In phase 2, when potential participants did not believe that they qualified for the study because of “computer illiteracy,” the research assistant explained that computer expertise was not need for this study.

Desire to participate in the study influenced one interviewee’s avoidance of the response choice “strongly disagree.” An interviewee who did not have any computer experience selected “strongly agree” or “agree” to all items. When asked about her choices, the interviewee admitted that she based her responses on the belief that computer expertise was a requirement of the study.
Because social desirability played a part in this interviewee’s responses, phase 2 participants were informed that computer expertise was not a requirement for participating, that researchers were interested in knowing what they actually knew about the internet and computers, and there was no penalty for not knowing about computers or the internet.

**Identifying Reliable Internet Health Information Survey (IRIHIS)**

Interviewees answered the questions in the IRIHIS based on information they remembered from the video. Interviewees had trouble with the stem and leaf format of the questions in the IRIHIS. They did not understand that each question related to the main stem. Once the stem and leaf format was explained interviewees were able to answer the questions and realized that the IRHIHS “showed me how well I understood the video.” In phase 2, the IRIHIS was revised so that each item was a separate, self-contained statement.

Interviewees had trouble with the 0–100 scale and saw the choices as percentages or grades that they associated with school, which they found intimidating and made them feel “stupid.” One interviewee said he felt nervous answering the questions because “I wasn’t sure if I was in the range of knowing the information.” Only an interviewee who had used a 0 to 100 scale before understood the instructions about how to select a choice from 0 to 100.

Interviewees recommended that the format of the IRIHIS mimic the eHEALs because the 5 selections from strongly agree to strongly disagree were familiar. In phase 2, the IRIHIS was changed to the same format as the eHEALs.

**Self-As-Carer Inventory (SCI)**

Interviewees enjoyed completing the SCI because it gave them an opportunity to look at themselves and their health. As one interviewee said, it “provided an honest explanation of my health. The reality of how I am living. I thought about what was detrimental or hurt my health,
smoking crack, risking incarceration, losing my housing. The questions helped me; they were a wakeup call to help me face my demons. I wanted to have a better life in order to have better choices. I should be at a place where I should not have to think about drugs or alcohol.” Another interviewee said “these are some good questions as to how I take care of myself. They make me think if I am doing what I need to do.”

The meaning of self-care was influenced by life experience. An explanation for choosing all “6s” or “very accurate” for all items on the SCI given by several interviewees was “I am not using drugs anymore; therefore, I am taking care of my health.” Social desirability may also influence the way interviewees answered the SCI. Interviewees did not want to be perceived as not taking care of their health while attending a health program. In order to compensate for these possibilities during phase 2, the research assistant was asked to instruct the client that “this tests looks at the many different ways people take care of themselves and their health “and participants were instructed to measure their self-care right now and not in comparison to when they were actively using drugs. Participants were also reassured that no judgments were made about their self-care choices and encouraged to answer honestly.

Although the SCI has 40 items, test fatigue did not appear to be a cause for the frequent selection of 6. Another possible cause for this selection of 6 might be lower reading comprehension, as expressed by one interviewee who admitted she had a 4th grade reading level, “I had to read the questions several times because my comprehension is not 100% real good.” When SCI items were read to this interviewee, there was less selection of the value 6. This difference may be because people have better comprehension of the spoken word compared with written material (Baker, 2006). In phase 2, the research assistant offered the participants a choice of having the SCI read to them or reading it themselves.
The biggest challenge the interviewees reported was the scale used in the SCI. The instrument used a numeric scale from 1 = not accurate at all to 6 = very accurate statement about how the respondent took care of his/herself. All the interviewees felt that the explanation at the beginning or the SCI did not help them understand how to respond to the items. Although interviewees appreciated that they had more choices than Yes or No, they expressed a preference for the five choice format of the eHEALs with familiar definitions for each numeric value. The lack of definitions or suggested explanation for each item choice in the instructions created difficulty for the interviewees, and the addition of a 6th choice made selection of a response more challenging for interviewees. As one interviewee said, “Because there were no words next to the numbers, I had to think about what the answers meant.”

Interviewees had different interpretations of the meaning of “accurate” and ‘inaccurate” when associated with health and self-care. One interviewee said that accurate meant “it fit with what I do” and inaccurate meant, “I am not capable of doing that.” Another interviewee said 1 meant “totally non-compliant” and 6 meant “interested in improving my life.” Still another interviewee interpreted 1 to mean “it does not pertain to me” and 6 to mean “the highest point, the best you can do.” One interviewee tried to provide definitions for a middle value; if 1 meant poor health and 6 meant healthy, 4 meant “like okay, not as bad as it could be and it could be better.” An interviewee said, “I figured out the answer by reading the question and knowing what I do myself and what would be the other answer if I was sick.” One participant had a clever solution to the scale problem. He said that he translated the numbers into the smiley faces used on the pain scale and suggest the Wong-Baker Pain Analogy Scale as a way to help potential participants understand the scale. Although this was a clever solution, it could not be implemented in phase 2 because the use of a visual scale instead of a numeric scale would have
required further testing for reliability and validity. The different interpretations of the terms used in the scale by the interviewees indicated that potential participants would have problems understanding the instructions and the terms accurate and inaccurate without specific concrete explanations.

In order to help participants understand the 1 (inaccurate) to 6 (accurate) scale, the modifying adjective “very” was used to differentiate between negative values 1 and 2 and positive values 5 and 6 for the terms “accurate” and “inaccurate.” The term “somewhat” was used to differentiate between accurate and inaccurate in the middle values of 3 and 4. In phase 2, participants were given a card with the scale that had definitions for each number:

1: This is a **very inaccurate** description of how I take care of my health
2: This is an **inaccurate** description of how I take care of my health
3: This is a **somewhat inaccurate** description of how I take care of my health
4: This is a **somewhat accurate** description of how I take care of my health
5: This is an **accurate** description of how I take care of my health.
6: This is a **very accurate** description of how I take care of my health

**The NLM Video**

Because the NLM video was required to answer the IRIHIS and was part of the intervention, the interviewees were asked to watch the video. All of the interviewees except one enjoyed the video. The interviewees repeated information stated by the narrator, read out loud with the narrator, or nodded their heads in agreement. One interviewee took notes during the video. An interviewee said, “The video makes me think about things I never thought of before when I go on the internet. The video explained what I need to look at: updates, advertisements, how the site uses information. Now I see how websites get your information. I never knew that
‘about us’ thing.” Another interviewee said, “I never paid attention. I never thought about information being out of date, privacy. The video influenced me on privacy. I’ve seen these things on the internet but never clicked them. If I hadn’t seen the video, my scores would be lower (on the IRIHIS.” Only one interviewee felt that the video was too slow and therefore, boring. He said, “As I watched the video, I was kinda paying attention and thinking I wish this would hurry up.” During phase 2, participants were informed that the video took about 15 minutes so that they were aware of how long they would be watching it.

Phase 2: Testing the Effects of the Two eHealth Interventions

Based on Orem’s theory, we hypothesized that both ehealth interventions would increase HIV health literacy, ehealth literacy, the ability to identify reliable internet health information and self-care agency in a sample of low income PLWH while controlling for basic conditioning factors. In addition, we hypothesized that the E-HELP intervention, compared to MEDLINE, would result in greater increases in the study variables.

Description of Phase 2 Sample

Recruitment

A total of 131 potential participants were approached for both interventional groups; 71 for the MEDLINE group and 60 for the E-HELP group (Figure 3). Seventy-one potential participants were recruited for the MEDLINE group and 3 potential participants were not eligible for the study: 2 people were not ADHC clients, and 1 person could not read or understand the consent. The remaining 68 potential participants consented to participate in the study. Of the 68 participants enrolled in the MEDLINE interventional group, 18 (26.4 %) did not complete the study; 13 participants were lost to follow up because they did not return to the program and could not be reached by phone, and 5 participants did not complete the second session.
Sixty potential participants were recruited for the E-HELP group and 59 potential participants were consented to participate. One person was not consented because he could not read and understand the consent form. Of the 59 consented participants for the E-HELP group, 9 (16.6%) did not complete the study: 5 people were lost to follow-up because they did not return to the program and could not be contacted, and 4 people did not complete the second session.

**Description of Sample**

The average participant was 50 years old, male, African American, not Hispanic/Latino, completed high school or less education. Because the category of “White” consisted of only one participants in each group and the remainder identified as other or Hispanic/Latino, these two categories were merged together into “Non-African American.” All participants were living with HIV and 39% of the sample had been diagnosed with Acquired Immune Deficiency Syndrome (AIDS). Chi-square analyses found no significant differences in the basic conditioning factors between the MEDLINE and-E-HELP groups (Table A11).

**Descriptive Data for Research Instruments**

There was a borderline Cronbach alpha for the HIV-Health Literacy instrument of 0.69 which approaches acceptable reliability (Burns & Grove, 2005, pg. 377; Table 4.3). This was consistent with the Cronbach Alpha found by the instrument’s developers, 0.69 (Ownby, et al., 2013). There are a limited number of instruments that assess HIV health literacy and none that are internet based or can be administered via a laptop, characteristics consistent with the overall goal of this study. Therefore, the HIV-HL was the best instrument for this study. All other Cronbach alphas were in an acceptable range.

Because the Identifying Reliable Internet Health Information Survey (IRIHIS) was developed specifically for this study and was based on the Medline video. A principal
components factor analysis of the IRIHIS was computed and one factor explained 73.39% percent of the variance indicating that the instrument is measuring one latent variable and has construct validity; the factor loadings ranged from .161 to 4.407 (DeVellis, 2012).

**Statistical Analysis of Study Variables**

In this study, we were seeking to determine if an ehealth intervention would make a significant difference on the study variables and whether E-HELP had more of an effect than MEDLINE.

The mixed model procedure, a Generalized Linear Modeling technique, was used in order to account for the longitudinal nature of the data. For longitudinal data, responses from the same subject are collected at multiple time points. The correlation of a given subjects repeated measurements must be taken into account – they are not independent, but are expected to be more alike than responses from two different subjects. The mixed procedure enables us to model this correlation or stated another way, we are controlling for subject. The mixed procedure allows for the modeling of the covariance structure to account for this correlation of the same subject responses. A restricted maximum likelihood approach (REML) was used and the covariance type was unstructured since we were not imposing any constraints on the values (theanalysisfactor.com, n.d.). A full model was fitted first for all study variables and included the basic conditioning factors of age, gender, race, ethnicity, education, and AIDS diagnosis. Model fitting was repeated eliminating the non-significant variables with the exception of time and the interaction of time and group. The independent variables (HIV health literacy, ehealth, and ability to identify reliable internet health information) were loaded to determine the effect of the intervention on the dependent variable, self-care agency. (Grace-Martin & Schnell, personal communication, February 15, 2016).
Hypothesis Testing

**Research Question 1:** Does the E-HELP, compared to the MEDLINE intervention, significantly increase HIV health literacy, ehealth literacy, the ability to identify reliable internet health information, and self-care agency irrespective of basic conditioning factors?

**Hypothesis 1:** E-HELP, compared to the MEDLINE intervention, makes greater significant positive differences in HIV health literacy, ehealth literacy, ability to identify reliable internet health information, and self-care agency controlling for basic conditioning factors.

**Effect of the Interventions on Self-Care Agency**

Self-care agency was measured immediately before the intervention and one week after the intervention. The mean scores for self-care agency were higher in the MEDLINE group compared with the E-HELP group at baseline (204 vs. 185) and one week after the intervention (205 vs. 187).

In the mixed model procedure for self-care agency, a full model was fitted first (Table A12). This model included age, gender, race, ethnicity, education, AIDS diagnosis, HIV health literacy, ehealth, ability to identify reliable internet health information, time, group, and the interaction of time by group. The dependent variable was self-care agency. Of the independent variables, group \((df=1, F=15.777, p=.000)\) and ethnicity \((df=1, t=4.834, p=.030)\) were statistically significant. Time was not significant \((df=1, F=1.522, p=.220)\). HIV health literacy, ehealth, ability to identify reliable internet health information had no effect self-care agency (Table A12). Akaike’s Information Criterion (AIC) was 1802.03.

Model fitting was repeated eliminating the non-significant variables with the exception of the time, group, and the interaction of time and group because we were interested in the effect of
these variables on self-care agency (Table A12). The main effect for group was significant ($df=97, F=13.992, p=.000$), but not for time ($df=98, F=.291, p=.591$) or the interaction of time and group ($df=98, F=.020, p=.887$). However, because time, group, and the interaction were of primary interest, the main effects for these variables were retained in the model.

Comparing the overall means (E-HELP and MEDLINE groups combined) there is little difference (194.95 vs. 196.39) with the time one week after the intervention being slightly higher but not statistically significant in the model ($p=.631$) (Table A12). For the overall effect of group (baseline and one week after the intervention combined) the difference is significant (204.640 vs. 186.698, $p < .000$) with the MEDLINE group continuing to score higher than the E-HELP group. Looking at time and group together (the interaction) shows that in both groups, self-care agency increases over time (not significantly) and at one week after the intervention, the MEDLINE group is again higher, as the non-significant interaction indicated ($df=98, F=.142, p=.887$). The only significant basic conditioning factor was ethnicity in that non-Hispanic/Latinos scored higher than Hispanic/Latinos (207.98 vs. 183.36, $p=.000$). Akaike’s Information Criterion (AIC) was 1834.28 which is slightly higher but not unexpected.

Hypothesis 1 was not supported in that there were no significant differences in the interaction of time and group or group for self-care agency and changes in HIV health literacy, ehealth, and ability to identify reliable internet health information did not affect self-care agency. Only ethnicity made a difference in self-care agency, with Hispanic/Latino persons having less self-care agency compared with Non-Hispanic/Latino persons.
Sub-hypothesis 1a: The E-HELP intervention compared to the MEDLINE intervention makes significant positive differences in HIV-health literacy.

In the mixed model procedure for HIV health literacy, a full model was fitted first (Table A13). This model included age, gender, race, ethnicity, education, AIDS diagnosis, time, group, and the interaction of time and group (Table A13). The dependent variable was HIV health literacy. Of the independent variables, time \((df=1, F=8.180, p=.001)\), gender \((df=1, F=5.001, p=.028)\), group \((df=2, F=6.231, p=.014)\), and age \((df=1, F=4.749, p=.032)\) were statistically significant (Table A13). The interaction of time and group was not significant \((df=2, F=.291, p=.748)\). Akaike’s Information Criterion (AIC) was 1316.48 for the full model.

Model fitting was repeated eliminating the non-significant variables with the exception of the interaction of time and group (Table A13). The main effect for group \((df=1, F=7.886, p=.006)\), time \((df=2, F=8.180, p=.001)\), and gender \((df=1, F=4.385, p=.039)\) were significant. The interaction of time and group remained non-significant \((df=2, F=.291, p=.748)\). However, since the interaction of time and group are of primary interest, the interaction was retained in the final model.

In the final model for HIV health literacy, comparing the overall group means (E-HELP and MEDLINE groups combined) for time, one week after the intervention, there is little difference in the mean scores (14.38 vs.15.33), which are higher but not statistically significant as shown in Table A13 \((p=.265)\). For the overall effect of group (baseline and one week after the intervention combined) the difference is significant (14.1 vs. 15.6 \(p <.027\)) with the E-HELP group scoring higher than the MEDLINE group (Table A13). Akaike’s Information Criterion (AIC) was 1324.34 for the final model.
Looking at the interaction of time and group together shows that both groups show a similar pattern over time in that HIV health literacy increases over time, but not significantly. At one week after the intervention the E-HELP group is again higher, but the difference is not significant \((\text{df}=98, t=-0.744, p=0.459)\). For gender, females scored higher than males \((15.39 \text{ vs. } 14.13, p=0.039)\) (Table A13). The overall group mean is 49.95 and that is the reason younger/older than age 50 years was used. For age, participants younger than 50 years of age scored better than participants older than 50 years of age. Although group made a difference, time did not make a difference, and the interaction between time and group did not make a difference. Based on these results, sub-hypothesis 1a was not supported in that participation in E-HELP compared to participation in MEDLINE did not make a significant improvement in HIV health literacy.

**Sub-hypothesis 1 b: The E-HELP intervention compared to the MEDLINE intervention makes significant positive differences in electronic health literacy.**

In the mixed model procedure for ehealth, a full model was fitted first (Table A14). This model included age, gender, race, ethnicity, education, AIDS diagnosis, time, group, and the interaction of time by group. The dependent variable was ehealth. Of the independent variables, time \((\text{df}=1, F=27.683, p=0.000)\) and age \((\text{df}=92, F=9.033, p=0.003)\) were statistically significant (Table A14). Akaike’s Information Criterion (AIC) was 1964.10 for the full model.

Model fitting was repeated eliminating the non-significant variables with the exception of group and the interaction of time and group; because these variables are of primary interest to the study, the main effects of those variables were retained in the model (Table A14). The main effect for time remained significant \((\text{df}=2, F=27.663, p=0.000)\). The main effect for group remained non-significant \((\text{df}=1, t=-2.146, p=0.146)\). The interaction of time and group remained
non-significant \((df=2, F=1.192, p=.308)\). Age remained significant \((df=1, F=11.072, p=.001)\). Table A14 displays the final model and Akaike’s Information Criterion (AIC) was 1980.62 for the final model.

Comparing the overall group means (E-HELP and MEDLINE groups combined) there is significant difference between the means for E-HELP and MEDLINE groups with the E-HELP group score significantly higher \((28.74 \text{ vs. } 30.19, p=.047)\) (Table A14). For the overall effect of time, (baseline and one week after the intervention combined) the difference is not significant \((25.4 \text{ vs. } 31.6, p =.545)\) with the E-HELP group scoring higher compared to the MEDLINE group.

Looking at time and group together (the interaction) shows that in both groups, ehealth increases over time; although E-HELP group scores are higher immediately after the intervention \((30.5 \text{ vs. } 32.4)\), this is not significant \((df=98, t=1.523, p=.131)\). At one week after the intervention, the E-HELP group is again higher \((30.2 \text{ vs. } 32.9)\), although the interaction is not significant \((df=98, t=.643, p=.521)\). The MEDLINE and E-HELP group means at each time point are not significantly different and the overall pattern is the same; the E-HELP mean increases slightly from right after the intervention to one week later while the MEDLINE mean goes down slightly but these are not significantly different. Based on these results, sub-hypothesis 1b is not was not supported in that participation in E-HELP compared to participation in MEDLINE did not make a significant improvement in electronic health literacy.

**Sub-hypothesis 1c: The E-HELP intervention compared to the MEDLINE intervention makes significant positive differences on ability to identify reliable health information.**

Mixed model procedures were conducted to determine if these changes made an actual difference over time (Table A15). The mixed model for ability to identify reliable internet health
information included age, gender, race, ethnicity, education, AIDS diagnosis, time, group, and the interaction of time by group. The dependent variable was ability to identify reliable internet health information. Of the independent variables, time \((df=98, F=64.984, p=.000)\) and time by group \((df=98, F=4.171, p=.018)\) were significant (Table A21). Group was not significant \((df=1, F=.898, p=.346)\). Age was significant \((df=92, F=5.282, p=.024)\). Akaike’s Information Criterion (AIC) was 1797.84 for the full model.

Model fitting was repeated eliminating the non-significant variables but retaining group because it is a variable of interest to this study (Table A15). The main effect for time was significant \((df=2, F=64.984, p=.000)\), but not for group \((df=1, F=1.540, p=.218)\). However, the main effect of the interaction of time and group was significant \((df=2, F=4.171, p=.018)\). Age remained significant \((df=1, F=5.282, p=.024)\). Akaike’s Information Criterion (AIC) was 1817.30 for the final model.

Comparing the overall means for time (E-HELP and MEDLINE groups combined), there is a difference \((22.3 \text{ vs. } 25.0)\) in means one week after the intervention being statistically significant higher as indicated in the model \((p=.028; \text{ Table A15})\). For the overall effect of group (baseline and one week after the intervention combined) the difference is not significant \((21.31 \text{ v. } 22.36, p=.079)\) with the E-HELP group actually scoring higher than the MEDLINE group. Looking at time and group together (the interaction) shows the E-HELP group score is significantly higher immediately after the intervention \((21.54 \text{ vs. } 24.29, p=.024)\); at one week after the intervention the E-HELP group is again higher compared to the MEDLINE group \((24.22 \text{ v. } 25.78)\), but the difference is not significant \((p=.259; \text{ Table A15})\). Based on these results, sub-hypothesis 1c is not was not supported in that participation in E-HELP compared to
participation in MEDLINE did not make a significant improvement in ability to identify reliable internet health information.

**Research Question 2**: Does participation in either the E-HELP or MEDLINE intervention increase HIV health literacy ehealth, the ability to identify reliable internet health information and self-care agency?

**Hypothesis 2**: There are significant positive differences in HIV health literacy, ehealth literacy, the ability to identify reliable internet health information and self-care agency through participation in either E-HELP or MEDLINE.

**Within Group Differences for Self-Care Agency**

As Table A16 illustrates, there are no statistically significant within group differences for the MEDLINE ($df=98, t=-1.060, p=.780$) or E-HELP ($df=98, t=-1.820, p=.631$) group and self-care agency in that, over time, the interventions did not make a difference.

**Sub-hypothesis 2a**: Participation in an ehealth intervention makes significant positive differences in HIV-health literacy.

Both the MEDLINE and E-HELP group show the same overall pattern of improvement in HIV health literacy over time. As illustrated in Table A17, there was no significant difference in HIV health literacy for either group from baseline to immediately after the first session (MEDLINE: $df=98, t=-.460, p=.324$; E-HELP: $df=98, t=-.320, p=.602$). For both groups, HIV health literacy is statistically significantly higher at the second session one week later compared to baseline (MEDLINE: $df=98, t=-1.080, p=.005$; E-HELP: $df=98, t=-.8.20, p=.045$). However, there were no significant increases in HIV health literacy from the first session to the second session (MEDLINE: $df=98, t=-6.20, p=.093$; E-HELP $df=98, t=-.320, p=.602$). Although HIV health literacy improved over time for both groups and the E-HELP group had higher scores
compared with the MEDLINE group at time 0 (15.1 vs. 13.6), time 1 (15.6 vs. 14.08), and time 2 (15.9 vs. 14.7), the interventions did not make a difference. However, within group differences from baseline to the second session showed significant positive changes for both groups.

**Sub-hypothesis 2b:** Participation in an ehealth intervention makes significant positive differences in ehealth.

As illustrated in Table A18, the pattern for within group differences over time for ehealth was the same for the MEDLINE and E-HELP groups. There was a statistically significant differences in ehealth from baseline to immediately after the first session for both groups (MEDLINE: $df=98$, $t=-5.020$, $p=.000$; E-HELP: $df=98$, $t=-7.140$, $p=.000$). For both groups, ehealth is statistically significantly higher one week later compared to baseline (MEDLINE: $df=98$, $t=-4.720$, $p=.003$; E-HELP: $df=98$, $t=-7.740$, $p=.000$). However, there were no significant increases in ehealth from the first session to the second session (MEDLINE: $df=98$, $t=300$, $p=.987$; E-HELP: $df=98$, $t=-300$, $p=.906$). Although ehealth improved over time and the E-HELP group had higher scores compared with the MEDLINE group at time 1 (32.2 vs. 30.5) and time 2 (32.9 vs. 30.2), these differences were not significant and the interventions did not make a difference.

**Sub-hypothesis 2c:** Participation in an ehealth intervention makes significant positive differences in ability to identify reliable health information.

As illustrated in Table A19, for both groups there were statistically significant difference in ability to identify reliable internet health information from baseline to immediately after the first session (MEDLINE: $df=98$, $t=-3.26$, $p=.004$; E-HELP: $df=98$, $t=-7.30$, $p=.000$) and from baseline to the second session (MEDLINE $df=98$, $t=-5.84$, $p=.000$; E-HELP: $df=98$, $t=-8.80$, $p=.000$).
The E-HELP and MEDLINE group means for ability to identify reliable internet health information at baseline and the first session are statistically significantly different from each other. Ability to identify reliable internet health information was statistically significantly higher at the second session compared to the first session only for the MEDLINE group \((df=98, t=-2.58, p=.000)\); within group differences were not significant from the first session to the second session for the E-HELP group \((df=98, t=-1.50, p=.082)\).

In summary, mixed models procedures demonstrated that the ehealth interventions did not make a difference in the study variables. HIV health literacy, ehealth, and ability to identify reliable internet health information had no effect on self-care agency. Only ethnicity made a difference in self-care agency in that Hispanic/Latino persons had less self-care agency compared to non-Hispanic/Latinos. Age and gender had an effect on HIV health literacy and age alone had an effect on ehealth.

There were within group differences from baseline to after the second session for HIV health literacy, ehealth, and ability to identify reliable internet health information. There was only within group changes from the first session to the second session for the E-HELP group. There were no within group changes for either group in self-care agency. In addition, interesting descriptive data emerged from the ehealth interventions.

**Descriptive Data about the E-HELP and MEDLINE Interventions**

The following section discusses the results of the at-home assignment and the second session. Comparisons of website selection, frequency and length of internet searches, responses on the at home assignment, and observations during the second session are described.
Length of time for teach-back for E-HELP Group

Participants in the E-HELP group interacted with the PI in a teach-back session to practice their skills in finding reliable internet sites for an average of 12 minutes (SD=3.25, range 7 to 20 minutes).

Time Spent Accessing the Internet for Health-related Information between Sessions

When participants returned for the second session, they were asked how many times they accessed the internet and how much time they spent looking for a health web-site during the intervening week. Participants in the MEDLINE group accessed the internet 1.6 times and spent an average of 22 minutes compared to 1.7 times and 19 minutes for the E-HELP group. Only one participant in the entire sample watched the NLM video again.

At-Home Assignment Data.

Both E-HELP and MEDLINE participants completed the at-home assignment (Appendix F) during the intervening week. At the beginning of the follow-up visit, the PI collected the at-home assignment that all participants submitted. They were then asked if they received any help with the assignment and 8 (16%) participants in the E-HELP and 16 (32%) participants in the MEDLINE group reported that they received help mainly from staff at the ADHC.

The at-home assignment consisted of seven items listed on Table A20, which included the six criteria and a fill in item for the name of the website. Responses are also presented on that table.

After submission of the at-home assignment, participants were asked to navigate to a HIV health information website. Forty-eight percent of E-HELP participants identified a reliable HIV health information website and compared to 60% of MEDLINE participants that identified a reliable HIV health information website. The mean score for the MEDLINE group was 38.32
(SD=25.091) and the mean score for the E-HELP group was 84.04 (SD=14.04). The PI observed participants as they navigated the web and answered each of the seven questions and those results are presented on Table A21. Descriptive data indicates differences between E-HELP and MEDLINE groups as their electronic-health literacy skills were objectively observed by the PI. These differences require further testing.

**Chapter IV Summary**

This chapter discussed the findings of Phase 1 and Phase 2 of the study. In phase 1, cognitive interviews were conducted in the Bronx site of the ADHC in order identify any confusing instructions, instrument formatting issues, or challenging item choices that participants in phase 2 may encounter when completing the instrument packet.

In phase 2, we sought to determine if the interventions made a significant difference in HIV health literacy, ehealth, ability to identify reliable internet health information and self-care agency by comparing the effect of the MEDLINE and E-HELP interventions on the respective groups. HIV health literacy, ehealth, ability to identify reliable internet health information, and the interventions did not result in significant changes in self-care agency for either group.

Hypothesis 1 was not supported. There were no statistically significant differences between groups in any of the study variables. The only basic conditioning factor that had a significant effect on HIV health literacy, ehealth, and ability to identify reliable internet health information was age; gender was significant only for HIV health literacy and ethnicity was significant only for self-care agency. Race, education, and AIDS diagnosis did not have an effect on any variable. Hypothesis 2 was partially supported. There were statistically significant within subjects’ differences in HIV health literacy, ehealth, and the ability to identify reliable internet
health information for both groups. There were no significant within group differences for self-care agency.

All participants in both groups completed the at-home assignment. The study sample searched for HIV health information on the internet an average of 1.65 times and spent an average of 20 minutes searching for information. Sixteen percent of participants in the E-HELP group asked for help and 32% of participants in the MEDLINE group asked for help. Sixty percent of the participants in the E-HELP group were able to identify a reliable HIV health information website compared with 40% in the MEDLINE group. Chapter V discusses the implications of these findings.
Chapter V

Discussion of Results

This chapter discusses the results of this study based on: (a) the two research hypotheses within the context of findings and related literature, (b) relationship of basic conditioning factors to study variables (c) theoretical implications for Orem’s Theory of Self-Care, (d) evaluation of the measurement instruments, (e) a review of the strengths and limitations of the research, and (f) implications for research, practice, and policy.

Overview of Study

Results suggest that both the MEDLINE and E-HELP interventions have the potential to be effective. Multivariate analyses determined that although both interventions demonstrated improvements in health literacy, ehealth, and ability to identify reliable internet health information, there were no significant differences between the groups. There were, however, significant within group differences from baseline to the second session for both groups in HIV health literacy, ehealth, and ability to identify reliable internet health information. This was the first study to explore the relationships between HIV health literacy, ehealth, ability to identify reliable internet health information, and self-care agency in this population using Orem’s theory of self-care agency as a theoretical foundation. Neither intervention had an effect on self-care agency. Results of the study did not provide sufficient evidence to expand Orem’s theory of Self-Care Agency to include health literacy as a foundational capability, or include ehealth and ability to identify reliable internet health information within the scope of power component #7. It is also the first study to test the NLM video in a chronically ill population.
Hypotheses

**Hypothesis 1:** E-HELP, compared to the MEDLINE intervention, makes greater significant positive differences in HIV health literacy, ehealth literacy, ability to identify reliable internet health information, and self-care agency controlling for basic conditioning factors.

E-HELP compared to the MEDLINE intervention, did not make greater significant changes in the study variables from baseline to the second session. Several reasons may account for the lack of significant difference between interventions. The one-week interval between session was insufficient for participants to increase HIV health literacy, develop confidence in ehealth skills, or to be able to identify reliable internet health information.

This was the first time many of the participants used a computer to find health information on the internet. Opportunities to access the internet were limited for this population; participants reported accessing the internet 1.7 times and spending approximately 20 minutes searching for HIV related internet information. Seventy-four percent of the sample did not have computers and relied on computers at the ADHC, the public library, or the computers of family and friends to complete the at-home assignment. Exposure to the internet and practice is necessary to develop confidence in ehealth skills; participants in this study needed more time to practice their ehealth literacy skills. The websites chosen by the participants during the intervening week may not have provided the HIV specific health information needed to improve HIV health literacy. Slightly more than half (51%) of the total sample selected a non-reliable website.

This population may not be aware of the benefits of internet health information to improve HIV health literacy. In a previous study, participants who did not see the advantage of ehealth or believed that computers were difficult to use were less likely to search the internet for
health related information (Choi & DiNitto, 2013). In a focus group study drawn from the same population, a general finding was that participants did not realize how the internet could be used for health information (Reyes, Nokes, & Hickey, 2013). For this population, there may be less motivation to use the internet for health information because access to reliable health information is readily available at the ADHC. There is a registered nurse on staff at all times who provides on-going HIV education.

Ninety percent of this population had a high school education or less. A lower level of education coupled with easily accessible and reliable HIV health information, may effect this population’s ability and need to use the internet for health information. E health studies demonstrate that education is factor in use of the internet for health information. In a study of the intention to use the internet for health information, 75% of respondents who graduated from high school intended to search for health information, whereas only 42.7% of those with a less than a high school education intended use the internet for health information (deVeer, et. al., 2015).

Although not significant, there were changes in the group’s ability to identify reliable internet health information (IRIHIS). Scores on the IRIHIS were slightly higher in the MEDLINE group compared with the E-HELP group (18 vs. 17) at baseline. After the first session, scores in the E-HELP group were higher compared to the MEDLINE group (24 vs. 21), which may reflect the effect of the teach-back intervention. However, after the second session, scores in both groups were similar (24.v. 26.) but not significant. Completing the at-home assignment may have allowed the participants in the MEDLINE group to “catch up” with the E-HELP group.

It is also possible that seeking assistance with the At Home Assignment had an influence on IRIHIS scores. Despite being asked not to seek assistance, 36% of participants received help
in the MEDLINE group compared with 16% of participants received help in the E-HELP group which may hint that participants in the MEDLINE group recognized that they needed the additional help that had been received by the E-HELP group. Re-watching the video did not have an effect, because only one person in the MEDLINE group watched the video again and none of the E-HELP participants watched the video again.

Comparison of mean scores for the At-Home Assignment (homework) and Observation during the second session present a different picture of the effect of the intervention and suggest that the teach-back may have effected actual skills. On the At-Home Assignment, the E-HELP mean score was 75.21 (SD=21.77) compared with the MEDLINE mean score of 55.77 (SD=27.29). The difference in group means for the At-Home Assignment were statistically significant \( (t=-3.93, \, df=98, \, p=.000) \). In the second session, mean score for the MEDLINE group went down, 38.32 (SD=25.09), but mean scores for the E-HELP went up 84.08 (SD=14.04). The difference in group means for the second session was also significant \( (t=-11.25, \, p=.000) \). The scores for responses on the At Home Assignment and observation during the second session demonstrate actual improvement in ability to identify reliable internet health information for the E-HELP group and not the MEDLINE group.

HIV health literacy, ehealth, and ability to identify reliable internet health information did not make a difference in the self-care agency. Self-care is complex for PLWH and requires both general health maintenance and the HIV specific self-care (Chou & Holzemer, 2004). The short time span between sessions was probably not enough time to incorporate new knowledge into self-care practices. In addition, limited availability of commuter access, brief internet search times, and the high rate of navigating to non-reliable websites may have impeded the assimilation of new knowledge and impeded the development of self-care agency.
**Hypothesis 2:** There are significant positive differences in HIV health literacy, ehealth literacy, the ability to identify reliable internet health information, and self-care agency through participation in either E-HELP or MEDLINE.

Analysis of the data found significant positive within group differences for both the E-HELP and MEDLINE groups in all the independent variables except for self-care agency, the dependent variable. It is possible that just watching the NLM video once with the principal investigator, completing the at home assignment, or the assistance that some participants received may have effected changes in some participants in both groups.

The lack of within group differences in self-care agency may be further evidence that limitations on access to the internet and the short time period between sessions prevented participants from searching, finding, and using internet health information for self-care agency. In general, one week may be insufficient for anyone with a chronic disease to effectively apply health information to self-care practices.

**Basic Conditioning Factors**

Participants in this predominately African American sample of PLWH had a mean age of 50, used government supported health insurance and public assistance payments were their only income source. Ninety percent had a high school education or less and only 10% had some college. This samples’ demographic profile was consistent with previous studies that described lower rates of health literacy, ehealth skills, and internet use among racial and ethnic minorities, persons of lower socioeconomic status, those with less education, older adults, and those with chronic illnesses (Zukuhr & Madden, 2013; Choi, 2011; Werner, et al, 2011; Jensen, et al., 2010). Demographic factors that had a significant effect on the study variables were age, gender,
and ethnicity; race, education, and AIDS diagnosis (health status) were not related to any study variable.

However, there were significant differences in this sample in terms of the effect of the basic conditioning factors on the study variables. Consistent with previous studies, age had an effect on HIV health literacy, ehealth, and ability to identify reliable internet health information (Serper, Patzer, Curtis, et al., 2014; Choi & DiNitto, 2013). In this study, participants younger than 50 years of age had better HIV health literacy, ehealth, and ability to identify reliable internet health information compared to participants older than 50 years of age.

Gender effected HIV health literacy; females had better health literacy compared with males in this study (15.40 vs. 14.31, p=.039). Because this study used a new instrument that specifically addressed HIV health literacy, there is no comparison for this finding in the literature. This finding is inconsistent with the only research studies that specifically investigated health literacy and gender in a population of PLWH using other non-disease specific health literacy instruments. Waldrop-Valverde, et al., (2009) found that women had lower health literacy scores compared with men and this was specifically related to numeracy on the TOFHLA. Another study of health literacy in PLWH conducted by researchers from the International AIDS Society using an online survey created for the study, found that women had lower health literacy compared with men; the reason for this difference was not explained (Thomas, Schulte-Hermann, Matteo, 2014). More research is needed to determine if differences in health literacy between genders is a significant finding.

Ethnicity effected self-care agency in that Non-Hispanic/Latino persons had better self-care agency compared with Hispanic/Latinos. Although this research did not find a relationship between health literacy and self-care agency for Hispanic/Latinos, other research supports a
relationship among basic conditioning factors, health literacy, and self-care for Hispanic/Latinos. The U.S. Department of Health and Human Services reports that 41% of Hispanic/Latinos lack basic health literacy, only 4% have sufficient health literacy proficiency to make informed health decisions or navigate the U.S. healthcare system (America’s Health Literacy, 2008). Limited English proficiency in Hispanic/Latinos was also related to poorer health status and low health literacy (Sentell & Braun, 2015), factors associated with poorer self-care. Hispanic/Latinos who are not acculturated to the United States healthcare system have less access to care and less interaction with health care providers (Lara, Gamboa, Kahramanian, Morales, & Bautista, 2005; Henao-Martinez & Castillo-Mancilla, 2013).

There is limited research about self-care agency in HIV positive Hispanic/Latino populations, but studies of medication adherence and provider-patient communication provide insight into possible reasons for less self-care agency among Hispanic/Latinos with HIV. Poor medication adherence, a self-care behavior, was related to limited English proficiency, less knowledge about the healthcare systems, and less communication with healthcare providers (Easton, Entwistle, & Williams, 2010; Mantwell & Schluz, 2015). Interactions between providers and Hispanic/Latino PLWH found that the communication pattern of the provider was less patient centered, more focused on the biomedical aspects of HIV, characterized by dominance of the healthcare provider, and displayed less psychosocial talk compared with provider interactions with White PLWH (Beach, Saha, Korthius, et al., 2010).

Language limitations, lack of access, and unequal relationships with healthcare providers do not support the development of self-care agency in Hispanic/Latinos. Instead, these factors may reinforce a Hispanic/Latino cultural belief, fatalismo or fatalism, that hinders the development of self-care agency. Fatalism is a belief that the individual does not possess the
power to prevent negative events from occurring, and this includes poor health or the complications of chronic disease (Cianelli & Villegas, 2016). From the perspective of the PLWH who are Hispanic/Latino, there may be little need for self-care agency, because illness and death are inevitable.

**Measurement Instruments**

**HIV-Health Literacy (HIV-HL).**

The developers of the HIV-HL determined that a score of 15 was the cut point to determine low HIV health literacy (Ownby, et al., 2013). This sample scored lower on the HIV-HL compared with the sample in the original study. At the end of this study, the overall mean score on the HIV-HL for this sample was 15.25; the score for the MEDLINE group was 14.07 and 15.95 for the E-HELP group. In the original study, the sample mean was 16.38. Ninety percent of participants in this sample had a high school education or less compared with 60% of the sample population in the original study (Ownby, et al., 2013). Health literacy is founded on literacy, and both require academic skills, cognitive abilities, and knowledge (Ownby, Acevedo, Waldrop-Valverde, et al., 2014). This study population may not have had the academic skills needed for proficient HIV health literacy. This population was also a low income, predominately minority population, older than fifty years of age, with a chronic disease, all factors related to having low literacy and low health literacy (Zukuhr & Madden, 2013; Choi, 2011; Werner, et al, 2011; Jensen, et al., 2010). This may have affected scores on the HIV-HL.

HIV health literacy, defined as the ability to use reliable health information from a multitude of sources to make decisions about self-care, understand disease processes, adhere to medication regimens, decrease the risk of opportunistic infections, and manage the symptoms of HIV and co-morbidities, is a complex concept. Because of its complexity, a measurement
instrument may not be able to fully address all its factors. HIV health literacy is also an evolving concept that has few measurement instruments. In addition, HIV disease is a rapidly changing disease in terms of treatment. Although the HIV-HL is the best instrument available at this time to measure the concept of HIV health literacy, it is still limited.

The HIV-HL focuses primarily on knowledge about medication administration. The instrument contains only two questions related to disease processes, one of which required the respondent to have knowledge of the pharmacokinetics of a class of antiretroviral medications. There were no questions about HIV symptom management. A recent qualitative study that sought to determine what components of HIV knowledge were relevant to PLWH found that health beliefs and clear communication with providers was more important than understanding biomedical concepts about the actions of mediations or HIV infection (Laws, Danielewicz, Rang, Kogelman, Wilson, 20115). Another study found that a PLWH’s beliefs about his or her experience of HIV symptoms and the effects of medication determined adherence, not knowledge about the biological effects of adherence (Corless, 2015). Input from PLWH about the concept of HIV health literacy is needed; their perspective about what knowledge is important to HIV health literacy may be different from the perspective of researchers or clinicians. Recent research by the International Nursing Network for HIV/AIDS Research may provide some insight into HIV health literacy (Corless, 2015).

Health literacy research is evolving to measure not only general health literacy but also disease-specific health literacy, similar to the way symptom instruments have evolved (Ishikawa & Kiuchi, 2010; Martensson & Hensing, 2012; Nguyen, Paasche-Orlow Kim, Han, & Chan, 2015; Altin, Finke, Kautz-Freimuth, Stock, 2014). To date, most of the research in HIV health literacy has tested a specific aspect of health literacy, medication adherence. Research findings
about the relationship of health literacy to medication adherence have been similar, those with higher health literacy have better rates of adherence (Geobers, Brainard, Loke, et al., 2015; Kalichman, Pope, White, et al., 2009). Perhaps, exploring the relationship of other aspects of HIV self-care and health literacy would provide information about other ways to positively influence adherence.

**Electronic Health Literacy Survey (eHEALS).**

In this study, the mean score for the total sample on the eHEALS at baseline was 25 (scores 8 to 40), a relatively high score for a group with limited exposure to the internet. At the end of the study, the mean score for the total sample was 31. The baseline score is similar to a population with low ehealth skills and the final score is similar to a population with high ehealth scores. The baseline score in this sample was comparable to the eHEALS score of 22 in an older population of Hispanic/Latinos with diabetes and who found the internet complex and confusing (Aponte & Nokes, 2016). The final score of this study population was similar to the eHEALS score of 31 in a study of older adults who reported experience using the internet for health information (Chung & Nahm, 2015). Two studies (reported in the same article) found that because the eHEALs measures confidence and not ability, it cannot distinguish between people with low health-related internet skills and people with high health-related internet skills (van der Vaart, et al., 2015). Interestingly, the developers of the eHEALS found no significant relationship between ehealth and overall use of information technology or actual skills (Norman & Skinner, 2006b). These findings indicate a need for an instrument that can measure ability rather than confidence in ehealth skills.

For this population, it is possible that social desirability may have played a part in participant scores on the eHEALs for this study population. Because the eHEALS is a self-report
instrument and measures confidence and not actual ability, participants in this study with some computer and internet experience may have overestimated their abilities prior to the study and at the completion of the study. Participants without internet experience may have believed, in spite of instructions, that computer skills were needed to join the study and reported more confidence in ehealth skills than they actually possessed.

**Identification of Reliable Internet Health Information (IRIHIS).**

It should be noted that this was the first time this measurement instrument was used in an interventional study. Consequently, there is no published research for comparison. However, because the Medline tutorial requires basic ehealth skills, which was limited in this sample population, this may have affected participants’ ability to retain and apply the skills taught in the Medline video. Because a large percentage of the sample selected non-HIV information websites, this may have presented another barrier to identifying reliable internet health information. The observational results of the second session indicate that 47% of the sample had problems identifying sponsors, how personal information would be used, and locating the most recent update of the website.

**Self-As-Carer Inventory (SCI).**

It should be noted that the SCI has only been used in the descriptive studies of basic conditioning factors related to self-care agency (Holstad, Pace, De, & Ura, 2006; Hurst, Montgomery, Davis, Killon, & Baker, 2005). To this researcher’s knowledge, this is the first time the SCI has been used in an interventional study. The 1 to 6 scale seemed unusual to these participants who were more familiar with a 1 to 5 Likert scale with specific definitions for each value. Although participants in this study were given definitions of each value on the scale of this instrument, it is difficult to know if they really understood each definition.
**Strengths and Limitations of the Study**

When exploring new fields of study, evolving fields, or expanding the concepts in a theory, it is expected that both strengths and limitations of the study will be identified. Both provide impetus for further research.

**Strengths of This Study**

This contributes to the body of knowledge about HIV health literacy, ehealth, and use of the internet in PLWH. A recent systematic review of HIV health literacy interventions found that there are only five interventional studies that test HIV health literacy and one that test ehealth literacy in PLWH (Perazzo, Reyes, & Webel, 2016). This may be because there is a lack of HIV health literacy specific instruments. This study was the first time since the development of the HIV HL that the instrument was used in a research study (Ownby, personal communication October, 2015). The cognitive interviews provided information on the patient experience of taking the HIV HL. That information, in addition to statistical analyses of HIV health literacy in this study will help the developer determine what revisions to the instrument need to be made to increase its reliability.

There is limited research about the development of ehealth in low income PLWH. This was the first time the IRIHIS was used in an interventional study, prior to this study it was used in a qualitative focus group study. Testing the IRIHIS in this study lays the foundation for the development of an instrument that researchers can use to measure actual skill in identifying reliable internet health information.

The NLM video is in the public domain, however, its developers have never tested its use in a population of chronically ill people and most of the research using this tool has been
conducted in an older, healthy, educated populations with access to the internet (Xie, 2013). This was the first time the NLM video was tested in a chronically ill population. The developers of the video at the NLM have requested that we share the findings of this study with them because they are interested in the effectiveness if the NLM video in chronically ill populations.

The results of the At Home Assignment and observation at the second session indicate that with further research and refinement, the E-HELP teach-back protocol may be an effective intervention in a clinical setting. Further research is needed to refine the intervention.

**Limitations of the Study**

The findings of this study have limited generalizability. Randomization was limited to geographic site and convenience sample selection was used within the selected site. The sample characteristics limit the study’s generalizability. The sample was predominately African American, urban, low income, living with a chronic disease, and no education beyond high school. Because the ADHC program only accepts PLWH who receive public assistance and healthcare insurance, no comparisons could be made between different income groups. Although the ADHC center provided a population was available for testing and re-testing required by this study, the site also presented a limitation. Participants had other readily available sources of HIV health information and that may have reduced motivation to seek internet-based HIV health information. In addition, computer access was limited for this population.

This study did not have a control group that received usual care, but rather compared two different interventions. Perhaps a control group would have provided more information about the effectiveness of each intervention or provided information about which intervention was most effective compared to usual care. In addition, this study did not observe or measure internet skills at baseline with a protocol similar to the one used in the second session, which would have
provided information about participants’ actual ability to find internet based health information, in addition to their perceived confidence.

A standardized reading test was not used to assess reading ability; participants were offered an individualized session with the research assistant who could read the materials as requested. Reading level may have informed the findings about scores on HIV health literacy, ehealth, and ability to identify reliable internet health information. It may also have provided an information about participants’ ability to understand the internet information that they found.

The one-week time period between the first and second sessions may have been insufficient to develop any of the variables tested in this study. This time period was selected because of the nature of this population, which is subject to healthcare disparities that prevent long term involvement in a study. Time constraints of the researcher and limited funding also prevented a more longitudinal study.

Implications for Research, Practice, Policy and Theory

Research

In general, there is a lack of interventional research in HIV health literacy and ehealth in populations of PLWH. Previous research has used instruments that measure general health literacy and not HIV specific health literacy. Now that there is an instrument to test HIV specific health literacy, this provides an opportunity to conduct research that reflects HIV specific health literacy. Further exploration of how HIV health literacy effects ehealth and self-care in PLWH is needed. Future research studies should be developed with input from PLWH, in order to provide their perspective about factors that comprise HIV specific health literacy.

Although the HIV-HL is an effective instrument for research, because it is a 20 item self-administered internet based instrument, it cannot be used by clinicians in practice. Further
research is needed to develop brief instruments that can be incorporated into electronic health records so that clinicians can tailor instructions to the PLWH’s HIV health literacy level.

Although there is a body of research that describes the use of internet health information by PLWH, there is a limited number of studies that test interventions that teach PLWH how to identify reliable internet health information. It is important that PLWH know how to recognize reliable internet health information because of the vast amount of information on the internet and the increased internet availability through smart phones, which are now available free to people who use public insurance (New York State Department of Health). The finding of this study, that more than half the participants selected unreliable internet health information sources indicates the need for future research that investigates the relationships between health literacy, ehealth, and PLWH’s ability to evaluate online health information.

**Practice**

This study has implications for clinical practice. Although healthcare providers remain the primary source of information for PLWH, because of chronic multiple comorbidities and limited time allotted to clinic visits, patients will need to find alternative sources of health information. This makes it important that HIV peer educators, case managers, nurses, and other healthcare providers screen patients’ internet health information seeking behavior. Clinic staff should create opportunities after the clinic visit to teach patients the criteria of a reliable HIV health information website. The NLM video, which is in the public domain, could be downloaded to a clinic kiosk for easy viewing by patients waiting for appointments.

Patients should be encouraged to bring downloaded internet information or the name of any HIV health information website to the clinic visit whenever possible. Healthcare providers, nurses, and other trained office staff should review the internet information source, determine the
patient’s understanding of that information, and correct any misinformation presented by the website. Clinicians can suggest HIV health information websites that meet the criteria outlined in the NLM video to supplement any education or instructions given during the clinic visit.

**Policy**

Limited HIV health literacy, ehealth literacy, and ability to identify reliable internet health information are social justice issues. Health Care Organizations and Federally Qualified Health Centers that receive federal funding are now required to provide health information to clients via patient internet portals and provide personal electronic health records for patients (CMS, 2016). PLWH who have low HIV health literacy and ehealth limitations will not be able to access these internet sources of health information or communication and this will impede their self-care. In addition, the increasing reliance on self-care for people with chronic illness with require ehealth skills for information about disease management (Gee, Greenwood, Paterniti, et al., 2015). PLWH will need ehealth skills and the ability to identify reliable internet health information to manage their self-care.

Nurses need to take leadership on an organizational level in responding to these changes in public policy that may disenfranchise a population of PLWH who have limitations in health literacy and ehealth skills. Organizational policies that support the development of HIV health literacy, ehealth literacy and access to the internet can empower PLWH to be pro-active in their care. Assessment of HIV health literacy and ehealth skills in PWLH needs to be an essential part of clinical practice policies and protocols in organizations that provide healthcare and other services for PLWH. Nurses can take a leadership position in developing health literacy and ehealth policies based on research that demonstrates effective HIV health literacy and ehealth interventions.
Theory: Implications for Orem’s Theory of Self-Care Agency

Orem’s theory was first published in 1971 and its last update and revision was in 2001. There have been many technological and conceptual advancements in healthcare since Orem’s theory was first published and last revised. This is the first attempt to expand Orem’s model to include advancements in health care communication technology and health literacy. Most research using Orem’s theory have measured the effect of basic conditioning factors on self-care agency (Fawcett, 2005). While the results of this study did not provide sufficient evidence that health literacy is a foundational capability and ehealth and the ability to identify reliable internet health information are part of power component #7 within Orem’s theory of self-care agency, it provides a foundation to further test the expansion of the theory. One issue that should be considered in future testing is the need for an up to date disease specific self-care agency measure derived from Orem’s theory.

Self-care agency was tested in this study using an instrument developed in 1979 and tested in a population of mostly white, healthy, middle-class college students in the Mid-west. This present study was conducted 36 years later in a population comprised of minority, older, low income, less educated participants with a chronic disease. Self-care activities for a healthy population are associated with health maintenance and disease prevention, whereas the self-care activities in an ill population are associated with preventing complications and managing the symptoms of disease. In addition, self-care agency, like health literacy, is both disease specific and general. The SCI measured general self-care agency. For this population, with a complicated chronic disease such as HIV infection, a disease specific measure of self-care agency, similar to the disease specific HIV-HL, may be needed to accurately measure the concept.
Chapter V Summary

This chapter analyzed the results of the study and proposed possible reasons for the lack of support for hypothesis 1, that the E-HELP intervention would provide significant positive increases in HIV health literacy, ehealth, ability to identify reliable internet health information, and self-care agency compared with the MEDLINE intervention. These reasons included the short time between sessions, the lack of internet access, the availability of HIV health information from other sources, the selection of non-reliable internet health information sources, and seeking help from ADHC staff members.

Hypothesis 2, that participation in either intervention would result in statistically significant increases in the independent and dependent variables, was supported for HIV health literacy, ehealth, and ability to identify reliable internet health information. The interventions, At Home Assignment or help from ADHC staff could have made a difference for some participants. Hypothesis 2 was not supported for self-care agency. The most likely reasons that self-care agency did not develop are the complexity of HIV self-care and the short time period between testing points.

Three of the six conditioning factors used in this study had an effect on the study variables. Age effected HIV health literacy, ehealth, and ability to identify reliable internet health information in that younger participants scored better than older participants on these variables. This was consistent with previous research. Gender effected HIV health literacy only, and this finding was different from previous research in that women had higher HIV health literacy compared with the men in this study population. Ethnicity effected only self-care agency; Hispanic/Latinos had less self-care agency compared with non-Hispanic/Latinos. This finding is consistent with research that shows that Hispanic/Latinos have poorer health outcomes compared
to non-Hispanic/Latinos. Race, educational level, and AIDS diagnosis did not affect any study variable.

This research did not provide definitive evidence that health literacy, ehealth literacy, and ability to identify reliable internet health information are part of self-care agency within the structure of Orem’ theory. The study was the first time a nurse researcher attempted to test the expansion of Orem’s theory to encompass new concepts. Further research is needed.

The strengths and weaknesses of this study were discussed. Strengths include testing the HIV-HL instrument to provide more data to increase its reliability and effectiveness. This research also was a first step in developing a tool to test people’s ability to identify reliable internet health information. Limitations of the study were related to the demographic characteristics of the study population, the need to randomize by geographic location, and financial and time constraints.

Suggestions for research included further testing of the HIV-HL and HIV specific health literacy, ehealth, and ability to identify reliable HIV internet-based health information. Practice implications included assessing patient’s internet health information seeking and suggesting reliable internet health information websites. Policy implications emphasized nursing’s role in developing organizational policies that respond to federal guidelines requiring electronic health information and communication with patients.
Appendix A

Table A1
Website Evaluation Criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sponsorship</td>
<td>Provision of an address, phone number, or email address for the website sponsor; most reliable websites have an “About Us” tab (LaVersin, et al, 2011).</td>
</tr>
<tr>
<td>Financial Disclosure</td>
<td>The website displays the names of all organizations or persons who provide funding. Financial relationships may affect the content if companies that produce or sell healthcare products provide grant funding for the website (Hanif, et al., 2009).</td>
</tr>
<tr>
<td>Quality</td>
<td>The websites identify authors and their qualifications; text information provided should site legitimate scientific research and peer reviewed journals (Roberts, 2010; Monheit, 2010). The information should not be presented as a substitute for the patient-provider relationship, offer a diagnosis based on symptoms, or promise miraculous cures.</td>
</tr>
<tr>
<td>Privacy</td>
<td>The website should have a published policy about the use of personal information. Higher quality websites will employ special precautions to secure personal information (Hanif, et al., 2009). Most legitimate health information websites will not sell personal information to advertisers.</td>
</tr>
<tr>
<td>Currency</td>
<td>Because health information changes rapidly, the website needs regular updates. Part of currency includes working links to other external sites (Roberts, 2010).</td>
</tr>
<tr>
<td>Advertising Policy</td>
<td>Website users must be able to differentiate between advertisements and health products. When advertisements are not clearly identified, or presented as health information, this may indicate that the content of the website is skewed towards the advertised products. (Monheit, 2010).</td>
</tr>
</tbody>
</table>

107
<table>
<thead>
<tr>
<th>Criteria/ Websites</th>
<th>AIDS Cure¹</th>
<th>Dr. Rath Foundation²</th>
<th>ReThinking AIDS³</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website Sponsor</td>
<td>One individual, no credentials given; email &amp; address for consultation fees and to purchase products. Sponsor does not answer emails except for billing problems.</td>
<td>No foundation members identified except for Dr. Rath</td>
<td>Board members listed and by-laws published. Some board members do not have healthcare credentials; those who do, have not published in greater than 10 years</td>
</tr>
<tr>
<td>Funding</td>
<td>Not listed, but products offered for sale</td>
<td>Profits of Dr. Rath vitamin products support the foundation</td>
<td>Links to donate, Tax Returns posted—unsigned by president of BOD</td>
</tr>
<tr>
<td>Quality</td>
<td>Outdated references, all articles written by sponsor, only cites sponsor in article; links to other denialist websites</td>
<td>Only cites self, no dates or source of information; Mostly opinion statements</td>
<td>Quotes that defend position; not attributed, source is not cited</td>
</tr>
<tr>
<td>Privacy</td>
<td>No policy listed</td>
<td>No policy listed</td>
<td>Privacy policy available</td>
</tr>
<tr>
<td>Currency</td>
<td>August 21, 2010</td>
<td>2013 Copyright date, No updates listed</td>
<td>1/20/2013 last update on “quotes page” only.</td>
</tr>
<tr>
<td>Advertising Policy</td>
<td>The website promotes the sale of the sponsor’s products; advertisements not clearly identified.</td>
<td>No advertisements on Foundation website, but there is a link to his commercial website; not identified as an advertisement</td>
<td>Website user may purchase their books denying HIV and AIDS. Not identified as an advertisement.</td>
</tr>
</tbody>
</table>

¹ [http://www.cqs.com/](http://www.cqs.com/)
³ [http://www.rethinkingaids.com](http://www.rethinkingaids.com)
<table>
<thead>
<tr>
<th>Conceptual (concepts that comprise Self-Care Agency)</th>
<th>Basic Conditioning Factors</th>
<th>Foundational capabilities</th>
<th>Power components</th>
<th>Operational capacity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theoretical</td>
<td>Age, educational achievement, race, ethnicity, gender, health status (AIDS diagnosis)</td>
<td>Health Literacy (knowing and doing capabilities-perception, reading, manual skills)</td>
<td>eHealth literacy</td>
<td>Self-care Agency (application of health information to actions and behaviors)</td>
</tr>
<tr>
<td>Empirical Measures</td>
<td>Demographic survey</td>
<td>HIV-HL</td>
<td>eHEALs IRIHS</td>
<td>SCI</td>
</tr>
<tr>
<td>Variable</td>
<td>Theoretical Definition</td>
<td>Operational Definition: Measurement Instrument</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Literacy</td>
<td>The wide range of skills and competencies people develop in order to seek out, comprehend, evaluate, and use health information to make informed choices, reduce health risks, and increase quality of life (Zarcadoolas, Pleasant, &amp; Greer, 2006).</td>
<td>We are specifically interested in HIV-health literacy which has been defined as the ability to understand information about HIV disease and its treatment and the behavioral skills needed to perform related behaviors; it is being measured by the HIV- Health Literacy Scale (HIV-HL; Ownby, Waldrop-Valerde, Hardigan, Caballero, Jacobs, &amp; Acevedo, 2012)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Electronic Health Literacy</td>
<td>The use of information technology to acquire health information to inform health decisions and engage in self-care (Norman &amp; Skinner, 2006a)</td>
<td>Electronic Health Literacy Scale (eHEALs; Norman &amp; Skinner, 2006a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identification of Reliable Health Information</td>
<td>A person’s ability to identify the six criteria of a reliable health information website</td>
<td>Identifying Reliable Internet Health Information Scale (IRIHS) Created by PI for this study</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-care agency</td>
<td>The ability of people to perform self-care based on the foundational capacity of knowing and doing, the power component of acquiring knowledge, and the operational capacity to apply knowledge to self-care operations (Orem, 2001).</td>
<td>Self-As-Carer Inventory or SCI (Taylor &amp; Geden, 1998)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic Conditioning Factors (BCF)</td>
<td>Demographic characteristics of race, ethnicity, gender, age, health status (AIDS diagnosis), and education (Orem, 2001)</td>
<td>Health status is being measured by AIDS diagnosis and a demographic Survey created for the study was used</td>
<td></td>
<td></td>
</tr>
<tr>
<td>INSTRUMENTS</td>
<td>Time 0: Baseline</td>
<td>Time 1: At end of 1&lt;sup&gt;st&lt;/sup&gt; Treatment Session</td>
<td>Time 2: At the end of 2&lt;sup&gt;nd&lt;/sup&gt; Treatment Session</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>-----------------</td>
<td>---------------------------------------------------</td>
<td>------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Demographic Survey</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV-Health Literacy (HIV-HL)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Electronic Health Literacy Survey (eHEALS)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Identifying Reliable Internet Health Information Survey (IRIHIS)</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Self-Care Instrument (SCI)</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Time spent on Activity</td>
<td>E-HELP Intervention</td>
<td>MEDLINE Intervention</td>
<td>Personnel</td>
<td></td>
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<tr>
<td>------------------------</td>
<td>---------------------</td>
<td>----------------------</td>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>FIRST SESSION</td>
<td>FIRST SESSION</td>
<td>RA, PI,</td>
<td></td>
</tr>
<tr>
<td>10 minutes</td>
<td>Explanation of the study tasks and informed consent obtained</td>
<td>Explanation of study and informed consent obtained</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>5 minutes</td>
<td>Demographic Survey administered</td>
<td>Demographic Survey administered</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>5 minutes</td>
<td>eHEALs administered</td>
<td>eHEALs administered</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>15 minutes</td>
<td>SCI Administered</td>
<td>SCI Administered</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>15 minutes</td>
<td>HIV-HL Administered</td>
<td>HIV-HL Administered</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>5 minutes</td>
<td>IRIHIS Administered</td>
<td>IRIHIS Administered</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>55 MINUTES</td>
<td>Total time for informed consent &amp; Instrument administration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>45 minutes</td>
<td>Participant Lunch</td>
<td>Participant Lunch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 minutes</td>
<td>NLM video</td>
<td>NLM video</td>
<td>PI</td>
<td></td>
</tr>
<tr>
<td>15 minutes: E-HELP</td>
<td>PI conducted teach-back session with participant to identify the 6 criteria of a reliable website.</td>
<td>N/A</td>
<td>PI</td>
<td></td>
</tr>
<tr>
<td>3 minutes</td>
<td>Participant instructed to practice at home and was given form to complete at home assignment, date to return was scheduled</td>
<td>Participant instructed to practice at home and given form to complete at home assignment, date to return was scheduled.</td>
<td>PI</td>
<td></td>
</tr>
<tr>
<td>25 minutes</td>
<td>Administered IRIHIS/eHEALs/HIV-HL</td>
<td>Administered IRIHIS/eHEALs/HIV-HL</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>Conclusion</td>
<td>Participant received $10.00 token of appreciation</td>
<td>Participant received $10.00 token of appreciation</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>1st TOTAL TIME</td>
<td>59 MINUTES: TOTAL TIME FOR E-HELP Intervention</td>
<td>41 MINUTES: TOTAL TIME FOR MEDLINE Intervention</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BETWEEN SESSIONS:</td>
<td>Participants will be called and reminded to practice and do the at-home assignment</td>
<td>Participants will be called and reminded to practice and do the at-home assignment</td>
<td>RA, PI</td>
<td></td>
</tr>
<tr>
<td>Mid-week</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 2</td>
<td>SECOND SESSION</td>
<td>SECOND SESSION</td>
<td>RA, PI</td>
<td></td>
</tr>
<tr>
<td>5 minutes</td>
<td>Review of at-home activity</td>
<td>Check of at-home assignment</td>
<td>PI</td>
<td></td>
</tr>
<tr>
<td>15 minutes</td>
<td>Participant identified reliability criteria after he or she navigated to a website without assistance</td>
<td>Participant identified reliability criteria after he or she navigated to a website without assistance</td>
<td>PI</td>
<td></td>
</tr>
<tr>
<td>5 minutes</td>
<td>Administered the IRIHIS</td>
<td>Administered the IRIHIS</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>5 minutes</td>
<td>Administered the eHEALs</td>
<td>Administered eHEALs</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>15 minutes</td>
<td>Administered SCI</td>
<td>Administered SCI</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>15 minutes</td>
<td>Administered HIV-HL</td>
<td>Administered HIV-HL</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>Conclusion</td>
<td>Participant received $10.00 in appreciation for their time</td>
<td>Participant received $10.00 in appreciation for their time</td>
<td>RA</td>
<td></td>
</tr>
<tr>
<td>Total Time 2nd Session</td>
<td>E-HELP 60 Minutes</td>
<td>MEDLINE 60 Minutes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Brooklyn (N=100) (percentage) MEDLINE site</td>
<td>Queens (N=100) (percentage) E-HELP site</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------------------------------</td>
<td>----------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td>100% Public Assistance</td>
<td>100% Public Assistance</td>
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<td></td>
</tr>
<tr>
<td>Education</td>
<td>78% less than High School</td>
<td>78% less than High School</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>36-71 years of age 53 years of age</td>
<td>26-68 years of age 50 years of age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>60.3%</td>
<td>70%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>39.7%</td>
<td>28%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transgender</td>
<td>1.7%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>85.29%</td>
<td>73%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>07.35%</td>
<td>15%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>07.24%</td>
<td>8.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>7.35%</td>
<td>15%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic/non-Latino</td>
<td>92.65%</td>
<td>85%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of Attendance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>1-7 years</td>
<td>1-7 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>2 years, 8 months</td>
<td>2 years, 6 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years with HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range of years with HIV</td>
<td>1-28 years</td>
<td>2-27 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average years with HIV</td>
<td>16.5 years</td>
<td>13.75 years</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(source: HELP/PSI annual report, 2013; N≈100 at each site)
<table>
<thead>
<tr>
<th>Treatment Fidelity Element</th>
<th>Description</th>
<th>Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study Design</td>
<td>(1) minimize contamination between treatment groups</td>
<td>(1) the treatments were given at different locations to prevent interaction between participants of the groups</td>
</tr>
<tr>
<td></td>
<td>(2) addresses predictable setbacks in implementation of intervention</td>
<td>(2) Between treatment sessions, participants received phone call reminders to practice and return</td>
</tr>
<tr>
<td></td>
<td>(4) cognitive interviews of measurement instruments</td>
<td>Computer equipment and internet access was checked prior to each session</td>
</tr>
<tr>
<td>Interventionist training</td>
<td>(1) training was standardized</td>
<td>(4) Cognitive interviews ensured that participants understood how to complete measurement instruments</td>
</tr>
<tr>
<td></td>
<td>(2) training was reinforced to minimize decay or drift</td>
<td>(1) The PI reviewed and practiced the with the PI. The Written protocols were available for review each data collection day.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2) After each data collection day, the PI and the RA reviewed recruitment, treatments, and administration of instruments, any drifts were reviewed and the protocol reviewed to prevent future occurrences.</td>
</tr>
<tr>
<td>Delivery of treatment</td>
<td>Implementation of the recruitment and treatment protocol(s) was standardized</td>
<td>The PI reviewed the treatment and recruitment protocols on a weekly basis with the RA.</td>
</tr>
<tr>
<td></td>
<td>and monitored so that it was delivered as intended</td>
<td></td>
</tr>
<tr>
<td>Receipt of treatment</td>
<td>There was a procedure to ensure that the treatment was received and understood</td>
<td>The PI checked that all instructions were understood and answered all participant questions before ending the session.</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Term</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>ADHC</td>
<td>Adult Day Health Care</td>
<td></td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
<td></td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral treatment</td>
<td></td>
</tr>
<tr>
<td>eHEALS</td>
<td>Electronic Health Literacy Scale</td>
<td></td>
</tr>
<tr>
<td>ehealth</td>
<td>Electronic Health Literacy</td>
<td></td>
</tr>
<tr>
<td>E-HELP</td>
<td>Electronic HIV Education and Literacy Program</td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>HIV-HL</td>
<td>HIV-Health Literacy Instrument</td>
<td></td>
</tr>
<tr>
<td>IRIHIS</td>
<td>Identifying Reliable Internet Health Information Scale</td>
<td></td>
</tr>
<tr>
<td>JAMA</td>
<td>Journal of the American Medical Association</td>
<td></td>
</tr>
<tr>
<td>PI</td>
<td>Principal Investigator</td>
<td></td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living with HIV</td>
<td></td>
</tr>
<tr>
<td>NAAL</td>
<td>National Assessment of Adult Literacy</td>
<td></td>
</tr>
<tr>
<td>NALS</td>
<td>National Adult Literacy Survey</td>
<td></td>
</tr>
<tr>
<td>RA</td>
<td>Research Assistant</td>
<td></td>
</tr>
<tr>
<td>SCI</td>
<td>Self-As-Carer Inventory</td>
<td></td>
</tr>
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</table>
Table A10 Phase 1 Sample Characteristics

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean (±)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>50.85 (±8.12)</td>
</tr>
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<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>5 (71%)</td>
</tr>
<tr>
<td>Male</td>
<td>2 (29%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American</td>
<td>6 (86%)</td>
</tr>
<tr>
<td>NOT African American</td>
<td>1 (14%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic/Latino</td>
<td>1 (14%)</td>
</tr>
<tr>
<td>NOT Hispanic/Latino</td>
<td>6 (86%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No AIDS DX</td>
<td>4 (57%)</td>
</tr>
<tr>
<td>AIDS diagnosis</td>
<td>3 (43%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some HS or less</td>
<td>2 (29%)</td>
</tr>
<tr>
<td>Completed HS or above</td>
<td>5 (71%)</td>
</tr>
<tr>
<td>Variable</td>
<td>MEDLINE (n=50)</td>
</tr>
<tr>
<td>---------------------</td>
<td>----------------</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>Mean (±SD)</td>
</tr>
<tr>
<td></td>
<td>50.58 (±8.98)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Frequency</td>
</tr>
<tr>
<td>Female</td>
<td>22 (44%)</td>
</tr>
<tr>
<td>Male</td>
<td>28 (56%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td>Frequency</td>
</tr>
<tr>
<td>African American</td>
<td>39 (78%)</td>
</tr>
<tr>
<td>Non-African American</td>
<td>11 (22%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>Frequency</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>11 (22%)</td>
</tr>
<tr>
<td>Non-Hispanic/ Latino</td>
<td>39 (78%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>Frequency</td>
</tr>
<tr>
<td>HS or less education</td>
<td>24 (48%)</td>
</tr>
<tr>
<td>More than HS</td>
<td>26 (52%)</td>
</tr>
<tr>
<td><strong>AIDS Diagnosis</strong></td>
<td>Frequency</td>
</tr>
<tr>
<td>No AIDS DX</td>
<td>33 (66%)</td>
</tr>
<tr>
<td>AIDS diagnosis</td>
<td>17 (34%)</td>
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<tr>
<td>Independent Variable</td>
<td>Numerator df</td>
</tr>
<tr>
<td>------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Time</td>
<td>1</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1</td>
</tr>
<tr>
<td>Group</td>
<td>1</td>
</tr>
<tr>
<td>Interaction of Time &amp; Group</td>
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Table A13 Tests of Fixed Effects on HIV Health Literacy

<table>
<thead>
<tr>
<th>Variables</th>
<th>Numerator df</th>
<th>Denominator df</th>
<th>F</th>
<th>Significance</th>
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</thead>
<tbody>
<tr>
<td>Time</td>
<td>2</td>
<td>98</td>
<td>8.180</td>
<td>.001</td>
</tr>
<tr>
<td>Gender</td>
<td>1</td>
<td>92</td>
<td>5.001</td>
<td>.028</td>
</tr>
<tr>
<td>Education</td>
<td>1</td>
<td>92</td>
<td>2.157</td>
<td>.145</td>
</tr>
<tr>
<td>Group</td>
<td>1</td>
<td>92,039</td>
<td>6.231</td>
<td>.014</td>
</tr>
<tr>
<td>Age</td>
<td>1</td>
<td>92</td>
<td>4.749</td>
<td>.032</td>
</tr>
<tr>
<td>Race</td>
<td>1</td>
<td>92</td>
<td>.043</td>
<td>.837</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>1</td>
<td>92</td>
<td>.176</td>
<td>.676</td>
</tr>
<tr>
<td>AIDS Diagnosis</td>
<td>1</td>
<td>92</td>
<td>.005</td>
<td>.942</td>
</tr>
<tr>
<td>Time &amp; Group Interaction</td>
<td>2</td>
<td>98</td>
<td>.291</td>
<td>.748</td>
</tr>
<tr>
<td>Variables</td>
<td>Numerator df</td>
<td>Denominator df</td>
<td>F</td>
<td>Significance</td>
</tr>
<tr>
<td>------------------------</td>
<td>--------------</td>
<td>----------------</td>
<td>--------</td>
<td>--------------</td>
</tr>
<tr>
<td>Time</td>
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<tr>
<td>Gender</td>
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<td>92</td>
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<tr>
<td>Education</td>
<td>1</td>
<td>92</td>
<td>2.265</td>
<td>.136</td>
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<tr>
<td>Group</td>
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<td>Ethnicity</td>
<td>1</td>
<td>92</td>
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<tr>
<td>Race</td>
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<td>92</td>
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</tr>
<tr>
<td>AIDS Diagnosis</td>
<td>1</td>
<td>92</td>
<td>1.067</td>
<td>.304</td>
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Table A15 Tests of Fixed Effects on Ability to Identify Reliable Internet Health Information

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<td>AIDS Diagnosis</td>
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<td>Group</td>
<td>Intervention Time Points</td>
<td>Mean Difference</td>
<td>df</td>
<td>Significance</td>
</tr>
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<td>-----------</td>
<td>--------------------------</td>
<td>-----------------</td>
<td>-----</td>
<td>--------------</td>
</tr>
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<td>MEDLINE</td>
<td>Time 1 to Time 2</td>
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Table A16 Within Group Differences for Self-Care Agency
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<th>Mean Difference</th>
<th>df</th>
<th>Significance</th>
</tr>
</thead>
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<tr>
<td>MEDLINE</td>
<td>Time 0 to Time 1 Baseline to first session</td>
<td>-.460</td>
<td>98</td>
<td>.324</td>
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<tr>
<td></td>
<td>Time 0 to Time 2 Baseline to second session</td>
<td>-1.080*</td>
<td>98</td>
<td>.005</td>
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<tr>
<td></td>
<td>Time 1 to Time 2 First session to second session</td>
<td>-.620</td>
<td>98</td>
<td>.093</td>
</tr>
<tr>
<td>E-HELP</td>
<td>Time 0 to Time 1 Baseline to first session</td>
<td>-.500</td>
<td>98</td>
<td>.255</td>
</tr>
<tr>
<td></td>
<td>Time 0 to Time 2 Baseline to second session</td>
<td>-.820*</td>
<td>98</td>
<td>.045</td>
</tr>
<tr>
<td></td>
<td>Time 1 to Time 2 First session to second session</td>
<td>-.320</td>
<td>98</td>
<td>.602</td>
</tr>
<tr>
<td>Group</td>
<td>Table A18 Within Group Differences for eHealth</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>-----------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MEDLINE</td>
<td>Intervention Time Points</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time 0 to Time 1 Baseline to first session</td>
<td>Mean Difference</td>
<td>df</td>
<td>Significance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-5.020</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Time 0 to Time 2 Baseline to second session</td>
<td>4.720</td>
<td>98</td>
<td>.003</td>
</tr>
<tr>
<td></td>
<td>Time 1 to Time 2 From First Session to second session</td>
<td>-.300</td>
<td>98</td>
<td>.987</td>
</tr>
<tr>
<td>E-HELP</td>
<td>Time 0 to Time 1 Baseline to first session</td>
<td>-7.140</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Time 0 to Time 2 Baseline to second session</td>
<td>7.140</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Time 1 to Time 2 From First Session to Second Session</td>
<td>.600</td>
<td>98</td>
<td>.906</td>
</tr>
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Table A19 Within Group Differences for Identification of Reliable Internet Health Information

<table>
<thead>
<tr>
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<th>Intervention Time Points</th>
<th>Mean Differences</th>
<th>df</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>MEDLINE</td>
<td>Time 0 to Time 1</td>
<td>-3.26</td>
<td>98</td>
<td>.004</td>
</tr>
<tr>
<td></td>
<td>Baseline to first session</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time 0 to Time 2</td>
<td>-5.84</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Baseline to second session</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time 1 to Time 2</td>
<td>-2.58</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>First session to second session</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E-HELP</td>
<td>Time 0 to Time 1</td>
<td>-7.30</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Baseline to first session</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time 0 to Time 2</td>
<td>-8.80</td>
<td>98</td>
<td>.000</td>
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<tr>
<td></td>
<td>Baseline to second session</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time 1 to Time 2</td>
<td>-1.50</td>
<td>98</td>
<td>.082</td>
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<tr>
<td></td>
<td>First session to second session</td>
<td></td>
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</tr>
<tr>
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<td>Time 0 to Time 2</td>
<td>-8.80</td>
<td>98</td>
<td>.000</td>
</tr>
<tr>
<td></td>
<td>Baseline to second session</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Time 1 to Time 2</td>
<td>-1.50</td>
<td>98</td>
<td>.082</td>
</tr>
<tr>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Item</td>
<td>MEDLINE Group</td>
<td>E-HELP Group</td>
<td>Total Sample</td>
<td>Test Of Significance</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>---------------</td>
<td>--------------</td>
<td>--------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Who is the sponsor of the Website?</td>
<td>Correct</td>
<td>Incorrect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>27 (54%)</td>
<td>23 (46%)</td>
<td>64 (64%)</td>
<td>.037</td>
</tr>
<tr>
<td>How did you tell the difference between advertisements and health</td>
<td>Correct</td>
<td>Incorrect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>32 (64%)</td>
<td>18 (36%)</td>
<td>65 (65%)</td>
<td>.834 Not significant</td>
</tr>
<tr>
<td>Can you identify the people who contributed or reviewed the health</td>
<td>Correct</td>
<td>Incorrect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>21 (42%)</td>
<td>29 (58%)</td>
<td>54 (54%)</td>
<td>.016</td>
</tr>
<tr>
<td>Will you use your personal information?</td>
<td>Correct</td>
<td>Incorrect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>17 (34%)</td>
<td>33 (66%)</td>
<td>47 (47%)</td>
<td>.009</td>
</tr>
<tr>
<td>How can you contact the sponsor of the website?</td>
<td>Correct</td>
<td>Incorrect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>30 (60%)</td>
<td>20 (40%)</td>
<td>71 (71%)</td>
<td>.015</td>
</tr>
<tr>
<td>What is the date of the most recent update of the health information?</td>
<td>Correct</td>
<td>Incorrect</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20 (40%)</td>
<td>30 (60%)</td>
<td>60 (60%)</td>
<td>.029</td>
</tr>
<tr>
<td>TOTAL SCORE</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>55.77 (27.29)</td>
<td></td>
<td></td>
<td>t=3.93, df=98, p=.000</td>
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</table>
Table A21: Percentage of Correct and Incorrect Responses during Skills Testing
Second Session

<table>
<thead>
<tr>
<th>Item</th>
<th>MEDLINE Group</th>
<th>E-HELP Group</th>
<th>Total group</th>
<th>Test of Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who is the sponsor of the Website?</td>
<td>Correct: 21 (42%)</td>
<td>Incorrect: 29 (58%)</td>
<td>Correct: 38 (76%)</td>
<td>Incorrect: 12 (24%)</td>
</tr>
<tr>
<td>How did you tell the difference between advertisements and health information?</td>
<td>Correct: 31 (62%)</td>
<td>Incorrect: 19 (38%)</td>
<td>Correct: 37 (74%)</td>
<td>Incorrect: 13 (26%)</td>
</tr>
<tr>
<td>Can you identify the people who contributed or reviewed the health information?</td>
<td>Correct: 16 (32%)</td>
<td>Incorrect: 34 (68%)</td>
<td>Correct: 37 (74%)</td>
<td>Incorrect: 13 (26%)</td>
</tr>
<tr>
<td>How will the website use your personal information?</td>
<td>Correct: 08 (16%)</td>
<td>Incorrect: 42 (84%)</td>
<td>Correct: 45 (90%)</td>
<td>Incorrect: 05 (10%)</td>
</tr>
<tr>
<td>How can you contact the sponsor of the website?</td>
<td>Correct: 15 (30%)</td>
<td>Incorrect: 35 (70%)</td>
<td>Correct: 47 (94%)</td>
<td>Incorrect: 03 (06%)</td>
</tr>
<tr>
<td>What is the date of the most recent update of the health information?</td>
<td>Correct: 17 (34%)</td>
<td>Incorrect: 33 (66%)</td>
<td>Correct: 41 (82%)</td>
<td>Incorrect: 09 (18%)</td>
</tr>
<tr>
<td>TOTAL CORRECT</td>
<td>Mean (SD) 38.32 (25.09)</td>
<td>Mean (SD) 84.08 (14.04)</td>
<td>Mean (SD) 61.20 (30.62)</td>
<td>t=-11.25, df=98, p=.000</td>
</tr>
</tbody>
</table>
Appendix B:

Approvals from HELP/PSI Corporation and Hunter Institutional Review Board

Appendix B 1: Letter of Support from HELP/PSI

HELP/PSI SERVICES CORPORATION
PRIMARY MEDICAL CARE
“Building Hope and Empowering Change”

EXECUTIVE OFFICE
373 PARK AVENUE SOUTH, 7th FLOOR, NEW YORK, NY 10016
(718) 681-8700
FAX (646) 545-5099
INFO@PROJECTSAMARITAN.ORG
WWW.PROJECTSAMARITAN.ORG

ADMINISTRATION AND SENIOR STAFF
PAUL D. VITAL, MPA
President and CEO
CAROL MOWRY, MBA, RN, MSN
Chief Operating Officer
Chief Nursing Officer
BARBARA C. ZELLER, MD, MPH
Chief Medical Officer
IAN FUCHS
Chief Fiscal Officer
ALAN ZWERLING, CPA, MS
Senior Vice President of Finance
CHARLES J. DEVLIN
Vice President
Substance Abuse & Development
JESSICA L. DUNN, MPA, CFRE
Vice President
Clinical Quality Improvement
ANDREW E. PHYFE
Vice President
Human Resources Support Services
KEVYN KALANDA, MS, PHR
Vice President
Human Resources
EVILYN HOBBS
Vice President
Clinical Information Services
DEBORAH VENTI III, MS, MPH, LCHC
Vice President
 Nursing
PATRICIA WILLIAMS
Executive Vice President
Clinical Operations
RICHARD WEINGART
Vice President
Intergroup Law
PHIL DORAN
Vice President
Business Development

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Board Chair
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Vice Chair
JAMIE CHUDIN
Secretary

DIRECTORS
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JEFF CARVER
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SHELLEY KUFFEL, DDS
THOMAS KENNEDY
CHARLIE MILLER
PARK O’DONNELL
DAVID ROSS
DAVID McFADDEN
Honorary Director

CORPORATE OFFICE: 373 PARK AVENUE SOUTH, 7TH FLOOR, NEW YORK, NY 10016 (718) 681-8700 FAX (646) 545-5099
BROOKLYN PRIMARY CARE CLINIC: 803 STERLING PLACE, BROOKLYN, NY 11216 (718) 613-1700 FAX (718) 613-0721
BRONX HEALTH AND WELLNESS CENTER: 260 EAST 144th STREET, BRONX, NY 10451 (855) 681-8700 FAX: (718) 294-4765
BRONX PRIMARY CARE CLINIC: 1545 INWOOD AVENUE, BRONX, NY 10452 (855) 681-8700 FAX: (718) 294-4765
QUEENS PRIMARY CARE CLINIC: 105-04 SUTPHIN BOULEVARD, JAMAICA, NY 11435 (718) 947-9100 FAX: (718) 947-9102

1/2/14

Dear IRB Committee Members,

This letter is to inform you that I support the research project submitted by Darcel Reyes, RN, MS, PhD(c). She has explained the project, and I believe that an opportunity to learn how to find reliable Internet-based health information would be a beneficial and educational experience for our clients. Ms. Reyes has explained that the clients will make their own decisions about participating in this research project. Ms. Reyes reassured me that she intends to abide by ethical research behavior and maintain the confidentiality of the clients who choose to participate in the study. Ms. Reyes has permission to conduct her research project at our facilities.

Respectfully,

Carol Murphy
Chief Operating Officer
Chief Nursing Officer
Appendix B 2: Hunter College IRB Approval

Human Research Protections Program
Hunter College (CUNY) HRPP Office

DATE: May 19, 2014
TO: Darcel Reyes, RN, MS
FROM: Hunter College (CUNY) HRPP Office
PROJECT TITLE: [0543.26-1] EFFECT OF AN INTERNET-BASED HEALTH EDUCATION PROGRAM ON SELF-CARE KNOWLEDGE IN PEOPLE LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS
SUBMISSION TYPE: New Project
ACTION: APPROVED
APPROVAL DATE: May 10, 2014
EXPIRATION DATE: May 15, 2015
RISK LEVEL: Minimal
REVIEW TYPE: Expedited Review
REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this project. The University Integrated IRB has APPROVED your research. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Please remember that informed consent is a process beginning with a description of the project and assurance of the participant’s understanding, followed by a signed consent form(s). Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document.

The University Integrated IRB has determined that a waiver of documentation of consent (for the concerning procedures) has been approved for this research, under 45 CFR 46.111.

Please note that any modifications/changes to the approved materials must be approved by this IRB prior to implementation. Please use the appropriate modification submission form for this request.

All UNANTICIPATED PROBLEMS (UPOS) involving risks to subjects or others, NON-COMPLIANCE issues, and SUBJECT COMPLAINTS must be reported promptly to this office. All sponsor reporting requirements must also be followed. Please use the appropriate submission form for this report.

This research must receive continuing review and final IRB approval before the expiration date of . Your documentation for continuing review must be received with sufficient time for the IRB to conduct its review and obtain final IRB approval by that expiration date. Please use the appropriate continuation submission forms for this procedure. PLEASE NOTE: The regulations do not allow for any grace period or extension of approvals.

- 1 -

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Appendix C:

Scripts for Recruiting Potential Participants

Appendix C1 E-HELP Script

Scenario 1: Potential participant agrees to be in study

**Principal Investigator (PI):** Hi! My name is Darcel Reyes, and I am a nurse from Hunter College and the Graduate Center of the City University of New York. Kathy Nokes, another nurse and I want to learn more about how to help people who have HIV use the internet to find health information to take care of their health. This is a research study. I am not selling anything. We are asking people like you who have HIV to help us. You do not have to be in the study. Nothing about your participation in HELP/PSI’s Adult Day Health Care Program (ADHC) will change if you say “No.” If you say “Yes,” you can still quit the study at any time. Does this sound like something you would be interested in doing?

**Potential Participant (PP):** Yes (or other indication of willingness to participate).

**PI:** Great! This will only take a few minutes. Let’s find out if you qualify. I have a few questions to ask. There are no right or wrong answers to these questions. At some point, I may end the questions if I discover that you don’t qualify. This has nothing to do with you. We simply are looking for people who meet certain criteria.

**Question 1:** In this study, you will hear someone giving information in English. When you hear someone speaking English, do you understand what the person is saying and are you able to answer the person in English?

**PP:** Yes

**PI:** Great! It looks like you are able to participate. In this study, you will first be asked to complete four surveys, and then watch a 16-minute video about using the internet to find health information. After watching the video, a nurse will help you to practice the skills taught in the video. Then, we will ask you to complete another survey. Completing the surveys, watching the video, and practicing the skills will take about 2 hours of your time in the first session. Then, we want you to practice the skills at home and return in 1 week to show us what you learned. Are you comfortable with this?

**PP:** Yes, (or another indication of willingness to participate).

**PI:** Thanks for volunteering. In order to participate in the study, you have to sign a consent form. [PRESENT THE CONSENT FORM TO THE POTENTIAL PARTICIPANT]. Here is the consent form. If you would like, someone will read it to you or you can read it yourself. Please take your time. Please let me know if you have any questions.
[THE FOLLOWING ARE POSSIBLE QUESTIONS AND ANSWERS]

PP: What happens if I say yes, but change my mind later?

PI: You can stop being in the study at any time. You will not be penalized and you will not lose any benefits that you have at HELP/PSI ADHC program.

PP: Who will see my answers on the survey?

PI: The only people allowed to see your answers will be the people who work on the study and the people who make sure we run the study the right way. Your survey answers, health information, and a copy of this consent will be kept in a locked cabinet. We cannot put your answers in your ADHC chart.

When we share the results of the study in healthcare journals or conferences, we will not include your name. We will do our best to make sure that no one outside of this study will know you are a part of the study.

PP: Will it cost me anything to be part of the study?

PI: no.

PP: Will being in this study help me in any way?

PI: You may learn how to use the computer to find health-related information, but we cannot promise you that you will learn anything.

PP: Will I be paid for my time? Or, Do I get anything for being in this study?

PI: We will give you $10.00 at the end of each session.

PP: Will this study be bad for me?

PI: Sometimes people become anxious learning new things or talking in a group. If that happens, and you want to stop participating, you can without penalty. If you want to talk to someone about how you feel, Darcel Reyes will take you to healthcare provider or social worker who could help you.

PP: What if I have questions during the study, or in the next few hours before the study begins?

PI: Please call me, Darcel Reyes, at ____-____-_____.

PP: What if I have questions about my rights as a participant, or feel I have been treated unfairly, or injured?
PI: You can call the office in charge of research at Hunter College. It is called the Human Research Protection Program and the phone number is: (212) 650-3053. This information is in the consent and you will get a copy of the consent.

PP: Do I have to sign the consent?

PI: You only sign the consent if you agree to be in the study

PP: What should I do if I want to be in the study?

PI: You sign this consent. We will give you a copy of the document to keep.

PP: [The potential participant agrees to be in the study]

PI: Have we answered all your questions?

PP: [The potential participant indicates yes]

PI: Okay, if you are sure you have no more questions, it is time to sign the consent form. But first, let’s just review a few things. By signing this consent form, you are saying you understand that:

- You agree to be in the study,
- We talked with you about the information in this consent form and answered all your questions
- You know that you can drop out of the study at any time without penalty
- You can call the office in charge of research at (212) 650-3053 if you have any questions

PP: The potential participant signs the consent form.

PI: Thank you very much for participating in this study. We will make a copy of the consent form and give it to you before we start the study. We will start the study at _(time)__. At that time, you will complete 3 surveys, watch the video, practice finding information on the internet, complete another survey. No one will be identified. I will remind you about this again before we start the research.
Scenario 2: Potential Participant does not want to be in the study

PI: Hi! My name is Darcel Reyes, and I am a nurse from Hunter College and the Graduate Center of the City University of New York. Kathy Nokes, another nurse and I want to learn more about how to help people who have HIV use the internet to find health information. This is a research study. I am not selling anything. We are asking people like you who have HIV to help us. You do not have to be in the study. Nothing about your participation in HELP/PSI’s Adult Day Health Care Program (ADHC) will change if you say “No.” If you say “Yes,” you can still quit the study at any time. Does this sound like something you would be interested in doing?

PP: No, I do not want to participate (or another indication that the person is not interested in participating) [REJECT]

PI: Thank you for listening. I will be here until 1:00 pm if you change your mind.

Scenario 3: Potential Participant does not qualify because of inability to understand and speak English

PI: Hi! My name is Darcel Reyes, and I am a nurse from Hunter College and the Graduate Center of the City University of New York. Kathy Nokes, another nurse and I want to learn more about how to help people who have HIV use the internet to find health information. This is a research study. I am not selling anything. We are asking people like you who have HIV to help us. You do not have to be in the study. Nothing about your participation in HELP/PSI’s Adult Day Health Care Program (ADHC) will change if you say “No.” If you say “Yes,” you can still quit the study at any time. Does this sound like something you would be interested in doing?

PP: Yes [CONTINUE-this is unlikely if the person cannot speak English, but there may be people who understand English, but cannot speak English or do not feel comfortable having a conversation in English]

PI: Great! Let’s find out if you qualify. I have a few questions to ask. This will only take a few minutes. At some point, I may end the question if I discover that you don’t qualify. This has nothing to do with you. We simply are looking for people who meet certain criteria.

Question 1: In this study, you will hear someone giving information in English. When you hear someone speaking English, do you understand what the person is saying and are you able to answer the person in English?

PP: [REJECT ANY VERSION OF THE FOLLOWING] “I have problems understanding when I hear English on the radio or TV.” OR “I understand English when I hear it, but I cannot speak
English.” OR “I understand English when I hear it, but I cannot converse (talk a lot, have a conversation, etc.) in English.”

PI: I am sorry, but unfortunately in this study participants needs to be able to speak English and listen to information in English. Thank you for your interest.

[REJECT IF THE PERSON REQUESTS A TRANSLATOR BY SAYING THE FOLLOWING: “I am sorry, but unfortunately in this study we cannot use translators, participants need to be able to speak and understand English. Thank you for your interest.”]

[IF THE PERSON RESPONDS IN ANOTHER LANGUAGE, SAY: Can we speak in English?” IF THE PERSON INDICATES “NO,” SAY: “I am sorry, but unfortunately in this study participants need to be able to talk to other people in English and listen to information in English. Thank you for your interest.”]

------------------------------------{END}-------------------------------------
Appendix C2: MEDLINE Script

Scenario 1: Potential participant agrees to be in study

Principal Investigator (PI): Hi! My name is Darcel Reyes, and I am a nurse from Hunter College and the Graduate Center of the City University of New York. Kathy Nokes, another nurse and I want to learn more about how to help people who have HIV use the internet to find health information to take care of their health. This is a research study. I am not selling anything. We are asking people like you who have HIV to help us. You do not have to be in the study. Nothing about your participation in HELP/PSI’s Adult Day Health Care Program (ADHC) will change if you say “No.” If you say “Yes,” you can still quit the study at any time. Does this sound like something you would be interested in doing?

Potential Participant (PP): Yes (or other indication of willingness to participate).

PI: Great! This will only take a few minutes. Let’s find out if you qualify. I have a few questions to ask. There are no right or wrong answers to these questions. At some point, I may end the questions if I discover that you don’t qualify. This has nothing to do with you. We simply are looking for people who meet certain criteria.

Question 1: In this study, you will hear someone giving information in English. When you hear someone speaking English, do you understand what the person is saying and are you able to answer the person in English?

PP: Yes

PI: Great! It looks like you are able to participate. In this study, you will first be asked to complete four surveys, and then watch a 16-minute video about using the internet to find health information. After watching the video, we will ask you to complete another survey about what you learned. Completing the surveys and watching the video will take about 1 and a half hours of your time in the first session. We want you to come back in 1 week for 1 hour and show us how you are doing and complete 2 surveys. Don’t worry, we are not testing you, we are trying to find out if this is a good way to teach people how to find information on the internet. Are you comfortable with this?

PP: Yes (or another indication of willingness to participate).

PI: Thanks for volunteering. In order to participate in the study, you have to sign a consent form. [PRESENT THE CONSENT FORM TO THE POTENTIAL PARTICIPANT]. Here is the consent form. If you would like, someone will read it to you or you can read it yourself. Please take your time. Please let me know if you have any questions.

[THE FOLLOWING ARE POSSIBLE QUESTIONS AND ANSWERS]
**PP:** What happens if I say yes, but change my mind later?

**PI:** You can stop being in the study at any time. You will not be penalized and you will not lose any benefits that you have at HELP/PSI ADHC program.

**PP:** Who will see my answers on the survey?

**PI:** The only people allowed to see your answers will be the people who work on the study and the people who make sure we run the study the right way. Your survey answers, health information, and a copy of this consent will be kept in a locked cabinet. We cannot put your answers in your ADHC chart.

When we share the results of the study in healthcare journals or conferences, we will not include your name. We will do our best to make sure that no one outside of this study will know you are a part of the study.

**PP:** Will it cost me anything to be part of the study?

**PI:** No.

**PP:** Will being in this study help me in any way?

**PI:** You may learn how to use the computer to find health-related information, but we cannot promise you that you will learn anything.

**PP:** Will I be paid for my time? Or, Do I get anything for being in this study?

**PI:** We will give you a $10.00 at the end of each session.

**PP:** Will this study be bad for me?

**PI:** Sometimes people become anxious learning new things or talking in a group. If that happens, and you want to stop participating, you can without penalty. If you want to talk to someone about how you feel, Darcel Reyes will take you to healthcare provider or social worker who could help you.

**PP:** What if I have questions during the study, or in the next few hours before the study begins?

**PI:** Please call me, Darcel Reyes, at ____-____-_____.

**PP:** What if I have questions about my rights as a participant, or feel I have been treated unfairly, or injured?

**PI:** You can call the office in charge of research at Hunter College. It is called the Human Research Protection Program and the phone number is: (212) 650-3053. This information is in the consent and you will get a copy of the consent.
PP: Do I have to sign the consent?

PI: You only sign the consent if you agree to be in the study

PP: What should I do if I want to be in the study?

PI: You sign this consent. We will give you a copy of the document to keep.

PP: [The potential participant agrees to be in the study]

PI: Have we answered all your questions?

PP: [The potential participant indicates yes]

PI: Okay, if you are sure you have no more questions, it is time to sign the consent form. But first, let’s just review a few things. By signing this consent form, you are saying you understand that:

• You agree to be in the study,
• We talked with you about the information in this consent form and answered all your questions
• You know that you can drop out of the study at any time without penalty
• You can call the office in charge of research at (212) 650-3053 if you have any questions

PP: The potential participant signs the consent form.

PI: Thank you very much for participating in this study. We will make a copy of the consent form and give it to you before we start the study. We will start the study at _(time)__. At that time, you will complete 3 surveys, watch the video, practice finding information on the internet, complete another survey. No one will be identified. I will remind you about this again before we start the research.

---------------------------{END}---------------------------

Scenario 2: Potential Participant does not want to be in the study

PI: Hi! My name is Darcel Reyes, and I am a nurse from Hunter College and the Graduate Center of the City University of New York. Kathy Nokes, another nurse and I want to learn more about how to help people who have HIV use the internet to find health information. This is a research study. I am not selling anything. We are asking people like you who have HIV to help us. You do not have to be in the study. Nothing about your participation in HELP/PSI’s Adult Day Health Care Program (ADHC) will change if you say “No.” If you say “Yes,” you can
still quit the study at any time. Does this sound like something you would be interested in doing?  

**PP:** No, I do not want to participate (or another indication that the person is not interested in participating) [REJECT]

**PI:** Thank you for listening. I will be here until 1:00 pm if you change your mind.

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

**Scenario 3: Potential Participant does not qualify because of inability to understand and speak English**

**PI:** Hi! My name is Darcel Reyes, and I am a nurse from Hunter College and the Graduate Center of the City University of New York. Kathy Nokes, another nurse and I want to learn more about how to help people who have HIV use the internet to find health information. This is a research study. I am not selling anything. We are asking people like you who have HIV to help us. You do not have to be in the study. Nothing about your participation in HELP/PSI’s Adult Day Health Care Program (ADHC) will change if you say “No.” If you say “Yes,” you can still quit the study at any time. Does this sound like something you would be interested in doing?

**PP:** Yes [CONTINUE-this is unlikely if the person cannot speak English, but there may be people who understand English, but cannot speak English or do not feel comfortable having a conversation in English]

**PI:** Great! Let’s find out if you qualify. I have a few questions to ask. This will only take a few minutes. At some point, I may end the question if I discover that you don’t qualify. This has nothing to do with you. We simply are looking for people who meet certain criteria.

**Question 1:** In this study, you will hear someone giving information in English. When you hear someone speaking English, do you understand what the person is saying and are you able to answer the person in English?

**PP:** [REJECT ANY VERSION OF THE FOLLOWING] “I have problems understanding when I hear English on the radio or TV.” OR “I understand English when I hear it, but I cannot speak English.” OR “I understand English when I hear it, but I cannot converse (talk a lot, have a conversation, etc.) in English.”

**PI:** I am sorry, but unfortunately in this study participants need to be able to speak English and listen to information in English. Thank you for your interest.

[REJECT IF THE PERSON REQUESTS A TRANSLATOR BY SAYING THE FOLLOWING: “I am sorry, but unfortunately in this study we cannot use translators, participants need to be able to speak and understand English. Thank you for your interest.”]
[IF THE PERSON RESPONDS IN ANOTHER LANGUAGE, SAY: Can we speak in English?”
IF THE PERSON INDICATES “NO,” SAY: “I am sorry, but unfortunately in this study participants need to be able to talk to other people in English and listen to information in English. Thank you for your interest.”}
Appendix D: Measurement Instruments

Appendix D.1 Demographic Survey

1. What is your sex or gender?
   a. Female
   b. Male

2. What was your age at your last birthday? ______________

3. What is your Race? (CIRCLE ALL THAT APPLY)
   a. Asian
   b. Native Hawaiian or Pacific Islander
   c. Native American or American Indian or Alaskan Native
   d. Black or African American
   e. White or Caucasian
   f. Other

4. Are you of Hispanic or Latino origin or descent?
   a. Yes, Hispanic or Latino
   b. No, Not Hispanic or Latino

5. What is the highest level of education you have completed?
   a. 6th grade or less
   b. 9th grade or less
   c. Some High School
   d. Completed High School
   e. GED
   f. College or Professional Degree

8. Where you diagnosed with AIDS?
   Yes__
   No__
Appendix D.2:

Electronic Health Literacy Scale (e-HEALs)

I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience right now.

1. I know **what** health resources are available on the Internet

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<tr>
<th></th>
<th>o1</th>
<th>o2</th>
<th>o3</th>
<th>o4</th>
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<tbody>
<tr>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Undecided</td>
<td>Agree</td>
<td>Strongly agree</td>
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</table>

2. I know **where** to find helpful health resources on the Internet

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<td>Agree</td>
<td>Strongly agree</td>
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</table>

3. I know **how** to find helpful health resources on the Internet

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<tbody>
<tr>
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<td>Disagree</td>
<td>Undecided</td>
<td>Agree</td>
<td>Strongly agree</td>
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</table>

4. I know **how to use** the Internet to answer my questions about health

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<tr>
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<td>Disagree</td>
<td>Undecided</td>
<td>Agree</td>
<td>Strongly agree</td>
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</table>
5. I know how to use the health information I find on the Internet to help me

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<tbody>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Undecided</td>
<td>Agree</td>
<td>Strongly agree</td>
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</table>

6. I have the skills I need to evaluate the health resources I find on the Internet

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<tbody>
<tr>
<td></td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Undecided</td>
<td>Agree</td>
<td>Strongly agree</td>
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</table>

7. I can tell high quality health resources from low quality health resources on the Internet

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<tr>
<td></td>
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<td>Undecided</td>
<td>Agree</td>
<td>Strongly agree</td>
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</table>

8. I feel confident in using information from the Internet to make health decisions

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Appendix D.3:

Identifying Reliable Internet Health Information Scale

Please rate how confident you feel right now to use the internet to find health information by circling a number from 1 to 6 on the scale below each question.

1. When I look at a health information website I am confident I can identify the sponsor of the website

   o1  o2  o3  o4  o5

2. When I look at a health information website I am confident I can identify How to contact the sponsor of the website

   o1  o2  o3  o4  o5

4. When I look at a health information website I am confident I can identify the difference between advertisements and health information

   o1  o2  o3  o4  o5

5. When I look at a health information website I am confident I can identify if the website is up-to-date or out-of-date

   o1  o2  o3  o4  o5

6. When I look at a health information website I am confident I can identify How the website will use my personal information

   o1  o2  o3  o4  o5

Appendix D.4:
Self-As-Carer Inventory

Instructions: Below are a number of statements about caring for yourself. The word “self-care” is used a lot. It means things you do for yourself to maintain life, health, and well-being. Use a #2 pencil to mark the number that best describes how you take care of yourself. Marking the number “6” means the statement is a very accurate statement about how you take care of yourself; marking number “1” means that the statement is not at all accurate.

1. My joints are flexible enough for me to take care of myself

1 2 3 4 5 6

2. I think about health information in choosing solutions to problems in caring for myself

1 2 3 4 5 6

3. The way I take care of myself fits well with my family life

1 2 3 4 5 6

4. I try new ways to take care of myself based on information from experts

1 2 3 4 5 6

5. My self-care routine fits in with other parts of my life

1 2 3 4 5 6
6. I watch for signs that tell me if I am taking good care of myself

| 1 | 2 | 3 | 4 | 5 | 6 |

7. I use different ways of thinking based on the kind of self-care problem I have

| 1 | 2 | 3 | 4 | 5 | 6 |

8. I watch for things around me that will make a difference in how I take care of myself

| 1 | 2 | 3 | 4 | 5 | 6 |

9. I am strong enough for the physical work of caring for myself

| 1 | 2 | 3 | 4 | 5 | 6 |

10. I pay attention to signs telling me to change the way I care for myself

| 1 | 2 | 3 | 4 | 5 | 6 |

11. I plan my self-care by how much energy I have

| 1 | 2 | 3 | 4 | 5 | 6 |

12. I am aware of things around me that affect how I take care of myself

| 1 | 2 | 3 | 4 | 5 | 6 |

13. I have the necessary skills to care for myself

| 1 | 2 | 3 | 4 | 5 | 6 |
14. I stick to my decisions about caring for myself even when I run into setbacks or problems

1 2 3 4 5 6

15. I know what I need to take care of myself

1 2 3 4 5 6

16. If the healthcare provider tells me to do something, I do it

1 2 3 4 5 6

17. I take care of myself because my health is important to me

1 2 3 4 5 6

18. I remember healthcare information about what I should do for myself

1 2 3 4 5 6

19. I know how much energy I need to take care of myself

1 2 3 4 5 6

20. To make decisions about my care, I look at both sides of my choices

1 2 3 4 5 6
21. It matters to me to care for myself

22. I know when I have enough energy to care for myself

23. I know where to find good information I need to help me take care of myself

24. I think about how the things I do fit together to help me reach my health goals

25. I have the physical balance I need in order to take care of myself

26. I fit new self-care actions into what I already do

27. My hearing and vision are good enough to allow me to care for myself

28. The way I take care of myself fits in with what I consider important in my life
29. I do what I know is best in taking care of myself even though I may not like it

1 2 3 4 5 6

30. I do my self-care in several different ways

1 2 3 4 5 6

31. I follow through with decisions I make about caring for myself

1 2 3 4 5 6

32. I have a set routine for caring for myself

1 2 3 4 5 6

33. I think about how decisions I make will affect my health and self-care

1 2 3 4 5 6

34. I knowingly spend my energies on the most important self-care needs

1 2 3 4 5 6

35. I use information from authorities to help me take better care of myself

1 2 3 4 5 6

36. I think about several choices before I make a decision about my self-care

1 2 3 4 5 6
37. I think about why I make the choices I do in order to care for myself

1 2 3 4 5 6

38. I know why I make the choices I do in order to care for myself

1 2 3 4 5 6

39. I know which actions to do first to best accomplish my self-care

1 2 3 4 5 6

40. Once I begin to care for myself in a certain way, I check to see if it is working

1 2 3 4 5 6
Appendix D.5:

HIV Health Literacy (HIV-HL)

QUESTIONS:

Question 1: correct answer = B. Always take the medicine with something in your stomach
USE GRAPHIC labeled “Warning Label Food” (NOTE: The new graphic is somewhat different from this one)

Question 2: correct answer = C. About every eight hours
Question 3: correct answer = C. ½ hour before or 2 hours after you eat

Question 4: correct answer = B. 2:00 in the afternoon
USE GRAPHIC labeled “Prescription Label Pretest Ibuprofen”

Question 5: correct answer = A. Take 2 pills instead of 1
USE GRAPHIC labeled “Prescription Label Pretest Ibuprofen”
Question 6: correct answer = C. 15 days
USE GRAPHIC labeled “Prescription Label Pretest Ibuprofen”

Question 7: correct answer = C. They’re the same AND D. It’s not possible to say
USE GRAPHIC labeled “Prescription Label Pretest Ibuprofen”

Question 8: correct answer = C. Take 3 pills in the morning . . .
Question 9: correct answer = A. Stop working

USE GRAPHIC labeled “Viral Resistance Paragraph”

INTRODUCTION TO VIDEO:

On the next slide, you will be able see a short video about a made-up medication. You’ll see a doctor telling a person how to take the medication. Please listen to the video. After you see it, we’ll ask you to answer some questions about it. You can go on to the video by clicking on the “Continue” button.

[Dr. Parker Video HERE]

USE VIDEO FILE labeled “DrParkerVLMay2012.avi”

[In the current version, the video is embedded in a separate page using a Flash video player that starts automatically. When completed, the participant clicks on a button labeled “continue” to go to the questions.]
Question 10: correct = A. Viral load

Question 11: correct = A. Headache

Question 12: correct = B. 2
NEW Question 13:

How many pills should the person take at night?

a. 1  
b. 2  
c. 3  
d. 4  

Correct answer = A. 1

Question 14:

Which of the following side effects is least likely to occur?

a. Headache  
b. Dry mouth  
c. Dizziness  
d. Metallic taste  

Correct answer = D. Metallic taste

Question 15:

What part of the body can the medicine affect?

a. Heart  
b. Lungs  
c. Nerves  
d. Liver  

Correct answer = D. Liver

Question 16:

How will the doctor tell if the medicine affects the woman?

a. Asking her questions  
b. Blood tests  
c. Looking in her eyes  
d. Weighing her  

Correct answer = B. Blood tests
Question 17: correct answer = D. Stop taking the medicine . . .

Question 18: correct answer = B. Maggie

Question 19:

What is the most serious side effect of the medicine?

a. Insomnia  
b. Blurred vision  
c. Headache  
d. Metallic taste

Correct answer = B. Blurred vision
Question 20: correct answer = A. Tell the pharmacist there’s a mistake

USE GRAPHIC labeled “PrescriptionLabelPretestDiacar” (NOTE: New graphic is slightly different and has different number of pills)

[NOTE: the answer marked in the picture is wrong]

Question 21: correct answer = D. Take the medicine with at least a full glass of water.

USE GRAPHIC labeled “Warning Label Water” (NOTE: the graphic is somewhat different from this one)

Question 22:

Medicines called protease inhibitors work by:

a. Raising HIV levels in your blood
b. Keeping HIV from getting into your body
c. Blocking HIV from making more of itself
d. Stopping HIV from getting into cells

Correct answer = C.
Question 23:

A nucleoside reverse transcriptase inhibitor (NRTI) works by

a. Inserting itself in viral DNA
b. Blocking HIV from getting into your body
c. Keeping HIV from making more of itself
d. Stopping HIV from getting into cells

Correct answer = A.

Question 24:

To prevent a person treated for HIV from developing viral resistance, what percent of the time does he or she have to take their medicine?

- A) 20%
- B) 50%
- C) 80%
- D) 95%

Correct answer: d

Question 25: correct answer = a.
Appendix E: Scripts for Intervention Protocols

Appendix E1: E-HELP Protocol Script

Principal Investigator (PI): First, we are going to watch this video.

(PI starts video, it runs for 16 minutes)7 PI: Now, we will find an HIV health information website.

(PI types in “http://www.hiv.va.gov/index.asp.” in address box)

Let’s look at this website together. Can you tell me who is sponsoring this website?

Participant (P) Yes,

PI: please show me or tell me how you know the sponsor.

PP: (points to “about us” tab) or says something that indicates he/she knows the sponsor

PI: How would you contact the sponsor?

PP: Indicates or says “Contact Us” tab

PI: Is this website trying to sell you something?

PP: Indicates or says “no”

PI: How do you know?

PP: person explains, does not see advertising, looks for policy

PI: Can you find who wrote the health information?

PP: Person looks and indicates or explains

PI: Can you find the last time the sponsor updated the website?

PP: indicates yes,

PI: What is the website date? Is the date recent (new) or old?

PP: Recites date, gives their opinion

PI: Does this website tell you what it does with personal information?

PP: person answers yes or no

PI: (if person answers yes) What does the website do with personal information?
PP: person explains.

PI: Good, now we want you to practice this skill at home. Here is a handout with the information. You can use this to write down what you find and bring it back next week. Let’s arrange a date for you to return. (arranges date, gives handout). We will call you to remind you, is that okay?

PP: indicates yes it is okay, or no, it is not okay.

PI: (If it is okay to contact the person) Great! I am going to write the date down on this handout to help you remember. See you then. Remember, look for some HIV websites and write down what you find. You can also come back and watch the video whenever you want by clicking this picture (shows the icon for the NLM video). You can also look at this video at the public library by typing in “EVALUATING INTERNET HEALTH INFORMATION” in the address box. If you forget, that information is on the handout. See you next week on__________ at _(time)__.

_____________ SECOND SESSION________________________

PI: Hi? How did your week go? Were you able to look for some websites during the week?
PP: Answers yes

PI: Show me what you found

PP: The participant navigates to a website

PI: That is correct, now can you show me the six criteria of a reliable website?

PP: The participant indicates the criteria of a reliable website without help from the PI.

PP: That is correct

___________________________________END______________________________________
Appendix E2 Script for MEDLINE Protocol

Principal Investigator (PI): We are going to watch this video.  

(PI starts video, it runs for 16 minutes)

PI: We want you to practice this skill at home. Here is a handout with the information. You can use this to write down what you find and bring it back next week. Let’s arrange a date for you to return. (arranges date, gives handout). We will call you to remind you, is that okay?

PP: indicates yes it is okay, or no, it is not okay.

PI: (If it is okay to contact the person) Great! I am going to write the date down on this handout to help you remember. See you then. Remember, look for some HIV websites and write down what you find. You can also come back and watch the video whenever you want by clicking this picture (shows the icon for the NLM video). You can also look at this video at the public library by typing in “EVALUATING INTERNET HEALTH INFORMATION” in the address box. If you forget, that information is on the handout. See you next week on___________ at _ (time)_.

__________________SECOND SESSION____________________________________

PI: Hi? How did your week go? Were you able to look for some websites during the week?  
PP: Answers yes

PI: Show me what you found

PP: The participant navigates to a website

PI: Correct, now can you show me the six criteria of a reliable website?

PP: The participant indicates the signs of a reliable website without help from the PI.

PI: Correct

OR:

PI: Thank you very much for showing me what you learned.
Appendix F: At Home Assignment

1. What is the name of the website? Write the name below:

________________________________________________________________________

2. Who is the sponsor of the Website? Write their name below:

________________________________________________________________________

3. How did you tell the difference between advertisements and health information?

________________________________________________________________________

4. Can you identify the people who contributed or reviewed the health information? Write their names and credentials (initials after last name like MD, RN, NP, MS, PhD, PA) below:

________________________________________________________________________

5. How will the website use your personal information?

________________________________________________________________________

6. How can you contact the sponsor of the website (e-mail, phone number, mailing address)?

________________________________________________________________________

7. What is the date of the most recent update of the health information?

________________________________________________________________________
Appendix G: Figures

Figure 1 Relationships Among Health Literacy, eHealth, Ability to Identify Reliable Internet Health Information, and Self-Care Agency
Figure 2 Relationship between Interventions and Study Variables
Figure 3: Participant Recruitment in MEDLINE and E-HELP Groups
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