

Running head: HIV/AIDS

HIV/AIDS Prevention and Treatment

The Role of the Parish Nurse

In Patient Care in Swaziland Africa

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To my Yia Yia and PaPo

And love always,
Dad, Mom, Adam, and Matt

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Table of Contents

Acknowledgments.....	4
Table of Contents.....	5
Abstract.....	8
Chapter I.....	9
HIV/AIDS Prevention and Treatment.....	9
The Role of the Parish Nurse.....	9
In Patient Care in Swaziland Africa.....	9
Introduction.....	9
Pathophysiology of HIV/AIDS.....	10
Types of HIV.....	10
Groups.....	11
Subtypes.....	11
Risk Factors.....	11
Sexual contact.....	11
Blood transmission.....	11
Implications of HIV/AIDS.....	11
Social impact.....	11
Financial impact.....	12
Research Purpose.....	13
Chapter II.....	14
Review of Literature.....	14
Etiology.....	14
Discovery of HIV/AIDS.....	14
Origin.....	14
Theories of transmission.....	15
HIV/AIDS in Sub-Saharan Africa.....	16
Knowledge and perception.....	16
Stigma.....	17
At Risk Populations.....	19
Mother to child transmission.....	19
Youth.....	19
Females.....	20
Cultural Factors.....	20
Polygamy.....	20
Status hierarchy.....	20
Economic security.....	20
Treatment and Interventions.....	21
Prevention via a vaccine.....	21
Drug therapy.....	21
Mother to child transmission programs.....	22
Virginity testing.....	22
Youth targeted education and preferred source.....	22
Abstinence and monogamy.....	24
Condoms.....	24

Community based groups	24
Coping and support	25
The Parish Nurse.....	26
Role	26
Parish nurses in Africa	27
Weakness in literature.....	27
Nursing implications.....	27
Chapter III.....	29
Methodology	29
Grounded Theory	29
Considerations.....	29
The researcher's bias.....	29
Procedure	30
Participant Criteria.....	30
Characteristics of participants.....	30
Ethical considerations.....	30
Data Collection	31
Data Analysis	31
Limitations	31
Chapter VI.....	32
Results.....	32
Swazi People Caring for Swazi People.....	32
Our people our problem	32
Enduring.....	32
Basic survival.....	32
Interdependence	33
Diagnosis.....	33
Initial diagnoses	33
Lack of knowledge.....	34
Denying.....	34
Accepting	35
Duty to Care	36
Commitment to nursing	36
Caring for the patient.	36
Frustration	37
Strength through Faith	38
Praying.	38
Healing.....	39
Ownership.....	39
Chapter V	40
Discussion.....	40
Holistic Care	40
Meeting Basic Needs	40
Role definition	40
Eating healthy.	41
Challenges of living in rural versus urban settings.....	41

Meeting Psychological Needs.....	42
Influence of Parish Nurse Program.....	42
Instilling hope.	42
Parish nurse successes.....	43
Treating both sexes	43
Implications for Future Nursing Research.....	44
Conclusion	45
Appendix A.....	46
Informed Consent for Parish Nurse	46
Informed Consent for Individual Living with HIV/AIDS	48
Appendix B	50
Discussion Topics	50
References.....	51

Abstract

The purpose of this research study is a better understanding of the culture, experiences, and responses of parish nurses and their patients in Swaziland, Africa in relation to the problem of the HIV/AIDS epidemic in the country. In this qualitative study, based on grounded theory, two parish nurses and two HIV/AIDS positive individuals that received care from a parish nurse were formally and informally interviewed about their experiences with HIV/AIDS and field notes were taken. The major themes of this study that are important to all participants is recognizing and taking ownership of the HIV/AIDS epidemic in their country through Swaziland people helping other Swaziland people. Participants felt that taking ownership of the epidemic and caring for each other was the first step to fighting against HIV/AIDS.

Chapter I

HIV/AIDS Prevention and Treatment

The Role of the Parish Nurse

In Patient Care in Swaziland Africa

Introduction

It is estimated that since 1981, there have been more than 60 million individuals around the world infected with the human immunodeficiency virus (HIV), and currently it is estimated that 40 million people are living with the virus. Also, 95% of the newest infected people are living in the developing world with the majority being young adults. Of those individuals with acquired immunodeficiency disorder (AIDS), 21.8 million people have died. In Southern Africa HIV/AIDS is the leading cause of death (Joint United Nations Programme on HIV/AIDS, 2006). In Swaziland, Africa, with an estimated population of 1,173,900 people, and out of that 1,173,900, 220,000 are living with HIV/AIDS (*The World Factbook*, 2006). As of the summer of 2000, Maternal Life International, a nonprofit world healthcare organization, focused on disease prevention, was awarded a \$272,900 grant to implement a parish nurse program in 25 Swaziland communities. The program, named A New Robe, is the first parish nurse program in Africa, with 25 nurses already trained. Many of the services that the parish nurse program provide are hospice homecare, testing and counseling, and community education of those affected by HIV/AIDS (*AIDS Weekly*, 2000).

Pathophysiology of HIV/AIDS

The Center for Disease Control defines AIDS as “all HIV-infected people who have fewer than 200 CD4+ T cells per cubic millimeter of blood. In addition, the definition includes 26 clinical conditions that affect people with advanced HIV disease” (U.S. Department of Health and Human Services, 2005). Many of the conditions are opportunistic infections that people without HIV would normally be able to fight off with their healthy immune system. (United States Department of Health and Human Services, 2005). HIV causes AIDS, although not all individuals with HIV develop AIDS. HIV consists of a ribonucleic acid core surrounded by a protein coat. It is able to replicate once it enters CD4+ lymphocyte cells of the immune system. The role of the CD4+ cells is to coordinate an immune response. The HIV will take control of the CD4+ cells and use them to make replicas of the virus killing the cell after it has made the replicas. This weakens the immune system so that the body is unable to fight off the virus as well as other viruses, bacteria, fungi, and parasites (Bullers, 2001).

Types of HIV. HIV mutates rapidly resulting in different strains that can occur in just one infected body. These numerous strains of HIV are categorized into types, groups, and subtypes. There are two different types of HIV known as HIV-1 and HIV-2, although they both can result in AIDS that is clinically indistinguishable. Both have the same routes of transmission through sexual contact, blood products, and mother to child. The major differences are HIV-2 transmits less easily through those routes, there is a longer transition period from initial infection to AIDS, and it is less common worldwide but highly concentrated in West Africa. HIV-1 is more common worldwide (Noble, 2004).

Groups. HIV-1 is categorized into three different groups, major group M, new group N, and outlier group O. Group O seems to be restricted to west-central Africa while group N was only recently discovered in Cameroon in 1998 and is very rare. Ninety percent of people infected with HIV-1 belong to group M (Noble, 2004).

Subtypes. Within group M there are least nine genetically distinct subtypes (or clades) of HIV-1 identified. These subtypes are A, B, C, D, F, G, H, J, and K (Noble, 2004).

Risk Factors

Sexual contact. HIV is most commonly spread through unprotected sexual contact through the mucous lining of the vagina, vulva, penis, rectum, or mouth of an infected partner. In sub-Saharan Africa, the highest rate of HIV transmission occurs through heterosexual contact (Hogan, Baltuseen, Hayashi, Lauer, and Salomon, 2005). Having a concurrent sexually transmitted disease increases the risk of infection of HIV-1 two-to five-fold (Oni, 2005).

Blood transmission. Mother to child transmission can occur during pregnancy, birth, or breast-feeding in one-quarter to one-third of pregnancies if the mother is not treated for the infection at all. Healthcare workers are put at risk because of the potential of needle sticks or direct blood contact through a skin lesion, eyes, or mucosal lining of the nose (Joint United Nations Programme on HIV/AIDS, 2006).

Implications of HIV/AIDS

Social impact. According to Danziger (1996, p. 1083) "AIDS is unlike most other epidemics. The modes of HIV transmission, the stigma attached to the disease, and the

absence of a cure all combine to render most traditional public health strategies inappropriate for AIDS control.” In sub-Saharan Africa, the average life expectancy is 47. If there were no one infected with HIV/AIDS the average life expectancy would jump up to 62 years of age. The number of sick adults in Swaziland has compromised their children’s education. Many of the girls have dropped out of school to care for their relatives that are infected resulting in a 36% drop in school enrollment (Mukherjee, Farmer, Niyizonkiza, McCorkle, Vanderwarker, Teixeira, and Kim, 2003). For the parents or relatives that do not survive AIDS 11 million orphans are the result in sub-Saharan Africa (Adesoji, 2005).

Financial impact. The rate of newly acquired HIV infections continues to rise in low and middle-income countries with 5 million newly infected and 3 million dead worldwide in 2004 alone (Hogan, Baltuseen, Hayashi, Lauer, and Salomon, 2005). As a result, according to Hogan et al. (2005, p.1431), “The HIV/AIDS pandemic now threatens the viability of health infrastructure, social systems, and economic growth in many resource poor countries.” In the sub-Saharan region the cost of interventions such as education through mass media, treatment for sexually transmitted diseases in female sex workers and the general population was <150 cost per disability adjusted life year (DALY) averted in 2000 international dollars (\$Int). Other average costs include: voluntary testing and counseling <\$Int350 per DALY averted, mother to child prevention of transmission <\$Int50 per DALY averted, and school based education and antiretroviral treatment strategies was between \$Int500 and \$Int5000 per DALY averted. Even since the United Nations in 2000 adopted the goal to decrease the spread of HIV by 2015, progress has been slow due to resource shortages and the estimated funding gap by 2007

is around 50% of the need (Hogan et al. 2005). These costs have a huge impact on the families. For example in Zambia, a drop of 80% in family income results due to the loss of the head of the household in two thirds of families (Mukherjee et al. 2003). In addition “economic models show that the AIDS pandemic in sub-Saharan Africa will have long term economic consequences that may be resolved only by international economic assistance (Dixon, McDonald, & Roberts, 2002, p.234).

Research Purpose

The purpose of this research study was to obtain a better understanding of the culture, experiences, and responses of patients living with HIV/AIDS, and the parish nurses giving them care in Swaziland, Africa. In this qualitative study, based on grounded theory, parish nurses and their patients were formally and informally interviewed about their experiences with HIV/AIDS. Field notes were taken as well. By gaining an understanding of experiences of patients living with HIV/AIDS in Swaziland and the experiences of parish nurses giving them care, nurses may be able to base some effective methods and interventions against HIV/AIDS for people of that country because, “through grounded theory, the processes that underlie social experience are discovered and become the basis for nursing interventions” (Fain, 2004, p. 278-79). In addition, a better understanding of the role of the parish nurse can lead to more effective training of future parish nurses and validate the important role parish nurses play in HIV/AIDS care.

Chapter II

Review of Literature

Etiology

Discovery of HIV/AIDS. The first known case of the HIV-1 worldwide was discovered in 1959 by a blood sample from a male living in Kinshasa, Democratic Republic of Congo. Through analysis of the blood it is speculated that HIV-1 may have originated in the late 1940s to early 1950s from a single virus although it is not known how the man was infected (Center for Disease Control (CDC), 2003). AIDS was not officially identified until 1983 in the United States although it was in 1981 when the United States Center for Disease Control and prevention (CDC) first disclosed a brief nine-paragraph summary reporting five different cases of a mysterious disease afflicting gay men but since then the HIV/AIDS epidemic has become recognized as a worldwide epidemic (Buller, 2001). Even though AIDS was not recognized until the early 1980s the CDC now knows that HIV had been in the United States as early as the mid to late 1970s (CDC, 2003).

Origin. HIV is a retrovirus but more specifically a subgroup of a retrovirus known as a lentivirus meaning “slow virus” due to the long amount of time it may take for symptoms to manifest (Kanabus, Allen, & Boer, 2005). The lentivirus has been found in various types of animals such as cats, sheep, horses, cattle, and monkeys. Specifically in monkeys is the Simian Immunodeficiency Virus (SIV). HIV-2 corresponds most closely with SIVsm found in the sooty mangabey also called the green monkey found in West Africa. Up until 1999 the corresponding strain to HIV-1 had not been discovered. In 1999 researchers made a major announcement from The University of Alabama that they had

found the corresponding strain of HIV-1 named SIVcpz found in the Pan troglodytes chimpanzee also once commonly found in West Africa. The findings were published and the researchers “concluded that wild chimps had been infected simultaneously with two different simian immunodeficiency viruses which had ‘viral sex’ to form a third virus that could be passed on to other chimps and, more significantly, was capable of infecting humans and causing AIDS” (Kanabus et al., 2005, para. 9).

Theories of transmission. Many people have speculated how HIV crossed species and there have been many theories put forth. The crossing of a virus between animals to humans is called zoonosis and these theories try to explain how zoonosis of SIV became HIV when transferred to humans. The most accepted theory is the hunter theory where hunters came into contact with infected blood through hunting and eating the species of monkey that carried the virus. Also, many think that due to the popularity of medication administration through syringes in the 1950s, a hunter who had been infected may have received administered medication through a syringe. Since the syringes were never sterilized or changed due to the cost, others may have become infected because of the contaminated needles. The colonialism theory also called the “heart of darkness” theory was presented in 2000 by James Moore to explain how HIV became widespread. HIV was first believed to be transferred to humans during the late 19th and early 20th century when colonialism was widespread in Africa and labor camps were common. In these camps conditions were harsh and food was scarce, and a meal on monkey may have been tempting. With the immune system already weak due to the conditions of the camp the person was less likely to fight off the virus. Vaccination for smallpox was a common practice to extend the life of the labor force. Prostitution was also common to keep the

workers happy. All these factors are thought to create the perfect conditions for the spread of the virus. Another theory that is controversial is the oral polio vaccine theory where an oral vaccine given to millions in the 1950s to people in the countries of Belgian Congo, Ruanda, and Urundi were infected with HIV. This theory has been highly investigated and since 2000 has been discredited due to analysis of the original vaccine. Lastly the conspiracy theory puts forth that the United States government actually made the HIV virus either as a biological war tool or to eradicate homosexuals and African Americans. This theory is not credible due to the fact that there is evidence of HIV being present in the 1950s and the technology would not have been capable of creating such a virus (Kanabus, Allen, and Boer, 2004).

HIV/AIDS in Sub-Saharan Africa

Knowledge and perception. In rural communities of Sub-Saharan Africa the primary source of HIV/AIDS information is acquired by media campaign headlines and rumors spread by word of mouth. Consequently the information obtained is not always accurate. Due to limited education and high illiteracy rates in rural areas, mass media campaign strategies addressing HIV/AIDS education and awareness are even less effective. In a grounded theory study, Mabunda (2004) determined that all 13 participants in the study gained majority of their knowledge about HIV/AIDS at support group meetings after they had already been diagnosed with HIV. Information that the participants did not know before the group included routes of transmission. One participant thought that using eating utensils and sharing a bed with a HIV/AIDS positive individual could spread HIV. Other statements by the participants indicated that they did not know the difference between HIV and AIDS and thought they were the same.

For adolescents, the primary source of HIV/AIDS information is print and broadcast media (62.0%), followed by friends and siblings (13.9%) and parents/family/elders (6.3%) according to Buseh, Glass, McElmurry, Mkhabela, and Sukati (2002) who conducted a quantitative study in Swaziland Africa to determine the primary medium of HIV/AIDS knowledge and by administering a comprehensive test adapted from the World Health Organization's knowledge, attitude, belief's practice (KABP) survey. The survey was administered to 941 students attending 1 of the 4 coeducational high schools located in 3 of the 4 regions in Swaziland. Two of the schools are located in rural areas and 1 school in an urban area.

Even though the majority of students reported the media as their primary source of HIV/AIDS information, differences were found between urban and rural students such as fewer rural students (60.8%) than urban students (62.8%) reported their primary source of obtaining HIV/AIDS information was the media. Also, a smaller proportion of rural students (9.7%) indicated that friends and siblings were the primary source for HIV/AIDS information compared to urban students (16.9%). Gender was not a factor that altered primary source of obtaining HIV/AIDS information.

Some important findings from this study include recognition of the differences between amount of information reaching rural and urban areas. Many media forms, magazines, radio, and television may not be affordable to all of the population especially in rural areas. Also, low literacy rates must be taken into consideration.

Stigma. Madru (2003) defines stigma as “ a socially constructed phenomenon that prescribes defined responses to people who are discredited and seen as less than human” (p.41). Labeling another human being reduces their humanity and permits treatment of

individuals with a disease such as HIV/AIDS as less than human. The social component that makes HIV/AIDS more stigmatized than other diseases is that there is a moralistic judgment passing blame and responsibility onto the person that has contracted the illness. The assumption is that the person participated in some behavior perceived as negative by society such as prostitution, intravenous drug use, and homosexual intercourse. Consequently, people that are HIV positive or have AIDS are labeled as unclean or impure and individuals without obvious signs of HIV/AIDS will try to pass as “normal.”

There is much stigma and misperception that surrounds HIV/AIDS in Sub-Saharan Africa. Campbell, Foulis, Maimane and Sibiyi (2005) conducted a comprehensive case study examining the sources of HIV/AIDS stigma through analysis of a youth HIV prevention program sponsored by the Christian Youth Alliance (CYA) in Ekuthuleni, a South African community. In order to obtain a broad range of opinions and attitudes, 44 people were interviewed including young people, peer educators, teachers, a school principal, community health workers, community leaders, CYA staff, a traditional healer, clinic nurses, parents, people with HIV/AIDS, church ministers, a government official, and representatives of a multinational company that employs some of the local people. Findings include that women are more commonly stigmatized as the vectors of HIV/AIDS spreading the disease to males with men portrayed as the innocent party. HIV/AIDS is also associated with promiscuous sex, drug abuse, and poverty. Even though many of the people in the community were HIV positive levels of disclosure is minimal with all the informants reporting that they were not sure who were the exact individuals in the community that had HIV/AIDS.

Strong family stigmatization has deterred many youth from seeking HIV/AIDS counseling for fear of punishment from parents. Children do not feel comfortable disclosing their HIV status to their parents or their level of sexual activity. Many parents feel that the young generation has no respect for their elders and are participating in more risky behaviors such as sex more than when they were young. If a member of the family is HIV positive the other members will hide a sick relative cutting off healthcare and support or will refuse to collect a relative's body from the mortuary. Another study showed that all participants in the study that had HIV/AIDS valued their relationships and opinions of family members and feared disclosing their HIV/AIDS status out of fear of losing those relationships (Mabunda, 2004). Not only is the person with HIV/AIDS stigmatized but also the stigma is passed onto the whole family (Madru, 2003).

Stigma has altered the effectiveness of programs promoting testing for HIV/AIDS (Madru, 2002). People are afraid of getting tested due to the stigma attached with the disease. In some cases persons have even been murdered as a result of their HIV/AIDS status (Oni, 2005). Nurses can help to reduce stigma by educating people about the disease and how to prevent it. Other interventions that nurses can implement to reduce stigma is role-modeling behavior accepting individuals with HIV/AIDS.

At Risk Populations

Mother to child transmission. Pregnant women are a group severely affected by HIV/AIDS. Prevalence of HIV is 37% in Swaziland and in 2002 64,000 babies were infected through mother to child transmission (MTCT) (Raisler & Chon, 2005).

Youth. It can take up to 10 years for clinical manifestations of HIV/AIDS to become present. As a result researchers have suggested that many people who have

HIV/AIDS may have been initially infected when they were adolescents (Buseh, Glass, McElmurry, Mkhabela, & Sukati, 2002). It is predicted that the number of deaths related to AIDS will peak between the years 2010 and 2015 (Oni, 2005).

Females. Women ages 15 to 24 are at the greatest risk for acquiring HIV/AIDS in Swaziland Africa with girls age 15-19, five to six more times likely to be infected than males their same age (Buseh, Glass, & McElmurry, 2002). There are many cultural factors that influence a woman's vulnerability to contracting HIV/AIDS and sociocultural factors that influence the spread of HIV/AIDS.

Cultural Factors

Polygamy. Polygamy, defined in a qualitative study conducted by Buseh, Glass, & McElmurry (2002) as taking more than one wife is a cultural norm in Swaziland Africa, more common in rural areas and for women with less education. The study was conducted in Swaziland Africa at St. Philips Mission Community and the participants consisted of 10 community men, 12 community women, and 10 healthcare workers at the mission all split into 3 separate focus groups. Even though women do not have multiple husbands they do have many sexual partners to ensure economic security.

Status hierarchy. Another common practice in Swaziland is for older women with high status to influence the choice of whom the younger women should date or marry so that the male will provide for her and her family. Many times the male is 15 to 35 years older than the female putting the female at a high risk for contracting HIV/AIDS due to the male already having had many sex partners (Buseh, Glass, & McElmurry, 2002).

Economic security. Economic factors that contribute to increased vulnerability of contracting HIV/AIDS are males from rural areas take jobs in bigger cities remaining at

work several months to years and finding other sexual partners while away. If the man is unfaithful and contracts a sexually transmitted disease (STD) he will blame the female for having an affair. When the woman is the unfaithful partner in many cases the husband may beat her, drive her away back to her family, or deny her rights to her children.

Nurses when caring for patients in Swaziland must consider certain cultural practices and traditions that might be barriers to protecting women from contracting HIV/AIDS.

Treatment and Interventions

Prevention via a vaccine. There is no current universally accepted curative drug for AIDS (Oni, 2005). Development of an AIDS vaccine would be one way to prevent the spread of infection, but pharmaceutical companies have little financial incentive to develop a vaccine due to the vaccine being less profitable. The speed of the virus mutation poses another challenge (Madru, 2002).

Drug therapy. Of the 5 million people infected with HIV/AIDS in South Africa only 20,000 have access to antiretroviral therapy. Antiretroviral drugs do not cure HIV/AIDS; rather the drugs fight against the virus and associated infections and cancers. The first group of drugs invented to combat HIV infection is nucleoside reverse transcriptase (RT) inhibitors slowing down the rate replication of the virus. Other drugs developed later include the non-nucleoside reverse transcriptase inhibitors, protease inhibitors, and fusion inhibitors. HIV can become resistant to any of the drugs so many of the drugs are given in a combination known as highly active antiretroviral therapy (HAART) (U.S. Department of Health and Human Services, 2005).

Mother to child transmission programs. Many prevention of mother to child transmission (PMTCT) programs are being developed and will provide pregnant women priority status to be tested, learn of their HIV status, and offered treatment (Raisler & Chon, 2005). For pregnant women the simple option is single-dose nevirapine 200 –mg tablet when the mother is in labor and the infant receives a syrup form within 72 hours of birth. The regime is inexpensive (\$4.00 US), easy to administer, and reduces MTCT in breastfed infants by 41%.

Virginity testing. An important sub-population to target for prevention of HIV/AIDS is adolescents, who are expected to be HIV/AIDS free unless they contracted HIV from their mother at birth (Buseh, Glass, McElmurry, Mkhabela, & Sukati, 2002). One option that was proposed by some individuals of one community was the reinstatement of virginity testing of females with rewards to the girls that pass the virginity test (Campbell, Foulis, Maimane, & Sibiya, 2005).

Youth targeted education and preferred source. The Ministry of Health and Social Welfare of Swaziland are the primary producers of information materials on HIV/AIDS distributed through radio, television, newspaper, and pamphlets with the intent of targeting adolescents. Other organizations involved in educating the general population about HIV/AIDS include The Swaziland National AIDS Program (SNAP), Schools HIV/AIDS Partnership Education (SHAPE), The Family Life Association of Swaziland, Non-governmental organizations (NGOs) and the mass media (Buseh, Glass, McElmurry, Mkhabela, & Sukati, 2002).

In the study conducted by Buseh et al. (2002) even though the print and broadcast media was the primary source of obtaining information on HIV/AIDS for adolescents in

Swaziland only 18.3% of students preferred that source. The preferred source students indicated were healthcare workers (41%), church/teachers/school personnel (14.7%), siblings and friends (14%), and lastly parents/ family/elders (11.6%).

Some notable differences in preference were dependent on location. Urban students (27.0%) reported receiving more information from friends and siblings than the rural students (17.3%). Rural students (17.3%) reported gaining more information from healthcare workers than their urban counterparts (8.3%).

Furthermore, distinctions were found between genders in information preference. More males (21.9%) than females (14.7%) preferred HIV/AIDS information from the media. More males (15.9%) than females (12.2%) preferred gaining information from siblings and friends, while more females (47%) indicated that they would prefer healthcare workers as a primary source of information than males (35.8%).

Successful health education programs keeping adolescents HIV/AIDS free could result in a group of healthy young adults and parents once they grow up. Through an accurate understanding of where youth obtain information about HIV/AIDS and what is the preferred source of where information, can help develop effective programs to educate youth and prevent them from contracting HIV/AIDS. Since healthcare workers were the most preferred source of obtaining information about HIV/AIDS, and nurses make up the majority of healthcare workers in Swaziland, nurses have a responsibility to try and facilitate education to the youth population. Also, educating parents is important to enhance and reinforce the education information (Buseh, Glass, McElmurry, Mkhabela, & Sukati, 2002).

Abstinence and monogamy. HIV/AIDS is a social issue and through education a change in behavior could be brought about within society (Oni, 2005). The easiest way to prevent HIV/AIDS infection through sexual contact is to remain abstinent. Another practice that decreases the risk of contracting HIV/AIDS through sexual contact is to remain faithful in the relationship.

Condoms. Even though the cost of condoms are cheap (around \$.03) availability, partner acceptance of using a condom, and no understanding of how to use a condom pose as difficult barriers to overcome to gain wide acceptance of condom use (Raisler & Cohn, 2005). Participants in one study recognized that condoms could help decrease the spread of HIV/AIDS but had no access to obtain condoms. There are no stores/pharmacies in many areas. There are some clinics associated with the Catholic Church and therefore do not give out condoms due to Catholic values not promoting the use of condoms. An additional limitation to condoms is that the female must negotiate the use of the condom. One female participant explained that asking a male to wear a condom will anger him making him think either the woman is a prostitute or if the woman is his wife, that she has been unfaithful (Buseh, Glass, & McElmurry, 2001).

Community based groups. The general consensus worldwide is that governments have been slow to respond to the AIDS epidemic and in response community based groups have developed "social service assistance, medical treatment, education and prevention projects, and legal advocacy efforts for people living with HIV/AIDS" (Madru, 2002, p. 45). Many of these groups have found success such as Kilimanjaro Women's Group in the Fight Against AIDS in Tanzania (KIWAKKUKI) who were familiar with the culture and traditions of the community (Madru, 2002).

Peer led education groups can be an effective method to educate communities about HIV education and prevention. Peers are trusted and the information they provide is seen as accurate. A study done by Murdock, Garbharran, Edwards, Smith, Lutchmiah, & Mkhize, (2003), examined the effectiveness of the Members of Partners who educated and trained 24 women from local settlements how to lead HIV education workshops. The purpose of the training and the program was to establish health norms in the communities through education about HIV prevention, hygiene, and sanitation. The 24 trained women informed 480 local residents and then these individuals passed on the information to their neighbors resulting in a community-based education approach spreading the message to over 1,440 residents. Results concluded that women trained by the Members of Partners program were an effective and credible method of information. Community residents trusted the women and the information presented about HIV education. This technique worked because "peer education seeks to empower lay people through placing health related knowledge in their hands. This increases the likelihood that people will feel they have some control over their health" (Campbell & Mzaidume, 2002, p. 324).

Coping and support. Research supports that post-traumatic stress disorder (PTSD) is one of the most prevalent psychiatric disorders found with people who have HIV/AIDS. In a study conducted by Olly, Zeier, Seedat, & Stein (2005) in Cape Town, South Africa out of the 149 participants recently diagnosed with HIV/AIDS (less than 1 year) and between the ages of 16-60 years old 14.8% 22 participants met the DSM-III-R criteria for PTSD. Of the 22 participants 20 of them were females.

Coping with the reality of having HIV/AIDS is important for those living with the disease. One of the themes identified in a research study conducted by Mabunda (2004)

emphasized the importance of acceptance of their HIV status and in order to cope and move on with life.

The Parish Nurse

Role. Parish nursing is a new role in healthcare that is still evolving. The American Association Nurses Association (ANA) Congress of Nursing Practice did not recognize parish nursing as a specialty until 1997 (O'Brian, 2003). There are many other terms that have developed to describe the parish nurse but The International Parish Nurse Resource Center retains the title of parish nurse. While *The Scopes and Standards* document uses the term faith community nursing, other common terms include congregational nurse, health ministry nurse, and wellness nurse (Hickman, 2006). Since parish nursing is a relatively new role little research is available on the exact functions of a parish nurse. Researching the role of parish nursing is important to the maturation and growth of parish nurse ministries but without role clarity through research the integrity of these ministries is compromised. Through an accurate description of the role of the parish nurse their services are recognized as meaningful. In addition, education programs can be developed to properly educate and prepare a parish nurse for their role (Solari-Twadell, 1999, p.18). One of the first parish nurses "identified seven functions of the parish nurse role: health educator, personal health counselor, referral agent and liaison with congregational and community resources, developer of support groups, trainers of volunteers, integrator of faith and health, and health advocate" (Solari-Twadell, 1999, p. 17). The spiritual comfort or a sense of peace that parish nurses help facilitate can enhance coping for those with illness or disability (O'Brian, 2003).

Parish nurses in Africa. In Swaziland Africa there are limited numbers of physicians, about 100 physicians in a county of 1 million people. Therefore nurses play a vital role in formulating diagnoses and treatment plans. Parish nursing offers multidimensional care through the interconnectedness of art, grace, and science (Mulcaire-Jones, 2004).

Weakness in literature. A review of the literature showed that most research studies mainly focused on the major groups at risk for contracting HIV/AIDS and prevention techniques. There was not a lot of research done on how to effectively treat those already living with HIV/AIDS and techniques to improve their quality of healthcare. Also, the government plays a huge part in combating HIV/AIDS in the country and there was a lack of analysis of the government role. Also most of the research was conducted in the country of South Africa and little research has been collected in Swaziland.

Nursing implications. A problem that must be addressed with current prevention and education programs is the importance of a thorough assessment of targeted population and collection of necessary information to develop effective ways to reach the population with cultural, gender, age, and location factors in mind (Buseh, Glass, McElmurry, Mkhabela, & Sukati, 2002). Currently "health authorities, government, nongovernmental organizations, sociologists, health educators, and various health-related researchers are reappraising the existing methods of curtailing infection" (Oni, 2003, p. 40). Constant reevaluation of methods is needed to ensure the methods are making a positive difference. Prevention and education, although helping to decrease the amount of people contracting HIV/AIDS does little to increase the quality and length of life for

those already infected (Mukherjee, et. al, 2003). Those already affected by HIV/AIDS need social support and coping skills as well.

Chapter III

Methodology

Grounded Theory

A qualitative methodology, based on Grounded Theory, developed by sociologists Glaser and Strauss (1967) was utilized for this thesis. The purpose of grounded theory is to generate a theory based on data obtained through research (Fain, 2004). Both inductive and deductive methods were used to analyze the data. Through induction, a substantive theory and formal theory emerged from the data. Substantive theory focuses more on specific topics, for instance patient care, while formal theory is used more for abstract topics such as stigma (Glaser & Strauss, 1967). Similar themes were pulled from the data. Symbolic interaction is key in Grounded Theory where the nature of social relations among individuals is the focus (Fain, 2004). The role of discovering a theory enabled the researcher to predict and explain a certain behavior (Glaser & Strauss, 1967). Therefore, core variables were identified that accounted for certain patterns of behavior and are relevant or problematic for the involved person (Fain, 2004). This theory is useful in the nursing profession in that “through grounded theory, the processes that underlie social experience are discovered and become the basis for nursing interventions” (Fain, 2004, p. 278-79).

Considerations

The researcher's bias. The researcher was more familiar with the HIV/AIDS situation in the United States. It is important that the researcher did not apply preconceived notions about HIV/AIDS in the United States to the HIV/AIDS situation in

Swaziland. Also, the researcher has been exposed to United States media and entertainment interpretation of African culture and must not base her knowledge of African culture on what she has previously been exposed to.

Procedure

Participant criteria. The total sample size of this study was 4 individuals (N=4). Two of the individuals were HIV/AIDS positive and 2 individuals were parish nurses. Criteria to be included in the research study included residents of Swaziland Africa, living with HIV/AIDS and had been treated by a parish nurse or parish nurses who had treated individuals living with HIV/AIDS. Participation was voluntary and the number of participants was not predetermined because “in theoretical sampling, sample size is determined by generated data and analyses” (Fain, 2004, p. 271-72).

Characteristics of participants. All participants were female. With the exception of one parish nurse all participants live in rural areas. The other parish nurse lives in an urban setting. The age of the retired parish nurses ranges between 60 and 70 years of age. As for the patients, one was in her early 20s and the other in her 30s.

Ethical considerations. The Carroll College Institutional Review Board approved the study. Confidentiality was discussed with all participants and data used would not have identifying characteristics and be kept in a secure location. One researcher collected the data. Informed consent was obtained before the interviews started. Participants were instructed about the risks and benefits of research and that they could withdraw from the study at anytime. Interviews were conducted in a private setting that the participant agreed to.

Data Collection

Data collection took place in May 2006 in Swaziland, Africa. The researcher was in the country of Swaziland for 12 days. Methods of collection were interviews varying from formal to informal to allow flexibility and comfort for participants and researcher observation. Questions included both open-ended and closed questions. The average length of interviews lasted between 30 to 60 minutes.

Data Analysis

The interviews were recorded on a digital recorder and transcribed by the researcher. Also, field notes were taken based on observations while in Swaziland.

Limitations

A language barrier existed between the researcher and one of the participants and a parish nurse was used as the interpreter.

Chapter VI

Results

Swazi People Caring for Swazi People

Our people our problem. Swaziland has one of the highest HIV/AIDS rates in the world. Every participant in this study had multiple personal experiences with HIV/AIDS whether it was a child, parent, or neighbor. Due to this fact, Swaziland has received national attention with financial and person-power support from abroad. Yet, according to all participants there are multiple people living in Swaziland receiving minimal to no healthcare from these resources. The healthcare that is being received is from each other, Swazi people helping Swazi people. Sometimes patients will come to their homes according to parish nurse participants, but the majority of their patients are their fellow neighbors and they go door to door to provide care to the members of their communities.

Enduring

Basic survival. The behavior pattern that emerged as important to both HIV/AIDS positive participants and parish nurse participants was enduring to survive from day to day. HIV/AIDS positive participants specifically expressed interest in learning basic survival needs such as what type of food they were supposed to eat. Therefore, much of the care and education provided by the parish nurse participants focused on teaching their clients on how to care for themselves due to lack of other resources such as antiretroviral medication (ARVs). One parish nurse participant described her home visits:

When I come across these families some of them did not have anything to eat or they are left alone but their children are in town. They are left alone

in their homes and nobody cares for them, those people are waiting on care providers to come home so they can cook food for those people. It is really a big problem to deal with, and we have an eye to see that people outside are living in such poverty.

One of the major sources of obtaining food for the people of Swaziland is growing the food themselves, especially for those living in rural areas. Just as healthcare facilities are inaccessible because of distance to travel so are places to buy food. Also, lack of income contributes to unhealthy nutritional status.

Interdependence. A diagnosis of HIV/AIDS affected everyone around the HIV/AIDS positive participants. Once they began to show symptoms of HIV/AIDS or secondary infections a component of interdependence became evident in order for them to survive. These HIV/AIDS positive participants relied on family members, parish nurses, or the community when they were no longer able to fully care for themselves. In one situation a parish nurse participant explained, "My nephew, now an orphan, now lives with me. His mother died of AIDS, he had to take care of her, she had chronic diarrhea, no pads, and he had to just continually wash the sheets." If there were no family members to take care of the HIV/AIDS positive participants many times members of the community would become care providers. Support and care from others was an essential element for survival.

Diagnosis

Initial diagnoses. HIV/AIDS positive participants did not go to clinics with the specific purpose to get tested for HIV. Other illnesses brought them to the clinics and the diagnosis of HIV was secondary. Common illnesses that brought individuals to seek

medical care were tuberculosis and herpes. Once these HIV/AIDS positive participants had presented with one of the other secondary illnesses common with HIV/AIDS were they then actually tested for HIV. One HIV/AIDS positive individual explained "I had this thing, Herpes Zoster, and I decided to go get tested and I found out I was HIV positive."

Lack of knowledge. Even though the participants that were HIV/AIDS positive had heard of HIV/AIDS before, there were knowledge deficits in the areas of what exactly HIV/AIDS was, how they contracted the virus, and actions they needed to take now that they were HIV positive. When asked if she knew what HIV/AIDS was, one HIV/AIDS positive participant answered "I once heard of HIV/AIDS, I heard of HIV through people talking about it, through school, you get it through sex." Another HIV/AIDS positive participant reported that she knew HIV/AIDS was spread through sex but not until after she found out that she was HIV positive. This participant also reported she now uses condoms as protection with her boyfriend. Other education that the parish nurse participants have given in regards to condom use is proper storage of condoms. A patient of one of the parish nurse participants confirmed that he was being compliant with the education she had given him and uses condoms now and stores them in a dry cool place and not in his pocket or wallet.

Denying. A common emotion with initial diagnosis was denial. An example of this was explained by a parish nurse participant in regards to one of her clients:

Another patient was very stubborn, he worked in the mines and he had money, he had a car, a good home and good furniture, the money, which he was using it this way and that way. He first resisted to be tested or to

admit he must go and test. He said, "You people you just call everybody positive, positive, positive, you don't check the blood, you just put this disease to us."

According to one parish nurse participant, in many cases females found out that they were HIV positive before their male partners. When confronted by their female partners, males were hesitant to accept the diagnosis or blamed their female partners even when they may have been the ones who initially contracted the virus. In other cases parish nurse participants highly suspected some of their clients were HIV positive but they either refused or could not get tested for various reasons. Some of these reasons given to parish nurse participants included their clients did not have transportation or could not afford transportation to testing centers. Another reason was that they were busy working and caring for the family and therefore did not have time to go test. Also, many were fearful of the results if they were to be tested and would rather live ignorant of the knowledge of their HIV status because they felt that nothing could be done for them any way.

Accepting. Once symptoms of illness became apparent focus shifted to survival and accepting the diagnosis. On finding out her HIV/AIDS status one HIV/AIDS positive participant stated "I wasn't scared, I thought this is a sickness, because once I tested, because when we are HIV positive, I say to myself I want to fix it, I go in and fix it." Those that had been tested and had access to ARVs saw an improvement in symptoms and gained hope. They reasoned that if they followed the doctors' and nurses' orders, take their ARVs, and eat right that they could still have a high quality of life for a couple of years.

Another source of hope was a belief in a higher power. God was seen as a source of strength and motivation to keep on living. All HIV/AIDS positive participants would practice their spirituality either through prayer, reading the Bible, or attending church services. Part of the care that every parish nurse provided was praying with their clients. Also, the church community was another source where HIV positive participants gained support and empathy.

Duty to Care

Commitment to nursing. The original intent of the New Robe parish nurse program was only to have retired parish nurses participate, but a few currently working nurses showed enthusiasm for the program and joined. When questioned about what made her want to become a parish nurse, one parish nurse participant stated that, “[she] was born to be a nurse,” and because of that her responsibility is “We [nurses] are born in this, die in this, and must give back to the community.” When the program originally started the nurses were paid a small fee but due to lack of funds they no longer receive compensation. Despite this all of the nurses have continued to work as parish nurses.

Caring for the patient. Some parish nurses have opened their own clinics, but the majority do home based healthcare. The most common services the nurses provide with home base healthcare include the following, reported by a parish nurse participant that works in an urban area:

I chart, get their addresses and ask them their history and then specific on the 5 s’, the 5 s’ stands for specific treatment; symptomatic treatment, supportive treatment, socially, how does the patient live, religiously, how to manage spirit wise. I do that to each patient, going to homes, go door to

door, to their home I wish to go with my feet, but where it is far I take the bus. The driver knows where the families with the very sick patients are and they will take me there. I go to the people, prescribe their drugs, take their blood pressures, give them medications, and a word of prayer.

Other services that the parish nurse participants fulfilled were keeping statistics of who was HIV positive in their area, how many people they treated, age, and gender. Other record keeping included client charts keeping track of vitals and care that was given.

Much of the treatment provided by the parish nurse participants was specific to their patients' needs. For their patients that were relatively mobile and independent, the nursing interventions were education on how to optimize health, and prescribing medications. On the other hand, for their patients that were unable to get out of bed, a meal might be cooked or a bed bath given.

Frustration. A common emotion reported by parish nurse participants was frustration. Much of the frustration was based on many factors including lack of compliance by clients and lack of resources. Part of the parish nurse role is education and prevention but one parish nurse participant explains part of her disappointment:

The problem is some of our children our lazy, the most important thing that is against them is they don't learn, they don't practice safe sex, and they don't take our advice. But we do try to give them advice. It's most challenging because before we did not go around in peoples' homes. You can't just go around to somebody's homes without something to do.

Not only are some of the adolescent ages in compliance with advice, but many of the adults can be in compliance as well. Some of the in compliance has to do with fixed beliefs and cultural factors. One parish nurse participant explained that most of their patients will seek the advice and treatment of a traditional healer before they revert to western medicine.

Lack of available resources is another issue that HIV/AIDS positive participants faced. There are a limited number of medications. ARVs are free in Swaziland, but HIV/AIDS positive participants must get to the clinics to pick up those medications and this was not a feasible option for one of the HIV/AIDS positive participants:

There is no one to send her to the doctor, no one to take her there. Who, when how? This is a serious problem, I usually think and think until I get mad, what can I do for this little one? People say they are going to try and do something, but they do nothing. I'm trying, trying, trying for her.

Also, many other important medications such as multivitamins and antibiotics are not free. To help solve this situation parish nurse participants will walk to clinics to get medications and deliver them to patients. Other times when medications run out parish nurse participants will buy the medications themselves with their own money. Some other items that are not available are sanitary pads or towels for the parish nurses' patients that are bed bound with diarrhea or for the young females who are menstruating.

Strength through Faith

Praying. Despite lack of supplies or other disadvantages one intervention that all parish nurse participants perform in prayer. Numerous times the only care some parish nurse participants claim they can give because of lack of resources or equipment is a kind

word of prayer. One parish nurse participant explained, "There are no painkillers, only love and touching." Not all of the parish nurse participants are of the same religion, some are Catholic others are Protestant, but they all pray for their clients and live by the belief that parish nursing has love, Christian faith, and a comforting umbrella for every client.

Healing. As important as medications are the parish nurse participants felt that a strong faith and praying were just as vital to getting well as physical treatments. One parish nurse participant talked about an incident where one of her clients got better:

The taxi driver is HIV positive as well as his wife, he told me his cell count went from 1 to 226, and reports he uses condoms. I did not even recognize him at first. I thought he was to die. I thank the Lord and praise him, hallelujah.

The belief in a higher power is extremely important part of parish nurse work. It gives them hope and a sense of accomplishment in the struggle against HIV/AIDS.

Ownership

All participants recognized that HIV/AIDS is a serious problem in their country and that they must take ownership of that problem. One way that the parish nurse participants are helping fight the epidemic in their country is to provide holistic care to all their patients meeting not only the physiological needs, but psychological, social, and spiritual needs. Their patients are their friends, family, community members, and strangers. All participants have been affected by HIV/AIDS and are all working together to endure this crisis together.

Chapter V

Discussion

Holistic Care

The parish nurse participants in this study have come out of retirement to dedicate themselves to fighting the HIV/AIDS epidemic in their country. For the HIV/AIDS positive participants, the parish nurses are their primary source for healthcare and information. Even though there are clinics and hospitals in Swaziland they remain inaccessible to many of the Swaziland people due to distance or illness. Therefore, parish nurses offer a vital service by providing home based healthcare in their communities. Also, they are effective in giving quality treatment to their patients because their patients trust and respect them. The trust and respect stems from that they are elders in the community. Lastly, they treat based on the parish nurse philosophy of providing holistic care that many clinics are unable to make available due to time and money constraints.

Meeting Basic Needs

Role definition. Research findings from this study indicate that the primary focus for parish nurses as well as their patients is basic survival needs. In order to survive dependence on another was identified. All participants in this study took on the role of dependent or caregiver. Many times research shows that the role of caregiver falls upon females. They end up becoming not only primary caregivers but “they are expected to produce food and provide other essentials for their families” (The Government of the Kingdom of Swaziland, 2006, p.6). Other times, children are forced to stop going to

school to take on the role of caregiver as was a case described by a parish nurse participant.

Eating healthy. Nutrition was a major area of concern for individuals with HIV/AIDS and parish nurses focused much of their teaching on what foods should be eaten, how the food should be prepared, or how to cultivate certain crops. According to the Second National Multisectoral HIV and AIDS Strategic Plan 2006-2008 (2006) HIV/AIDS has had a significant impact on agriculture, which provides 25% of the GDP and sustains around 70% of the population. Production has decreased due to lack of labor by those affected by HIV/AIDS and a decreased income also results. Furthermore, good nutrition is essential for the health of those with HIV/AIDS and on antiretroviral therapy but not everyone is receiving the proper nutrition owing to inadequate access to the right foods either by poverty or inability to cultivate the crops themselves.

Challenges of living in rural versus urban settings. Results in this study are more specific to rural Swaziland versus urban Swaziland. Only one of the research participants lives in the urban area but focus in rural areas is needed for research because 78% of the people of Swaziland live in rural areas (The Government of the Kingdom of Swaziland, 2006). The challenges faced by the participants living in rural areas were different from individuals living in urban areas. For example, a challenge faced by rural parish nurses is walking many miles to see their patients with no available public transportation versus parish nurses serving in urban areas must use extra precaution to avoid violence. Two parish nurses that serve in an urban area report that they travel together for safety reasons. Even though parish nurses in Swaziland do not receive compensation, those in the

profession of nursing are perceived as making decent money and were at an increased risk to being a victim of robbery.

Meeting Psychological Needs

The rate of HIV/AIDS is so dramatic that the parish nurse program has adopted the slogan, "some are infected with HIV but all are affected by HIV." Not only have the parish nurses had to care for their patients but they have also had to treat their own family and friends that have had HIV/AIDS. Having personal family and friends infected with HIV or have died from AIDS helped to strengthen the commitment the parish nurses to the parish nurse program.

A diagnosis of HIV has negative consequences on physical health, but also effects the mental health of the HIV positive individuals interviewed. In recent studies, post-traumatic stress disorder (PTSD) has been discovered to have a high prevalence rate, 30% to 64% of those infected with HIV/AIDS (Olley, Zeier, Seedat, & Stein, 2005). With a diagnosis of HIV there was a sense of loss and for HIV positive individuals and fear, the diagnosis meaning "AIDS equals death". Due to all the psychological effects, the parish nurses put emphasis on praying and just listening to their patients and their concerns. Other ways in which HIV positive individuals met their own psychological needs was gaining support from another person they knew was HIV positive as well.

Influence of Parish Nurse Program

Instilling hope. HIV/AIDS individuals that participated in this study indicated that the parish nurses provided them with hope and many times played both a minor role as a caregiver or a major role as their only healthcare provider. In regards to the achievements

of the parish nurse program, Thandiwe Dlamini (2006), head of the program in Swaziland, contributes much of the parish nurses success to their years of experience, expert skills, and most importantly the respect people in their communities have for them.

Parish nurse successes. There has been only one other research study on the parish nurse program in Swaziland done by the Center for Interdisciplinary Research on AIDS by Yale University of Medicine (2003), and their study supports that the program has been relatively successful:

Intangible achievements include the patients that have recovered and gone back to work, the mobilization of communities to aid those infected and affected by HIV/AIDS, spiritual peace, drawing on the wealth of expertise of retired professional nurses, and helping the church extend its services in real terms to their respective parishes.

Education given by respected members of the community, such as parish nurses has met great success in Swaziland. In another study conducted in South Africa by O'Hara et al. (2002) 24 women of a community were trained to educate 480 female residents in their area about HIV/AIDS. A pre-post knowledge as well as a focus group concluded that the female peer educators were perceived as "credible sources of information and were well accepted by other women in their communities as messengers of HIV prevention" (O'Hara et al., 2002, p. 509). Another unexpected benefit of the education sessions originally targeted at female residents was that men showed an interest in the education as well.

Treating both sexes. In Swaziland, where males are more culturally dominate, finding a way to reach the male sector is important. Researchers Raisler and Cohn (2005)

found through their research done in sub-Saharan Africa that both sexes perceived the male as the partner to choose to use condoms or not. Therefore, education must be targeted at both males and females to be effective. Both the parish nurses reported treating both male and female patients. They feel that education is a crucial part of their treatment and both males and females listen to them. One of the reasons that the males do value the advice of the parish nurses is associated with their age and elders are to be treated with respect.

Implications for Future Nursing Research

Since Parish nursing is relatively new more research is needed to examine the effectiveness of Parish nurses in Swaziland Africa. Many of the research studies were conducted in the country of South Africa and more research is needed focusing on the country of Swaziland. In addition, since large portions of the people of Swaziland are living with HIV/AIDS already, more research needs to be conducted on effective treatment and healthcare for that group rather than just focusing on prevention techniques. This research supports the positive use of training Swaziland people to care for and educate fellow Swaziland people. Part of the success is due to the trust and respect of elders rather than foreign individuals imposing the same sort of treatment but lacking the element of trust replaced. Rather foreigners and Western medicine is viewed with suspicion. More research should be conducted about the effectiveness of training respectable members of the community such as retired parish nurses as a way to educate and treat the people of Swaziland that have HIV/AIDS.

Conclusion

With the high HIV/AIDS rate in Swaziland Africa there will continue to be a need for prevention, education, and treatment for those infected and affected by the epidemic. The parish nurse program, A New Robe, has been one successful way in which retired nurses have contributed to help in their own country. Parish nurses treat their patients not only physically but mentally, socially and spiritually. They are respected by their communities and provide invaluable services. In many cases they are the primary or only health care provider in their community. The experiences of parish nurses and their patients infected with HIV/AIDS can be used to validate the need for respected individuals such as parish nurses to give home based healthcare to those in need that have no other access or means of affording healthcare. Along with treating individuals in need, parish nurses also educate and have helped to prevent the spread of HIV/AIDS.

Appendix A

Informed Consent for Parish Nurse

Consent to Participate in HIV/AIDS Study

I, _____, have been invited by Katy Stergionis, an undergraduate nursing student researcher to participate in a voluntary research study. The purpose of this study is to gain a better understanding of the experiences of parish nurses, and individuals living with HIV/AIDS.

If I choose to participate in this study, my participation will consist of providing general information, and an audio taped private interview lasting about 60 minutes. In the interview I will talk about my experiences as a parish nurse and caring for patients with HIV/AIDS. I may withdraw from this study at anytime. There are no risks to my participation in this study. Confidentiality will be maintained throughout the study, and at no time will my name or identifying characteristics be used. I am aware that this research is to advance nursing care and there will be presentations and publications associated with this study. I am aware that if I have questions I can call Katy Stergionis at (406)-868-7601.

I agree to participate in this study

Name _____

Date

Katy Stergionis _____
Student RN

Date

Informed Consent for Individual Living with HIV/AIDS

Consent to Participate in HIV/AIDS Study

I, _____, have been invited by Katy Stergionis, an undergraduate nursing student researcher to participate in a voluntary research study. The purpose of this study is to gain a better understanding of the experiences of parish nurses, and individuals living with HIV/AIDS.

If I choose to participate in this study, my participation will consist of providing general information, and an audio taped private interview lasting about 60 minutes. In the interview I will talk about my experiences living with HIV/AIDS and the care I have received from parish nurses. I may withdraw from this study at anytime. There are no risks to my participation in this study. Confidentiality will be maintained throughout the study, and at no time will my name or identifying characteristics be used. I am aware that this research is to advance nursing care and there will be presentations and publications associated with this study. I am aware that if I have questions I can call Katy Stergionis at (406)-868-7601.

I agree to participate in this study

Name _____

Date

Katy Stergionis _____
Student RN

Date

Appendix B
Discussion Topics

1. What inspired you to become a parish nurse?
2. Tell me about a memorable patient?
3. What do you feel needs to be done to fight HIV/AIDS?
4. Tell me about your life living with HIV/AIDS?
5. How did you find out you were HIV positive and what was your initial reaction?
6. What are some challenges that you face living with HIV/AIDS?
7. How has a parish nurse helped you?

References

- AIDS Weekly. (2000). *Maternal Life International awarded grant for AIDS care in Africa*. Retrieved March 18, 2006 from http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12349743&dopt=Abstract
- Borgia, P., Marinaci, C., Schifano, P., & Perucii C.A. (2005). Is peer education the best approach for HIV prevention in schools? Findings from a randomized controlled trial. *Journal of Adolescent Health, 36*(6), 508-516.
- Bradely-Springer, L., Vojir, C., & Messeri, P. (2003). Hard-to-reach providers: Targeted HIV education by the national AIDS education and training centers. *Journal of the Association of Nurses in AIDS Care, 14*(6), 25-36.
- Bullers, A. C. (2001). Living with AIDS—20 years later. *Federal Drug Administration Consumer, 35*(6), 29-35.
- Buseh, A. G., Glass, L. K., & McElmurry, B. J. (2001). Cultural and gender issues related to HIV/AIDS prevention in rural Swaziland: A focus group analysis. *Health Care for Women International, 23*, 173-184.
- Buseh, A. G., Glass, L. K., McElmurry, B. J., Mkhabela, M., & Sukati, N. A. (2002). Primary and preferred sources for HIV/AIDS and sexual risk behavior information among adolescents in Swaziland, Southern Africa. *International Journal of Nursing Studies, 39*(5), 525-538.
- Campbell, C., Foulis, C. A., Maimane, S., & Sibiyi, Z. (2005). "I have an evil child at my house": Stigma and HIV/AIDS management in a South African community. *Public Health Matters, 95*(5), 808-815.

- Campbell, C., & Mzaidume, Y. (2002). How can HIV be prevented in South Africa? A social perspective. *British Medical Journal*, 324, 229-232. Retrieved January 29, 2006, from bmj.com.
- Carpenito-Moyet, L. J. (2004). *Nursing Diagnosis* (10th ed.) Lippincott, Philadelphia.
- Center of Disease Control. (2003). Retrieved February 26, 2006 from <http://www.cdc.gov/hiv/pubs/faq/faq3.htm>
- Chernoff, R. A. & Davison, G. C. (2005). An evaluation of a brief HIV/AIDS prevention intervention for college students using normative feedback and goal setting. *AIDS Education and Prevention*, 17(2) 91-104.
- Danziger, R. (1996). An epidemic like any other? Rights and responsibilities in HIV prevention. *British Medical Journal*, 312, 1083-1084.
- Dixon, S., McDonald, S., & Roberts, J. (2002). The impact of HIV and AIDS on Africa's economic development. *British Medical Journal*, 324, 232-324. Retrieved January 29, 2006, from bmj.com.
- Fain, J. A. (2004). Reading, understanding, and applying nursing research. Philadelphia: F. A. Davis Company
- Glaser, B. G. & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. Chicago: Aldine Publishing Company.
- Government of the Kingdom of Swaziland. (2006). The second national multisectoral HIV and AIDS strategic plan 2006-2008. Swaziland: The Government of the Kingdom of Swaziland.

- Guenter, D., Majumdar, B., Willms, D., Travers, R., Browne, G., & Robinson G. (2005). Community-based HIV education and prevention workers respond to a changing environment. *Journal of the Association of Nurses in AIDS Care*, 16(1), 29-36.
- Hickman, J. S. (2006) Faith community nursing. Philadelphia: Lippincott Williams & Wilkins.
- Hogan, R. D., Baltussen, R., Hayashi, C. Lauer, A., & Salomón J. A. (2005). Cost effectiveness analysis of strategies to combat HIV/AIDS in developing countries. *British Medical Journal*, 331, 1431-1437. Retrieved January 29, 2006, from bmj.com.
- Joint United Nations Programme on HIV/AIDS. (2006). Retrieved February 6, 2006, from <http://fshgroup.org/hiv%20AIDS%20Update%202006.pdf>.
- Kannabus, A., Allen, S., & Boer, B. D. (2005). The origin of HIV and the first cases of AIDS. Retrieved February 26, 2006 from <http://www.avert.org/origins.htm>
- Lentine, D. A., Hersey, J. C., Lannacchione, V. G., Laird, G. H., McClamroch, K., & Thalji, L. (2000). HIV-related knowledge and stigma-United States, 2000. *Morbidity and Mortality Weekly Report (MMWR)*, 49(47), 1062-1064).
- Mabunda, G. (2004). HIV knowledge and practices among rural South Africans. *Journal of Nursing Scholarship*, 36(4), 300-304.
- Madru, N. (2003). Stigma and HIV: Does the social response affect the natural course of the epidemic? *Journal of the Association of Nurses in AIDS Care*, 14(5), 39-48.
- Mukherjee, J. S., Farmer, P. E., Niyizonkiza, D., McCorkle L., Vanderwarker, C., Teuxeira, P., & Kim, J. Y. (2003). Tackling HIV in resource poor countries.

- British Medical Journal*, 327, 1104-1106. Retrieved January 29, 2006, from
bmj.com.
- Mulcaire-Jones, G. (2004). Parish nurse ministry in Swaziland, Africa. Paper presented at
the meeting of Swaziland study abroad trip, Helena, Montana.
- Noble, R. (2004). Introduction to HIV types, groups, and subtypes. Retrieved February
26, 2006 from <http://www.avert.org/hivtypes.htm>
- O'Brian, M. E. (2003). Parish nursing healthcare ministry within the church. Sudbury,
Massachusetts: Jones and Bartlett Publishers.
- O'Hara Murdock, P., Garbharran, H., Edwards, M. J., Smith, M. A., Lutchmiah, J., &
Mkhize, M. (2003). Peer led HIV/AIDS prevention for women in South African
informal settlements. *Health Care for Women International*, 24, 502-512.
- Olley, B. O., Zeier, M. D., Seedat, S., & Stein, D. J. (2005). Post-traumatic stress disorder
among recently diagnosed patients with HIV/AIDS in South Africa. *AIDS Care*,
17(5), 550-557.
- Oni, A. A. (2005). Education : An antidote for the spread of HIV/AIDS. *Journal of the
Association of Nurses in AIDS Care*, 16(2), 40-48.
- Raisler, J. & Cohn, J. (2005). Mothers, midwives, and HIV/AIDS in Sub-Saharan Africa.
Journal of Midwifery & Women's Health, 50, 275-282.
- Secure the Future Monitoring and Evaluation Unit Center for Interdisciplinary Research
on AIDS Yale University School and Medicine. (2003). Caritas Swaziland-
Maternal Life International Parish Nurse Programme. *Final Evaluation Report*, 1-
41.

Solari-Twadell, P. A. (1999). *Parish nursing: Promoting whole person health within faith communities*. Thousand Oaks, California: Sage Publications Inc.

U.S. Department of Health and Human Services. (2005). HIV infection and AIDS: an overview. Retrieved February 6, 2006, from <http://www.niaid.nih.gov/factsheets/hivinf.htm>.

Whitmore, S. K., Zaidi, I. F., & Dean, H. D. (2005). The integrated epidemiologic profile: Using multiple data sources in developing profiles to inform HIV prevention and care planning. *AIDS Education and prevention*, 17, 3-16.

The World Factbook. (2006). Swaziland. Retrieved March 18, 2006, from <http://www.cia.gov/cia/publications/factbook/geos/wz.html>