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HIV Education and Empowerment A program for the Women of Kiryabicooli, Uganda

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Abstract

Background: HIV continues to be a serious health, social and economic burden in Uganda. Early in the epidemic, the government's rapid response brought the HIV infection rates from 30% in the 1990s to 4% by 2000, however rates are rising with some district's reporting the HIV rate rising up to 7.8%. Myths surrounding transmission, disease progression and treatment compound the country's vulnerability. The goal of this Quality Improvement project is to educate women with children under 13 years old about the facts of HIV, in the hopes that with that knowledge they can take action to decrease their own infection rates as well as their children's.

Methods: An HIV education curriculum was used for women who have children under the age of 13. The women who chose to participate received a pre-training test with questions related to HIV transmission, testing, and treatment.

Results: Thirty women from the three villages with close proximity to the Health Clinic in Uganda were the participants. Each woman completed all three class sections as well as completing the pre and post-tests. The pre and post-test scores were rated and found to have discrepancies in the individual identifiers. Because of this, it was impossible to determine score changes for individual participants. Instead, the trends were noted to determine value of the classes themselves.

Conclusion: Women were empowered through education about the HIV facts to help them to protect themselves. Secondly, the mothers will become health educators to their children. The relationship of trust and love between mother and child m empower the next generation to be armed with the truth, effectively protect themselves from the virus and in doing so, decrease the rates of HIV infection in this area.

Keywords: *HIV, Prevention, Mothers and Children and HIV, Rural Uganda stigma*

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Introduction

HIV/AIDS is a disease that continues to be a major factor in every aspect of life in Uganda. The disease's impact is detrimental to the health of the individual as well as the community/village. It has a significant effect on the already over-burdened health and struggling financial system. Since the year 2000, the HIV prevalence rate has increased from 4% to 7.6% in some rural communities and continues to rise (Avert, 2016). Eighty percent of all new worldwide HIV infections occur among women and young girls (The Global Fund, 2018). Women and children are a disproportionate growing number of those infected, therefore the need to empower this group with education about the truths of HIV is critical if HIV is to be stopped. The myths surrounding HIV are dangerous as they mislead many to not use proven prevention methods, avoid testing or seek care; directly lending to the increase in HIV incidence.

Background

In the area of Buseesa there are no official HIV services or government-sponsored programs in HIV education or testing being offered in this remote area. The closest clinic that supplies HIV medications is 20 miles away from Em's Health Clinic, which is quite far as most people travel by foot. The overall HIV prevalence rate of adults in Uganda aged 15 – 64 is 6.2%. In Uganda, 1.2 million people are living with HIV in a country of 41 million (Avert, 2017). There are approximately 95,000 children living with the disease in Uganda (UPIHA, 2017). Of all those infected, only 59% are in care and on antiretroviral medications (ARVs) with undetectable viral loads. With this poor measure, HIV continues to spread throughout the country.

Uganda was initially the first country in East Africa to rapidly respond to the HIV epidemic in the 1990s. At that time the prevalence rate was between 18% and 30%. By 2011, the rate was 4.5% (Albuquerque, 2014). Since that time, the rates have begun to climb again. This is in direct relation to a multitude of issues such as persistent stigma, lack of education, gender inequality, polygamy, limited access to condoms, inadequate availability of HIV testing and prevention counseling sites as well as a severe shortage in clinics supplying antiretroviral medications per district. Another significant factor contributing to the increase in the infection rate is the legislation that makes it illegal to be a homosexual. Among the many physical and mental health outcomes this legislation negatively impacts, it is keeping the Ugandan LGBTQ population away from government clinics (Strangl, 2014).

Legislation directly affecting the HIV prevalence among women and children is the legislation that mandates: in the event a pregnant woman tests positive during her prenatal care, the healthcare worker must notify the father and the family. The woman's privacy is no longer respected making hospital deliveries something to fear, therefore many women are returning back to the villages for home delivery where the rates of death for mother and child are much higher. Home deliveries have the additional consequence of creating a barrier to the initiation of vital Prevention of Mother to Child Transmission (PMTCT) intervention and services (Stangl, 2014). It is because of these factors that improved HIV prevention interventions must be developed and implemented in order to bring the prevalence rates of HIV in Uganda back down, ultimately to zero. WHO has set the expectation that all countries will comply with the goal of 90-90-90 (WHO, 2017). Worldwide, 90% of those that are HIV infected will know their status. Of those infected, 90 % will be in care and receiving ARVs. Of those linked to care, 90% will have viral loads that are undetectable.

Problem Statement

The increasing rates of HIV infection in rural Uganda among women and children are related to the lack of HIV prevention education as well as the myths that surround the disease. This Quality Improvement project was an educational program for mothers with children 13 and under in the home, that provided them with the tools needed to protect themselves as well as teach their children the truth about HIV as a method of generational prevention.

Organizational "Gap" Analysis of the Project Site

The World Health Organization strongly recommends that all people 16 to 65 get tested for HIV (CDC, 2017). Currently, there is no cure for HIV. The end of this epidemic will come from the halting the spread. In order to do that, every person that is HIV positive must know their status, get connected to lifelong care and take ARVs in order to suppress the HIV viral load.

Once the viral load is undetectable, less than 20 HIV particles per millimeter of blood, then that person is no longer able to spread the disease (CDC, 2017). The goal is to prevent the spread of HIV with the use of medications as a form of prevention, ultimately protecting those who are HIV negative. The Ugandan Health Ministry has the following goal: zero new infections, zero discrimination, and zero AIDS-related deaths (UNAIDS, 2013). Testing, education, care, and treatment should be provided to all regardless of the ability to pay.

It wasn't until Em's Clinic opened in Kiryabicooli in November 2014 that free testing and prevention education became available to this community. Until there is a true understanding about what HIV is, how it is spread and how it is treated, the goals set forth by all of the international guidelines will not come to fruition. Development and implementation of an education and prevention program was planned to fill this gap. As a method of prevention, the HIV education program was offered to all mothers with children under the age of 13. This

expanded the number of people that have the correct knowledge to prevent HIV, and will have an impact on their homes and their communities.

Review of the Literature

HIV/AIDS continues to be a devastating disease in Sub Saharan Africa. In Uganda, the rates of infection are once again climbing. Women and young girls are the most affected group with the highest rates of infection. There continues to be stigma, fear, falsehoods, and lack of services and education that perpetuate this epidemic. The only way this will change is if there is access to education, prevention, testing and treatment available to all Ugandans without fear of disclosure, retribution and alienation. This review will focus on the following questions:

1. Is there evidence that HIV education will empower women to protect themselves from HIV acquisition?
2. Will educating mothers help to prevent HIV infections in their children as they reach adolescence?

The purpose of this literature review was to document evidence-based interventions that address the role of education for women and to determine if in fact education improves and decreases HIV rates of infection in this population. A detailed search of the literature for the value of education as a tool for improved health and HIV prevention was performed in the following databases: PubMed, Google Scholar, Cumulative Index of Nursing and Allied Health Literature (CINAHL) and the UMass Amherst Library search engine. The Medical Subject Headings (MeSH) for PubMed and CINAHL were: *HIV/AIDS, prevalence, Education as prevention, mother to child communication, health education outcomes*, *health literacy*, *education and impact on sexual behavior.* When searching Google Scholar, the same terms were used as well as *stigma and health education.*

Initially, PubMed, CINHAL and Google Scholar retrieved approximately 17,000 articles as these MeSH were interpreted very broadly. After refining the searches to include the terms *HIV Education as Prevention, Women and adolescents, health literacy,* and *Uganda,* multiple articles were removed as they related to perinatal infection, circumcision, community members as health educators, contraception and family unit structure. Additionally, there were many that were focusing on countries other than Uganda and this was felt to distract from the cultural importance of Uganda itself where women are in a distinct role. Once this search was refined, 13 articles were chosen. Inclusion criteria were studies that were directly related to the posed questions, in the English language, and only from the last ten years, except for landmark studies.

The search yielded three articles addressing maternal education and health outcomes. The point of these is to determine the worth of implementing an education program that will offer the women more information as a form of empowerment. One was meta-analysis investigating the effectiveness of prevention interventions on minority women who are poor (Ruiz-Perez, Murphy, Pastor-Moreno, Rosa-Garcia, Rodriguez-Barranco, 2017), one was a survey design looking at literacy and health status (Juliana, Ekama, Innocent, 2013) and one was a randomized control trial investigating the impact of knowledge on behaviors (Karlan, Thuysbaert, Gray, 2017). Two articles relating to mother's education and child's nutrition status were studies looking at previously gathered data, one form the Demographic Health Survey (Abuya, Ciera, Kimani-Murage, 2012), and the other from the Nairobi Urban Health and Demographic Surveillance System (Alderman, 2017).

With regards to the impact of maternal education on adolescent sexual health and HIV prevention, seven articles were chosen. One was a review of the literature of multiple studies investigating parent-child communication and its effects on behaviors associated with HIV in

sub-Saharan Africa (Bastien, Kajula, Muhwezi, 2011). Additionally, there was an ethnographic research study used to determine the relationship between parent-child communication and sexual health in Tanzania (Wamoyi, Fenwick, Urassa, Zaba, Stones, 2010), and a meta-analysis of parent-adolescent communication and behaviors (Wildman, Choukas-Bradley, Noar, Nesi, Garret, 2015). Two surveys were included that interviewed youth about the relationships they have with their mothers and if those relationships are beneficial regarding sexual health (Dilorio, Kelly, Hockenberry-Eaton, 1999; DiCemente, Wingood, Crosby, Cobb, Harrington, Davies 2001).

Two education models were included to provide support for tools of education having validity and improved results (Bhana, McKay, Mellins, Peterson, Bell, 2010 and Edwards, Reis, 2014).

HIV Education as a Means to Empower Women

Juliana et al. (2013) performed a survey study to investigate the effects of HIV health literacy and prevention among women in Nigeria. A cohort of 432 women from poor villages in the Cross River State was surveyed and it became clear that there is a high positive correlation between literacy and HIV prevention, meaning that the more educated a woman is the more likely she is to have the tools to help prevent HIV acquisition. Illiteracy was found to put women at a much higher risk of transmission indicating a need for a greater investment needed in primary and secondary education, in addition to health education for women who are undereducated and marginalized.

In a systematic review and meta-analysis, Ruiz-Perez et al, (2017) evaluated the effectiveness of HIV interventions targeting socioeconomically disadvantaged ethnic minority women. The outcomes measured were: improved knowledge of HIV transmission, behavior

change regarding HIV transmission and reduction in the incidents of sexually transmitted infections. What was found to be most beneficial was designing learning tools that were culturally appropriate based on a cognitive behavioral approach and the use of small groups led by trained facilitators. The education of these women had an impact on their overall health behaviors, which shows the benefit of educational interventions even with the most marginalized of women.

Several of the studies also indicate that in fact, the more educated a woman is, the higher the likelihood is that she and her children will be healthier (Diloria, 1999, Brown 2010, Edwards, 2014). In many countries, only primary school is available and required, and these tend to be the developing areas where food access, education, and financial security are at its most tenuous. Developing countries very similar to Uganda have evidence of poor maternal and child health related to a lack of formal, consistent education when measuring the nutritional status of their children. Stunting of growth is very prevalent among the more undereducated groups (Alderman, 2017 and Abuya, 2012).

One very interesting cluster randomized design looked at the benefits of community education on the context of microcredit meetings (Karlan, 2017). Comparing groups with just women to groups consisting of both men and women, the researchers found that providing education to the co-ed group was more empowering to women because the men began to see them as equals in the areas of finance and health; allowing the women to have a voice. This study raised the concern for teaching women only and that perhaps men should at some point be included to improve the program.

Maternal Education and Impact on Children's Health

A literature review by Bastien et al. (2017) and a meta-analysis by Wideman et al. (2015) both evaluated studies that looked at parental or caregiver and child communication about sexuality and HIV/AIDs in Sub-Saharan Africa. The outcomes investigated were whether children who had open communication with their parents would delay first sexual experience, decrease the number of overall sexual partners and increase condom use. It is known that parents play a large role in shaping the behaviors of their children including in gender and sexual socialization of their children (Widman, 2016). There were multiple barriers that were determined: religion, cultural norms, lack of knowledge about HIV/AIDS, time with children, as well as the myths that were often perpetuated by the adult. The youth also found that the use of fear tactics by their parents was not an effective way to dissuade risky behavior. The children were ignoring the threats rather than finding them as good learning tools for behavior change. There is also a cultural norm for parents in Uganda that their children will learn what they need to know in school and therefore they do not take on the role of educator.

Once the barriers were determined, researchers found that when the information was shared between parents and their children there was a decrease in risky sexual behaviors, especially in the girls that spoke with their mother (Widman, 2016). Boys were impacted by their fathers more than their mothers, but not as much as the girls. It was determined that the parents felt like they were more helpful if they were actually formally educated on the truths of HIV. Empowered with an education, they were not dependent on myths or cultural beliefs and were better equipped to teach the truth to their family and community as informed people (Bastien, 2011).

Bastien et al. made it clear in their literature review that more education for parents has the potential to impact the HIV/AIDS outcomes for themselves as well as their children. The traditional relationship of parents as strict and often punishing prevented the children from approaching their parents. Wamoyi et al. (2011) performed an ethnographic research study that used interviews, focus groups, and participant observation. What was observed reiterated what was found in the Bastien (2011) review. When parents would speak to their children about sexuality and HIV/AIDS it would be in the form of warnings with the goal of scaring them into improved behaviors. It was found that even parents who were very uncomfortable talking about sexuality felt obligated to discuss HIV as this was a reflection on the family. If one were to become infected, then it would be a financial burden on the entire family. Again this was done in the form of deterrence through fear, not through education on prevention and condom use. With this finding, it becomes clear that the lack of parent-child communication about sex has prevented the children from coming forward with questions and concerns for fear of punishment or suspicion.

Two studies from the United States investigated the benefits of parental and child communication and sexual behaviors (DiClemente, 2001; Dilorio,1999). These were included in this review as there is a universality of parent-child love that translates across cultures. However, it must be recognized that the power of women in the U.S. versus Uganda is alarmingly different. Both articles found an increased benefit when parents were involved with addressing sexual behaviors with their children with regards to HIV prevention. It was evident in both that mothers have more impact on both male and female children.

Edwards et al. (2014) and Bhana et al. (2010) have studied several methods developed to improve the communication between parent and child when discussing HIV/AIDS. The rates of

infection of HIV/AIDS in the youth of sub-Saharan Africa are alarming and helping parents find a way to feel comfortable having an open dialogue may help their children have better outcomes for their sexual health as they enter reproductive age and must navigate it in the face of HIV. Two programs appear to be beneficial: Collaborative HIV Prevention and Adolescent Mental Health Program (CHAMP) and The Five-Step Process for Interactive Parent-Adolescent Communication. Both of these programs worked with HIV negative and HIV positive parents and children. The results of both methods were very similar in that they included:

1. Open dialogue between parent and child was needed, creating a safe space.
2. Having some educational materials was helpful for parents and children.
3. Determining the child's and parent's prior knowledge level helped to serve them better.

It is imperative that in order to decrease the rates of HIV infection in youth, the parents must be given the tools to guide their children in a non-punitive manner that allows the children to come forward with questions when they need help making choices. The women who become educated will, in turn, feel empowered to protect themselves and their children.

The literature review presented materials that verify the need for increased interventions to prevent the continued spread of HIV in Uganda. The articles chosen included a variety of methods used to evaluate the results. All in some way reported positive effects of educating women for their own health benefit but also for the benefit of their children.

The strongest level of evidence, based on the scale from evidence-based nursing care guidelines (Evidence-Based Practice for Nursing: levels of Evidence), level 1, is seen with the meta-analysis and literature reviews as they had numbers and trials that cumulatively led to increased statistical power. The meta-analysis and review of the literature relating to parent-child communication both substantiate the importance of this relationship for children to make better

choices about their sexual health. The additional meta-analysis indicated the importance that education interventions do have an impact on women from ethnic minorities and those who are economically disadvantaged. Each of these helps to support the validity of the proposed QI project.

The surveys cited are Level VI but are found to substantiate what was found in the previous articles mentioned. Although the actual impact of these parent-child communications is not clear, it is apparent that there is some benefit. For the purposes of the QI project, even a small benefit is helpful in a place where no other programs exist to help reduce the burden of HIV. The literature does, in fact, support the educational program. Women do have improved health when they are informed and share that knowledge with their children. When the mothers attend a formal school and can complete all of high school they have healthier children. However, most of the women of Kiryabicooli have had no schooling at all, therefore, it is critical that they are given some education to compensate for this.

There is enough evidence to support this intervention as a method of improving the health of the mother, but also the health of her children. Information on truths about HIV should assist the mother in making choices for herself to reduce her risk, and with that powerful information she has the tools to impart this information to her children. The project included providing a structured HIV class for mothers of children under age 13 with the objective to empower them to become the HIV prevention resources themselves and for their families. With an appropriate understanding of the truths surrounding HIV, women and their children will have the power to make choices based on those truths. It is clear that education empowers women to make better choices regarding their health (Brown, 2010). Not only will these mothers be the students, but they will then be the teachers for their children.

Theoretical Framework

Leininger's Transcultural Theory **"**attempts to provide culturally congruent nursing care through cognitively based assistive supportive, facilitative, or enabling acts or decisions that are mostly tailor-made to fit the individual, groups, or institution's cultural values, belief and lifeways" (Nursing Theory, para. 2). When working with groups from other cultural backgrounds, it is important to gain a clear understanding of the beliefs that guide them in regards to their health. Generational ideas that have led to the choices of the family and community must be considered. To truly care for the patient, the provider must develop an understanding of who they are serving and provide services within the confines of what is culturally acceptable. It is imperative to work within the cultural framework of the community being served.

There was a cultural gap between the DNP student and the Ugandan community being served by this QI project, therefore it was crucial that the DNP student take the lead and instruction from the medical staff of Em's Health Clinic, as well as the participants, while determining what is important and what method of teaching and empowerment will work. No assumptions were made about the women of Kiryabicooli, and expectations were flexible. Curbing one's own preconceptions is required in order to be open to learning the ways of those being served and cared for. We ensured that during the program the women felt safe and in charge. They were in a safe setting without observers, no men present and no specific questions were asked during the training. It was important to the staff that the women did not feel "put on the spot" or feel that they must reveal anything that they did not want to reveal in order to build trust.

Goals, Objectives and Expected Outcomes

The goal of this educational program was to increase the knowledge about HIV/AIDS in women and their children allowing them to protect themselves from infection. The objective was to gather 30 women from villages close to Em's Health Clinic, in Kiryabicooli, Uganda, to participate in a training that provided the education needed to increase their knowledge base pertaining to HIV. Additionally, the goal of this project was to improve the level of HIV literacy of mothers with children under age 13 in the areas of HIV transmission, disease progression and treatment, with a primary focus in prevention methods to use for themselves, as well as to teach their children to prevent HIV infection before they become sexually active.

It was expected that 80% of the participants would have increased post-test scores following the educational intervention. With this increased knowledge the mothers stated they felt an increased comfort addressing HIV risks with their partners and peers as well as teaching and talking to their children about HIV. The objective was that the children of these participants would be empowered to put this new knowledge into practice as they reach puberty to increase their well-being and help them remain HIV negative. All of the women affirmed that the class was helpful in understanding HIV when asked by the trainers. The majority of women clearly stated that they were able to have conversations about HIV using the knowledge gained from the class.

Project Site and Population

Kiryabicooli is located in North Western Uganda. It is known to be one of the poorest areas of this country (NPHC, 2014). Prior to the development of Buseesa Community Development Centre and Em's Health Clinic, there were no health services located in this area that could provide basic health care and education. There was not any access to free HIV tests or

any materials on prevention. In the larger cities of Uganda, you can find public health information about HIV, but not in the remote areas of Uganda.

The women for this program came from surrounding villages that access Em's Health Clinic in Kiryabicooli Uganda. These women are primarily subsistence farmers. They may have any number of children at home. Inclusion criteria are that participants must live within the villages accessing Em's Health Clinic, be female, have children under age13 in the home and have never participated in any HIV training in the past.

The health workers that assisted with this program were all certified by official Ugandan institutions who have licensed them to work in their field. The health worker staff included a Clinical Officer (equivalent to a Physician Assistant in U.S.) and two comprehensive nurses. These are the full-time employees of Em's Health Clinic. They were integral and trusted members of the community.

Methods

The participants were recruited by the trained health outreach team of Em's Clinic. Participants were given an identification number rather than their name so that the information was protected. The participants then gathered for both sessions of their classes in July of 2018 as well as attending the follow-up session in January 2019. A nurse who had been trained and certified by the Ugandan Health Ministry to be an HIV educator and test counselor and the DNP student taught the class together. The class was given in a lecture format with time during the class to ask questions. There were two sessions one week apart. Prior to session one, the pretest was given in a group format and again after session two (Appendix A). Based on these pre and post-test results, as well as the discussion that occurred during session 3 in January of 2019, a determination was made that the program should be expanded to all villages that are served by

Em's Clinic. The expected goal is that after the educational intervention is completed the women will have the knowledge base to have an impact on the rates of HIV infection of the next generation.

Setting facilitators and barriers: The nursing staff of Em's Health Clinic recruited the participants, as they are trusted members of the community. Trust was crucial for this project to work, as HIV has so much stigma associated with it. If there was a possibility that the women would be thought to be HIV positive because they are participating, they would decline. Additionally, literacy in this area within the adult population is low (Uganda Bureau of Statistics, 2014). This prevented the women from expressing themselves clearly while working with the translator. Additionally, women may have been afraid to answer truthfully because they are not anonymous to the translator. This is why the trust in the staff was so important. Em's Clinic has now been in the community for four years. Patients have learned that their privacy is protected and that they can speak openly to the staff without judgment, which assisted in creating a community of trust in the sessions.

Implementation

The proposed QI project began in July of 2018. The team of Em's Health Clinic recruited 30 women with children under the age of 13 from the surrounding villages that use Em's Health Clinic as their healthcare base. The recruitment staff included the Comprehensive Nurses who have been providing care since November 2014. They are trusted members of the Kiryabicooli Community. They presented this as a project organized by "Dr. Em" from the U.S. as part of her improvement in care for the community. HIV is known as an important health issue and they know that prevention, testing, and linkage to care are critical services offered by the clinic free of charge.

Once the women agreed to participate and the cohort of 30 had been identified, they arrived for class. Prior to the teaching, a pre-test was given covering HIV: transmission, myths, testing, disease progression, treatment options, and effectiveness. The test had yes and no questions only. Each test was labeled with the participant's designated number rather than their name for privacy. The list of participants with names and their designated numbers is being kept by the DNP student in the U.S.

Once the pretest was completed, the two sessions were offered to the whole group on the topics mentioned above. These classes were held in one of the empty classrooms of Deidre Ann Academy School. The goal to have a female trainer who speaks the dialect of this area (Runyoro) was met. Each class lasted about 120 minutes and included multiple aspects of HIV/AIDS (Appendix B). Snacks were served. Questions were encouraged and often shared. There were no observers from the community, including children. Childcare was offered in one of the classrooms for the mothers that were unable to leave their children at home.

Once the classes were completed, the women immediately completed the post-test as a group with the original staff. The same questions were presented in the pre and post-test (Appendix A). The results were evaluated, and the misconceptions were clarified and were addressed with the women during the third session, which took place in January 2019. This session was to clear up any misunderstandings as well as to discuss with the participants the importance of their participation in the prevention of HIV for themselves and their children. The third session also sought to understand if the women feel that they now have the material needed to successfully teach their children the truths about HIV. Additionally, information was gathered in the form of open discussion with the women to find out what tools would make this easier for

them to educate in their homes (Children's books, pictures, etc.), as well as with the women of their community.

Measurement Instrumentation

A pre and post-test was given to the participants before and after the two sessions of HIV disease education. These tests were done in an open group setting translated by the nurse of Em's Health Clinic as the literacy rates often prevented the individuals from taking the test alone. The test developed by the DNP student with input from her Ugandan health staff (Appendix A) consisted of 30 questions about the three areas of HIV previously mentioned: prevention/transmission, disease progression, and treatment. The questions for the test were based on known HIV information combined with the myths and misconceptions within the culture. An HIV curriculum was developed and presented by the DNP student and the certified HIV educator from the Ministry of Health in Kiryabicooli for all three sessions (Appendix B).

Results

Thirty women with children under 13 years old were recruited from surrounding villages into the program during a 1-month period prior to session one. Informational sessions were offered by the nursing staff of Em's Health Clinic within the clinic and also in the villages. The women who were interested were screened for the following: they must reside in the chosen Villages, they must have children under age 13 (number of children not important), and they have never participated in an HIV education program offered elsewhere. All interested women who met the criteria were accepted by the nursing staff reaching the goal of 30 participants. Session one had exactly 30 participants, session two had more as some of the women brought friends to listen.

Pre-intervention

The pre and post-test tool had been developed by the DNP student and Clinical officer of the Health Clinic to give to the 30 women that participated in the HIV educations program. This test had questions related to truths and myths, based on the beliefs of the community where this intervention took place. The two-session class covered the truths about HIV prevention, transmission, disease progression, and treatment. The class addressed the prevailing myths that are perpetuated in this area.

An additional session was provided six months after original sessions that addressed the women's concerns about teaching and counseling their children and peers about what they have learned to protect them from HIV in the future and what their thoughts were on the effectiveness of the previous sessions and suggestions for improvement. The post-test was only given to the women that had participated in session one. At the six month follow up, 28 of the original 30 returned and brought along other women to learn. The data collected focused only on the women that attended all three sessions.

Post Intervention

The pre and post-tests were brought back to the U.S. for analysis. As the pre and post-tests were scored and the data organized and it was determined there were some problems matching individual's pre-test scores with post-test scores. Since we used a new sheet of paper for the post-test instead of using the original one, the participant ID numbers appeared to get reassigned at check-in (Appendix D). The staff did not take the original roll sheet and reproduce the actual identifier assigned to that women. The staff was then not able to align the identifiers up for test 1 and test 2, so it was essentially impossible to compare individual scores. These

errors in the gathering of the pre and post tests were evident on the tests themselves and did not allow for direct comparisons of individuals.

With these errors, it became evident that more teaching was needed to improve the effectiveness of the class structure and content. In January of 2019, the test was then discussed question by question with the group as a whole as a way to reintroduce what had been covered six months earlier. The nurse read each question and the women as a group going answered each question out loud to clarify the persistent areas of confusion that the women still held. The women were then interviewed as a group to find out how they were feeling about the content of what they had learned and how it applied to their lives as women and as mothers and members of their communities. This qualitative data was organized into themes and is presented in tables.

Data Analysis

Since the participant ID numbers were not aligned, we could not measure changes from pre and post-test scores on an individual level. However, an overall analysis of the scores pre and post-test did indicate improvement in some areas and room for improvement in other areas (Table 1).

Table 1. Aggregated group response to written survey post-HIV Education

Questions: [1]	**Pre-Test [2]**	**Post-Test[3]**	**% of Change[4]**
General Knowledge			
Have you heard of AIDS?	100%	100%	0%
Can a person live a normal life with AIDS?	96%	96%	0%
Myths			
Is AIDS only a disease of African People?	73%	92%	19%
Are women more at risk for infection than men?	56%	77%	21%
Can AIDS be prevented by washing the genitals?	70%	96%	26%
Can you get AIDS from a mosquito bite?	73%	96%	23%
Can a person get AIDS from a curse?	96%	100%	4%
Can herbs and potions cure AIDS?	96%	92%	-4%
Testing			
Should every person who is sexually active get an HIV test?	19%	36%	14%

Prevention			
Will condoms protect you from AIDS?	86%	85%	-1%
Can AIDS be prevented by family planning?	86%	100%	14%
Transmission			
Can you catch AIDS from kissing?	76%	88%	12%
Can a baby catch AIDS from their mom?	96%	100%	4%
Babies can be infected while in the uterus?	70%	96%	26%
Can a person get AIDS from sex?	100%	100%	0%
Can you catch AIDS from someone sneezing or coughing?	96%	96%	0%
Treatment			
Is there treatment for AIDS?	63%	88%	25%
Are there medications in Uganda to treat AIDS?	86%	88%	2%
Do you need to have money to get AIDS medicine?	83%	92%	5%

[1]Table 1 does not include all of the questions asked. It represents aggregated questions. The questionnaire was not presented to participants with the categories included in this table. Possible answers to each question were either: yes or no. [2]Pre-Test % represents % answered correctly. [3]Post-Test % represents the % answered correctly at the end of the session. [4]Represents the % of change between the Pre-Test and Post-Test.

Improved areas in the group from the educational intervention to measure changes in knowledge of HIV included: myths, prevention, transmission, and treatment. Most notably, there was a greater than or equal to 20% improvement between sessions for the following questions: 1) Can AIDS be prevented by washing the genitals? 2) Babies can be infected while in the uterus? 3) Is there treatment for AIDS? 4) Can you get AIDS from a mosquito bite? 5) Are women more at risk for infection than men? All five questions address HIV/AIDS myths, transmission, prevention, and treatment, respectively.

The overall improvement in knowledge of the group is indicative of the fact that the sessions were addressing the HIV educational needs of the women in attendance. Even though the pre and post-test did not measure individual changes in knowledge due to the mix up of participant ID numbers, it is clear that the women retained the information provided in curriculum and overall, changed their misconceptions or preconceived notions when presented with HIV facts by the facilitators.

A notable question was the question addressing testing: Should every person who is sexually active get HIV test? It was the lowest percentage of correct answers with only 19% answering yes. The post-test showed an only 14% increase resulting in a total of 36%. The results for this question exemplifies the stigma and fear that persists in this community around HIV testing. To effectively combat the HIV epidemic, it is most necessary to eliminate the stigma of testing for HIV.

Follow- up

In January of 2019, the women were requested to return. Twenty-two of the women returned. Many of them brought friends so the total group turned into 40 women. We gathered in the same classroom. The first order of business was to go over the test one more time as a group to clarify the answers that were repeatedly incorrect (Table 2).

The following questions were asked of the women:

Table 2. Survey of January 2019 Class

Question	# of hands raised	%
Do you feel that this class helped you understand HIV?	22	100%
Did you correct someone when you heard them saying something incorrect about HIV?	18	81%
Did you talk to your partners about HIV?	17	77%
Did your partner agree to get an HIV test?	7	31%
Did you get HIV tested in the last 6 months?	11	50%
Did you take a friend for an HIV test?	12	54%
Did you have a discussion with your children about HIV?	13	59%

The floor was then opened to the women to ask whatever questions they wanted. Direct quotes from this discussion are unavailable due to the fact that the session was conducted completely in the local language then translated to the DNP student for her knowledge. The concern with providing those direct translations is that they do not accurately represent the thoughts and opinions of the participants.

Once again the topic of sexual risk, sharp object risk, and testing accuracy were reviewed. There was a myth that the author was unaware of. It is thought by many that if you take Paracetamol you will have a false negative HIV test. This was corrected and education was provided that there is no interaction between Paracetamol and the rapid HIV antibody test.

What became very apparent is that many of the women (24) wanted to be certified to be educators because they feel there are so many women in their villages that have a very poor understanding of the truths of HIV and they want to teach them. This class gave them the confidence to speak to others including men. They made it very clear that unless the men learn the same information nothing will change. Uganda is a patriarchal culture. Polygamy is also a cultural practice, leading men to often have multiple wives. If the men are unaware of the truths of HIV or are unwilling to talk about it then the spread of HIV will continue. The men must take responsibility for their behavior because women don't have the power to promote or negotiate their own safety. Women have the power to teach their children and to openly talk with other women but they don't have the power to enforce safe sex practices. The women requested multiple times that this class be offered to men.

It was agreed that the health team would be available the following week and if men were to show up they would get a class and it would then be determined if they were in fact interested in participating fully. At the time of the class 19 men showed up for a 90-minute session. All of them agreed to participate in a formal class when the author returns in July. The men in attendance were very open and it was clear that they have much to learn.

Social Support in Group Discussion

As the women first gathered they were very quiet and did not speak out at all. They giggled often but in a way that showed their discomfort. After about 30 minutes a number of

brave women in the room, who appeared a bit older than the others, began asking questions along with stating their opinions about topics being discussed. Their confidence to express their opinion eased the tension in the room and connected the women. None of the women in this class had ever participated in a group discussion about health let alone HIV and as a result, were very hesitant to make their voices heard. As stated in the literature, when a woman feels safe and comfortable in the setting of HIV counseling she will be more likely to participate in testing and prevention education (Asiime, 2016).

The stigma associated with HIV has kept people in the dark about the truth. It has created an environment of myths and misinformation that has led to an increase in HIV infections (PHI 360, 2012). This was evident in this group of women. Many said that they have never been in a place where they were taught the truth. They had never been in a setting where they could safely ask questions and get clarification. Several women said that our session was the first time they even talked about HIV to anyone.

By the end of the session, the women realized that they had gotten enough information to educate other women. Several asked for training to certify them to be legitimate health educators so that they could take this information to the surrounding villages. They felt that they could be effective in helping women who were too uncomfortable to come to a class like this.

Discussion

There is evidence that community-based HIV counselors teaching in rural Uganda have improved outcomes in caring for newly diagnosed HIV patients and making sure they stay linked to care (Hatcher, 2012). This finding would imply that community members teaching about prevention and testing would likely have the same improved outcomes. The more local women have a voice the more likely stigma will decrease in the community. More education and less

stigma will lead to a healthier community where mothers continue to pass down the necessary tools for effective HIV prevention and the realization of the goal of generational prevention can be achieved.

HIV Prevention and Testing Guidelines

The Ugandan guidelines state that all people who test positive for HIV should be given treatment immediately. One no longer has to wait for declining immune status or illness to get care (WHO, 2015). This will only happen if there is increased comfort in getting tested. It is known that fear and stigma keep people away from testing centers. When asked how many of the participants took someone to go get tested in the six months between July and January, seven women said they had taken another woman to get tested and that those women had never been tested before. Eleven of the women were able to talk to their husbands about what they had learned and they had agreed to go get tested with their wives. Five women stated that their husband stated that didn't need testing but that they could test whenever they wanted. They were very frustrated by this.

It is clear that unless the men are involved there will be no stopping HIV; the primary infection is through heterosexual sex in Uganda. It is the intention to include a session for the men of the community as requested by these women. Cultural norms indicate the importance of including men to achieve sustainable gender equity for women. Leininger's Transcultural Theory reinforces the necessity to adjust the training according to the needs and advice of the women - regardless of the opinions or pre-conceived norms of the DNP student. In order for a program to work in this area of Uganda, it must also be acknowledged how the patriarchal society inherently oppresses a woman's agency. Educating women in a vacuum might lead to generational prevention; including men will result in long term community and cultural prevention. The

objective is not to change but to respect the cultural norms while empowering the men and the women with the information necessary to protect their health and well being.

Barriers

The barriers noted in the literature review were evident as we proceeded with this program. Stigma prevents open and comfortable participation; it prevents open dialogue between families and community members. It has interfered with the understanding of HIV and how it is contracted, treated and how it affects the body over time. It is clear that increased comfort allows for dialogue and this was evident over the course of several hours of the women being together. The impact of the understanding they were in a safe space where there would be no judgment or ridicule cannot be understated. This allowed the flow of dialogue and empowered the women as many of them expressed strong interest in teaching others including their children. The women concluded the sessions feeling as though they now had the tools to talk to their children about the truths of HIV with the hope to have an effect on health outcomes of their children and effectively stop HIV in the next generation.

Cost-Benefit Analysis/Budget

The costs of this project were minimal as it took place in Uganda where the dollar is highly valued. The exchange is $1 = 3,600 USH. The staff at Em's Clinic are on year-round payroll, therefore this will be one of the duties that they are already compensated for. The costs incurred were from the following: trainer from the health ministry, time and transportation, petrol, forms and copying, food for participants and gifts for participants. The benefit to the clinic and the community is well worth the money spent. The costs came from the DNP students' personal budget as the clinic has no extra funds for health programming, at this time. The clinic covers the salaries of Em's Clinic staff members involved in the project as its only expenditure.

The most significant cost was on time spent by staff, educators and the DNP student (Appendix C).

Timeline

This project began in June of 2018 with the approval of the proposal. Recruitment for participants began in June 2018 and was completed by the third week of June. The education interventions took place with all 30 women in the first week of July. The first two classes were completed within five days. The post-tests were then examined between the second and fourth week of July.

Results from these pre and post-tests were analyzed in October 2018. In January 2019, the DNP student traveled again to Uganda to speak with staff, trainers and participants about the implementation of learned skills, strengths and weaknesses as perceived by the participants. The DNP student determined if there are benefits felt by the community and positive outcomes were seen then the cycle will repeat every six months with a different cohort of women.

Conclusion

HIV continues to impact Uganda at rates that are unacceptable. Women and children are greatly affected by this problem. It is known that 80% of all new infections worldwide occur in women and girls (The Global Fund, 2018). The myths that surround HIV, as well as gender inequality, are perpetuating the problem. The goal of this quality improvement project was to empower women with the truths about HIV so that they can then protect themselves as well as teach their young children in an effort to initiate generational HIV prevention. As the next generation reaches the age of sexual activity they will have the knowledge necessary to protect themselves from infection.

A group of 30 women from nearby villages were recruited to participate in an educational program that consisted of a pre-test, two educational sessions, a post-test and a third follow up session. The women had the opportunity to ask questions in a safe environment and offer ideas for improvement, as this project must fit into the cultural context of this area. The intention is to develop an educational program that can continue to be replicated in the area of Kiryabicooli so that the women and children of this area can become community resources to protect themselves as well as their peers.

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Appendix A

HIV PRE & POST–TEST

Participant identifier #: _____ Date: _____

Name of person conducting test _____

Questions:		**Answers: YES *OR* NO**	
1	Have you heard of HIV/AIDS?	YES	NO
2	Can a person live a normal life with AIDS?	YES	NO
3	Can a person get HIV from a curse?	YES	NO
4	Can a person get HIV from sex?	YES	NO
5	Is there treatment for AIDS?	YES	NO
6	Can a baby catch AIDS from mom?	YES	NO
7	Can a baby catch AIDS from mom *while in the uterus?*	YES	NO
8	Can a baby catch AIDS from mom *from breastfeeding?*	YES	NO
9	Are women more at risk for infection than men?	YES	NO
10	Can you catch AIDS from kissing?	YES	NO
11	Can you catch AIDS from sharing your home with a person that has AIDS?	YES	NO
12	Can you get AIDS from a mosquito bite?	YES	NO
13	Can you catch AIDS from sitting next to someone with AIDS in the classroom?	YES	NO
14	Will condoms protect you from AIDS?	YES	NO
15	Can you catch AIDS from sharing food?	YES	NO
16	Can you get AIDS from sharing sharp objects like needles?	YES	NO
17	Can you catch AIDS from someone sneezing or coughing?	YES	NO
18	Can you get AIDS from animals?	YES	NO
19	Can you get HIV from breathing the air?	YES	NO
20	Can AIDS be prevented by washing the genitals?	YES	NO
21	Can AIDS be prevented with family planning?	YES	NO
22	Can herbs and potions cure AIDS?	YES	NO
23	Are there medicines to treat AIDS?	YES	NO
24	Can you tell if a person has AIDS from looking at them?	YES	NO

Appendix B

HIV/AIDS Educations Curriculum
Kiryabicooli, Uganda

1. **Basic Information and Incidence**
    A. What is HIV? What is AIDS?
    B. Who is at risk for getting HIV?
    C. How long can people live with HIV or AIDS?
    D. Can I get a vaccine to prevent HIV infection or AIDS?
    E. Is there a cure for AIDS?
    F. How many people are living with HIV/AIDS?
        a. Worldwide, Africa, Uganda
    G. What is the status of the epidemic in Uganda?
2. **Transmission**
    A. How is HIV spread from one person to the other?
        a. Review of fluids, activities (i.e. unprotected sex, injection drug use, etc)
    B. Is HIV easy to get?
    C. Does everyone who is exposed to HIV get the disease?
    D. HIV transmission via sexual contact specifics
    E. Needle use/sharing
3. **STIs and the relationship with HIV transmission**
4. **Risks of multiple partners and HIV transmission**
5. **Mother to child transmission**
    A. Pregnancy, delivery, breastfeeding
6. **Can a person who is not sick or has no symptoms pass HIV to another?**
7. **Other myths and truths about transmission**
    A. Kissing, human bite, mosquito bite, casual contact, food, water, tattoos, piercing, razors
8. **What about injections or procedures at the medical facility?**
9. **Testing**
    A. Is there a test for HIV?
    B. Who should get tested?
    C. How do I get tested?
    D. Privacy and testing?
    E. What is informed consent?
    F. Should I wait for symptoms before getting tested?
    G. How soon after exposure can HIV infection be detected?

a. Window period
b. Antibody production
c. Pregnancy and Testing

10. Risk Reduction

A. Is there a 100% way to prevent sexual transmission?

a. Condoms
b. Partner on ARVs.
c. No protection from contraception
d. Do not use soap or douche as prevention.

A. Pregnancy and transmission
B. Injection drug use

11. How does HIV enter the body?

12. What does HIV do to the immune system?

13. When does an HIV positive person have AIDS?

14. Can a person tell if they have HIV or AIDS?

15. What does a person with HIV or AIDS look like?

16. What are the symptoms of HIV infection?

17. Why should a person seek medical care?

18. Are there medications to prevent infections?

19. What are Anti-retroviral and how do they work?

20. What illnesses occur in untreated HIV patients?

21. Where can one get tested?

22. Infection rates in children. Perinatal infection vs sexual contact.

A. How should parents talk to their children about HIV and AIDS?
H. Can HIV positive children live a normal life?

23. How do we protect our girls once they become sexually active?

24. How do we teach our boys to protect themselves?

25. Gender Equality for our children.

Appendix C

Cost Analysis/Budget

The following is the cost analysis for the development of the QI project: HIV educations for the Women of Kiryabicooli, Western Uganda. The following costs were incurred for the rollout and implementation of this ongoing project.

Cost-benefit analysis

EDUCATION	ITEMS	COST
	Clinical officer / RN	$0
	PAPERWORK / COPYING SERVICES	$50.00
	Participant Pamphlets	$200.00
	Fuel	$50.00
	Health Ministry	$40.00
	Mosquito Netting	$300.00
	Food & Beverages	$30.00
	Total	$670.00
Data Analysis		
	Test Results analysis	$0
	DNP Housing	$100.00
	Total	$100.00
Technology		
	Paper Ink Supplies	$100.00
	Phone Minutes	$30.00
	Total	$130.00
	Grand Total	**$900.00**

$900 is equal to 3,240,000 Ugandan Shillings

Appendix D
Participant ID Log

Participant ID #	AGE[1]	# of Children[2]
100	34	5
101	28	4
102	22	6
103	24	3
104	25	4
105	26	2
106	31	1
107	19	5
108	19	3
109	21	4
110	24	2
111	32	6
112	41	2
113	33	2
114	22	5
115	31	6
116	28	3
117	26	3
118	24	1
119	18	4
120	17	3
121	34	5
122	40	3
123	33	3
124	43	5
125	23	4
125	26	2
126	24	6
127	22	1
128	31	3
129	30	4
130	27	2

[1]Average age of participant: 27.4 [2]Average # of children per participant: 3.5