A DNP PROJECT

TITLE: IMPROVING HIV SELF-MANAGEMENT KNOWLEDGE WITH THE USE OF VISUAL IMAGE INTERVENTIONS

STUDENT NAME: Christina Carrier, BSN, RN

DNP PROJECT CHAIR: Darcel Reyes, PhD, ANP-BC
DNP TEAM MEMBER(S): Suzanne Willard, PhD, APN, FAAN

DATE: 4/19/2019
# Table of Contents

Abstract ............................................................................................................................................................... 4  
Background and Significance ............................................................................................................................ 5  
Problem Statement ............................................................................................................................................... 7  
Needs Assessment ............................................................................................................................................... 8  
Aim and Objectives ........................................................................................................................................... 9  
Review of Literature .......................................................................................................................................... 9  
Theoretical Framework ..................................................................................................................................... 14  
Methodology ................................................................................................................................................... 15  
  Project Design .................................................................................................................................................. 16  
  Project Interventions .................................................................................................................................... 17  
Outcome Measures ........................................................................................................................................... 18  
Estimated Length of Involvement of Participants ......................................................................................... 20  
Setting .............................................................................................................................................................. 21  
Population and Recruitment ............................................................................................................................ 21  
Consent ............................................................................................................................................................. 22  
Risks and Benefits ........................................................................................................................................... 22  
Data Maintenance and Security ....................................................................................................................... 22  
Data Analysis ................................................................................................................................................... 23  
Subject Cost and Compensation ..................................................................................................................... 24  
Timeline and Budget ......................................................................................................................................... 24  
Findings .............................................................................................................................................................. 25  
Discussion ......................................................................................................................................................... 27
Abstract

People living with HIV (PLWH) and adequate health literacy understand pertinent knowledge needed for self-management, including the importance of CD4 counts, viral loads, drug resistance, and need to adhere to a strict antiretroviral therapy (ART) regimen. The purpose of this project was to improve HIV-related knowledge and intent for self-management for PLWH and limited health literacy. Visual educational interventions have been shown to enhance self-management knowledge. This project was piloted at a local HIV support group. A visual educational intervention that discussed the pertinent aspects of HIV was implemented for all participants. The visual educational intervention consisted of a brief video followed by the distribution of a pocket-sized handout and further discussion to enhance the knowledge learned from the video. The handout was given to take home to help serve as a reminder for the need to continue the use of a strict ART regimen. A pre and post design was used to measure health literacy and self-management intent before implementing the visual educational intervention and after the implementation phase was completed. After the intervention, participants with limited health literacy achieved moderate health literacy. Majority of participants scored with high self-management intention prior to the intervention. No change was seen after the intervention was implemented. A negative correlation was found between age and HIV-related health literacy. The findings of this project support the use of the visual interventions to enhance self-management discussion for PLWH.

*Keywords*: health literacy, antiretroviral therapy, intention, education
Improving HIV Self-Management Knowledge with the Use of Visual Image Interventions

People living with HIV (PLWH) who have adequate health literacy are more aware of the HIV disease information needed for self-management, such as the significance of CD4 counts and viral load; they are also more likely to achieve viral suppression (Kalichman, Benotsch, Suarez, Catz, Miller, & Rompa, 2000; Lindgren et al., 2017; Jones, Cook, Rodriguez, & Waldrop-Valverde, 2012; McCall & Wilson, 2015; Phillips & Arya, 2015; Wawrzyniak, Ownby, McCoy, & Waldrop-Valverde, 2013). Increasing HIV knowledge improves HIV-related health literacy and the ability to self-manage HIV disease. Limited health literacy and HIV significantly impacts people with lower economic status and groups who are marginalized (U.S. Department of Health and Human Services Office of Disease Prevention and Health Promotion, 2010, p. 4; Phillips & Arya, 2016). Limited health literacy for those living with HIV interferes with HIV self-management, contributing to disease progression and worsening health outcomes (McCall & Wilson, 2015). The goal of this project was to use visual educational interventions to increase HIV knowledge and health literacy in PLWH in order to enhance HIV self-management knowledge.

**Background and Significance**

Self-management and health literacy are particularly important in HIV treatment. Self-management is the person’s ability to use his or her essential understanding of disease to manage the symptoms and perform the tasks needed to maintain optimal health in the presence of a chronic disease (Lindgren et al., 2017). Self-management includes managing dosing schedules, food requirements, side effects, preventing opportunistic infections, and ensuring proper medication storage.
Health literacy is defined as the general understanding of disease process that leads to the effect of knowledge on self-management (Lindgren et al., 2017). HIV-related health literacy includes knowledge about HIV disease and specific HIV self-management requirements, which includes the ability to understand and use reliable health information to perform fundamental tasks, such as adhere to a medication regimen needed to achieve viral suppression of HIV (Reyes & Steilen, 2018). Limited HIV health literacy results in misperceptions about the knowledge needed for the HIV self-management skill of antiretroviral therapy (ART) adherence and may lead to drug resistance and poor health outcomes (Graham, Bennett, Holmes, & Gross, 2007; Wawrzyniak et al., 2013).

PLWH who have limited health literacy are more likely to have diminished health, including low CD4 counts, elevated viral loads, and trouble managing ART (McCall & Wilson, 2015). In addition, limited health literacy increases the risk of HIV transmission due to lack of knowledge about prevention measures (Graham et al., 2007; Phillips & Arya, 2016). PLWH may believe that they have adequate knowledge to manage their disease, however, screening tools often indicates that they have limited health literacy (Graham et al., 2007; McCall & Wilson, 2015). For this reason, patients should be screened for health literacy in all clinical settings.

It is necessary to screen for health literacy and intervene with patients who have less than adequate health literacy scores to improve HIV self-management. Using a screening instrument coupled with an educational intervention has the potential to improve self-management and encourage patients to become more involved in care. The evidence suggests that visual educational interventions, such as a booklet or video, improve self-management activities, enhance patients’ health discussion with providers, and increase medication adherence (Eckman et al., 2012, p. 147). This suggests that the use of visual educational interventions that provides
HIV specific information could improve HIV-related health literacy by increasing HIV disease knowledge and thus self-management.

**Problem Statement**

Less than half (49%) of PLWH in the United States who are aware of their status achieve viral suppression (Centers for Disease Control and Prevention, [CDC], 2017) and need further support to achieve this goal. Limited health literacy interferes with achieving viral suppression (McCall & Wilson, 2015; Phillips & Arya, 2016; Rebeiro et al., 2018; Wawrzyniak et al., 2013; Kalichman et al., 2013a), which is dependent on self-management, specifically, the ability to manage ART. Knowledge of the effect of ART on viral suppression is a component of HIV-related health literacy and necessary for effective self-management. HIV health literacy screening coupled with a visual educational intervention that provides the information needed for ART self-management may improve adherence in PLWH and limited health literacy. The purpose of this DNP project was to increase HIV self-management knowledge about ART and intent to self-manage ART in PLWH and limited health literacy.

**Clinical Question**

This educational intervention addressed the issue of HIV self-management knowledge about ART for patients with limited health literacy at a local HIV support group. The PICOT question for this project was:

In PLWH who attend a local HIV support group, what is the effect of a visual educational intervention on HIV self-management knowledge about ART, HIV-related health literacy, and intention to improve self-management compared with standard education within one month?
Needs Assessment

This needs assessment consisted of interviews with informants in a local HIV clinic and observation of patient-provider interactions. During a six-month clinical rotation, direct observation showed a lack of disease process understanding by the patient during visits. In general, many patients appeared to understand that they needed to take their medications to improve “their numbers” because this is discussed at every clinical visit. However, for many patients, a recurring question about the significance of a viral load or CD4 count persisted after education was provided at the clinic visit. While interviewing the community health workers (CHW) at this clinic, it was noted that many patients do not understand the meaning of a CD4 count and viral load. In addition, the CHWs indicated that patients do not feel comfortable asking providers these questions.

The CHW interviews are supported by the literature; although patients trust providers, they sought information from other healthcare workers, such as CHWs, because PLWH felt that providers did not want to discuss certain sensitive topics (Lindgren et al., 2017). This is a potential problem because information may be missed, or patients may be confused about certain HIV related information and this may contribute to a lack of disease related knowledge and poor HIV self-management skills. In addition, findings from a study that examined reading difficulty and willingness to ask for assistance by PLWH found that standard interventions to improve HIV self-management for PLWH who had limited health literacy are insufficient (Kalichman et al., 2013b, p. 328).

Interviews with clinic providers and staff at this clinic revealed that a health literacy assessment is not currently in practice and indicated the need for a standardized HIV specific health literacy screening instrument. During the interviews, the clinic staff commented on the
need for an educational intervention that enhanced knowledge of the basics of HIV disease process. The staff was particularly interested in a simple and easy to understand intervention that could be sustained within the clinic on a long-term basis.

Interviews and observations from this clinic were vital to support the need for this project. This needs assessment found that PLWH may need additional interventions to support self-management, particularly with ART. This DNP project, piloted at a local HIV support group, assessed the impact of two visual educational interventions on HIV-related health literacy and self-management intention to determine usability of this visual educational intervention for PLWH.

Aim and Objectives

The aim of this DNP project was to improve HIV-related health literacy, self-management knowledge about ART, and intent for self-management of ART in PLWH who attended the support group by using a visual educational intervention.

The objectives of this study were as follows:

- To identify the HIV health literacy of participants using a HIV health literacy screening instrument prior to implementation of the visual educational intervention.
- To compare HIV-related health literacy scores after implementing the visual educational intervention to scores obtained prior to the intervention.
- To assess the effect of the visual intervention on HIV knowledge about ART adherence, HIV health literacy, and intent to improve HIV self-management.

Review of Literature

The purpose of the literature review was to investigate the body of research about assessing health literacy in PLWH, identify an effective instrument to evaluate HIV health
literacy, explore the effectiveness of health literacy interventions, identify a valid instrument to assess intent for self-management, and determine usefulness of visual images to enhance health literacy for people with chronic illnesses. A search was conducted using the Rutgers University Database Search Engine. The databases searched were CINAHL, ScienceDirect, Scopus, Social Sciences Citation Index, Google Scholar, and PubMed. The search terms that were used in various combinations were knowledge, illustrations, pictorial images, education, intervention, HIV, health literacy, scale, ART, self-management, intent, and adherence. When using these search terms, 8,889 articles were found in the databases. Articles were excluded if they discussed topics related to children or adolescents, did not use visual educational interventions, or were focused on a particular race or gender only. Only articles that discussed visual image interventions to improve health literacy for adults with chronic illnesses, self-management intention instruments and health literacy assessment instruments were included in this review. After careful review, only fifteen articles were found that specifically related to the DNP project topic.

Assessing Health Literacy

Health literacy is a factor in predicting self-management for both patients and providers. Many providers are not aware of their patients’ health literacy levels because less than half (48%) of patients asked for assistance with reading or interpreting medical information (Kalichman et al., 2013b). Patients may also not be aware of their health literacy ability if it is not routinely screened and perceive their health literacy level as significantly higher than their actual health literacy scores (McCall & Wilson, 2015). This may lead both the patient and providers to believe that patients understand what is required for self-management, when further education is needed.
Use of General Health Literacy Tools in HIV Populations

Few health literacy screening tools have been created that specifically target HIV. One study tested the use of a general health literacy screening tool, the Newest Vital Sign (NVS), in a HIV positive population to determine usability and found it to be a reliable indicator of health literacy in PLWH ($\alpha=0.7$) (Kordovski, Woods, Avci, Verduzco, & Morgan, 2017). However, this study did not assess HIV self-management, but rather a general understanding of pill administration (Kordovski et al., 2017).

HIV Health Literacy Tools and Self-Management

Assessing HIV health literacy independently from general health literacy can provide insight into the knowledge needed for self-management. Two HIV specific health literacy instruments have questions that address HIV self-management; the Brief Estimate of Health Knowledge and Action- HIV Version (BEHKA-HIV) and the HIV-Related Health Literacy Scale (HIV-HL) (Osborn, Davis, Bailey, & Wolf, 2010; Ownby et al., 2013). The BEHKA-HIV, an eight-item health literacy screening tool that assesses HIV-related knowledge and HIV self-management skills, was created and compared against the Rapid Estimate of Adult Literacy in Medicine (REALM), a general health literacy screening tool to test for validity (Osborn et al., 2010). This instrument is 0.76 sensitive and 0.82 specific in estimating ART self-management (Osborn et al., 2010, p. 186). BEHKA-HIV health literacy scores are highly correlated with ART self-management reports ($p < 0.001$) proving to be a strong self-management indicator (Osborn et al., 2010, p. 184). Although this instrument proved to be valid in the assessment of HIV-related health literacy, it is outdated and its use in clinical practice has not been documented.

The HIV-HL scale, a twenty-question instrument that can be administered using a touch-screen computer, specifically targets HIV health literacy (Ownby et al., 2013). The HIV-HL was
measured against a well-known health literacy assessment tool, TOFHLA, and found to be highly comparable and a good indicator of health literacy ($p = 0.01$) (Ownby et al., 2013, p. 716). Assessing patient HIV health literacy scores can help structure interventions to improve HIV knowledge of self-management for PLWH.

**HIV Care Intent**

Few instruments have been developed to assess intent for self-management, and only one has been developed to examine intention for HIV self-management, the HIV-Intention Measure (HIV-IM) (Nelsen et al., 2012). This instrument measures intention for HIV care and HIV knowledge, which is needed for viral suppression (Nelsen et al., 2012). There are ten items addressing intent for HIV self-care and four questions assessing HIV knowledge ranked on a Likert scale. This instrument is a reliable measurement instrument for both intent for HIV care and HIV knowledge ($\alpha=0.81$ and $\alpha=0.86$ respectively). Statistical analysis of the instrument demonstrated a strong correlation ($p < 0.001$) between intent and knowledge (Nelsen et al., 2012).

**Interventions to Improve Health Literacy**

The use of visual educational interventions has been examined in relation to limited health literacy in many chronic illnesses. A study conducted on diabetes health literacy implemented teach-back and visual image interventions to improve diabetes knowledge (Negarandeh, Mahmoodi, Noktehdan, Heshmat, & Shakibazadeh, 2012). Improvements were seen in knowledge, medication adherence, and diet after the interventions (Negarandeh et al., 2012). Pictograms also improve medication adherence knowledge in an acute disease setting, such as in postoperative cataract medication instruction (Braich, Almeida, Hollands, and Coleman, 2011).
The use of visual images to assist with education for people with limited health literacy is an effective modality for presenting information required for chronic disease self-management. A study by Eckman et al. (2011) used a booklet and VHS/DVD in two intervention arms to improve coronary artery disease (CAD) knowledge. One arm focused on using the booklet to improve knowledge while the other arm used both the booklet and VHS/DVD. These two arms were compared to demonstrate which intervention had a greater impact on knowledge. These interventions improved CAD knowledge. In addition, patients were more likely to actively discuss medical care with their providers after this intervention was implemented; 91% of persons involved in both the booklet and video arm of this study and 86% of persons who received just the booklet intervention were more engaged in their care as indicated by asking providers more questions about CAD (Eckman et al., 2011, p. 147).

The use of multiple intervention modalities may increase health literacy. A systematic review examined different health literacy interventions for PLWH, including counseling, visual images, and computer-based interventions to specifically improve HIV self-management knowledge and general HIV knowledge (Perazzo, Reyes, & Webel, 2017). Counseling interventions coupled with visual image interventions improved HIV knowledge (Kalichman, Cherry, & Cain, 2005; Finocchario-Kessler, Catley, Thomson, Bradley-Ewing, Berkley-Patton, & Goggin, 2012). A computer-based health literacy intervention also showed an improvement in HIV knowledge (Ownby, Waldrop-Valverde, Caballero, & Jacobs, 2012).

Dowse, Barford, and Browne (2014) created informational leaflets with easy to understand pictograms to guide HIV self-management knowledge for PLWH. This intervention increased HIV-related knowledge, including ART knowledge, from 62% to 94%. And self-efficacy also showed a consistent improvement in the mean score over six months (Dowse et al.,
Another study that used visual image assisted counseling sessions to improve HIV knowledge showed a statistically significant increase in HIV knowledge, incentive to take ART medications, and self-management ($p < 0.01$, $p < 0.05$, $p < 0.05$ respectively) after the intervention and sustained for three months (Kalichman et al., 2005, p. 12).

Only one study did not find that pictograms improved HIV self-management knowledge in PLWH and limited health literacy (Kalichman et al., 2013a). However, this study mainly focused on ART regimen knowledge instead of overall HIV disease and self-management knowledge (Kalichman et al., 2013a). Although the use of a pictogram was discussed, the study did not provide an example. An image of the pictogram educational intervention may provide insights regarding the reasons that this study was not successful.

Finocchario-Kessler et al. (2012) used a “target tool” and a “brick wall image” as a part of a study to improve HIV disease process and HIV self-management knowledge for those with limited health literacy. The study compared usual patient education about ART adherence with the use of a visual educational intervention that consisted of a “target tool” (an image that focuses specifically on taking ART at the same time every day) and a “brick wall image” (a representation of the effects of ART on a person’s immune system). Overall HIV knowledge increased by 12.4% post-intervention after 48 weeks compared to the non-intervention arm (usual patient education) that saw a 1.8% decrease in knowledge after 48 weeks (Finocchario-Kessler et al., 2012, p. 168). The “brick wall image” served as one component of the visual educational intervention for this DNP project.

**Theoretical Framework**

The health literacy social ecological model (HLSEM; See Appendix A) focuses on addressing health literacy, not only on an individual level, but on the interpersonal,
organizational, community, and macro policy level. (McCormack et al., 2017). This model suggests that an intervention that can result in an effect on a greater level results in lasting change (McCormack et al., 2017). The HLSEM strategy for enhancing health literacy interventions used in this project is the convergence strategy, which posits that an intervention that impacts many levels will consistently influence each other leading to the support of the proposed result of the intervention (McCormack et al., 2017). This project aimed to reach three of these levels: the individual, interpersonal, and organizational. The individual was impacted using the educational intervention, which used images and easy-to-understand language. The interpersonal impact resulted from enhanced communication about health literacy and self-management as a result of the intervention with the support group coordinator. Lastly, the organizational facet was achieved with the use of the intervention after the conclusion of this project at the support group (McCormack et al., 2017, p. 10). The support group coordinator was educated about the use of the visual educational intervention with future support group members. This will ensure the sustainability of this intervention.

Finally, improving HIV related knowledge creates an opportunity to address ART self-management issues by providing PLWH with a “template,” the ART Brick Wall graphic, to discuss adherence barriers with providers and/or other clinical staff at medical follow-up appointments. The participants were encouraged to bring the pocket-sized brick wall image to their clinical appointments to begin a dialogue with providers about ART adherence and self-management.

Methodology

This quality improvement project assessed the impact of visual educational interventions that consisted of a 4-minute educational video about the impact that ART has on health for
PLWH supplemented with an ART self-management graphic about HIV knowledge, health literacy, and intent for self-management. The video was created by Dr. Bradley-Springer, nursing scholar with expertise in HIV and health literacy, for the AIDS Education and Training Center Resource website. The video is in the public domain and is approximately 4 minutes long and explains the effect of ART on the immune system (Appendix B).

The second component of the intervention consisted of a handout that uses a “brick wall” graphic to explain the importance of ART self-management. The brick wall graphic served as the foundation for the development of the video and the handout reflects and reinforces the information in the video (Appendix C). The designers of the brick wall handout reported that use of the intervention resulted in a significant increase in HIV self-management knowledge (Finocchario-Kessler et al., 2012, p. 168). The extent of knowledge gained and changes in intent for self-care as a result of the visual educational intervention was assessed using the ASK-HIV and the HIV-IM (Appendices E and F respectively).

**Project Design**

This DNP project used a one group pre and post design to evaluate the effect of the visual educational intervention. After receiving Institutional Review Board (IRB) approval, this educational intervention was implemented by the principal investigator at a local HIV support group that meets weekly at a community center conducted by a licensed clinical social worker (LCSW) who is the supervisor of HIV/AIDS services. PLWH who attended this support group were asked to participate in this project prior to implementation and consent to participate was obtained. A brief demographic survey (Appendix I) and pretest (Appendices E and F) were administered to each participant prior to the intervention. The principal investigator implemented the visual educational intervention. After the completion of the intervention, the principal
investigator encouraged questions and discussion of the information received from the intervention. The posttest was administered (Appendices E and F) after the intervention to determine the impact of the visual educational intervention. A brief evaluation survey (Appendix H) was provided at the conclusion of the posttest.

**Project Interventions**

This project combined two HIV educational interventions that have been tested in clinical research and found to be effective: a video and a graphic that represents the ART as a brick wall that protects the immune system (Bradley-Springer, 2014; Finocchario-Kessler et al., 2012). The intervention consisted of a short 4-minute video that was created based on the “brick wall” graphic to be an easy to understand representation of HIV disease process, the effectiveness of ART, and the need for self-management (Bradley-Springer, 2014). The “brick wall” graphic (Finocchario-Kessler et al., 2012) was turned into a patient education handout. The ART wall video and the “brick wall” graphic handout were combined in this project to comprise the visual educational intervention.

**ART wall video intervention.** The ART Wall video is in the public domain and easily accessible through YouTube (Appendix B). The ART wall video describes HIV in a simplified format, comparing the patient’s immune system to a brick wall (Bradley-Springer, 2014). The video explains in simple language that the wall represents the patient’s defense mechanism against the virus. If ART medications are not taken as they are prescribed, the wall becomes weaker allowing the virus to break through and multiply. This video also describes drug resistance, which is a complicated process, in an easy to understand manner. At the end of the video, a summary reinforces HIV information and the need for HIV self-management. This
video was shown to participants in a group setting. Participants were encouraged to ask questions about the video.

**Brick wall intervention.** After the video concluded, participants were given a pocket-sized copy of the brick wall handout to take home if they chose to do so (Appendix C). This was optional since some participants may not want HIV-related material in their home because of risk of unwarranted disclosure. The brick wall handout emphasized the main take-aways from the ART wall video, including basic HIV knowledge, HIV self-management necessity, and drug resistance (Finocchiaro-Kessler et al., 2012). The information on the brick wall handout was reviewed with the participants.

The brick wall pocket card handout served as a reminder of the knowledge gained from the ART wall video. Participants were encouraged to bring the brick wall intervention to their routine visits to discuss with their prospective providers. These interventions provided knowledge that can be used for self-management of HIV and the easy access to the video and pocket card provided a readily accessible visual explanation of how the virus impacts immune function.

**Outcome Measures**

This DNP project examined the effect of the visual educational intervention (combined video and handout) on HIV self-management knowledge, HIV-related health literacy, and self-management intent. It was expected that the educational intervention would have a positive effect on the dependent variables; HIV-related health literacy, self-management knowledge, and intent for self-management. The outcome variables were measured using the tools discussed below.
Data Collection Instruments.

1. **HIV-Related Health Literacy Screening Instrument**: The HIV-related health literacy screening instrument, Assessment of Self-Management Knowledge-HIV (ASK-HIV), was created by the principal investigator to test the effectiveness of this intervention. It was evaluated by a HIV specialist. All questions in this instrument are based on evidence-based data derived from validated tools, BEHKA-HIV and the HIV-HL scale, to cover the main aspect of this project, HIV self-management knowledge. The ASK-HIV was created according to the principals for tool development set forth by Bandera (Pajares & Urdan, 2006). The ASK-HIV is comprised of questions related to HIV knowledge and the use of that knowledge for self-management (Appendix E). All questions assess knowledge related to self-management discussed in the project intervention including drug resistance, the importance of viral load, CD4 count, and self-management. Participants could score between 0-10 on this instrument. A total score of 8-10 on this instrument indicated that participants had proficient HIV-related health literacy. A total score of 5-7 indicated moderate HIV-related health literacy and a total score of 0-4 indicated limited HIV-related health literacy (Appendix G).

2. **HIV Self-Management Intention Instrument**: The HIV Intention Measure (HIV-IM) examines the participants willingness to participate in HIV care, including attending appointments and self-management (Appendix F). This instrument has been validated and consists of ten questions regarding intent to care with answers ranging from strongly disagree (1 point) to strongly agree (6 points) on a Likert scale with questions 6 and 10 scored inversely (Nelsen et al., 2012). Ten questions assess the participants’ confidence in their ability to manage HIV and four questions assess
participants’ knowledge about HIV. Scores ranging from 67-84 were classified with high intent for self-management. Scores ranging from 27-66 were classified with average intent for self-management. Scores ranging from 14-26 were classified with low intent for self-management.

3. **Demographic Survey:** A demographic survey (Appendix I) collected basic demographic information about participants. Data collected included age, gender, race/ethnicity, highest level of educational attainment, and year of HIV diagnosis. Most recent CD4 count and viral load were obtained by participant self-report.

4. **Evaluation Survey:** An evaluation survey (Appendix J) was administered after the posttest to gauge participants' reactions to the visual educational intervention. This survey consists of four questions ranging from strongly agree to strongly disagree on a Likert scale and one open-ended question allowing for any additional thoughts/comments regarding this project.

**Estimated Length of Involvement of Participants (Minutes)**

The estimated total time for participants to be enrolled in this project was approximately 75 minutes divided between two visits. See below for further breakdown of time:

First visit:

1. Demographic Survey (5 minutes)
2. Pre-test:
   - ASK-HIV (15 minutes)
   - HIV-IM (10 minutes)
3. Visual educational intervention:
   - Brief 4-minute video (4 minutes)
   - Pocket-sized visual image distributed to each participant (1 minute for explanation)
   - Time for discussion (10 minutes)

Second visit:
1. Post-test:
   - ASK-HIV (15 minutes)
   - HIV-IM (10 minutes)
2. Project Evaluation Survey (5 minutes)

Setting

This project took place at a local HIV support group in New Jersey.

Population and Recruitment

The sample population consisted of PLWH who participated in the HIV support group in April 2019. All support group participants were eligible and invited to participate in this project.

A recruitment flyer (Appendix K) was given to the support group coordinator to be posted at the support group prior to the scheduled date of implementation of the project. The support group coordinator was aware of the project and involved in recruitment. Participants were also recruited during the support group on the day of implementation to create a convenience sample. The support group had approximately 7-9 participants total according to the support group coordinator. A maximum of 15 participants were allotted to be enrolled in this project to account for extra participants attending the support group during implementation. Participants in the support group were informed of the project, asked directly about willingness to participate, and all questions were answered.

Inclusion and Exclusion Criteria. Participants were eligible to be included in this DNP project if they were living with HIV, attended the support group, were eighteen years of age or older, and spoke and understood English. Participants were excluded from this project if they did not speak English or had a visual impairment that could not be corrected with glasses.
Consent

Consent was obtained from each participant who was eligible and willing to participate in this project. Participants were encouraged to read the consent form, and it was also read aloud. After distributing the consent form, the project was explained in full, including the measurement of health literacy, the project intervention, the assessment of HIV self-management intention, the demographic survey, and the evaluation survey. Participants were encouraged to ask any questions pertaining to the project prior to beginning the project and giving their full consent to become actively involved in this project. The consent was signed prior to the start of the project and each participant was given a copy of the consent form. The consent (Appendix D) was created using the Rutgers template and has been modified appropriately to include the aims of this project. Participants were made aware that their involvement in this project was strictly voluntary and they were able to discontinue participation in this project at any time during the intervention. Participants were also made aware that their involvement in this project was strictly confidential.

Risks and Benefits

The risk for a breach in participant confidentiality was minimal. Signed consent was the only personal identifier collected during this project. All data was reported in aggregate. Participants were made aware of the steps that would be taken to ensure confidentiality. A potential benefit of this project was an increase in HIV knowledge about CD4 counts, viral load, HIV self-management, and drug resistance for the participants, but it was not guaranteed.

Data Maintenance and Security

To protect private personal information for project participants, anonymity was key. All data collection instruments, except the demographic surveys and evaluation surveys, had a
numerical code for participants that linked the pre and post tests and was known only to the principal investigator. No participant identifiers were collected on the data collection instruments.

During implementation, each participant was given a folder that included the pretests. Each folder had a number that corresponded to the data collection instruments (pre and post tests). Each brick wall image had a number on the back that corresponded to the pre and post tests for each participant. Participants were instructed to return to the next support group one week later with the brick wall image in hand to identify the appropriate distribution of the post tests.

The demographic surveys and evaluation surveys did not have a linked number. Demographic data was only reported in the aggregate. The demographic information included age range, gender, highest level of education, and race/ethnicity. CD4 count, viral load, and year of HIV diagnosis were collected by self-report and were reported in the aggregate. Individual participant results were not reported.

All data was stored on the principal investigator’s password protected computer. This computer also requires facial identification of the principal investigator for access. All surveys were kept in a locked office only accessible by the principal investigator and the chair of the project. After data analysis, all data collected was retained in accordance with Rutgers policy.

Data Analysis

Data analysis was conducted using SPSS software version 25 (IBM Corporation, 2017). Descriptive statistics were used to analyze the demographic data, CD4 count, and viral load. Gender, educational attainment, year of diagnosis range, age range, race/ethnicity, and viral load
are categorical variables and were reported as a number and percentage only. CD4 count is a continuous variable and was reported with mean and median.

An analysis was conducted on the responses to the ASK-HIV. Comparison of the health literacy (ASK-HIV) pre and post test scores were analyzed using the Wilcoxon signed-rank test, a non-parametric statistical test, to reflect the impact of the educational intervention on HIV-related knowledge. This data analysis determined if a change in knowledge was achieved after implementing the intervention. Results of the data analysis were reported in the aggregate.

A pretest-posttest analysis using the Wilcoxon signed-rank test was also conducted on the data collected from the HIV-IM instrument to determine the effect of the intervention on self-management intention.

Further analysis was conducted using another non-parametric statistical test, Spearman’s rho, to identify if any statistically significant correlations were seen between variables.

**Subject Cost and Compensation**

There was no cost for the participants in this project. The educational intervention took the place of the group meeting that participants usually attend; therefore, participants did not incur any additional costs for transportation. The participants were provided with snacks and refreshments during the educational session of this project. This was stated in the informed consent.

**Timeline and Budget**

The drafting of the proposal took approximately twelve months. Obtaining IRB approval from Rutgers University took approximately two months. The implementation of this project took place in April of 2019, after receiving Rutgers IRB approval.
The principal investigator solely funded this project. The budget included printing materials needed for the pocket-sized brick wall tool as well as a laminator and paper cutter. The budget for a poster presentation was also included. The total cost of this project was approximately $200.00.

Findings

Demographics

A total of 7 participants were enrolled in this project. Most of the participants were male (85.7%), less than 50 years of age (57.2%), and African American (42.9%). Over 80% of participants had a High School diploma/GED or some college. Many of the participants were living with HIV for less than 20 years (57.1%) and had an undetectable viral load (80%). The average CD4 count of the sample was 565 with a median of 563.5 (Table 1).

HIV-Related Health Literacy

The ASK-HIV scores were reviewed prior to the educational intervention and compared to those scores after the intervention. Prior to the educational intervention, most participants were categorized as having proficient health literacy (57.1%), which remained the same after the intervention was implemented (57.1%). After the intervention, participants with limited health literacy (28.6%) achieved moderate health literacy (42.9%), however this change was not statistically significant (p = .564; Table 2).

Self-Management Intention

The HIV-IM scores were also reviewed prior to the educational intervention and compared to scores after the intervention was complete. Prior to the intervention, most participants had high intention for HIV self-management (85.7%). There was no change seen in self-management intention after the intervention (p = 1.000; Table 3).
Correlational Findings

A statistically significant negative correlation was found between age and baseline HIV-related health literacy ($r = -0.845, p = 0.017$). This finding is supported by literature. Research has shown that older adults are more likely to have lower health literacy (Gakumo, Enah, Vance, Sahinoglu, & Raper, 2015; Institute of Medicine, 2004).

The level of educational attainment and baseline HIV-related health literacy did not demonstrate a statistically significant correlation ($r = -0.710, p = 0.074$). Also, length of time living with HIV and baseline HIV-related health literacy was not correlated ($r = -0.725, p = 0.065$).

Evaluation Results

The evaluation survey assessed four main topics; understanding of HIV, knowledge of the importance of HIV medications, if the intervention was easy to use, and if the project met the participants expectations. These topics were assessed on a Likert scale ranging from strongly agree to strongly disagree. When asked if this intervention “increased my understanding of HIV” and “has helped to improve my knowledge about the importance of HIV medications,” 57.1% of participants strongly agreed. The majority of participants (71.4%) strongly agreed that the intervention was easy to understand and met their expectations (Table 4). One participant commented that “this project was very well explained and easy to understand”.

Post-Intervention Discussion

The educational intervention did prompt additional learning and questioning. Participants were particularly interested in discussing the effect of ART medications on the immune system when suffering from another illness, such as the common cold. As well, participants questioned the use of ART medications when drinking alcohol. These points were further discussed with the participants.
Discussion

Implications for Practice

Healthcare Quality and Safety. Visual educational interventions should become a more standard form of education for PLWH to guide patient education about the importance of ART self-management. This visual educational intervention is easy to use as a supplement to standard education about ART adherence. Participants provided feedback about the potential use of this intervention for newly diagnosed HIV positive patients to enhance knowledge, especially regarding self-management with ART, CD4 count, viral load, transmission, and resistance. This may be an avenue for further research regarding this visual educational intervention.

As well, additional feedback was provided on the impact that this visual educational intervention could have if provided in multiple languages, particularly Spanish. This was originally evaluated during the creation of this project and was noted to be a limitation. Further research to create a Spanish ART Wall video and Brick Wall handout to make this intervention more versatile is needed.

The safety implications of improving knowledge and intent for self-management were not measured in this project. However, it may be an avenue of further research after this project is completed.

Policy Implications. Retention in care is necessary for self-management and is directly linked with improving health care outcomes (Kay, Batey, & Mugavero, 2016). Proficient HIV-related health literacy has been shown to improve CD4 count and viral suppression rates (Wawrzyniak et al., 2013). Developing a standardized educational program for PLWH, especially one that can be used shortly after diagnosis, can help to enhance patient-provider communication, encourage HIV-related health literacy, and lead to better self-management with
ART. A policy can be drafted at the clinic level to incorporate the use of supplemental educational interventions for PLWH and limited health literacy, which may provide an interesting area of further research.

**Economic Benefits.** This was a low-cost intervention to improve HIV knowledge regarding self-management with ART. Visual interventions may lead to an improvement in self-management and overall health outcomes. Increasing knowledge and self-management intent may impact adherence rates and prevent loss to care. This was not measured in this project but may be an important aspect of future research.

**Sustainability.** The ART Wall video and pocket cards were provided to the support group coordinator for future use with newly diagnosed PLWH and new members of the support group to provide for sustainability of this intervention. The pocket cards were given to all participants and these participants were encouraged to bring them to their provider appointments to help open the lines of communication regarding ART self-management.

As well, leadership of a Ryan White funded HIV healthcare center has requested permission to use the visual educational intervention, including the ART Wall video and pocket cards for a “HIV 101” program that is being developed. The discussion about the potential benefit of using this visual educational intervention for newly diagnosed PLWH and/or PLWH and limited health literacy was further discussed with the healthcare center. Their target population for an “HIV 101” program will be newly diagnosed PLWH and anyone struggling with achieving viral suppression.

**Plans for Future Scholarship**

A plan for further research to evaluate the reliability and validity of the ASK-HIV instrument is in progress with a Rutgers faculty member. Also, a plan to assess the use of the
Dissemination of the findings from this project have occurred in the form of a poster presentation and a PowerPoint presentation at Rutgers University. The findings may also be translated to a broader group by presenting at a conference.

Conclusion

The visual educational intervention elicited questions and prompted discussion about HIV, drug resistance, transmission, and ART among the participants. Length of time living with HIV, education level, and participation in the support group may have limited the effect of the intervention on outcomes because participants had some HIV knowledge prior to the project. The participants were involved in a support group and truly invested in their care of HIV.

An interesting finding was that older age was negatively correlated with health literacy; this finding was supported by the research. Higher rates of limited health literacy are seen with older age (Gakumo et al., 2015; Institute of Medicine, 2004). This finding warrants further research to examine how health literacy and age impact PLWH. Education level and length of time living with HIV were not correlated with health literacy, however the sample size was too small to generalize any findings. Visual image health literacy interventions may be more likely to increase the HIV knowledge and self-management of people newly diagnosed and older adults. Further research in these populations is needed.

This project was the first use of the ASK-HIV instrument. This instrument was developed by the principal investigator and reviewed by a HIV specialist. Findings indicate that it has potential as a HIV specific health literacy instrument, but more research is needed to determine its validity and reliability. Further discussion that was prompted by the visual educational
intervention lead to a conversation with participants regarding the use of ART medications when ill as well as with alcohol use. The ASK-HIV instrument does examine the use of ART medications if using alcohol or illicit drugs, however, it does not address the use of ART medications when suffering from an acute illness. Adding items to the instrument that address acute illness may prove beneficial when further investigation of the ASK-HIV instrument is undertaken.

In conclusion, the intervention was easy to understand and provided a platform for further inquiry into the management of HIV with ART. Piloting this intervention at a local HIV support group did provide some useful results regardless of the limitations of this project. It also provided a foundation for many aspects of further research, including the use of the visual educational intervention with newly diagnosed PLWH as well as with older adults living with HIV.
References


Graham, J., Bennett, I., Holmes, W., & Gross, R. (2007). Medication beliefs as mediators of the


Kay, E., Batey, D., & Mugavero, M. (2016). The HIV treatment cascade and care continuum:


Appendix A

Health Literacy Social Ecological Model: Convergence Strategy (McCormack et al, 2017)
Appendix B

ART Wall Video

https://www.youtube.com/watch?v=1PEisyVjHsI

Appendix C

Brick Wall Intervention

When you are taking your medications correctly, 95%–100% of the time, HIV has little chance of getting through

The less you take your medications on time everyday, the weaker the wall becomes

If the wall is too weak HIV learns how to get through

CONSENT TO TAKE PART IN A RESEARCH STUDY

TITLE OF STUDY: “Improving HIV Self-management Knowledge with the Use of Visual Image Interventions”

Principal Investigator: Christina Carrier, BSN, RN

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. The purpose of the research is to assess the impact that a short video and handout have on how well you understand HIV and how you take care of your illness. If you take part in the research, you will be shown a video and given a handout. You will also be asked to complete a demographic survey, a pre-test, a post-test, and an evaluation survey. This will take place over two support group sessions.

At the first group session, the demographic survey, the pre-test, and the handout will be given, and the video will be shown. At the second group session, one week later, you will return for your support group and you will be given a post-test. The post-test will consist of the surveys completed in the pre-test. An evaluation survey will be given also.

Your time in the study will take a total of about 75 minutes over two separate support group sessions. Possible harms or burdens of taking part in the study may be a minimal risk for a breach in confidentiality and possible benefits of taking part may be an improvement in knowledge how to take care of your HIV illness o but this cannot be guaranteed. Your alternative to taking part in the research study is not to take part in it.

The information in this consent form will provide more details about the research study and what will be asked of you if you choose to take part in it. If you have any questions now or during the study, if you choose to take part, you should feel free to ask them and should expect to be given answers you completely understand. After all of your questions have been answered and you wish to take part in the research study, you will be asked to sign this consent form. You are not giving up any of your legal rights by agreeing to take part in this research or by signing this consent form.

Who is conducting this research study?
Christina Carrier, BSN, RN is the Principal Investigator of this research study. A Principal Investigator has the overall responsibility for the conduct of the research. However, there are often other individuals who are part of the research team.

Christina Carrier may be reached at cmb501@sn.rutgers.edu, 65 Bergen St., Newark, NJ 07107.

The Principal investigator or another member of the study team will also be asked to sign this informed consent. You will be given a copy of the signed consent form to keep.
Why is this study being done?
The purpose of this study is to determine if a video and handout when given to people living with HIV helps to improve their knowledge about taking care of themselves.

Who may take part in this study and who may not?
You may take part in this study if you attend Bergen Family Center’s HIV support group, if you are living with HIV, if you are eighteen years of age or older, and you speak and understand English. You may not be eligible to participate in this study if you are younger than eighteen years of age, do not speak English, or have a visual impairment that cannot be corrected with glasses.

Why have I been asked to take part in this study?
You are being asked to take part in this study because you attend Bergen Family Center’s HIV support group.

How long will the study take and how many subjects will take part?
This study will take a total of approximately 75 minutes over two separate support group meetings. The first session will take approximately 60 minutes. The second session will take approximately 15 minutes. All eligible support group members may take part in this study. A maximum of 15 subjects will take part in this study.

What will I be asked to do if I take part in this study?
At the first group session, the demographic survey will be given to collect information on your demographic data such as age, gender, highest level of education, and race/ethnicity. Last known CD4 count, viral load, and year of HIV diagnosis will also be collected. Then the pre-test will be completed. This consists of two separate surveys that will examine your knowledge regarding HIV, how to manage HIV, and your intent to manage HIV at home. The visual educational intervention will then be administered. This consists of a 4-minute video, a pocket-sized visual image, and further discussion.

At the second group session, one week later, you will return for your support group and you will be given a post-test. The post-test will consist of the two surveys completed in the pre-test. A project evaluation survey will be given also.

What are the risks and/or discomforts I might experience if I take part in this study?
There is a rare risk for a breach in confidentiality if you take part in this study. This risk will be minimalized through strict anonymity.

Are there any benefits to me if I choose to take part in this study?
The benefits of taking part in this study may be an improvement in knowledge of HIV self-management skills. However, it is possible that you may not receive any direct benefit from taking part in this study.

What are my alternatives if I do not want to take part in this study?
Your alternative is not to take part in this study.
How will I know if new information is learned that may affect whether I am willing to stay in the study?
During the course of the study, you will be updated about any new information that may affect whether you are willing to continue taking part in the study. If new information is learned that may affect you after the study or your follow-up is completed, you will be contacted.

Will there be any cost to me to take part in this study?
No, there will be no cost for you to take part in this study.

Will I be paid to take part in this study?
You will not be paid to take part in this study. Refreshments will be provided during the implementation of this study.

How will information about me be kept private or confidential?
All efforts will be made to keep your personal information in your research record confidential, but total confidentiality cannot be guaranteed. All data will be stored on the principal investigator’s password protected computer. This computer also requires facial identification of the principal investigator for access. All surveys will be kept in a locked office only accessible by the principal investigator and the chair of the project. After data analysis, all data collected will be deleted from the principal investigator’s computer and all documents will be destroyed.

What will happen to my information collected for this research after the study is over?
After information that could identify you has been removed, de-identified information for this research may be used by or distributed to investigators for other research without obtaining additional informed consent from you.

What will happen if I do not wish to take part in the study or if I later decide not to stay in the study?
It is your choice whether to take part in the research. You may choose to take part, not to take part or you may change your mind and withdraw from the study at any time.

If you do not want to enter the study or decide to stop taking part, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

You may also withdraw your consent for the use of data already collected about you, but you must do this in writing to Christina Carrier, cmb501@sn.rutgers.edu.

If you decide to withdraw from the study for any reason, you may be asked to return for at least one additional visit for safety reasons.

Who can I call if I have questions?
If you have questions about taking part in this study or if you feel you may have suffered a research related injury, you can contact the principal investigator Christina Carrier, cmb501@sn.rutgers.edu.
If you have questions about your rights as a research subject, you can call the IRB Director at: (973)-972-3608 or the Rutgers Human Subjects Protection Program at (973) 972-1149.

### AGREEMENT TO PARTICIPATE

**1. Subject consent:**

I have read this entire consent form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form and this study have been answered. I agree to take part in this study.

Subject Name: ____________________________________________________________

Subject Signature: ___________________________ Date: ________________

**2. Signature of Investigator/Individual Obtaining Consent:**

To the best of my ability, I have explained and discussed all the important details about the study including all of the information contained in this consent form.

Investigator/Person Obtaining Consent (printed name): ________________________

Signature: ___________________________ Date: ________________

---

<table>
<thead>
<tr>
<th>Subject Name</th>
<th>Subject Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>--------------</td>
<td>-------------------</td>
<td>------</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Investigator/Person Obtaining Consent (printed name)</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix E

Assessment of Self-management Knowledge-HIV (ASK-HIV)

1a. What is a CD4 cell (also known as T-cells)?
   A. A type of white blood cell that supports the immune system
   B. The amount of virus detected in blood
   C. A type of infection that occurs when you do not take your HIV medications
   D. None of the above

1b. The goal of taking HIV medications (also known as antiretroviral therapy) is to…
   A. Make my CD4 cell count higher
   B. Make my CD4 cell count lower
   C. None of the above

2a. What is a viral load?
   A. A type of white blood cell that supports the immune system
   B. The amount of virus detected in blood
   C. A type of infection that occurs when you do not take your HIV medications
   D. None of the above

2b. The goal of taking HIV medications is to…
   A. Make my viral load higher
   B. Make my viral load lower or undetectable
   C. None of the above

3. To make sure my HIV medications continue to work how often do I have to take them?
   A. At the same time every day
   B. When I remember to take them
   C. Only when my CD4 cell count goes lower
   D. Only when my viral load goes higher

4. When I do not take my HIV medications every day I am at risk of becoming resistant to my medications. Resistance means…
   A. My medications will keep working to make me healthy
   B. I have a small amount of HIV in my blood
   C. That my medications might not work as well as they used to
   D. I only have to take my medications when my viral load is high

5. What does an undetectable viral load mean?
   A. There is a lot of HIV in your blood that the lab test cannot count it
   B. You can stop taking your HIV medications
   C. You do not have HIV anymore
   D. There is such a small amount of HIV in your blood that the lab test cannot count it

6. I stop taking my HIV medications when they make me feel bad.
7. I stop taking my HIV medications when I feel sad.
   A. True  
   B. False

8. I stop taking my HIV medications if the pills are too big to swallow.
   A. True  
   B. False

9. I stop taking my HIV medications when I feel good.
   A. True  
   B. False

10. I stop taking my HIV medications when I am taking alcohol or drugs.
    A. True  
    B. False

Appendix F

HIV Intention Measure (Nelsen et al., 2012)

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>

**HIV Intention Measure**

Please Circle:

1. Coming regularly to my HIV clinic appointments is good for my health.  
   1 2 3 4 5 6

2. My treatment plan for HIV will make a big difference in keeping my HIV infection under control.  
   1 2 3 4 5 6

3. HIV medications help to control HIV disease.  
   1 2 3 4 5 6

4. If HIV medications are prescribed, it is important to take the medications every day to control HIV infections.  
   1 2 3 4 5 6

5. Not taking HIV medications every day affects how well the HIV treatment works.  
   1 2 3 4 5 6

6. An HIV patient who is feeling well can safely stop taking HIV medications.  
   1 2 3 4 5 6

7. An HIV infected person who follows recommended care for HIV can expect to live long.  
   1 2 3 4 5 6

8. There is a lot I can do to control my HIV infection.  
   1 2 3 4 5 6

9. What I do can determine whether my HIV infection gets better or worse.  
   1 2 3 4 5 6

10. My actions will have no effect on the outcome of my HIV infection.  
    1 2 3 4 5 6

**HIV Knowledge Measure**

Please Circle:

1. I know a lot about living with HIV infection.  
   1 2 3 4 5 6

2. I know a lot about how HIV is spread from one person to another.  
   1 2 3 4 5 6

3. I know a lot about medication to treat HIV infection.  
   1 2 3 4 5 6

4. I know a lot about the side-effects of medications used to treat HIV infection.  
   1 2 3 4 5 6

Appendix G

Assessment of Self-management Knowledge-HIV (ASK-HIV) Scoring Sheet

<table>
<thead>
<tr>
<th>Total Points Available</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questions 1A-2B</td>
<td>0.5 point each</td>
</tr>
<tr>
<td>Questions 3-10</td>
<td>1 point each</td>
</tr>
</tbody>
</table>

**Proficient Health Literacy:** Total Score of 8-10. Must have all correct answers for questions 1-5. If not, will be categorized with moderate health literacy regardless of score between 8-10.

**Moderate Health Literacy:** Total Score of 5-7.

**Limited Health Literacy:** Total Score of 0-4.
Appendix H

HIV Intention Measure (HIV-IM) Scoring Sheet

**Points Per Question**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 point</td>
<td>2 points</td>
<td>3 points</td>
<td>4 points</td>
<td>5 points</td>
<td>6 points</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 points</td>
<td>5 points</td>
<td>4 points</td>
<td>3 points</td>
<td>2 points</td>
<td>1 point</td>
</tr>
</tbody>
</table>

**Total**

<table>
<thead>
<tr>
<th>Intention Classification</th>
<th>Score (Points)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Intent</td>
<td>67-84</td>
</tr>
<tr>
<td>Average Intent</td>
<td>27-66</td>
</tr>
<tr>
<td>Low Intent</td>
<td>14-26</td>
</tr>
</tbody>
</table>
Appendix I
Demographic Survey

1. What is your gender?
   A. Male
   B. Female
   C. Transgender
   D. Other gender. Please specify: ________________________

2. Which group below includes your age?
   A. 18-25
   B. 26-29
   C. 30-39
   D. 40-49
   E. 50-59
   F. 60 or older

3. What race/ethnicity/nationality best describes you? May choose more than one.
   A. Hispanic or Latino
   B. Black or African American
   C. White
   D. Asian
   E. Other race/ethnicity. Please specify: ______________________
   F. Nationality. Please specify: ______________________

4. What is the highest level of school you have completed or the highest degree you have received?
   A. Less than high school diploma or GED
   B. High school diploma or GED
   C. Some college
   D. Associate degree
   E. Bachelor’s degree
   F. Graduate degree

5. In what year were you diagnosed with HIV?
   ________________________

6. What is your most recent CD4 count (T-cells)? Leave blank if unknown.
   ________________________

7. What is your most recent viral load? Leave blank if unknown.
   ________________________
Appendix J

Evaluation Survey

Please take a few moments to complete this evaluation form. Thank you!

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Somewhat Disagree</th>
<th>Somewhat Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Overall Evaluation</th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>This education:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased my understanding of HIV</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Has helped to improve my knowledge about the importance of my HIV medications</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Was easy to understand</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Met my expectations</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

Please provide any additional thoughts or comments about this project and any suggestions for improvement.
Appendix K

Recruitment Flyer

Research Participants Needed for an Educational Study

“Improving HIV Self-Management Knowledge with the Use of Visual Image Interventions”

Background:
- Health literacy is the understanding of disease that influences how to take care of yourself
- Taking care of yourself is known as self-management
- Visual interventions can improve the knowledge needed for self-management
- The purpose of this DNP project is to evaluate the effect that a short video and a handout have on HIV knowledge, health literacy, and self-management

Eligible Participants:
- People living with HIV who attend the Bergen Family Center’s HIV support group
- Eighteen years of age or older
- Speak and understand English

Location of Project:
- Bergen Family Center
  10 Banta Place, Hackensack, NJ 07601

Benefits:
- No benefits guaranteed
- Potential of an increase in HIV knowledge about CD4 counts, viral load, HIV self-management, and drug resistance

Time Commitment:
- A total of approximately 75 minutes during two separate sessions
  - First session: 60 minutes
  - Second session: 15 minutes

How to Participate:
- Please contact the principal investigator

For further information or if you are interested in participating, please contact:
Christina Carrier, BSN, RN, DNP Student, Principal Investigator
65 Bergen Street, Newark, NJ, 07107
Cmb501@sn.rutgers.edu
732-277-6340
Table 1. Demographic Data

<table>
<thead>
<tr>
<th>Demographic Data</th>
<th>26-29: 14.3%</th>
<th>30-39: 42.9%</th>
<th>50-59: 28.6%</th>
<th>60 and older: 14.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td>Male: 85.7%</td>
<td>Female: 14.3%</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td>Hispanic or Latino: 28.6%</td>
<td>Black or African American: 42.9%</td>
<td>White: 14.3%</td>
<td>Other: 14.3%</td>
</tr>
<tr>
<td><strong>Highest Level of Education</strong></td>
<td>High School Diploma or GED: 42.9%</td>
<td>Some College: 42.9%</td>
<td>Bachelor’s Degree: 14.3%</td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosis Year</strong></td>
<td>1990-1999: 42.9%</td>
<td>2010-2019: 57.1%</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CD4 Count</strong></td>
<td>Mean: 565.5</td>
<td>Median: 563.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Viral Load</strong></td>
<td>Undetectable: 80%</td>
<td>Detectable: 20%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 2. HIV-Related Health Literacy

<table>
<thead>
<tr>
<th>ASK-HIV Pretest Results</th>
<th>ASK-HIV Posttest Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited Health Literacy: 14.3%</td>
<td>Limited Health Literacy: 0%</td>
</tr>
<tr>
<td>Moderate Health Literacy: 28.6%</td>
<td>Moderate Health Literacy: 42.9%</td>
</tr>
<tr>
<td>Proficient Health Literacy: 57.1%</td>
<td>Proficient Health Literacy: 57.1%</td>
</tr>
</tbody>
</table>
Table 3. Self-Management Intention

<table>
<thead>
<tr>
<th>HIV-IM Pretest Results</th>
<th>HIV-IM Posttest Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Intent: 0%</td>
<td>Low Intent: 0%</td>
</tr>
<tr>
<td>Average Intent: 14.3%</td>
<td>Average Intent: 14.3%</td>
</tr>
<tr>
<td>High Intent: 85.7%</td>
<td>High Intent: 85.7%</td>
</tr>
</tbody>
</table>
**Table 4. Evaluation Survey Results**

<table>
<thead>
<tr>
<th>Evaluation Survey Results</th>
<th>Strongly Disagree: 14.3%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased my understanding of HIV</td>
<td>Agree: 28.6%</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree: 57.1%</td>
</tr>
<tr>
<td>Has helped to improve my knowledge about the</td>
<td>Strongly Disagree: 14.3%</td>
</tr>
<tr>
<td>importance of my HIV medications</td>
<td>Agree: 28.6%</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree: 57.1%</td>
</tr>
<tr>
<td>Was easy to understand</td>
<td>Strongly Disagree: 14.3%</td>
</tr>
<tr>
<td></td>
<td>Agree: 14.3%</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree: 71.4%</td>
</tr>
<tr>
<td>Met my expectations</td>
<td>Strongly Disagree: 14.3%</td>
</tr>
<tr>
<td></td>
<td>Agree: 14.3%</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree: 71.4%</td>
</tr>
</tbody>
</table>
## Evidence Table

<table>
<thead>
<tr>
<th>Article #</th>
<th>Author &amp; Date</th>
<th>Evidence Type</th>
<th>Sample, Sample Size, Setting</th>
<th>Study findings that help answer the EBP Question</th>
<th>Limitations</th>
<th>Evidence Level &amp; Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>Kalichman, S., Pellowski, J., &amp; Chen, Y. (2013)</td>
<td>Cohort Study</td>
<td>474 participants with low health literacy were recruited from AIDS services and community outreach in Atlanta, GA.</td>
<td>This study significantly supports the need for health literacy screening and use of tailored health literacy interventions for PLWH. It also demonstrates the fact that even when people ask for assistance, like with reading, further intervention needs to be done to improve specific health literacy.</td>
<td>This study consisted of a convenience sample which may not be generalizable. Also, self-report was used to assess for reading difficulties and disclosure to providers.</td>
<td>Evidence Level: II Quality: B</td>
</tr>
<tr>
<td>#2</td>
<td>McCall, J., &amp; Wilson, C. (2015)</td>
<td>Descriptive Design-Survey</td>
<td>102 patients participated in the survey from an HIV program (both inpatient and outpatient), interdisciplinary team members were also surveyed consisting of 15 nurses, seven physicians, one social worker, one dietician, one pharmacist, and one occupational therapist.</td>
<td>This study supports the need to screen for health literacy and act upon those findings. Although many patients perceived themselves as having a higher health literacy, when screened that was not the case. This encourages the need for health literacy interventions, especially within HIV care.</td>
<td>This study was limited to one HIV program and the providers within that program. It may not be generalizable until further investigation is completed.</td>
<td>Evidence Level: III Quality: C</td>
</tr>
<tr>
<td>#3</td>
<td>Kordovski, V., Woods, S., Avci, G., Verduzco, M., &amp; Morgan, E. (2017)</td>
<td>Case Report</td>
<td>78 participants were included in this study. They were recruited from the local HIV clinics and the San Diego community. Participants were included in they were living with HIV. Participants were excluded if they had a severe psychiatric disorder, a chronic medical or neurological condition, non-HIV-related.</td>
<td>The NVS was found to be a valid and more sensitive indicator of health literacy for PLWH when compared against the REALM and the SILS.</td>
<td>This study specifically excluded PLWH with lower IQs as well as with other medical or psychiatric conditions.</td>
<td>Evidence Level: III Quality: C</td>
</tr>
<tr>
<td>#4</td>
<td>Health literacy in the context of HIV treatment: Introducing the Brief Estimate of Health Knowledge and Action (BEHKA)—HIV version</td>
<td>Osborn, C., Davis, T., Bailey, S., &amp; Wolf, M. (2010)</td>
<td>Case-control study</td>
<td>204 HIV patients that were cared for at outpatient infectious disease clinics at Northwestern Memorial Hospital in Chicago, Illinois and Louisiana State University Health Sciences Center in Shreveport, Louisiana. Patients were excluded from this study if they were on their current ART regimen for less than 2 weeks, too sick, or if they had dementia, were blind that could not be corrected with glasses, or deafness that could not be corrected with a hearing aid. This study compares an HIV focused health literacy assessment tool (BEHKA-HIV) against a general health literacy assessment tool (REALM). It may prove to be beneficial to utilize a screening tool that specifically targets the disease itself since the intervention will be focusing on improving HIV self-knowledge. Even if this health literacy tool is not utilized, it still may prove to be helpful. It is a brief tool that may assist in the development of an abbreviated tool that can be sustainable within the clinic. This study utilized self-report as a means of identifying adherence, which may not always be reliable. As well, a small, localized sample was used within this study. Evidence Level: II Quality: B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td>#5</td>
<td>Development and validation of a brief computer-administered HIV-related health literacy scale (HIV-HL)</td>
<td>Ownby, R., Waldrop-Valverde, D., Hardigan, P., Caballero, J., Jacobs, R., &amp; Acevedo, A. (2013)</td>
<td>Case-control Study</td>
<td>124 participants were originally recruited from providers offices who treated people living with HIV in Broward County, Florida. 120 participants were present for the second visit which tested the HIV-Related Health Literacy Scale (HIV-HL). This study discussed an HIV focused health literacy tool. It is a tool that can be independently completed on touch screen computers and does not need clinician oversight. As well, it is a brief tool that should take only about 10-15 minutes to complete. This study tested the validity of this tool and it was determined to be valid and user-friendly. This tool must be used on a computer which may not be feasible in a resource poor clinic. This tool is also used independently to screen for health literacy so information that an examiner may obtain from an assisted tool may be missed. Further investigation Evidence Level: II Quality: B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>#6</td>
<td>Development and validation of a measure for intention to adhere to HIV treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>--------------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>287 participants were included in this study from two HIV clinics in Houston, Texas. Questionnaires were completed and charts reviewed to determine most recent viral load. Each participant was asked to complete a 53-item questionnaire that included items assessing HIV knowledge and intention to remain in HIV care. After analyzing the results from the survey, two specific topics were included: knowledge and intention. Fourteen questions were also included in the final survey. Knowledge and intention for HIV care were significantly correlated. This was the preliminary validation of a new assessment instrument.</td>
<td>This study used a convenience sample of people living with HIV who were already established in care and on ART medications. This study also only examined intention for HIV care at the time of survey completion.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>#7</th>
<th>Teach back and pictorial image educational strategies on knowledge about diabetes and medication/dietary adherence among low health literate patients with type 2 diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Negarandeh, R., Mahmoodi, H., Noktehdan, H., Heshmat, R., &amp; Shakibazadeh, E. (2012)</td>
<td>Randomized Controlled Trial</td>
</tr>
<tr>
<td>135 participants from a diabetes clinic in Saqqez, Kurdistan were included in this study. They were randomly assigned to one of the three groups: pictorial image education, teach back education, or the control group. 127 participants actually completed the entire study. This study found that both teach-back and pictorial image educational tools helped improve medication adherence and dietary control for people with low health literacy living with diabetes when compared with standard care. This supports the use of a visual guided educational tool to improve self-management. They also assessed their participants six weeks later and found improved health knowledge. This supports the use of teach-back and a visual image tool’s sustainability on disease knowledge.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>#8</th>
<th>Effects of pictograms in educating 3 distinct low-literacy populations on the use of postoperative</th>
</tr>
</thead>
<tbody>
<tr>
<td>A total of 225 patients participated in this study from the Uma Eye Clinic in Chennai, Tamil Nadu, in association with Unite for Sight; the Krishna</td>
<td>The use of pictograms, especially when taken home, helped improve postoperative cataract medication adherence. This arises an interesting possibility in that creating a visual aid helps to improve adherence, however, even low levels of medications could have been the result of</td>
</tr>
</tbody>
</table>

| Evidence Level: III | Quality: B |
| Evidence Level: I | Quality: B |
| Evidence Level: I | Quality: A |
| #9 | Impact of health literacy on outcomes and effectiveness of an educational intervention in patients with chronic diseases | Eckman, M., Wise, R., Leonard, A., Dixon, E., Burrows, C., Khan, F., & Warm, E. (2011) | Randomized Controlled Trial | 170 adult patients at 3 hospital-based ambulatory practices at the Division of General Internal Medicine randomly assigned to one of the two intervention groups. | This study supports the need for specific disease-related educational interventions in order to improve health knowledge overall. Although this study focused on coronary artery disease, it can be generalized to many chronic illnesses, such as HIV. This study assessed for health literacy; however, they saw an increase in knowledge amongst patients with both low and high health literacy. In turn, this improved patient engagement in their care. | Many people did not show up for their scheduled appointment, leaving the study size to 170 people. There was no control group to compare the intervention groups to. | Evidence Level: I Quality: A |
| #10 | A systematic review of health literacy interventions for people living with HIV | Perazzo, J., Reyes, D., & Weibel, A. (2017) | Systematic Review | A systematic review was completed to examine interventions to improve health literacy for PLWH. This review was conducted from October to December of 2015 using multiple electronic databases. | This review included ten articles that specifically examined health literacy interventions for PLWH. These articles examined multiple modalities of interventions to enhance health literacy, including visual aids, counseling, and computer-based interventions. This review also examined the effectiveness of these interventions. This was broken down into three sections: adherence, knowledge/behavior, and electronic health literacy. | This review only focused on studies reported in English and were conducted in the United States. The number of articles that addressed the topic were limited. | Evidence Level: II Quality: B |
| #11 | Nurse-delivered antiretroviral treatment adherence intervention for people with low literacy skills and living with HIV/AIDS | Kalichman, S., Cherry, J., & Cain, D. (2005) | Case Report | 45 participants were interviewed to determine barriers to taking ART medications. A self-management intervention was created for PLWH and low health literacy, including the use of graphics and counseling sessions, and a pilot study was conducted. 30 PLWH were included in this pilot. | The interviews found that health literacy impacted ART use. The intervention was shown to increase HIV-related knowledge. The number of missed doses of ART was also reduced after the intervention. | This was a pilot study that included a small sample size that cannot be generalizable. There was no control in this study. This study also included follow-up using self-report. | Evidence Level: III Quality: C |
| #12 | Patient communication tools to enhance ART adherence counseling in low and high resource settings | Finocchario-Kessler, S., Catley, D., Thomson, D., Bradley-Ewing, A., Berkley-Patton, J., & Goggin, K. (2012) | Randomized Controlled Trial | 204 participants were assigned at random to one of three groups: standard care, motivational interviewing-based Cognitive Behavioral Therapy (MI-CBT) adherence counseling, or MI-CBT with modified directly observed therapy. | This study developed a visual image educational tool to educate people living with HIV on the virus itself and the mechanism of ART medications to help improve self-management for those with low health literacy. | Patients who were randomly assigned to the intervention spent more time with the counselors which may have contributed to increased knowledge. | Evidence Level: I Quality: A |
| #13 | Baseline medication adherence response to an electronically delivered health literacy intervention targeting adherence | Ownby, R., Waldrop-Valverde, D., Caballero, J., & Jacobs, R. (2012) | Case Report | This study created an electronic health literacy intervention, tested the intervention, and examined the impact of the intervention for PLWH. 5 participants tested the intervention prior to the completion of this study. Participants were recruited from HIV practices in Broward County, FL. 124 participants were enrolled, 120 returned for the second visits, and 109 participants were included in the findings. | Self-reported knowledge and behavioral skills significantly improved throughout the study. This study also included the development of a health literacy intervention and the impact of that intervention over 3 months. | The limitations of this study include a limited sample and no control group. | Evidence Level: III Quality: B |
| #14 | Simple, illustrated medicines information improves ARV knowledge and patient self-efficacy in limited literacy South African HIV patients | Dowse, R., Barford, K., & Browne, S. H. (2014) | Randomized Controlled Trial | 16 patients at baseline with a mean education of 7.3 years; only 64 patients at the 6-month follow-up. | Self-efficacy after 6 months was significantly improved post-intervention. Antiretroviral therapy knowledge also improved. These improvements were still seen at the 6-month follow-up after the interventions, which utilized pictograms and simple texts, were provided. This supports the need for a visual image educational tool for PLWH with low health literacy to help improve self-efficacy and knowledge. | High drop-out rate, only conducted in one town which hinders generalizability | Evidence Level: I | Quality: A |

| #15 | Randomized clinical trial of HIV treatment adherence counseling interventions for people living with HIV and limited health literacy | Kalichman, S., Cherry, C., Kalichman, M., Amaral, C., White, D., Grebler, T., … & Schinazi, R. (2013) | Randomized Controlled Trial | Participants were recruited from AIDS services and community outreach in Atlanta, GA. Multiple HIV clinics were contacted and interested parties scheduled to participate. Participants were randomly assigned to the pictograph intervention, standard care, or | This study did not see an improvement in adherence in either intervention group, however, it does provide necessary support for the standardization of health literacy screening at office visits. | Sample was only from Atlanta which may hinder generalizability of this study. Also, self-report was utilized to measure adherence. | Evidence Level: I | Quality: A |
the general health improvement intervention.