Understanding the Experiences of Nurses Providing HIV Care in Rural Uganda

By

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Abstract

The era of HIV in Uganda has impacted every sector of society, especially the health system. Nurses are commonly the only health professionals available at rural health facilities, working with heavy workloads in difficult circumstances. This study examined how rural nurses cared for people living with HIV and AIDS, explored challenges to care, experiences of stress and coping strategies. Using a focused ethnography, the study took place from September 2010 to February 2011 and included 5 focus groups and 14 interviews with nurses in Kabarole District, Uganda. Structural challenges included staffing and drug shortages and social challenges included stigma, poverty and gender inequality, which prevented nursing care for patients with HIV and AIDS. Nurses felt demoralized and helpless, and relied on teamwork and faith to cope with their workload. Suggestions for policy interventions include improved staffing, using a mix of incentives and increased policy involvement to improve the nursing situation.

Preface

(Mandatory due to research ethics approval)

This thesis is an original work by Harmony McRae. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Understanding the Personal Impact of HIV/AIDS on Rural Nurses in Kabarole District, Uganda: A Mixed Methods Approach", No. Pro00014155, August 20, 2010.

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Acronyms and Abbreviations

AIDS: Acquired Immunodeficiency Syndrome

ART: Anti-retroviral Treatment

DHO: District Health Officer

HAART: Highly Active Anti-retroviral Therapy

HIV: Human Immunodeficiency Virus

LMIC: Low - Middle Income Countries

MoH: Ministry of Health

NGOs: Non-governmental organizations

PI: Primary Investigator

PLWHAs: Persons Living with HIV and AIDS

VCT: Voluntary Counseling and Testing

PMTCT: Prevention of Mother to Child Transmission

UN: United Nations

WHO: World Health Organization

Introduction

Since the HIV epidemic began in sub-Saharan Africa in the mid-1980s, it has impacted every sector of civil society. In particular, the disease has placed strain on health care systems already compromised by a history of colonialism, civil conflict, and political unrest. As one of the countries affected by this epidemic, Uganda has achieved moderate success at containing the spread of HIV and AIDS through prevention programs and the introduction of universal antiretroviral therapy (ART) in 2004 (Uganda AIDS Commission, 2008). Access to universal ART has been hampered by financial, structural and human resource shortages, particularly in rural areas (Uganda Ministry of Health, 2010). As a result, HIV epidemic control measures continue to play a large role in public health programming throughout Uganda.

Nurses play a vital role in delivering healthcare in Uganda. As the largest group of professionally trained health staff in Uganda, nurses provide care at all levels of facilities to patients of all ages, and are commonly the only health care provider available in rural areas (Uganda Ministry of Health, 2010). Nurses in Uganda manage patient care in the face of systemic shortages, including drug, equipment, staff, and finances, low wages and poor advancement options. Lack of investment in the Ugandan public health system has led to a significant shortage of trained health care workers, equipment, medicine and support staff (Uganda Ministry of Health, 2010). Consequently, there have been very high nurse-to-patient ratios in Uganda, contributing to poor patient outcomes and nurses seeking employment outside of the country (Bärnighausen, 2007; Fournier, Kipp, Mill, & Walusimbi, 2007). The challenges faced by Ugandan nurses are exacerbated in rural areas, where nurses are often the only healthcare providers available, and face severe resource and personnel shortages (Dieleman, Bwete, et al., 2007; Fournier et al., 2007).

Long term monitoring and treatment of patients living with HIV and AIDS (PLWHAs) has added a new level of care to the workload of nurses in Uganda. As nurses continue to work under the constraints of an under-resourced health system, it is feared they may not be able to provide the care they feel obligated to give their patients. Emerging evidence suggests nurses experiencing high levels of workplace stress may develop burnout (Dieleman, Bwete, et al., 2007; Harrowing & Mill, 2010). They may leave their positions or seek work outside the health sector (Corley, 2002).

Fournier and colleagues (2007) identified poverty to be a source of nurses' stress when working in resource poor situations, as it diminishes nurses' capacity to provide adequate care to patients. Little research has been conducted about the impact of HIV on the development of workplace stress on nurses in low to middle income countries (LMIC), however a study of Zambian nurses reported that caring for patients with HIV has added considerably to the already overburdened nursing workload (Dieleman, Bwete, et al., 2007). Most studies in this area conclude that caring for PLWHAs in resource depleted settings significantly contributes to the nurses' workload, yet more research is necessary to assess the interplay between the presence of HIV within a community and the ability of the health providers of that community to provide adequate care.

Background

The Ugandan Health System

The Ugandan health system is based on a mix of public, private and private not for profit health care providers, with the Government of Uganda operating public facilities (Uganda Ministry of Health, 2010). The publicly funded health system is administered through a system of health districts in which the planning and management of health facilities, including staffing, supply management and reporting outcomes are the responsibility of each district. A minimum package of health care is available for all Ugandans; all user fees were eliminated for publicly-funded health care in 2001(Uganda Ministry of Health, 2010). User fees are still required for private facilities and private wings in public facilities, which are often the first choice for those who can afford it (Uganda Ministry of Health, 2010).

A mix of regional and referral hospitals, health centers (HC), and village health teams (VHTs) provide health care in each district. The regional and referral hospitals manage complicated patients, offer a variety of acute care services and are generally found in larger urban areas. Health centers, which range from level II to level IV, provide basic out-patient care such as immunizations, antibiotic and malaria treatment, maternal care, and referral to higher-level health facilities as necessary (Uganda Ministry of Health, 2010). The majority of Ugandans (72%) live within 5 kms of a health facility, however geographic access may be limited by lack

of infrastructure, including accessible roads and affordable transportation (Uganda Ministry of Health, 2010). Shortages of medication, equipment, and health care providers limit access to high-quality care at health facilities (Uganda Ministry of Health, 2010).

The Era of HIV in Uganda

HIV is an immunosuppressive disease requiring continuous monitoring and treatment. Without ART, most patients will progress to AIDS (Acquired Immunodeficiency Syndrome), become susceptible to opportunistic infections, and inevitably die (Braitstein et al., 2006). The government of Uganda has addressed the HIV epidemic through prevention and treatment programs. Prevention programs promote safe sex for adults through the 'Abstinence, Being Faithful, and the Use of Condoms [ABCs]' of HIV prevention; (Uganda Ministry of Health, 2010). The use of ABC programming has been contentious, however, and the reported results have been mixed (Zikusooka, 2006). The prevention of mother to child HIV transmission (PMTCT) during birth is a priority for programming, and all pregnant women in Uganda who receive prenatal care at a public facility are tested for HIV. Once diagnosed, they will begin ART, with the goal preventing transmission of HIV to the fetus during birth (Uganda Ministry of Health, 2010).

The first HIV case in Uganda, reported in 1982, was the beginning of the era of HIV and AIDS in Uganda. The epidemic peaked in the 1990's, with Uganda's HIV prevalence estimated to be 29% in the sexually active adult urban population (Uganda Ministry of Health, 2010). By 2005, the HIV prevalence was estimated to have dropped to 6.4% in the urban adult population (Uganda District Health Survey, 2006). However, data from 2011, showing that HIV prevalence had increased to 7.2 %, raised alarms both in country and abroad regarding the efficacy of Uganda's HIV programming (WHO, 2013).

The health care system in Uganda, fragile after years of civil conflict, has been overwhelmed by the dramatic influx of HIV and AIDS patients into the health system. Since 2004, Ugandans who are HIV sero-positive and are at a particular stage of the disease qualify to receive free ART provided by the government. Treatment is provided free of charge by the government once the person living with HIV or AIDS (PLWHA) has reached a threshold CD4 level of count $\leq$ 350 cells/mm^3 (Uganda Ministry of Health, 2010). As of 2011 only 54% of those eligible for treatment were receiving it (WHO, 2013). People living with HIV and AIDS require a CD4 test prior to being eligible for ART. CD4 tests cost approximately 32,000 UGX ($16.00

CAN) and are too expensive for many patients, most of whom live on less than $1/day (Uganda Ministry of Health, 2010).

While the number of PLWHAs in sub-Saharan Africa has risen dramatically, there has been a concurrent reduction in the numbers of front line health workers to provide care (Matsiko, 2010). The health system in Uganda has been compromised by the impact of HIV on health workers themselves. An estimated 20% of Ugandan health workers have already been lost to the disease (Matsiko, 2010). Increased efforts to combat the disease have been well-intentioned, yet lack of investment in health worker numbers and capacity have limited program effectiveness and hampered controlling the spread of the disease (Bärnighausen, 2007).

Currently, HIV transmission occurs most commonly in the age group of 30-35 years, typically between heterosexual married couples (Uganda AIDS Commission, 2011). Factors influencing the spread of HIV include having multiple sex partners, discordance of HIV status within married and cohabiting couples, and infection with a sexually transmitted infection (STI) (Uganda AIDS Commission, 2011). The continued spread of HIV within this demographic represents a "normalization" of the virus due to a decline in behaviours that prevent transmission of HIV, including the 'ABCs' (abstinence, faithfulness and condom use) of HIV prevention (Uganda AIDS Commission, 2011).

Stigma and denial of HIV also continues to contribute to the spread of the virus. Many PLWHAs face discrimation and exclusion if they disclose their status to their partners or family. Women in particular are vulnerable to HIV infection as they may not be able to negotiate condom use with their sexual partners due to gender norms for women in Ugandan society, including women's ecomonic dependence on men, and the expectation of their acquiesence to men's demands (Mill & Anarfi, 2002; Uganda AIDS Commission, 2011; Young, 2010). This has also contributed to a continued problem of vertical tranmission of the virus, from mother to child; it is estimated that vertical transmission is responsible for 1 out of 5 new diagnoses in Uganda (Uganda AIDS Commission, 2011). Additionally the lack of psychosocial support and treatment programmes for PLWHAs makes the burden of dealing with the stigma of HIV and AIDS even more challenging (Holzemer et al., 2007). The need for increased prevention and treatment programming is great, and additional investment now is necessary to prevent catastrophic health issues in the future.

The Role of Nurses in HIV Care

Nurses provide HIV-related preventive and curative services for AIDS patients in every department and level of facility in Uganda. They are responsible for promoting prevention, initiating and referring patients for HIV testing, prescribing treatment and managing opportunistic infections. Nurses are also responsible for pediatric HIV prevention and treatment, ranging from PMTCT, to managing pediatric HIV infections. At many of the rural facilities in Uganda, the nurse is often the only trained health care provider available, and can be the first and last contact with the health system for many patients (Matsiko, 2010).

Working conditions for many nurses in rural Uganda can be challenging. Health workers remain scarce, with a ratio of nurses and midwives to population of 1:2,609 (Uganda Ministry of Health, 2010). The government of Uganda has had difficulty maintaining adequate levels of staffing in publicly-funded facilities due to low salaries, poor working conditions, and limited training opportunities (Uganda Ministry of Health, 2010). The majority of nurses earn between $350,000-500,000 UGX ($175-250 CAN) per month and are considered to be the lowest paid nurses in East Africa (Uganda Ministry of Health, 2010). Recruitment and retention in rural areas is particularly problematic, with 53% of level II health centers nationwide having vacant positions, resulting in understaffing in many facilities (Uganda Ministry of Health, 2010).

Nurses in sub-Saharan Africa must contend with limited influence in policy making in the health system (Richter et. al., 2013), and in Uganda a growing negative public perception of nurses (Harrowing & Mill, 2009). Both the media and government have blamed nurses for HIV drug shortages. Even high-ranking government officials have accused nurses of stealing drugs to sell for profit (Kagumire, 2011). The limited access to health care in rural areas affects how individuals seek care, and may encourage them to seek health care from traditional healers or private health providers rather than through publicly-funded facilities (Konde-Lule et al., 2010).

Despite the overwhelming barriers to providing adequate HIV care, nurses continue serving their communities, sometimes at great risk to themselves. Nurses in Uganda use coping strategies to mitigate workplace stress in low-income settings, including improvising care and transferring patient care to relatives (Ehlers, 2006), supplementing income with work at private facilities, seeking jobs in more developed regions and leaving nursing altogether (Harrowing, 2009). Harrowing (2009) demonstrated that education for nurses is an effective tool for improving nurses' ability to cope with their workload and advocate on behalf of their patients.

Yet there remains little research on other effective tools and strategies for rural nurses to cope with their workload in Uganda and few resources to help them improve the care provided for their HIV and AIDS patients.

Study Goals and Objectives

Very little research has been conducted into the experience of nurses caring for patients with HIV in rural Uganda. Nurses in Uganda are the largest group of health care providers, and provide the majority of care at rural health facilities (Uganda Ministry of Health, 2010). Many of the impacts of HIV upon health systems throughout sub-Saharan Africa have been studied yet the impact of HIV upon front line health workers, and nurses in particular, has been poorly researched throughout Sub-Saharan Africa, including Uganda (Fournier et al., 2007; Harrowing, 2009). Furthermore, the social and contextual influences on care provision are poorly understood. There is little information regarding the factors affecting the workload of nurses working in rural areas, how they cope with their stressors, support systems, and possibilities for improvement, particularly related to HIV care. Given current HIV rates and structural support shortfalls in Uganda, an investigation of nurses' perception of HIV care is critical for ensuring adequate programming is implemented.

The goal of the current study was to address existing gaps in understanding of how nurses in rural Uganda care for patients living with HIV, the institutional and organizational factors influencing the provision of HIV care, how nurses cope with their workload, and strategies to improve their situation.

Specific study objectives are:

(1) To understand nurses' perceptions of the quality of care provided for PLWHAs in rural areas;

(2) To identify aspects of HIV care that contributes to the nurses' excessive workload;

(3) To identify various forms of stress (emotional, physical, mental) experienced by nurses providing HIV care to PLWHAs; and

(4) To assess various forms of support for rural nurses, including support at the institutional, communal or individual level.

Literature Review

Search Strategy

A literature review was undertaken using a variety of scholarly journal databases, including CINAHL, Medline, Pub Med, and supported with Google Scholar and Google. Sources of literature included peer-reviewed articles published in scientific journals, theses, textbooks, and grey literature (including policy briefs and reports, published books, newspaper articles and discussion papers). Search terms included *Ugandan nurses, HIV nursing, rural nursing, nursing workload, nursing stress, nursing coping strategies, nursing burnout, and moral distress.* Terms were used in combination, with only English results being considered.

The literature search produced a large body of published literature regarding HIV nursing and nursing stress. The majority of literature came from western countries, with a focus on acute care, and had little in common with the context of rural Ugandan nursing. Of the literature that was published from African contexts, many studies were critical of the nursing care provided, and focused on the patient's experiences. Very few publications (Fournier et al., 2007; Harrowing, 2009; Nabirye, Brown, Pryor, & Maples, 2011; Ziegler, Anyango, & Ziegler, 1997) have studied the perspective of the nurses themselves, with even fewer (Dieleman, Bwete, et al., 2007) studying the challenges to rural nursing practice in Uganda.

Prior to discussing the specific literature pertaining to my study goal I will describe in some depth the Ugandan Health System and some challenges facing the system in order to provide the context for the study.

The Ugandan Health System: A Brief History

Historically, Uganda's formal health system evolved under British colonial rule in the late 1800's. As a British Protectorate, hospitals were built and doctors supplied to treat the colonial workers, especially British citizens working on expanding the Ugandan railway (Okunonzi & Macrae, 1995). However due to large scale epidemics, including malaria, smallpox and syphilis, care began expanding to local Ugandans to prevent transmission to colonial and Indian railroad workers (Okunonzi & Macrae, 1995). At the same time, the evangelical movement began sweeping across Uganda, and missionaries began building hospitals to treat local Ugandans (Okunonzi & Macrae, 1995). Upon Uganda's independence from Britain in 1962,

a network of health care institutions had been established. However its focus on acute hospital-based care had limited ability to provide adequate preventative care (Okunonzi & Macrae, 1995).

Uganda's post-independence era, spanning from 1962 to1970, saw large-scale expansion of hospitals and health facilities across Uganda (Okunonzi & Macrae, 1995). In 1970, a civil war began, affecting all parts of the country, causing widespread poverty and erosion of the publicly-funded health system (Okunonzi & Macrae, 1995). In 1972, all Asian citizens were expelled from Uganda, resulting in the number of doctors in the country being halved (Okunonzi & Macrae, 1995). With the war raging, finances were limited for health services, and many of the health gains made post-independence were lost. During the civil war era, large numbers of the population were displaced, leading to increases in malnutrition and epidemic levels of communicable diseases (Okunonzi & Macrae, 1995). By the time Yoweri Museveni gained control as President in 1986, the HIV epidemic had begun to rage across the nation, following troop movements and the internally displaced civilian population (Okunonzi & Macrae, 1995).

Health system financing

Following the resolution of Uganda's civil war in 1986, the country entered a period of stabilization and recovery, with a focus on rebuilding the publicly funded health system. However, the widespread poverty following the dislocation of civilians prevented the government from collecting a stable source of tax revenue to fund social programs (Okunonzi & Macrae, 1995). During and immediately following the civil war, the need for foreign assistance, including emergency health aid, was high. Humanitarian relief agencies, especially international NGOs, began offering services that typically would be provided by a publicly funded health system (Okunonzi & Macrae, 1995). Many of these international agencies operated outside of the scope and mandate of the local and central governments, and at the national level were poorly coordinated (Okunonzi & Macrae, 1995). Numerous international agencies provided funding and treatment for one specific area, such as immunization, rather than providing funding for the government to rebuild the public health system (Okunonzi & Macrae, 1995). This vertical programming, as it came to be known, has dominated the health provision in Uganda in recent years, and overshadowed the rebuilding of the public system (Okunonzi & Macrae, 1995). Vertical programming from international donors continues to be an issue in Uganda today. For example, by focusing on a single issue, funding bodies often prioritize services that may not be congruent with the priorities of the local or national health bodies, or may duplicate services

already provided within the publicly-funded system (Uganda Ministry of Health, 2010).

In 1986/7 Uganda spent 0.1% of its GDP on health services, which was only 16.1% of the 1970 level of per capita health spending (Macrae, Zwi, & Gilson, 1996). By 1990, foreign donors accounted for 60% of health spending in the country (Macrae et al., 1996). The International Monetary Fund (IMF) and World Bank instituted a series of reforms tied to structural loans for low-income countries, including Uganda. These reforms required countries to reduce public spending by controlling public wages, reducing public expenses, privatizing public enterprises, eliminating subsidies, and devaluing the currency (Buchan & Calman, 2004). Whereas these reforms were meant to increase economic activity in low-income nations, they had several unintended effects. The reforms often prioritized vertical programming of health projects rather than strengthening the health system as a whole. This effectively increased donor control over funding and spending priorities (Biesma et al., 2009; Macrae et al., 1996). Additionally, reforms tied to aid limited capacity building among health workers, which resulted in freezing staffing levels and wages, sometimes for years (Buchan & Calman, 2004). The result was a country dependent on aid to maintain its health systems, yet unable to prioritize rebuilding of its own health system as a consequence of the aid.

In 2001, Uganda signed onto the Abuja Declaration, in which member countries pledged to spend 15% of their GDP to reach 8 Millennium Development Goals (MDGs) by 2015 (World Health Organization, 2011). The purpose of the Abuja Declaration was to encourage member nations to prioritize the health of their citizens, with the MDGs acting as guideposts in policy and financing for health systems (World Health Organization, 2011). However, following the economic crash of 2008, donor fatigue and reductions in external funding commitments have reduced external financing for Uganda's health sector (World Health Organization, 2011). While high-income countries struggle to maintain their financial security and reduce their foreign assistance budgets, Uganda struggles to maintain the gains made in reaching the MDGs and improving the health status of its population (Oomman et al., 2007; World Health Organization, 2011).

The Ugandan governments' 2009 expenditure on health was 9.6% of its GDP, less than its commitment of 15% under the Abuja Declaration (Uganda Ministry of Health, 2010). Coupled with the large population growth in the country of 3.2% per annum, the health expenditure may not be adequate to support the health needs of the population in the future

(Uganda Ministry of Health, 2010). As a result of inadequate government and external funding, Uganda has been unable to make significant progress towards meeting the MDGs, and is not predicted to meet MDG 6 (to combat HIV/AIDS, malaria and other diseases) by 2015 (Millennium Development Goals Report for Uganda 2013; World Health Organization, 2011).

Corruption within the Ugandan health system

Along with lack of investment, corruption continues to plague the Ugandan health system. Transparency of fund use has become a major issue in Uganda, with 2.4 billion Ugandan Shillings of 'questionable expenditures' in the health budget in 2005/6 alone (Okwero, Tandon, Sparkes, McLaughlin, & Hoogeveen, 2010). The lack of adequate and timely documentation on the part of health facilities and districts, as well as lack of transparency in contract procurements and financial management have resulted in wasted health spending (Okwero et al., 2010). Health staff have been accused of stealing drugs from public facilities to sell privately, and this is thought to have contributed 1.3 billion Ugandan Shillings in wasted health spending in Uganda in 2005/6 (Okwero et al., 2010). At the same time, health care providers have been found working in both the public and private health sectors, and may be paid by the public system while working in the private system for extra money (Kyaddondo & Whyte, 2003; Okwero et al., 2010). This double payment is a drain on limited resources, affecting the credibility of the government to transparently manage aid funding and their own expenses.

With the influx of NGOs providing health services in Uganda, some services have been duplicated. Parallel data collection systems for health providers have contributed to more paperwork for the front line staff and in turn, less time for patient care. In essence, these duplicate systems are contributing to health staff inefficiency (Biesma et al., 2009; Macrae et al., 1996). The result is a health system mired in bureaucracy and duplication, unable to prioritize health needs, yet dependant on meeting targets set by outside organizations to continue to meet its health system funding requirements (Streefland, 2005).

Current Ugandan health situation

In 2001, the Ugandan health system was decentralized to districts. A decentralized district health system provides the structure for health administration, and through which a minimum package of health care is provided to each citizen (Uganda Ministry of Health, 2010). The Ugandan minimum package for health focuses on four priority areas: disease prevention,

community health and health promotion; maternal and child health; communicable and non-communicable disease control (Uganda Ministry of Health, 2010). In 2001 user fees were eliminated within the publicly–funded health system but are still required at private facilities and private wings of some public facilities (Uganda Ministry of Health, 2010). The private health sector encompasses private-for-profit and not-for-profit facilities, which both require user fees.

In addition to the formal system, there are also traditional and complementary medicine practitioners providing health care in Uganda. With an estimated 60% of Ugandans seeking treatment with these providers before seeking treatment from the publicly-funded health system, their influence remains important (Uganda Ministry of Health, 2010). Yet these practitioners remain largely unmonitored and unregulated, and it is thought that they play a significant role in poor patient outcomes, especially in late referrals, medical, surgical and obstetrical complications, and an overall increased morbidity and mortality in the population (Uganda Ministry of Health, 2010).

Since the establishment of the Museveni-led government in 1985, several improvements have been made in the overall health of Ugandans, including an increase in life expectancy from 45 years in 2003 to 52 years in 2008 (Uganda Bureau of Statistics, 2012). Despite these gains, large scale heath issues continue to plague Uganda's population, estimated to be 34.1 million in 2012 (Uganda Bureau of Statistics, 2012). The majority (over 75%) of the burden of disease in Uganda is due to preventable diseases, including malaria, acute respiratory illness, malnutrition and diarrheal diseases (Uganda Bureau of Statistics, 2012). Improving the overall health of Ugandans remains an important goal for the health system and the country as a whole.

Poverty plays an important role in health and illness in Uganda. Within Uganda, poverty has decreased overall, with 35% living below the poverty line in 2005 compared to 52% in 1992 (Uganda Ministry of Health, 2010). Despite these improvements, Uganda continues to be ranked poorly on the human development index at 161 out of 187 countries, equivalent in its development to Haiti (UNDP, 2013). In Uganda the majority of poverty is concentrated in rural areas, with 85% of the population living in rural areas (Uganda Bureau of Statistics, 2012). Poverty has been correlated with an increase in communicable diseases, morbidity, mortality, and higher health care costs (Krishna et al., 2006). Rural Ugandans continue to struggle with poverty, as the majority of rural Ugandans are subsistence farmers with little income to subsidize health services (Konde-Lule et al., 2010). Many people in Uganda find paying for health services

difficult, with funds for private health services jeopardizing other necessities, such as nutritious food (Konde-Lule et al., 2010). The poorest Ugandans have fewer options to access health services and rely heavily on the publicly funded health system.

Health system shortages

Since the end of the civil war, there has been an emphasis on rebuilding damaged health infrastructure. However, due to funding shortfalls, there has been a little investment in the maintenance of rural health facilities and infrastructure such as electricity, running water and sanitation systems (Uganda Ministry of Health, 2010). The lack of investment to maintain current infrastructure in rural areas has led to rural health facilities having limited resources to provide adequate care, resulting in patients receiving inadequate care at many rural facilities (Uganda Ministry of Health, 2010).

Drug shortages, or a lack of basic drug supplies at health care facilities, have been problematic nationwide with many public health facilities having consistent supply shortages; in 2008 the Ugandan Ministry of Health reported that the average public facility had stock outs for 73 days of the year, compared to 8 days in private facilities (UNGASS, 2008). When public health facilities are out of stock, many private drug pharmacies still have stock. However most patients, earning around $1/day, cannot afford to buy the drugs at private facilities (Uganda Ministry of Health, 2010). This has led many patients not to seek care when ill, or first seek care at private facilities, where drug supplies may be more reliable (Konde-Lule et al., 2010). Private facilities are common in rural areas but are poorly regulated by the government and many operate with untrained staff (Uganda Ministry of Health, 2010).

Of growing concern in Uganda is the challenge of counterfeit drugs. With 90% of drugs being imported from India and China, it is difficult to regulate drug safety and quality nationwide. Many drugs on the market are counterfeit, contributing to antibiotic resistance and poor patient outcomes (Uganda Ministry of Health, 2010). The government of Uganda recognizes this growing area of concern, yet lack of funding and staffing shortages continue to hamper advances in this area.

Nursing in Uganda

Recruitment and Retention Issues

Health worker motivation continues to be an important issue in the recruitment and retention of nurses in Uganda. As the population continues to rise in Uganda, there has been a concurrent reduction in the number of front line health care staff, including nurses. Delayed release of funds from external donors has hampered fund distribution within Uganda, affecting the payments due to health care workers (Uganda Ministry of Health, 2010). Delayed payment is thought to be a contributing factor in high rates of absenteeism and low-productivity of the Ugandan health workforce (Uganda Ministry of Health, 2010). Contributing to the issue are the funding priorities of external funders, which generally focuses on vertical programming, such as immunizations, with little or no funding provided for health staff scale up (Macrae et al., 1996). As a result, there is a critical shortage of nurses within the Ugandan health system at all levels of care, which is exemplified by the vacancy rate within public facilities. For example, at level II, III and IV health care facilities, the national vacancy rate of nurses is 53%, 54% and 37% respectively (Uganda Ministry of Health, 2010).

Low pay and lack of influence on health policy have contributed to an out-migration of nurses from the rural areas of Uganda to the larger city centers, and out of the country, to countries where remuneration and working conditions are better (Uganda Ministry of Health, 2010). Within Uganda, staff attrition has been related to poor and delayed payments in the public sector, lack of promotion and training opportunities (Matsiko, 2010), poor leadership, poor working conditions including lack of staff accommodation, and exposure to HIV and malaria (Fournier et al., 2007; Matsiko, 2010). Health worker attrition is due mainly to staff who have left the profession (30%), those staff who have had been dismissed or had their practice licenses revoked (26%), and some from death or illness (16%) (Matsiko, 2010, p.50). Staff poaching from the health system to NGOs and global health projects has also been reported in Uganda (Starling et al., 2005). These factors combine to affect nurse-staffing levels, and continue to be important issues affecting the health status of Ugandans.

Nursing Education in Uganda

The Ugandan nurse-training curriculum focuses mainly on curative acute care rather than preventative care. As a result, many nurse graduates may not have adequate knowledge to

provide sufficient preventative care, especially in rural areas with fewer acute services (United Nations Fund for Population Activities, 2009). Furthermore, the Ugandan National Nurses and Midwives Council, has little influence over policy level decisions at the national level (Matsiko, 2010; United Nations Fund for Population Activities, 2009). The disconnect between the burden of communicable disease within the population and the focus on curative care within nurse education curricula may be exacerbating the current health issues facing everyday Ugandans.

Formal nursing education in Uganda includes training for: enrolled nurses and midwifes (2 years); enrolled comprehensive nurses (ECN) (3 years); and nurses educated at the Bachelor of Science level (4 years). There are many training schools for nurses in Uganda and although the schools have basic training packages, the core training varies (United Nations Fund for Population Activities, 2009). The core curriculum of the nursing programs are not directed by the Ugandan Ministry of Health, but by the Ministry of Education, which has led to some discussion about the alignment of nursing curriculum with priority health needs facing the country (Matsiko, 2010).

Nursing Care of PLWHAs

As nurses comprise the largest body of health workers in Uganda, they provide critical front-line care for PLWHAs. At rural health facilities, nurses are often the highest cadre of workers available to patients, and may be the only contact a person has with the health system. Depending on where they work nurses are responsible for providing counseling for HIV testing, prescribing HIV treatment, counseling discordant couples on virus prevention, prevention of mother to child transmission, pediatric HIV counseling, treatment of opportunistic infections and palliative care (Uganda Ministry of Health, 2010). The nursing curriculum in Uganda has limited focus on current HIV medications, and training for new HIV treatments are often sporadically provided through in-service sessions; thus nurses' understanding of HIV treatment and ARTs may be limited and affect the quality of care given to patients (Fournier et al., 2007).

The provision of care to PLWHAs by rural nurses is influenced by a variety of factors. Studies of nurses working in low-income countries have identified several barriers to providing quality health care to patients living with HIV, including stigma and discrimination (Mbanya, Zebaze, Kengne, Minkoulou, & Awah, 2001; Mill et al., 2013; Mill & Anarfi, 2002), inadequate knowledge (Walusimbi & Okonsky, 2004), negative attitudes towards work (Mbanya et al., 2001), heavy workloads (Dieleman, Biemba, et al., 2007; Fournier et al., 2007); vengeance from

HIV-positive patients (Ehlers, 2006); lack of resources (Mill & Anarfi, 2002), lack of adequate barrier protection and consequently fear of infection (Delobelle et al., 2009; Dieleman, Biemba, et al., 2007; Ehlers, 2006; Fournier et al., 2007)..

Workplace stress among nurses can be influenced by internal factors such as nurses' personal feelings or stigma around HIV and external factors, such as the lack of resources at a health facility. Jameton (1984) has conceptualized external factors causing nursing stress as moral distress. Moral distress is described in nursing when "one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984, p. 6). Austin et al. (2005) similarly described moral distress as an experience that occurs "when one believes one knows the right thing to do but does not do it" (p. 198). Moral distress can be experienced in different ways, manifesting in a variety of physical, emotional, cognitive and behavioral symptoms, and can ultimately overwhelm the ability of the nurse to provide adequate care, contributing to the burnout and attrition of nurses from the healthcare sector (Harrowing, 2009). Thus the stress that nurse's experience in caring for PLWHAs may contribute to the development of moral distress. More research is necessary in this field as there are few studies of workplace stress of nurses working in high HIV prevalent areas.

Nurses in sub-Saharan Africa have limited influence in policy making in the health system (Phaladze, 2003; Richter et. al., 2013; Zelnick & O'Donnell, 2005) , and in Uganda must contend with growing negative public perception of nurses (Harrowing & Mill, 2009). As a consequence of not being able to provide adequate care, these nurses may experience emotional anguish and moral distress, a factor contributing to nurses leaving the workforce (Harrowing & Mill, 2009). In order to continue to provide patient care through difficult circumstances, health care providers have used a variety of coping strategies. Research has revealed some of the coping strategies used by nurses to mitigate workplace stress in low-income settings including improvising care and transferring patient care to relatives (Ehlers, 2006), supplementing income with work at private facilities, seeking jobs in regions with higher incomes, and leaving nursing altogether (Harrowing & Mill, 2009; Matsiko, 2010). Recently, Harrowing (2009) reported that continuing education could mitigate the effects of moral distress in Ugandan nurses affected by caring for patients living with HIV. Few studies have assessed work-related stress in nurses employed in rural areas. A Canadian study suggests that rural nurses experienced heavy workloads and lack of staff and social support, contributing to already difficult working

conditions and staff burnout (LeSergent & Haney, 2005). The study emphasized the unique working conditions of rural nurses, requiring coping strategies and institutional interventions that are different than urban nursing situations. Although there are several studies of workplace stress of nurses in high-income countries, very little data has been collected on the working conditions and subsequent stress of rural nurses in low-income countries, especially in the region of sub-Saharan Africa.

The literature review demonstrated large gaps in research aimed at understanding the experience of nurses caring for patients with HIV in Uganda, especially in a rural context; research that strives to understand the contextual and organizational factors that influence nurses' ability to provide HIV care; research regarding the coping strategies of rural nurses in low-income contexts; and research on strategies to improve HIV nursing in the context of rural low-income countries.

Methodology

The research objectives for this study necessitated developing a deeper understanding of the nurses' experience providing HIV care within the rural Ugandan context. A focused ethnography (Mayan, 2009) was chosen to facilitate answering the 'how' and the 'why' questions pertaining to the perceptions and experiences of a group of nurses working under very similar circumstances. The paradigm underpinning this research is constructivist in nature, meaning that social constructs such as society, class, race and gender of both the researched and the researcher shape meaning (Mayan, 2009). In other words, there are multiple meanings, and the relationship between participant and research is shaped by their interaction (Denzin & Lincoln, 2011).

Focused ethnography differs from traditional sociological ethnographies in that it is considered experientially intensive, using short-term visits to collect a wealth of communicative data, and focusing on particular structures and patterns of interaction rather than entire groups or systems (Knoblauch, 2005). Within focused ethnography, data can be collected over a short amount of time, focus on a particular question, and include a small number of participants (Mayan, 2009). As the research questions encompassed perceptions and challenges to HIV nursing care during the time available to complete the data collection, a focused ethnography was the most appropriate methodology to answer the study questions.

Study Setting

Kabarole District in western Uganda was chosen as the study setting. This setting was selected for several reasons. Primarily, little research had been conducted in this area on the topic of nurses providing HIV care, and it was thought this research could contribute to the body of knowledge of rural nursing in an HIV prevalent area. Secondly, the University of Alberta School of Public Health has had a long relationship with the District Health Office in Kabarole District, with many students conducting research projects in this area. Thirdly, because of the research history in Kabarole, there were many local staff that had been trained in research methods and were available to work as research assistants.

Kabarole District

The study was conducted in Kabarole District in Western Uganda, which is located near the border with the Democratic Republic of the Congo. In 2006, the population of this region was 359,180 (50.1% male and 49.9% female) (Uganda District Information Handbook, 2006). The city of Fort Portal is beautifully situated within the backdrop of the Ruwenzori Mountains, and is surrounded by lush green hills and tea plantations, peppered with small deep crater lakes. Fort Portal is the capital city of Kabarole District, with a population of 40,605. The majority of the population are subsistence farmers, with tea companies being the largest employers in the area (Uganda District Information Handbook, 2006).

The district has 51 health centers and 3 main hospitals that service the needs of the population. The health centers, operated by the government, vary in the size and scope of services provided, and very often are staffed and run by a nurse. All 3 hospitals are located in the town of Fort Portal. The nurse to patient ratio for the country is 1:2609 (Uganda Ministry of Health, 2010), and the current number of nurses working in the district is reported to be over 110 (Uganda District Information Handbook, 2006).

The HIV prevalence in Kabarole District is reported to be 11.3%, higher than the national average of 6.2% (*Kabarole District Local Government Approved 5 Year Development Plan for years 2010/11 - 2014/15*, 2009). A recent study revealed the HIV prevalence among adults living in Fort Portal to be 16.1% (Rubaihayo, Surat, Ezekiel, & Andrew, 2010). Predictors of HIV infection included adults over the age of 35, and those with little or no education (Rubaihayo et al., 2010). These authors also indicated that although awareness of HIV prevention was widespread, high-risk behaviors associated with HIV continued to be common, including having

multiple sex partners, use of prostitutes and lack of condom use. Interestingly, the study found that complacency about the availability of ART was also a contributing factor in HIV prevalence, as many people now believe that HIV is manageable with treatment, will not result in death, and therefore many people have lost fear of acquiring the virus (Rubaihayo et al., 2010).

Data Collection

The study took place from August 2010 to January 2011, and involved focus groups and interviews with nurses and midwives throughout Kabarole District in western Uganda. Originally the study design was a mixed methods approach, utilizing both quantitative and qualitative data collection methods. The quantitative component involved using a questionnaire to quantify the workplace stress of nurses, with qualitative interviews and focus groups used to explore sources of stress, how stress impacted nurses' workload and subsequent coping mechanisms. Upon administration of the questionnaire, many nurses were reluctant to provide written feedback and did not complete the questionnaire. Participants did not disclose their reasons for not wanting to complete the written questionnaire, however they were willing to provide verbal feedback through interviews and focus groups. The quantitative component was subsequently abandoned and a purely qualitative approach was utilized for the study. Ultimately, the study shifted from a mixed methods methodology to a focused ethnography.

Data were collected using interviews and focus groups with the nurses, as well as passive observation at health facilities. Open-ended interviews were selected as the data collection technique to collect in depth responses to a series of standard questions to "allow respondents to express their own understanding in their own terms" (Patton, 2002, p.343). This type of data collection tool is useful in collecting data in a multicultural setting, in which the researcher may be unfamiliar with the topic (Teddlie & Tashakkori, 2010). An interview guide was developed (see Appendix I). The interviewer determined which questions to ask depending on the flow of the conversation.

Interviews lasted between 20 and 60 minutes and were conducted face to face by the primary investigator or research assistant. They were conducted at the participants' place of work or at another site chosen by the participant. Interviews were tape-recorded with the advance written consent of the participant, and notes were taken throughout the interview. The recorded interviews were transcribed and reviewed for emerging themes. All the participants were given

the option of speaking in their first language (Rutooro) or English, however all interviews and focus groups were conducted in English, with the exception of a few Rutooro words. The trained research assistant completed translation of these few words. The interview guide was refined throughout the research process to reflect themes emerging from the data.

A focus group is essentially a group interview, focusing on a narrow field of interest. A moderator provides questions to ask to the group, and the individuals in the group respond, often building on one another's feedback to guide the responses. Within focus groups, meaning is partly shaped by the interaction between participants (Marshall & Rossman, 2010). This type of data collection strategy is useful in qualitative research as it generates a safe space for participants to share their thoughts and feelings (Holloway & Wheeler, 2002). Focus group discussions typically include 5 to 10 participants of similar backgrounds to discuss a focused subject for approximately 2 hours. The session is moderated by a trained individual and supported by an assistant (Holloway & Wheeler, 2002).

An interview guide was used in the focus groups to generate discussion among participants, with supplemental questions being asked as the sessions progressed. The sessions were recorded with the written consent of the participants and notes were taken in the place of a recording if the participants preferred. A trained research assistant fluent in English and Rutooro, moderated the focus group sessions. During the sessions, the researcher acted as note-taker and would direct the flow of conversation by prompting the moderator with written questions. Recordings and field notes were translated by a trained research assistant and transcribed by the researcher and a research assistant.

Participant Recruitment

Enrolled nurses, nurse managers, nursing officers and midwives employed in the Kabarole District were asked to participate. Criteria for participant inclusion were nurses who: had completed a minimum of an enrolled nurse-training program; were native Ugandans; were over 18 years of age; spoke English; and had cared for at least one patient with HIV per week.

Purposive sampling was used to recruit participants (Mayan, 2009). Potential participants were contacted initially at their health center by a letter of introduction (see Appendix II), and asked to participate in either a focus group discussion or interview. Before approaching nurses directly, permission was obtained by speaking with the chief administrators, first from the district health level, and then from the level of the hospital or health center. This

step often took several days of meetings with hospital administrators. Then, administrators would inform the researcher which unit might have interested nursing staff. We were then free to walk through the hospitals and health units and speak to the nurses. If staff were busy, which they often were, we would wait until they had spare time, provide them with the information sheet (see Appendix II), describe the study, and ask if they would be interested in attending a focus group or an interview at their time and location of choice.

Consent was explained by the research assistant before the interview or focus group began and time was allowed to answer participants' questions about the research. Signed consent was obtained (see Appendix III) prior to beginning any interview or focus group session. Before each interview or focus group discussion, interviewers reassured participants that they did not have to answer any of the questions they did not want to, and could leave the discussion at any time. Many participants were very concerned that administrative staff might discover their participation in the research, and that they might experience negative consequences as a result of their participation. Participants were reassured that no names or identifying information would be released in the study, and that their confidentiality would be protected. In order to provide a safe space for group discussion, participants were asked not to share any of the names of the other participants attending the session, or disclose any information discussed.

Research Assistant

Initially, the primary research assistant who was recruited was an enrolled nurse and taught public health nursing courses at the local university. She was well known in the nursing community and knew many of the study participants personally. During the consent process, she exerted her status to coerce other staff to participate in the study. After gathering feedback on this research assistant, it was thought that her high status and personal knowledge of many of the participants was not ideal for the purposes of this study. A second research assistant was sought. Another research assistant was recruited, who had previous research experience in the area but was not employed in nursing.

The research assistant had worked on several other health projects with students from the University of Alberta, and had experience in conducting interviews, moderating focus groups and was familiar with the concepts of confidentiality and informed consent. She lived in the area, spoke Rutooro and was familiar with the layout and structure of the health system within Kabarole District. Before beginning this study, the research assistant was provided training on

obtaining informed consent, the interview process and techniques for probing, focus group moderating and documentation.

Data Analysis

Content analysis, an established method for analyzing qualitative data, was used to analyze the data in this study. Mayan (2009) describes latent content analysis as "identifying, coding and categorizing the primary patterns in the data" (p.94). Analysis of the data occurred concurrently with data collection to identify emerging themes and address them in subsequent focus groups and interviews (Knoblauch, 2005). The process of analysis involved transcribing the data, immersing in the data through frequent reading of transcripts, organizing the data into manageable pieces, creating categories, grouping categories together and identifying themes (Holloway & Wheeler, 2002). Memos were made to record initial themes and concepts emerging from the data analysis.

Although the participants were encouraged to speak in whichever language they felt most appropriate, all interviews and focus groups were conducted in English, with a few words being spoken in the local language, Rutooro. The research assistant translated the few words requiring translation. Once these words were translated, the primary investigator completed transcription. Content analysis began with an initial reading and rereading of the transcripts, in which notes were written in the margin. Coding was then conducted to provide an overall reading and surface analysis of the transcript, identifying general themes and possible subthemes (Holloway & Wheeler, 2002). Initially simple coding was done using line-by-line open codes, reflecting initial impressions. Once the simple coding was completed, excerpts with their codes were manually cut out and arranged into categories and grouped together thematically. These categories were organized and reorganized until broader themes emerged, which will be analyzed in the body of this paper.

Rigor

Mayan (2009) suggests that qualitative inquiry has developed its own set of concepts that set it apart from quantitative research. These concepts were initially developed by Lincoln and Guba (1985), who argued that qualitative inquiry is essentially different from quantitative research, and therefore cannot be evaluated using the same positivist concepts typically applied to rigor, specifically the concepts of reliability, validity, and generalizability. Instead, the authors

developed unique terms that describe rigor in qualitative research: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). These concepts are widely recognized and used in qualitative research today.

Ensuring that rigor is incorporated into the research process can occur in numerous different ways. Credibility refers to the accuracy of the data collected (Mayan, 2009). In this study, credibility was ensured by the use of prolonged engagement; researcher immersion in the study setting is considered a method for ensuring credibility (Mayan, 2009). Prolonged engagement occurred over several months, as there was a wait time to obtain ethics approval from Makerere University and the Ugandan Government before beginning data collection. This allowed time to immerse myself in the daily life of the area, shopping at local markets, visiting hospitals and health centers regularly, becoming familiar with the layout of the area, taking public transit and understanding some of the nuances of the culture.

Transferability, which replaces the concept of generalizability in the quantitative realm, refers to how the results may be transferred to individuals in other settings (Mayan, 2009). Operationally, transferability is achieved by providing a detailed description of the study setting and participants to give readers a better understanding of the study's context and whether the results may be applicable to other study situations (Mayan, 2009). The concept of generalizability in qualitative research is a contentious one, as results may not be applicable to all settings. Importantly however, the study results may still be relevant in similar contexts and settings.

Dependability, which replaces reliability, refers to how the research decisions were made, which can be confirmed through analysis of an audit trail (Mayan, 2009). The audit trail "enables the researcher to document why, when and how decisions were made throughout the research process." (Mayan, 2009, p. 112). Documents used in an audit trail include personal journals, field notes, emails, and analysis documents, including transcripts. Post hoc review of these documents provides important rationale as to why decisions were made, including in this case, the decision to change from mixed methods to a qualitative only approach.

Confirmability refers to how logical the findings are and replaces the concept of objectivity in quantitative research (Mayan, 2009). Lincoln and Guba (1985) describe confirmability as requiring reflexivity, which allows results to emerge from the data without preconceived ideas from the researcher that may influence the findings. Holloway and Wheeler (2002) argue that the researcher must be open and honest about their background and feelings

regarding the research, to provide clarity related to any preconceived ideas that may be influencing the research. Techniques to support this process require the use of an audit trail, so that the results can be traced from its source, rather than from the researcher (Mayan, 2009).

Support and feedback was sought from experts in the field, including supervisors and students who had previously worked in Kabarole District. Their feedback was elicited about on the best strategy to recruit participants, to manage data, train research assistants, and to navigate the health system of Kabarole District. Their guidance was critical in facilitating the research process.

Ethics

Approval for this study was initially obtained from the University of Alberta's Department of Public Health Sciences and the Health Research Ethics Board – Panel B. Following this, in country approval of the study was granted by Makerere University School of Public Health, Uganda's National Council for Science and Technology and the Kabarole District Health Officer prior to beginning data collection.

Written informed consent was obtained from all study participants. The study participants were assigned a pseudonym to ensure the maintenance of privacy during data collection. Data confidentiality was maintained throughout the course of the study by restricting access to study documents to the principal investigator and co-investigators. In order to maintain anonymity within the focus group setting, participants were asked to maintain the confidentiality of the other participants and keep information shared within the discussion private.

Since the research topic could prove to be emotionally distressing, participants were reminded that they could withdraw their participation from the study at any time. All possible measures were taken to protect the respondent's confidentiality and avoid harm during the research process This included the discreet recruitment of participants, choosing a study location that was private and neutral for group discussions and interviews, and using respondent pseudonyms instead of names to protect confidentiality.

Incentives

Participants were offered reimbursement for their travel expenses if their travel was

required to participate in an interview or focus group session. The average reimbursement amount was $5,000 UGX (approximately $2.00 CAN), provided only to participants who required travel expenses to be covered. Participants who were interviewed at the workplace were not reimbursed, as they were not required to travel. Snacks and drinks were provided at focus group sessions out of courtesy to partially compensate individuals for their time to participate.

Results

A total of 14 interviews and 5 focus groups sessions were undertaken with nurses and midwives throughout the Kabarole District. Altogether, 50 nurses (Table 1) participated in the research: 14 in interviews and 36 in 5 focus groups sessions. The focus group sessions lasted from 1-3 hours, and took place at the Kabarole District Health Office after regular work hours, or at an off-site location. All of the participants had completed a minimum 2-year enrolled nurse-training program, with many of the nurses also receiving training as midwives, and having enrolled midwife status.

Table 1. The number of participants who participated by level and type of health center

Level of Health Center	**Number of Participants**
Referral Hospital	15
Health Center Level IV	11
Health Center Level III	21
Health Center Level II	3

Participants shared many stories about their experiences providing care to rural populations and detailed the many aspects of the health system and social issues that prevent them from providing adequate care. Four main themes emerged from the analysis: responsibility, struggle, failure and resilience. Responsibility emerged as a theme describing how nurses felt about providing HIV care in rural areas. Struggle emerged as a theme as nurses described the structural and social issues involved in providing rural HIV care. These issues included understaffing, drug and equipment shortages, salary and transportation, administrative problems, the role of non-governmental organizations and private clinics in HIV care, HIV training for nurses, and the role of the Uganda Nursing Council and Uganda Nursing Union. The theme of failure emerged throughout the study, evident in the nurses' perception of systemic failures in patient care. Poor client care affected the nurses themselves, and the nurses believed that these factors contributed to the continued spread of HIV in Kabarole District. Resilience emerged as nurses discussed their faith as a strategy to help them cope. They believed that teamwork and coordination mitigated their work stress and their dedication to their community motivated them to keep going.

Responsibility: The Role of the Nurse in Rural HIV Nursing Care

Nurses working in rural areas no longer had to worry simply about providing basic health services, but were also responsible for providing additional HIV care in their daily work. As a result, HIV care had been integrated into everyday nursing practice. Aubrey described the everyday care given to patients who may not know their HIV status at her health unit:

> *We examine them, send them to the lab for [HIV] screening, send them to the counselor to receive their results, we give them general health education and those found ready to begin on treatment, we enroll them in HIV/AIDS care. In case we don't have some medicines we advise them with condoms, then family planning for those we see that need it, then PMTCT and continue with ART.*

Patients who were aware of their HIV status could receive outpatient care at most health facilities, where patients routinely came to refill prescriptions and attend to opportunistic infections. Arianne described:

> *'…a few are getting inpatient care but most of them are getting outpatient care, which involves counseling, testing, then counseling on adherence, issuing of drugs to those who want refills, those who have reactions they come, we give them information and maybe if the reaction is so severe we refer them to other health centers.*

One of the roles of the nurse was to provide counseling to discordant couples. 'Discordant' refers to couples when one partner in the couple is HIV positive, whereas the other is negative. The focus of nursing care in this situation was to prevent the HIV negative partner from acquiring the virus. Autumn described the how nurses were responsible for the care provided for discordant couples at her health unit:

> *'Discordants… of course. We counsel them to stay together and not to separate, if they stay together we advise them to use some protectors so that the infected does not infect the other, and we advise the negative one to keep on testing, maybe every three months because you can never know what happens.'*

Prevention of PMTCT was a primary focus of care with pregnant women living with HIV. Nurses were responsible for counseling mothers on how to prevent transmission to the fetus during pregnancy, labour and after birth. Eden described:

> *'Basically these are pregnant mothers, they are screened and tested in the lab, for those who are HIV negative we give them [an] appointment of testing again and even inform them of their male partner involvement, then for the positive ones they are actually given more information of prevention of the mother to child transmission.'*

As one of the few trained health providers available in rural areas, nurses often delivered babies and provided antenatal care. In providing pediatric HIV care, screening and treatment was age-specific, as Eden described here:

> *'...for the children when born, let's assume they have gone through PMTCT so the test is done at 6 weeks, the PCR DNA test. If they are positive at 6 weeks it means they are positive. So any child below 2 years of age and is found HIV positive is started on ARVs, there's no need for CD4 (testing).'*

Depending on the level of health center, nurses provided a variety of HIV prevention and treatment programs, from adults and couples to children and neonates.

Struggle: Structural Challenges to Care

The health system presented many difficulties for nurses who were struggling to provide care for patients. Nurses reported health centers were chronically understaffed, with drug and equipment shortages at most health facilities. Poor pay and limited transportation hampered the nurses' ability to provide follow-up care for patients, and supports for staff were limited and not consistently implemented. A lack of acknowledgment by nursing administration was reported by participants, who described facing a punitive rather than supportive management style. As a result, nurses often reported poor outcomes for their patients.

Understaffing

As the number of PLWHAs has risen, the number of nursing staff has remained the same. At the time of this study, one senior nursing officer reported that there had been a hiring freeze on nurses for the past 4 years. The impact of HIV, in combination with understaffing, contributed to the heavy workload of the nurses. Isla outlined this challenge in an interview:

> *'Okay, when we talk of drugs, we have not experienced, ehh… long periods of stock outs, so drugs are always there, except that we have ARVs but not drugs for the rest of the patients… then when you look at staffing, I think I'll talk of our health center 3, HIV and the clinic of ahh, the HIV clinic, has become a health center of its own, because it has a lot of work, it has a lot of recording, reporting, reports are very long, and yet the staffing has not increased with the addition of that clinic, which is so heavy, and it has to run its route, considering other departments, the HIV clinic really needs more staffing.'*

The paperwork necessary to facilitate HIV care added to the workload of the nurses. In maternity, the situation was the same, with chronic understaffing and heavy workloads being the norm. With the influx of Patients with HIV in maternity wards, the resulting workload often

prevented nurses from being able to deliver the quality of care expected. Autumn highlighted this serious problem:

> *'… for us who work in the deep rural areas and this is the only health center… I can tell you I get eighty mothers in a day… you can't even do what you are supposed to do… we have to health educate, weigh and so many other things… you are supposed to give health talks, you can't do it because you're in a hurry, so because of all that I really get tired.'*

It often happened that the nurses had so many patients they couldn't see them all in one day. Patients became upset with having to wait. Victoria described the workload at her health unit:

> *'Sometimes I found myself alone here… we are just few staff, there are many people and you need to see a person in full but [at] times we fail. For example doing counseling you need to talk about nutrition, safe sex… everything… you find that you will not talk about all that, you need to weigh them, others are shouting and complaining, you need to write in their files… you find that it's stressing on our side. You find that I am alone or we are two, one is checking for files, I am giving drugs, I need to counsel, I need to dispense, weigh… there's a lot of work.'*

Without question, the nurses working at the rural facilities were very busy, and with the influx of patients with HIV occurring throughout the country, the nurses were having difficulty provide adequate care. Many nurses working at rural facilities often worked alone, and were required to do all of the care and all the paperwork needed for the PLWHAs. Having inadequate staff only compounded the other issues within the system.

Drug and Protective Equipment Shortages.

Overwhelmingly, one of the biggest issues for nurses providing HIV care was the lack of drugs required to treat PLWHAs. Nurses identified stock outs of HIV medication, including ART and prophylactic antibiotics, as a major issue affecting HIV care in Kabarole district. Many of the nurses reported that they were currently out of drug stock. In this situation, the nurses knew what the patients needed, yet were unable to provide it for them, which may have resulted in poor patient outcomes. Lorelei mentioned this situation in a focus group:

> *'There is still another problem when the drugs are out of stock --- when the drugs are available we get good reports and our patients regain their health and their virus decreases but when the drugs are out of stock – when you tell someone to go and buy drugs and yet they don't have money, they just sit in the village and the virus increases and they end up dying.'*

ART medications were especially important for HIV sero-positive pregnant women, to prevent transmission to the fetus. Some participants reported that babies had become infected during labour due to a lack of specific HIV medications, such as Nevarapine. In cases such as these, the nurses knew what to do however lacked the drugs to prevent transmission from occurring. Autumn described the challenges associated with drug stock outs:

> *'I can talk about our site here because I have worked here for a long time… before we used to have the prophylaxis drugs for the infected but as I talk now, we are out of stock. It's a challenge, you tell a mother to swallow Septrin everyday and when she comes here there's no Septrin. You tell them to be with Nevarapine, to take it at some moment at the onset of labour, but there's no Nevarapine… it's the same with the baby… you may deliver a mother and you don't have Nevarapine for the baby… you tell the mother to go to Buhinga (hospital), but she doesn't have (money for) transport… You find you would have helped but then you can't because of such challenges and in the end the baby gets also infected… drugs is the most challenge we have here…'*

ART stock-outs continued to be a major system-wide issue, however nurses provided counseling to patients about other issues, even if there were no drugs to treat them. Some of the nurses felt that the continual stock outs affected their credibility, as patients lost trust in them. Aubrey described the issues associated with the lack of supplies:

> *'We are the people telling these patients never to miss taking their drugs and we are the same people not constantly supplying them with the drugs. Another challenge is that we don't have drugs, syrups, for the children who test positive. Mothers come here and because they don't get the drugs for the children some of them lose trust in us and they never come back. Sometimes we even run short of testing kits, some people come willing to test and know their stand [status] but they come here and we keep tossing them up and down, come tomorrow, come next week, and people get tired and end up not testing.'*

The nurses were aware that the drug shortage was nation-wide and beyond the control of the nursing staff. The government was responsible for its coordination, however the public might not be aware of this. Gabriella described the drug shortage at her health facility:

> *'Eeeehh----for instance when you have not given the patient Septrin and yet he doesn't have the money to buy it, you feel bad and you put the blame on yourself --- you feel really bad even if the blame is not brought by you but you feel it because you have not helped the patient and the blame is still on the government not to supply enough drugs.'*

Some nurses reported that patients thought that the nurses were stealing the drugs to sell privately. Paige and Colletta discussed this problem:

'Paige: And another thing, me I'm not satisfied, like, sometimes we normally get stock outs of drugs, and when the public complains they say the health workers take drugs, so that one alone, makes us thieves…
Colletta: You are thieves, you nurses? (Laughter all around)
Paige: …laughter… because these people never believe that drugs get finished, so when you have like, a small drug shortage, they see… they think every drug you're selling is theirs, yes. So when you tell a client or a patient there is no drug, they never believe, they know you are hiding the drugs, to go and sell, and they tell us.'

Protective equipment necessary to treat PLWHAs was also in short supply in rural Uganda. Nurses required protective gear, including gloves and masks, to prevent exposure to the virus during care. Without these necessary supplies, nurses faced a dilemma in providing care to PLWHAs. They put themselves at risk of exposure when equipment was unavailable. Autumn talked about the challenges she faced protecting herself:

'What I can do is to protect myself as I carryout those procedures, but still there's a challenge, I can talk about protecting myself and there are no gloves… I can't say I will buy gloves, I don't have enough, enough money… I can't put on a 'kavera' (polyethylene bag), but yet I am supposed to help that person. I can say there's still a challenge when we tell those mothers to at least come with a pair of gloves... when they go back they take it differently… they go to the sub county (office) and report that we are telling them to buy things, yet Museveni (Ugandan president) is saying everything is free… there's still a challenge.'

Nurses working with protective equipment shortages were expected to place themselves in danger of HIV exposure to provide adequate nursing care. The nursing staff were aware that the government was supposed to supply adequate equipment and supplies, yet during equipment shortages, the nurses were blamed by the patients for the shortfalls, contributing to the low public perception of nurses in Uganda.

Salary Issues.

The issue of nurse salary and remuneration was a contentious one in Uganda. Some of the study participants indicated that the nursing salary they were paid was not adequate, and was further proof that nurses lacked social recognition. Ava described the issue:

'If us, the nurses, can at least be facilitated with some more little finances as our lives are more at risk especially caring for these patients, I think at least the situation can improve. I feel we are at the forefront and have the upper hand in improving this situation, many people trust and believe in us but we really do a lot of work even out of our profession, but we are least recognized.'

Several participants also reported lack of pay commensurate with nurses' education. Olivia outlined the issue in a focus group discussion:

> '*I know someone who was a nursing aide before, a nursing assistant, and now she's a registered nurse or nursing officer, but they pay you as a nursing assistant for almost twenty years, still on that pay.*'

Not only were salaries reported to be poor, but they were sometimes not commensurate with a staff's training or experience, which could be demoralizing to staff.

Transportation Issues.

Transportation in rural areas was costly for both the nurses and patients, as there was no organized public transport and the road conditions limited travel in the rainy season. Study respondents identified two main issues regarding transportation: for the nurses to get to their places of work and subsequently to do follow-up care; and for the patients to get to the health centers. Poverty limited patients' ability to seek care as transport was expensive for those living far from health centers, and therefore most patients did not have adequate access to care. Poor patient outcomes were often the result. Cora highlighted some of the challenges to follow-up care:

> *'Another problem, like, ahh, exposed infants, when they come and we see the exposed infants, we get their contacts, but then in the due process, we fail to get means of making follow ups, like motorcycle, bicycle, or we fail to get means to get phone contacts because we are not facilitated with airtime, we fail to call, so therefore outcomes are poor.'*

The nurses ended up paying the cost of transportation to work and for follow-up care for patients, which was problematic due to the high cost of living in combination with poor wages for nurses. Gemma shared:

> *'And this one brings about the problem in caring for the patients because when the nurse is coming from far and they bring the patient who is badly off, and when transport is not readily available, this becomes difficult for her.'*

Poverty limited patients' ability to seek care because transport was expensive for those living far from health centers, and therefore most did not have adequate access to care. Audrey highlighted the transportation challenges:

> *'There are some patients who fail to get transport to come and pick up their drugs, so when we decide to follow them up they say 'forgive me I failed to get money to transport me' – but when we are going for follow up we go with their drugs because we have their files and names – when we get there we really see they are willing, but the problem is*

transport from the villages. So sometimes the hospital provides a vehicle to go and see that man or lady and him or her drugs accordingly.'

Transportation and the lack thereof, affected the ability of nurses to provide adequate care, especially for those requiring follow-up care in the community. Patients' poverty also affected their ability to pay for transportation to access health services, leaving a gap in care that was difficult for nurses on limited incomes to overcome.

Administration Issues: 'We Are Not Being Helped the Way We Should'

When administrative issues were discussed with the nurses, many study participants' emphasized dissatisfaction with the District Health Office (DHO), and were focused mainly on the availability of promotions. Some nurses were hired initially as enrolled nurses (EN), and continued on with their education to receive their registered nurse certificates. Despite this, they continued to work as an EN for years awaiting a promotion. Victoria shared: 'actually I am a registered nurse, but here in Kabarole I am working as an enrolled nurse… I have worked in that position for six years just waiting for a promotion that has not come.' Overall, nurses' felt that the lack of pay and promotions were symptomatic of a larger lack of acknowledgment and appreciation of nurses nationally, and further contributed to the frustration nurses felt as a group. The most commonly described issue related to the DHO was the perceived lack of promotions and training opportunities. Arianne described the lack of extra training as demoralizing:

'I for one say… the support we need is not what we get because with our field… I can say medicine is not static, sometime you would want to go and maybe take another course, and improve but when you get there they say no… So somehow we are not being helped enough and when we reach there, they try to discourage us, they push us down… if you don't force it you can't go. Those who are lucky and they force it, they push ahead. On my side I feel there's somewhere we are being suppressed, we are not being helped the way we should be helped.'

The staffing issues that have plagued Uganda have forced nurses to take on ancillary roles without supplementary pay, and have contributed to the nurses' perceived lack of appreciation by the administration. Autumn commented: 'We are doing jobs we are not supposed to do, according to our job specifications, the things we do are not supposed to be done by nurses, yet they don't consider us… they don't value us.' During the 2010 presidential election campaign, Uganda's President Museveni was widely criticized for giving large bonuses to all Members of Parliament in the country only weeks before the election, using the country's national budget as a

source of funds. During the interviews this issue arose. Some of the nurses highlighted this as being symptomatic of a system that did not value the contribution of health workers, yet rewarded the politicians. Mia illustrated the situation in a focus group discussion:

> *'…In Uganda, health workers are not considered to be important. Because if I can say, like, the member of parliaments, recently they were given 25 million (Ugandan shillings), their salaries were not put aside, their allowances were not there, but they were just given the 25 million, just in this recent time… but for health worker, they have just announced on the radio that they have increased their salaries, and yet it was just 10,000 (Ugandan shillings), and yet we are saving so many of the lives of the people, so I feel I'm not satisfied…'*

Most of the nurses suggested that the problems at the district level were symptomatic of larger issues within the health system, and that the DHO had little influence over the issues. Despite the training workshops, on the whole many of the nurses perceived themselves to be unappreciated by the district and higher levels of health administration. This contributed to a sense of frustration and feelings of demoralization among nurses.

The style of management arose as an issue affecting several nurses at many health facilities. Nurses worked diligently to provide the best care possible under difficult circumstances, yet were sometimes reprimanded by the administration for poor patient outcomes. Penelope described the management style on her maternity ward:

> *'Sometimes – in my department you find you have delivered about five mothers normally, very well the babies have scored highly, but at the end you get like one mother, as you monitor her, but at the end, that mother gets a problem. So the problem is that they will not consider the five you have delivered, but will only look at the problem that has happened… maybe the mother or baby has died… they will not appreciate the work done…'*

There was consensus that the supervisors tried their best to manage the issues affecting many of the health facilities. Some nurses reported a punitive style of management, in which nurses felt chastised by the administration rather than supported. Overall most of the nurses felt supported by their immediate supervisors despite dealing with workload and supply issues. Supervisors coordinated with other health centers to prevent drug and supply shortages. Caroline highlighted this effort in the following passage:

> *'Well, sometime back, we had a problem in maternity. By that time we didn't have, like, excuse me, cotton wool, gloves, and everything of that nature, and they had not yet sent us drugs from anywhere, so he [supervisor] had to go around, and beg from other health centers so that he could rescue us.'*

The Role of Non-Governmental Organizations and Private Clinics in HIV Care

Since the emergence of the HIV epidemic, NGOs have provided a large amount of HIV care in Uganda. However the methods used by NGOs to provide this care have led to issues arising with the public health system, including staff poaching. When an NGO moves into the area, they usually hire local staff, which are often paid better than the public system staff, especially the nurses. Ultimately this has led to a drain of staff from the public system. When NGOs were functional, most nurses would agree that they provided critical services to many PLWHAs, however their staff was often paid more than government staff. When NGOs programs ceased, gaps in care remained, leading nurses to pick up the pieces.

This situation was detailed in a focus group conversation:

> *'Charlotte: Yes, it's difficult, because now, this new program that's coming in, it's recruiting new staff, and we are the people to orient them to what they are supposed to do. These people when they are coming they are coming with…*
> *Hazel: No experience. But they have higher salaries…*
> *Harmony: Oh, (laughter)…*
> *Hazel: So we mentor them, we show them what they can do so that we can work as a team, we are forced to in fact to give them our knowledge…'*

Hanna described how this phenomenon affected the morale of nurses:

> *'For me I will talk about myself, I think we are not satisfied… because we see our fellow health workers working in NGOs getting paid lots of money, yet we are doing the same work over and over, so I feel we are not satisfied.'*

Some nurses felt that NGO provision of HIV care was contributing to a culture of recklessness with HIV, with some people believing that an HIV diagnosis enabled better access to health care. Audrey described the situation in one focus group conversation:

> *'Before I came to (this hospital) I was working with an NGO… that organization cared for those people, it would give them drugs and sometimes help them with clothes. Now the patients became so dependent to this clinic – when someone would get malaria and maybe we had no anti-malarials in the clinic, then that person would just go and die… would not bother to go and buy or try another clinic, but for them they assume when you get HIV, either the government or NGOs are supposed to give them free mosquito nets, free food, the government will take care of the children… which is a very bad culture which is developing within the sick people… So you find these services make some people not to mind saying 'after all if I fall sick the government will give me food, drugs and take care of me – my friend is sick but is better off, he's on drugs, gets free mosquito nets, has a jerry can of water, they give her transport to go and pick drugs.'*

The nurses depicted a culture of dependency growing from the presence of NGOs. Obviously NGOs contributed to HIV care for PLWHAS, especially in rural areas. However when NGOS poached staff from the public system, the remaining public staff felt demoralized from watching their colleagues receive higher wages. Both situations made working with NGOs difficult for the nurses.

Due to the public-private mix in the Ugandan health system, those able to pay for extra services could seek HIV testing and treatment at private clinics. Unfortunately, some private clinics provided a negative HIV results if the patients paid enough for it. Adelaide described this challenging situation:

> *'…you may screen someone and find they are HIV positive after carrying out all the tests because a person may not accept, saying it's not real, they will go to the private clinics and they tell them they are HIV negative, contradicting your results.'*

Private clinics sometimes used HIV testing as a source of profit. Adelaide mentioned in one focus group discussion:

> *'…those private clinics only want money, not minding about the life of patients and they are not really giving proper ways… you go, they say testing is five thousand shillings, you pay and you are given results – you are negative… there's no documentation in the private clinic.'*

Nurses in the study reported that private clinics accepted patient money in exchange for a negative HIV diagnosis, hindering proper management of the virus.

HIV Training for Nurses

Throughout the discussions, many of the nurses suggested that their current HIV training was limited, and some of the staff were not adequately trained in HIV care. Amelia outlined the impact of HIV training on patient care:

> *'Here are the challenges. Some of the staff are not trained for HIV, ART, drugs. So for me I think it's another challenge, if they are not trained, they do not have to work in the ART clinic. So me, I think, if they are trained… we need more staff in that ART clinic.'*

A limiting factor in nurses' HIV training was the lack of training facilities and training opportunities in Kabarole district. This limited the nurses' ability to receive further education and in return, higher pay or a promotion. Compounding these factors, training institutions were primarily located far away from their homes and nurses had to sacrifice family time in order to attend. Fiona illustrated the situation:

'I can talk about going for further studies… some of us we cannot go for further studies because of the little payment. Again, some of us who are married and have families, when you think of going to a very far place for studies, you find yourself failing and remaining on the lower cadre, yet you have the potential, but you remain [at a] lower cadre… there are no institutions in the district… we lack institutions around the district, if we had them and maybe they bring weekend or evening studies for some of us, that would help us…'

The Ugandan Ministry of Health has a policy of Continued Professional Development (CPD). This policy requires that staff from each facility be sent for training regularly and upon their return to the health unit they share what they are taught with other staff. While the concept of CPD is good in theory, many barriers to its implementation existed. Lorelei highlighted the challenges of peer learning:

'Continued Professional Development ---- like if you learn about something new --- you sit with your fellows and you tell them what you have learnt and those who have not understood, they will ask you questions so that whenever you get new knowledge, you share it so that you are all on board – this one can help because you can find only two people who are trained and most times it is only those two people who are always called because nowadays they are not bringing trainings ---- real trainings--- it is like refresher courses. So you find it's only those two people who are trained --- so it is good if you keep on sharing with them.'

Nurses considered training in HIV care very important but it was not consistently provided. Some staff did not receiving adequate basic training in HIV, and continuing education was not always available to staff. When training was provided, often the same staff was chosen to go repeatedly, and upon returning did not share the information with their fellow staff.

The Role of the Uganda Nursing Council and Nursing Union

As in most countries, the Ugandan Nursing Council maintained standards for practice, and was the licensing and disciplinary body for all nurses working within the country. Olivia outlined the role of the council in one focus group session, saying: 'most of all, it prepares examinations for all the nurse graduates, it gives license to nurses who work, it licenses you to work. It also enforces the conduct of nurses.'

Kabarole District is located in the far western area of the country, several hundred kilometers away from the capital of Kampala, where the Council was located. Most of the nurses were critical of the function of the council, which they felt was too far from Kabarole district to have any real effect. Lorelei believed that the council focused its efforts on nursing conditions within the capital region:

'…it's always there above, taking our views, our problems, but sometimes it doesn't reach the grassroot… it stays there, up, and those who don't put in the membership they are left aside without knowing what it does and how it helps… these days they no longer carry out workshops nor provide information to the new nurses coming in. So, it becomes difficult for someone to join something she doesn't know.'

The Uganda Nursing Union, separate from the Council, was intended to provide advocacy and support for nurses. However, the majority of nurses, when asked whether the union provided any support for nurses, answered with one word, 'no.' Many of the nurses were unsure of the function of the union, as highlighted by Addison: "I hear about it but I really do not know much… I don't have any information or any idea, I just hear it in words." Both the Nursing Council and Union of Uganda seemed to reinforce a system that was out of touch with rural nurses. This contributed to the nurses generally feeling unheard and underappreciated rather than having a source of support and advocacy, as intended. This was counterintuitive to their intended purpose and goals.

All of these structural factors within the health system influenced the level of support and stress nurse's experienced in their day-to-day work. Critical drug and equipment shortages limited the nurses' ability to provide adequate patient care. Similarly, limited support and involvement of the health administration diminished the support nurses could rely upon to provide patient services and mitigate the effects of the systemic shortages. Nurses were left to coordinate care and rely on themselves to fill the gaps left in the system.

Struggle: Social Factors and HIV Care

The nurses identified several social factors as the leading causes of stress for nurses caring for PLWHAs: poverty, stigma and denial of HIV/AIDS, and gender inequality of women in Ugandan society. These factors are interdependent, interwoven and interact with one another.

Poverty

The poverty experienced by many PLWHAs was a limiting factor in their ability to maintain their health. Poverty limited their ability to pay for drugs and necessary tests, manage opportunistic infections, afford nutritious food, and pay for transportation to health centers. As many of the individuals in the Ugandan rural countryside are subsistence farmers, many nurses in this study found their patients' poverty played an important role in their lives.

Inability to afford drugs

For patients living with HIV, their inability to afford their medications could mean the difference between life and death. These drugs, both the HIV medications and antibiotics used prophylactically to prevent opportunistic infections, were often out of stock at public health centers. Patients were then forced to buy the drugs from private drug stores, which was not possible for many. Sophia described this problem:

> *'According to the level of health center two, we have a problem of Septrin prophylaxis, they (the government) give us very few Septrins… You counsel a person, tell her she's to take Septrin for the rest of her life and you will be coming here to collect it and the day she's here you don't have it… so when she comes and doesn't find the Septrin she goes back unhappy, telling you she has no money to buy…'*

Nurses often had to turn patients away empty handed. Patients sometimes become upset due to the shortages, which ultimately could affect the nurses. Haley recalled:

> *'And when they come you tell them there are no drugs especially Septrin – and there are some of them who are not even able to buy it --- some of them end up crying and you also feel bad and yet you don't have any way you can help that person – you don't have any other words to tell that person who is crying and doesn't have any money at home – so emotionally you also get affected.'*

Nutrition

Many rural PLWHAs are subsistence farmers, growing enough crops to feed their families with little to spare. Sometimes adequate nutrition was problematic to PLWHAs, as detailed in an interview with Arianne:

> *'The other problem is because they are poor, their diet is also poor. Much as we are trying to give them the drugs, but sometimes you really see the person you are giving a strong drug [to] has no food. You ask if he/she can get an egg or a hen… no. You ask if he or she has somewhere to get local nutrition that doesn't require spending… someone says no… this makes adherence become a little bit poor, even the patient doesn't respond so well as you would have expected him or her to respond.'*

Due to the nature of the HIV disease process, inadequate nutrition can affect a patient's health status. Nurses advised these patients to supplement their diets with local foods when possible. Victoria describes the situation at her health unit:

> *'Many of them are willing to take the drugs but some reach a time and stop taking them… they come here and when you look at them you feel petty when you ask. They say they are taking their drugs but you still see they are deteriorating… and when we go on talking about nutrition they agree they are not taking the right meals and on time. Some complain about having no money to buy the food… we advise them on using the local foods.'*

Nurses were aware that many of their patients must choose between paying for their HIV treatment and having adequate food. Yet nurses continued to counsel their PLWHAs to eat well using local foods to supplement their diet. However when they saw their patients deteriorating, nurses had few resources available to help their patients.

Faith

Nurses found that some of their patients became overwhelmed as a result of their positive HIV diagnosis. In turn, patients sought solace in the haven of their beliefs, turning to prayer for support when the system failed them. After an HIV diagnosis, some people put their hope in their faith rather than treatment, as Savannah described:

> *'…but another big problem is that people in the village trust so much in God and yet God will not help them unless they have helped themselves first… they will not test or will test positive but will not take the drugs but instead will go for prayers… if we get to such people we advise them about coming to hospitals and to get the right treatment.'*

Relying on faith in the battle against HIV may give some patients' comfort and hope. But prayer alone was not sufficient to improve health outcomes and it posed a challenge for nurses to convince patients to seek treatment.

HIV Stigma and Denial in the Community

Stigma and denial played important roles in patients accepting their diagnosis, disclosing their HIV status and accepting treatment. Many patients were afraid of their partners and family finding out their positive HIV diagnosis, and kept their diagnosis secret. Some denied their diagnosis until it was too late. Ava described some of the challenges related to denial:

> *'The biggest problem we have is denial, most patients never accept they have tested HIV positive, so they keep on testing many times and from different places and by the time they accept they are very sick and sometimes they die… another problem is stigma. The common ties (family and friends) still point fingers to these patients blaming them for being careless with their lives and this has made treatment and adherence very poor, and this has led to stress as these patients think that's the end of life.'*

Patients were reluctant to accept their positive status, afraid of the fallout from having their families and friends discover they were HIV positive. Lorelei highlighted this issue:

> *'The biggest problem is after the patient has begun taking the treatment then they begin withdrawing from the community. She doesn't want any other person to see or know… that's what is causing us a problem because these people don't want to come at the same time and sit together… we encourage them that would help others also to know that there are services, that you can live with HIV. The level of stigma is still high, actually previously they used to come very late in the evening or very early in the morning - he/she has come wants to use the behind (back) door, so it's taking them a long time... Sometimes as we give health talks you want to encourage someone to say something, but will say "no, no… I don't want my neighbor to know." You say what if you are very weak and can't send somebody to pick the drugs? They still say no… the stigma is still intense.'*

Nurses struggled to encourage patients to accept their diagnosis and live positively, disclosing their status to their friends and family in the hope they would receive support. PLWHAs that were not willing to disclose their status might transmit the virus to their spouse or other sexual partner, contributing to the spread of the infection within the community. Zoe described this challenge *'...when they are tested positive, they don't want to disclose either to their parents or any caregivers, so they keep on spreading the infection.'* When patients did accept their diagnosis and begin treatment, their health was often regained. This is known as the Lazarus effect, as patients seemed to have returned from the edge of death (Walton et al., 2004). Once treatment became effective, PLWHAs often looked healthy but continued with past behaviors without disclosing their HIV status. Sophia described the 'downside' of ARTs:

> *'Me, I think ARVs have also brought a problem of their own, because when people improve they go back to their past behaviors… there has not been behavioral change as how we were expecting. We counsel them, they accept to deal with behavioral change, after getting*

fine, they change… go back to what they were doing. I don't think there will be a change, every time the gap is going up, and especially with Kabarole (district).'

The behavioral changes emphasized in previous HIV campaigns had not translated into long-term changes in behaviors in Ugandan society. Nurses continued to emphasize behavioral change in addition to HIV treatment.

Stigma has a powerful influence over patient disclosure, and can cause some patients to hide their diagnosis and their HIV medications from their partners. Women especially hid their diagnosis from their husbands. Alexander described his experience in one focus group session:

'…we get a challenge when we test mothers and a mother tests positive – yes, there's a provision for mothers but then these other people… the men, older people… so if you enroll a pregnant mother and don't enroll the husband… first of all disclosure will be difficult, the adherence to the drugs – if she has not disclosed it means she will be swallowing her drugs under the bed… (Laughter)… that's a big challenge… men's involvement is not encouraged.'

Nurses continued to counsel their patients to disclose their positive status, balancing the confidentiality rights of the PLWHA with the safety of their sero-negative partner. Catherine described the issue of gender imbalance:

'…the wife is HIV positive and says don't tell the husband, the husband tests positive but warns you never to tell the wife… things are all challenging, it's difficult to get them together and talk about it… you have to observe confidentiality, we are meeting such a challenge as well.'

When dealing with discordant couples nurses faced a challenge encouraging partners to disclose to their spouses:

'Caroline: Yes, there's another problem we normally get in maternity, with mothers who come alone without their partners, and you find that this mother is positive. Most of them don't want to disclose to their husbands, eh. And at times it becomes difficult for these mothers to attend to get these drugs.
Colletta: How, how does it become difficult?
Caroline: Okay, they fear, eh, they fear to take those drugs because their partners don't know they are positive.'

Gender Inequality

The lower gender status of women in Uganda meant most women tended to be married and that women were generally dependent on their husbands to support them. Many young women of

marrying age stopped taking their HIV medication to hide it from their future spouse. Paige described this situation:

> *'Another situation, is about the adult clients, these adults, most of them got the infection from their mothers, when they grow up, especially girls, at one time, they will stop ARVs, they will get married, and most of them die. I think in our clinic, we've lost I think four, five… when they grow up, they reach somewhere, then they stop ARVs, then they die, all they want to do is get married, so most of them they stop…'*

The combined effect of poverty and gender disparity meant that when women were diagnosed they might be blamed for acquiring the virus and lose the support of their husband, support that they required to survive. Isla discussed the issue of gender imbalance:

> *'In fact another stress, maybe it goes from poverty. Most of our mothers, most of them depend on husbands, without a husband she cannot make herself stand. So if you tell a mother to go and explain to the husband that she's positive, she automatically knows that she will be, she will be chased away from the home, which is a failure of life. So when you explain and the mother tells you about her story, actually you feel stressed, and pity for yourself and herself, yeah.'*

Lack of men's involvement in prevention programs has been problematic in the past, and has contributed to poor outcomes for the women in their lives. Women with HIV may not be able to take their medication openly, be kicked out of their homes, or even killed if their husbands find out about their status. The challenges related to engaging men were discussed in the following conversation:

> *'Cora: There was a mother, but she died last week actually, but the baby has grown, the baby is two years, and she attended antenatal, they just followed her since she was found to be HIV positive, they gave her Septrin and followed her, but she refused completely, she'd say that 'ah my husband, for us there is this belief of the "sacca" we believe that this medicine, whatever, it does not cure, my husband can beat me, he can even kill me if he sees me taking these drugs.' We try to explain to her to do what, the woman completely refused, and I heard last week that she died, but she completely refused…*
> *Mia: I think this is due to the lack of the husband's involvement, and it is hard to bring it about…'*

Additionally, the focus of HIV prevention programming has been women and children, further limiting men's involvement:

> *'The major problem or challenge I see is that most of the organizations that come into assist put more emphasis on women and children and that brings bad feelings in men because they feel left out and that's why they say men don't care, it's always the men who are bad… all the emphasis is on women and children… that's a big challenge considering men's involvement.'*

Nurses had the responsibility to counsel women to disclose their positive HIV status to their partners, while knowing that doing so might put the woman at personal risk from her partner. Nurses were aware of this dilemma, yet continued to counsel patients to live positively, disclose their status and be advocates for themselves within their community. Nurses must continue to encourage men's involvement in HIV prevention programming.

Failure: Impact on nurses, and the continued spread of HIV

Failure emerged from participants as a common theme in HIV care: nurses failed to provide basic care for patients with HIV and watched their patients struggle. As a result of this failure, the nurses experienced stress from their workload in the struggle to provide care to these patients.

Failure of life: Poor patient outcomes

Although many nurses were aware of the policies in place regarding HIV care, systemic issues played a role in preventing nurses' ability to provide adequate care. The influx of PLWHAs, coupled with the lack of staff and resources, has resulted in the poor care of patients. Nurses saw firsthand the consequences of the failure of the health system to stem the tide of HIV. Failure emerged as a common word used by the nurses to describe the current state of HIV in their region. Natalie and Colletta described the lack of follow-up care for patients as a personal failure:

> *'Natalie: Yeah, those are the challenges we are meeting at our health unit. Even you find, you assist a mother who is HIV positive, and even we fail her when we follow her. That's also a problem, we don't have means of following our patients.*
> *Colletta: What do you mean following them up?*
> *Natalie: What I mean is receiving them in their homes.'*

Some nurses perceived that they failed to help individual patients when some patients were not accepted into programs that were full. Catherine described her thoughts on the situation:

> *'Recently a certain woman was calling me, wanting to enroll her nephew… the nephew had full blown AIDS and when he came to Virika (hospital) to be enrolled, but they told him they are full and yet they had sent him from Kampala to be enrolled in Fort Portal but reaching here they told him they are full - so the man is stranded… he's stressed, psychologically he's not thinking. There's no way forward, Virika (hospital) sent him to Yerya (health center) and they had written on his forms some specific drugs he would take and Yerya they were just saying… 'come tomorrow'… there's no one to stand in the gap to help him. Psychologically he's disturbed and there are many people like that.'*

When discussing the state of HIV, some of the nurses felt that the situation was deteriorating. Many nurses saw this situation as a failure of the health system, some as a personal failure. Various structural, social and contextual factors played a role in influencing the care PLWHAs received, however poor quality of care was the result. Nurses had little control over these factors.

Work Stress

Nurses continued to empathize with PLWHAs but had little control over issues within the health system, such as drug shortages. Ultimately, nurses felt they had a moral obligation to ensure their patients received care, and became morally compromised when care was inadequate. Autumn outlined her perspective:

> *'As a service provider I don't feel well because I have not done my duty… I feel there's a gap between me and my patients… most of our patients are illiterate, they can't understand why we keep promising maybe to keep the mother in touch and saying 'Go, come back after two weeks' and such things, but when you try to put yourself in that patients' picture, you find you are really touched. As a service provider I find I have not done my work as I am supposed to do it.'*

The nurses' lack of control over these issues contributed to a feeling of helplessness over the situation their patients faced:

> *'Abbie: Sometimes these patients abuse us, they tell you that 'if you knew you don't have the medicine, you don't have the drugs, why did you test me? Now we are going to die, what, what,' they start complaining.*
> *Colletta: They start complaining…*
> *Cora: And you don't have anything you can do for them.'*

The feeling of helplessness contributed to staff becoming disheartened over time. Lucas described his feelings of stress when there were no medications:

> *'As a service provider at times I feel demoralized. I also feel stressed up because there are scenarios when you leave this place when so stressed and even feel a headache… you just reach home when not in your moods, but personally I have ever felt demoralized. When you diagnose people and they have to do CD4 assessment but there's no money… so I feel as if I am not doing my best… this person looks at me as a person supposed to help him… so I feel demoralized.'*

Many nurses expressed frustration with the elements of the health system that were failing the patients, such as the short supply of medication and equipment. Aubrey outlined her feelings in an interview:

> *'I feel so bad, I feel hurt… our patients complain, lose trust in us, others deteriorate and die and after that these people and the offices start saying we are not working. It's very bad and unfortunate. How shall we work if they can't supply us with necessary equipments?'*

Nurses were aware of the care that PLWHAs required, however were sometimes unable to provide this care, due to lack of resources or staff shortages. The result was a situation in which

nurses felt helpless to assist their patients, and blamed themselves for the poor care given to patients. Nurses became emotionally affected by the situation, eroding morale overtime. This may have contributed to nurses leaving their posts or seeking employment outside the field of nursing. Anecdotally, after each focus group session and several of the interviews, the participants in the study asked me how they could come to Canada to practice nursing.

Resilience

Despite all of their struggles, the nurses in this study continued to serve the PLWHAs in their communities, even with overwhelming shortages of resources and institutional support. The nurses outlined the systemic issues that resulted in PLWHAs experiencing poor outcomes. The nurses themselves experienced stress from their work and sometimes expressed a desire to leave their profession. Nurses used teamwork and coordination to combat systemic shortages, and shared that their faith motivated them to continue to serve their patients and be a part of their community.

Pushing Through: Teamwork

As with most nurses, working together to solve workplace issues was a necessary part of the job. In this case, with the heavy workload, teamwork became not only a necessity of care provision but also a source of support. Paige described the teamwork in her work place:

> *'What has kept me working is, one, actually teamwork, like when you are near actually exhausted, a colleague tells you what you are supposed to do and counsels you on some other difficulty, and guides you, they give us this guidance so you can go on and keep going.'*

Coordinating the workload with other team members also seemed to help relieve some of the burden of work. Lucas described:

> *'…we agreed that if we can work together as a team, we can do a lot of work and that's mostly what we do. For example, if we are doing HIV testing, I can divide the work, since I am prescribing, so and so can do the counseling, and so and so do the testing and that's how we help each other or how, how my colleagues also support me.'*

Working in rural areas required creative problem solving, as resources were often sparse. Coordination therefore occurred not only within health centers, but also between them. Fiona and Colletta described this spirit of cooperation:

'Fiona: I really feel bad and in most cases we have borrowed from other health centers, that's how we have managed, we borrow from nearby health centers…
Colletta: Don't these health centers also get stock-outs?
Fiona: They also do, and sometimes they also come to our own clinic and we give them… it's a problem almost in the whole district… we even go beyond, up to Kaswa, Kabarole hospital or even Fort Portal hospital and in case they also get such a problem, they can also come to us… we all coordinate.'

Through the coordination of care between staff and health units, nurses relieved the impact of drug stock outs while easing some of the burden of work at the individual units.

'We Are Here to Serve': Dedication to Community

One of the main motivators for the nurses was the commitment they had to their jobs and their community. Not everything that happened in HIV care was negative, and the patients that did begin recovery encouraged the nurses to continue working. Lorelei spoke about the rewards of providing good care:

'When you get results ---- good results from your work you just feel you should continue. Like if you started with a patient who was down and you see this patient tomorrow --- and he is moving and says thank you "Musahu" (Doctor) --- you feel great and that you should continue and bring people up.'

Commitment to the communities in which they lived and served was another motivator, as the nurses saw themselves as part of the same community as their patients. One focus group conversation highlighted the nurses' relationship to their community:

'Abbie: Again, you have to keep coming because, eh, these people, the community, it's where we live, we are part of them.
Colletta: You are part of them?
Abbie: Yes, so we cannot drop them, we have to help them, yes.
Cora: We are a community as well as nurses.
Colletta: You are community, eh?
Cora: Even one day, you will be like that patient… (Laughter)…
Hanna: We are working, we are here to serve, and you forget all the bad things… (laughter)… and we continue to do our jobs, because we have chosen to serve.'

Nurses empathized deeply with their patients, and many nurses hoped that one day a cure to HIV would be found, although they were realistic about its development. Arianne summarized her hopes for the situation:

'The belief is that maybe the situation will change as researchers continue to do their work, but what makes me feel helpless… almost all the patients… for how long will our patients stay taking drugs and waiting for a cure to come at one time? Actually with that

feeling you just sit and look at somebody and then imagine so many will have gone by the time we get the cure. So it makes you really helpless but of course you are faced with a situation where you are seeing somebody in that situation and you don't have to discourage that person… it's kind of as if you are bearing that deep in you… There are some patients who have taken up positive living… at times they make fun, saying the cure will come… it's true we also feel discouraged somehow.'

Nursing as a 'Call from God'

Faith is an important part of Ugandan culture and helped the nurses stay motivated. They felt it was their calling and duty to God to serve their patients. Several nurses throughout the study referred to their positions as a 'calling', and some described it as a 'call from God.' Aubrey described the role of faith in nursing:

'True, compared to what we go through… if it was not for God's will the most of us would have run away from this profession. Recently people have joined the health sector thinking there's money and others have run away and the few that are still in the sector have lacked commitment and there are the people not fulfilling their work, they get disgusted very fast.'

Some of the nurses felt that nursing was a mixed blessing, and that those who practiced in faith were better care providers. Lucas described his perspective:

'A call from God, yes and no. The yes part of it is that somebody who's called by God or a call from God after pursuing your career, even when you are in the field there's a way you always have that heart of humanity, even if you are tired or what and see someone badly off and needs help, you first forget about your fatigue and attend to that person. But with the no part of it, there are those I think are there by mistake, because a person will leave a person to die and goes away, I don't think that is a call from God. Actually I say that this profession is inborn. Yes, you can train, but if it's not within you, you'll totally fail to perform your duty.'

Ultimately many nurses kept working out of a sense of duty to their profession and their community. Their faith gave them hope to keep going, day after day. And despite all the overwhelming challenges, most nurses remained hopeful of change in the future, especially for a cure for HIV and AIDS.

Discussion

The objectives of this study were: (1) To understand nurses perceptions of the quality of care provided for PLWHAs in rural areas; (2) To identify aspects of HIV care that contribute to the nurses' excessive workload; (3) To identify various forms of stress (emotional, physical,

mental) experienced by nurses providing HIV care to PLWHAs; and (4) To assess various forms of support for rural nurses, including support at the institutional, communal or individual level.

This study produced results similar to previous research on nursing in high HIV-prevalent areas of low-income countries, contributing to our understanding of the unique challenges faced by rural nurses working in these areas. The theme of *responsibility* emerged when nurses in this study reported feeling responsible for being unable to provide an adequate level of care for PLWHAs. This challenge to care arose due to a variety of health system and social factors. Nurses *struggled* to care for patients in the midst of critical shortages of essential HIV drugs, staff and supplies. In addition poverty resulted in many patients struggling to care for themselves when the health system could not. Stigma and denial contributed to patients hiding their status and as a result spreading the disease within the community. Nurses reported that they had experienced a *failure* to care for the patients with HIV and AIDS, and as a result had to watch their patients struggle with their illness. The theme of *resilience* emerged when nurses felt there was little they could do to improve the outcomes for their PLWHAs, yet continued to work in challenging circumstances. The results of this research will be discussed in the following sections.

Responsibility: The Impact on Nurses of Health System Shortages in HIV Care

Overwhelmingly, the nurses in this study reported having a heavy workload due to the influx of patients with HIV. Many of the nurses also reported inadequate numbers of staff to manage the volume of these patients. Lack of staff and heavy workloads for HIV nursing care are linked in complex ways. For instance, it could be suggested that without the added weight of HIV care, nurse-staffing numbers would be adequate in Kabarole district. However, as a result of a combination of these factors, nurses are often unable to provide basic services to their patients with HIV. These findings echo the results of a Ugandan study (Dieleman, Bwete, et al., 2007) to explore the impact of HIV patients on nurses working at rural hospitals. These authors reported an increased workload for nurses, due to both the influx of patients with HIV, and poor staffing levels. Similarly, Fournier and colleagues 2007 study found that nurses in urban hospitals felt unable to provide adequate levels of care to their patients with HIV due to heavy workloads and lack of staff. Studies of HIV nursing in other sub-Saharan African countries have also reported similar findings (Delobelle et al., 2009; Dieleman, Biemba, et al., 2007; Harrowing & Mill, 2010; Mavhandu-Mudzusi, Netshandama, & Davhana-Maselesele, 2007).

The majority of past studies have focused on the experience of nurses working in urban hospitals or large hospitals in rural areas. Staff working in rural health centers in Uganda have higher staff vacancy rates than their urban counterparts, and work under even more severe staff shortages (Uganda Ministry of Health, 2010). Few studies have investigated the impact of HIV on nursing care in rural health centers. Future research must focus on reducing the workload stress of Ugandan nurses and developing a culturally appropriate instrument to measure nurses' workload stress.

Struggle: The Intersection of HIV Stigma and Nursing Care

The impact of stigma on patients with HIV has been well documented in Uganda and other sub-Saharan African countries. Research into this area has centered around patients with HIV facing stigma and discrimination (Rankin, Brennan, Schell, Laviwa, & Rankin, 2005). Several studies in sub-Saharan countries have reported nurses demonstrating discriminatory behavior against patients with HIV and a hesitancy to report a needle-stick injury, as the result of a lack of HIV knowledge and training, a lack of resources, and fear of contagion (Mbanya et al., 2001; Mill et. al., 2013; Mill, Nderuitu & Richter, 2014; Walusimbi & Okonsky, 2004). Fournier and colleagues (2007) reported that when the patient's sero-status is unknown, the fear of contagion may contribute to altering the nurse's behavior and practices, and may contribute to nurses avoiding or denying patient care. Nurses in the current study reported that many of their patients hid their HIV diagnosis, from both family and nursing staff, based on their fear of discrimination. Further research may be warranted to explore the lack of resources in rural areas and their resulting effect on HIV nursing care.

In Uganda, all women receiving antenatal care at a public health facility receive a mandatory test for HIV; there is no mandatory testing for men, although it is available upon request (Uganda Ministry of Health, 2010). Nurses reported that both men and women hid their HIV diagnosis, fearing the repercussions of stigma and discrimination. Women in sub-Saharan Africa are especially vulnerable, as their families often abandon them upon discovery of a positive diagnosis (Mill & Anarfi, 2002). The lower gendered social and economic status of women in Uganda make them particularly vulnerable to domestic violence, and may be a contributing factor to women hiding their diagnosis (Young, 2010). Participants reported providing counseling for patients to live positively with their diagnosis, to inform their partners and to begin treatment. Walusimbi and Okonsky (2004) reported that when resources are scarce,

Ugandan nurses might only be able to provide "emotional, spiritual and physical support for their patients" (p.98). The nurses in the current study also recommended that HIV prevention programming also be targeted towards men, as most programs are currently geared towards pregnant mothers and children. This suggestion is echoed by a recent study in Kabarole District, which reported a need for male-specific programming to combat the higher than national average HIV rate in the area (Rubaihayo et al., 2010). The continued inclusion of men in HIV programming may help both men and women combat the stigma associated with the virus, perhaps helping to mitigate its spread. Further research is needed to develop strategies to implement male-specific HIV programs and to evaluate their effect on stigma and HIV rates in rural Uganda.

Failure: Moral Distress and the loss of Trust in Ugandan Nurses

Nurses in this study often used the term 'failure' when discussing their ability to care for PLWHAs. The nurses provided examples of their inability to care for individuals when they were short of drugs and supplies; they described situations when they failed to provide adequate testing for HIV and had to turn patients away without knowing their diagnosis. Nurses also reported a failure to provide adequate PMTCT, resulting in children becoming infected with the virus. Overall the nurses reported a large-scale failure to mitigate the spread of the HIV infection within their community, although most felt they knew what was required to contain the illness. As a result, some of the nurses reported that their patients had experienced poor outcomes, and felt that the public had lost trust in them.

In Uganda, the inability of nurses to provide comprehensive nursing care has led to nurses developing high levels of work-related stress (Nabirye et al., 2011), moral anguish (Fournier et al., 2007), and moral distress (Harrowing & Mill, 2010). Nurses experience moral distress when they are unable to provide adequate care to patients through no fault of their own (Jameton, 1984). The experience of moral distress has been explored in a variety nursing environments, including ICU and critical care (Embriaco, Papazian, Kentish-Barnes, Pochard, & Azoulay, 2007), mental health (Austin, Bergum, & Goldberg, 2003; Deady & McCarthy, 2010), peri-operative and medical/surgical units (Cox, 2008; Rice, Rady, Hamrick, Verheijde, & Pendergast, 2008; Salmond & Ropis, 2005), rural and long-term care (LeSergent & Haney, 2005), military nursing (Fry, Harvey, Hurley, & Foley, 2002), oncology (Toh, Ang, & Devi, 2012) and HIV care (Kalichman, Gueritault-Chalvin, & Demi, 2000; Harrowing & Mill, 2009).

Nearly all of the research on moral distress in nursing has been conducted in North America and Europe. In these instances nursing care focused almost completely on providing life-saving measures, which is often not the focus of rural nursing care in Uganda. Thus, moral distress among nurses in low-income countries may need to be conceptualized differently given the different nursing contexts.

Moral distress in nurses has been shown to contribute to physical and emotional symptoms, as well as problems in the professional realm. Several nurses in the current study reported feeling tired, having headaches, feeling 'stressed up,' and demoralized. These results coincide with physical symptoms, including headaches, fatigue, and sleep disturbances, reported from previous studies on nurse moral distress, (Austin et al., 2005; Corley, 2002; Edward & Hercelinskyj, 2007; Gutierrez, 2005; Schluter et al., 2008). Psychological and emotional symptoms of moral distress have included anger, guilt, self-criticism, fear, discouragement, disgust, frustration, sadness, and despair (Austin et al., 2005; Corley, Minick, Elswick, & Jacobs, 2005; Gutierrez, 2005; Sundin-Huard & Fahy, 1999). These symptoms mirror the symptoms experienced by some of the nurses in the current study. An investigation of the different symptoms that are experienced by nurses working in low-income rural areas with heavy HIV workloads is warranted.

Some nurses in this study reported a feeling of helplessness for their patients with HIV. The feeling of helplessness when caring for patients has been previously documented as a symptom of moral distress (Edward & Hercelinskyj, 2007). Professionally, nurses experiencing moral distress have also reported a lack of concern for patients or capacity to care (Nathaniel, 2002), a loss of professional integrity (Robinson, 2010), and burnout or interest in leaving their position or profession (Fournier et al., 2007; Sundin-Huard & Fahy, 1999). Harrowing and Mill (2010) have suggested that the poor public perception of Ugandan nurses is a potential source of moral distress. The status of nurses in Uganda has recently been compromised by President Museveni who accused nurses of stealing drugs to sell for profit (Kagumire, 2011). With the credibility of nurses in question by the government for which they are employed, it may become difficult for nurses to be motivated to continue working in their positions.

Many nurses in the current study felt that they were underpaid compared to other public servants. In addition they were often blamed for health system issues, such as drug shortages, that were not their responsibility. The professional working environment for Ugandan nurses may

contribute to nurses feeling demoralized, and may result in nurses leaving their positions for better paying positions in high-income countries, or leaving the profession altogether. Most nurses in the current study reported feeling committed to serving their communities, while at the same time asking how they could become a nurse in Canada. One Ugandan study (Nguyen et al., 2008) reported that the majority (70%) of nursing students in a large nurse training academy would prefer to work outside the country. In addition they intended to migrate to either the United States [US] or the United Kingdom [UK] within 5 years of graduation. Intention to migrate continues to be a serious issue with nurses in Uganda. With a critical shortage of professionally trained health staff, and a continually growing number of patients with HIV, Uganda cannot afford to lose any nurses. Policies addressing recruitment and retention are required to prevent the loss of invaluable nursing staff. Further research in this area should focus on interventions to improve the public perception of nurses in low-income countries such as Uganda, to attract new nurses and to help maintain current staffing levels.

Resilience: Room for Improvement

Part of this study explored nurses' suggestions for improving the situation with patients with HIV. Nurses in the current study reported being poorly paid compared with other civil servants. These results reflect a study of Sub-Saharan African countries (Chen et al., 2004), which reported that the health system funding for front line health workers, especially nurses, is insufficient and requires an increase. Buchan and Calman (2004) indicate that the use of financial and non-financial incentives would increase nurse recruitment and retention in low-income countries. Hagopian and colleagues (2009) reported that Ugandan health workers were interested in better pay, better staffing and decreased workload, and more participation in organizational decision making. Richter and colleagues (2013) suggested that there is an urgent need for nurses to be involved in HIV policy development, and for that development to be supported by management. The is a need for better recruitment and retention strategies, however funding for these strategies may limit their implementation.

The Ugandan Ministry of Health has recognized the need to address nurse recruitment and retention, and in 2008 developed a strategy to address human resources for health issues (Uganda Ministry of Health, 2008). This strategy sets out measurable and time-sensitive goals for a number of initiatives, from better salaries and benefits for staff, to safe work environments. Despite these goals, the funding required to implement these strategies has not become available,

and the reality is that Uganda's health system is chronically underfunded. Currently, health system funding is approximately 9.6% of GDP, significantly below the 15% promised under the Abuja Declaration to be implemented by 2015 (Zikusooka, Kyomuhang, Orem, & Tumwine, 2009). Recent political issues arising in Uganda surrounding anti-gay legislation have caused several donor countries, including major donors in the US, UK, and Denmark, to redirect funding out of the governments hands (Mahoney, 2014). The result is unstable and unpredictable funding for health system requirements, with no improvement in sight for the front-line health workers.

Non-financial incentives, including HIV education and workshops, were also recommended by nurses in the current study to promote worker motivation. Although the Ugandan Ministry of Health has a policy on continued professional development (CPD), many of the nurses in this study were not chosen to attend CPD workshops. Continued education has been reported to be a mitigating factor in moral distress among nurses in Uganda (Harrowing, 2009). Dieleman and colleagues (2007) also reported the benefit of educational sessions for nurses caring for patients with HIV. The provision of regular, consistent educational workshops and sessions for all nursing staff would provide a two-fold benefit: 1) all staff would be able to provide care to PLWHAs which could offset the nursing workload in regards to HIV care; and 2) education sessions could improve the morale of staff. In the absence of increased financial benefits for staff, public health planning should focus on improving nursing education, including the provision of regular, consistent HIV training to all staff. Further research into this area could include the level of HIV education necessary to mitigate the stress from HIV nursing care, as well as the timing of continued training workshops.

Many nurses in the current study described 'a call from God' as their reason for entering the nursing profession. Other studies have similarly reported faith and religion as sources of support for nurses (Dieleman, Biemba, et al., 2007; Meltzer & Huckabay, 2004). Some nurses in the current study felt that nurses who were not 'called to serve' were not nursing for the right reasons. These nurses felt that their calling was a duty, and they were chosen for the profession. The nurses chose to focus on their duty rather than their workload in order to cope. The use of faith and religion by nurses may have a positive impact on nurses' ability to cope with their workload; more research may be needed to understand this coping strategy.

Strengths and Limitations of the Study

The data collected in this study reflects the experiences of nurses working in one district in Uganda. The conclusions drawn from this study may not applicable in other cultural or social contexts. However, with a large sample size, and respondents from every level of health centre, the results are likely reflective of the nursing situation throughout the Kabarole District. The primary researcher was Canadian born and English-speaking, and data were collected in an area where the main language was not English. The subtleties and nuances of the Rutooro language had to be elucidated by the research assistant. However having the interviews and focus groups conducted in English allowed the researcher to participate in the conversations taking place. It is possible that the primary researcher may have misunderstood data collected in Rutooro.

The nurses in this study were sampled purposively, and there were a variety of participants from different backgrounds, gender, ages and working situations. Despite this there may be sampling bias in the type of nurse that responded to the request for an interview or focus group session. Additionally, the use of money to reimburse participants for their transportation costs as needed may have affected study recruitment, in an area where poverty has very real consequences.

Having a white western woman conduct research in rural Uganda may have created some power-imbalances that influenced study participation. Having an outsider conduct the research may have been of benefit to recruiting participants, as an outsider may have been seen as less influenced by the poor perception of nurses often held by local Ugandans. The interpretation of results may likewise have been affected by the cultural background and context of the researcher. Despite this limitation, the analysis was rigorous, with all transcription and analysis completed by the researcher. It was thought that because the researcher came from a nursing background in Canada, some nursing experiences might be shared with the participants.

On a personal note, this study was challenging both operationally and emotionally. While being in Uganda, it felt as if many road blocks had to be overcome, from obtaining the required ethics approvals, shifting from a mixed methods to a purely qualitative study, finding a suitable research assistant, and collecting large volumes of data in a short amount of time. Emotionally, this study was most challenging after returning back to Canada, knowing that while I may benefit from the outcomes of this research, the nurses who participated may not. One can only hope something concrete may one day come from the this study.

Dissemination of Findings

The sharing of the study results will occur in a variety of ways. A manuscript will be submitted for publication in a peer-reviewed journal. Presentations will be given at public health forums and knowledge sharing events such as conferences. The researcher will share the findings of this study with the academic institutions with which the research was affiliated, including the University of Alberta School of Public Health, Makerere University School of Public Health, and Uganda's National Council for Science and Technology. Additionally, a summary of results will be sent to each health facility that participated in the research study in Kabarole District, including the Kabarole District Health Office. It is hoped that this research can be used to improve the working situations for nurses in rural health centers in Kabarole District, which will in turn improve HIV care.

A copy of the research will be available online through the University of Alberta library website for future researchers to access.

Conclusion

Since the beginning of the era of HIV, Uganda has achieved some measure of success at containing the spread of the virus: the current HIV rate hovers around 7.2% (World Health Organization, 2013). Nurses are on the front lines of HIV care, providing service to every age of patient at every facility. In rural areas, nurses are often the only trained healthcare provider, responsible for programs including preventing mother to child transmission, conducting HIV testing, managing ART regimens, treating opportunistic infections, and referring as necessary. While massive efforts have been made to provide ART to all those requiring it, health system shortages including poor staffing, drug supply and infrastructure issues have limited the effectiveness of the campaign, and created difficult working situations for Ugandan nurses. With only 54% of those requiring ART receiving it, and an incredibly high population growth rate, Uganda requires continued effort to combat the spread of HIV, including scale-up of nursing staff. The goal of the current study was to understand the effect of the influx of patients with HIV on the workload and coping mechanisms of nurses working in rural Uganda.

The results indicated that nurses were largely negatively influenced by a variety of social and health system factors. Health system issues, particularly drug and equipment shortages meant that nurses were often unable to provide basic care to PLWHAs and may have placed themselves at risk in order to provide comprehensive care. Additionally, drug and staffing shortages contributed to the already heavy nursing workload. Social factors, including stigma and poverty, limited nurses' ability to help patients with HIV deal with a failing public health system. When they were no drugs at the health centers, patients could rarely afford to buy them.

As a result of social and structural factors, nurses often watched their patients and communities suffer, causing nurses' demoralization and helplessness. Yet nurses continued to work in these difficult situations, largely out of their unfettered commitment to the communities in which they lived, and the hope that one day there would be a cure for HIV. The continued lack of nurse involvement in policy development meant that nurses had little say in how policies were applied in their working situations, and as a result the policies were often poorly implemented. As the financing required to improve staffing and equipment shortages continues to be tenuous and unreliable, planning should be directed at non-financial methods of mitigating the work stress of nurses.

If the gains that have been made in the fight against HIV are to be maintained, it is crucial that nurses not only become more involved in HIV policy development and implementation, but also more valued within the health system. Without large-scale investments in front-line nursing, past successes in mitigating HIV in Uganda could be lost.

Recommendations:

Based on the concerns raised by the nurses in this study, I recommend the following actions be taken to improve HIV nursing care in Kabarole. However, many of these recommendations may be limited by funding constraints.

- Nurse staffing levels should be improved at each level of health centers; vacant nurse positions at rural health facilities should be filled and maintained
- A combination of financial and non-financial incentives should be used to promote recruitment and retention in rural health centers, including housing allowance and/or transportation reimbursement for nurses working in deeply rural areas
- Nurses should be provided with regular monitoring and supervision, promotion and salary increases
- All nursing staff should be provided with a basic level of HIV training with ongoing training provided regularly for all nursing staff
- Every effort should be made to ensure consistent supply of HIV medication in rural areas, including the consideration of developing in-country manufacturing and distribution, tracking and procurement systems
- Nurses should be included in each stage of HIV program planning and development, implementation and evaluation
- HIV prevention programs targeting men should be considered for development
- Ministry of Health staff should focus efforts on creating a supportive administrative culture that focuses on rewarding nursing service rather than punitive measures
- Uganda and their donor countries should be encouraged to make every effort to meet health funding levels outlined in Abuja Declaration

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APPENDIX I: Focus Group/Interview Guiding Questions

The purpose of this study is to assess workplace stress or rural nurses caring for patients with HIV/AIDS in Kabarole District, to understand what some of the major issues in providing nursing care and to explore strategies to improve the quality of nursing care for HIV/AIDS patients.

1. Describe some of the ways in which you provide nursing care for patients living with HIV/AIDS.
2. Describe some of the successes and challenges you face in providing nursing care for patients with HIV/AIDS.
3. What are some of the personal issues you have experienced while providing nursing care for patients with HIV/AIDS?
4. Describe some of the emotions or feelings that arise when you care for HIV/AIDS patients.
5. What kinds of things do you do to help resolve these feelings?
6. How do you cope with your workload?
7. What are some ways that nurses can help themselves or one another when caring for patients with HIV/AIDS?
8. How can nursing care for HIV/AIDS patients be improved at your facility?
9. Any other suggestions, questions or comments?

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APPENDIX II: Information Letter: Nurse Focus Group Discussions/Interviews

Project Title: Assessing Work Stress of Rural Nurses from HIV/AIDS Care in Kabarole District, Uganda

Principal investigator:
Harmony McRae, Principal Investigator
Master of Science Student, Global Health
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB
Contact number: 0788448888

Supervisor:
Dr. L Duncan Saunders, Supervisor
Professor and Chair
Department of Public Health Sciences
School of Public Health
University of Alberta, Edmonton, AB
Contact number: +17804926814

Dear Sir or Madam:

You are being asked to participate in a research project assessing workplace stress on rural nurses caring for patients living with HIV/AIDS. This study is being done by the University of Alberta with the support of the Kabarole District Health Department and Makerere University in Kampala.

Purpose of the study: The purpose of this study is to assess the personal impact of caring for patients with HIV/AIDS on rural nurses in Kabarole District of western Uganda, and ways that nurses cope in these situations.

Procedure: If you decide to participate in a focus group discussion or interview, a trained interviewer will ask you a series of questions regarding nursing and HIV. The discussion will last 45 to 90 minutes and will take place in a healthcare facility at a convenient location. The group discussion or interview will be conducted in English and Rutooro, and will be audio taped. If you do not wish to participate in the group discussion, please inform the interviewer.

Possible benefits:
There are no direct benefits from participating in this study. However, your answers may help to guide the development and implementation of future nursing interventions in Uganda. All participants will be reimbursed for the travel costs incurred in traveling to the focus group sessions.

Possible harms:
There are no expected harms from participating in this study. If you do not feel comfortable with any of the questions, you can chose not to answer the question or stop participating in the study at any point in time.

Confidentiality and voluntary participation:
In the focus group discussions, complete confidentiality cannot be guaranteed. All participants will be reminded that the names of volunteers and what is discussed are to remain confidential. If there is something you would not like to discuss or have known, please do not feel any pressure to share it with the group. During the study, information provided from the discussions will be kept in a secure area. After the study, the information will be kept for at least five years in a secure area at the University of Alberta in Edmonton, Canada. However, your name and any identifying information will be removed from it.

Freedom to withdraw:

If you agree to participate in the study, you may choose to leave at any point in time by informing the researcher without having to provide a reason. The participants' employment will not be affected by early withdrawal or non-participation in this study.

For more information on the study:

If you have any concerns about this study or would like more information, please contact the principal investigator at hmcrae@ualberta.ca or by phone at 0788448888 or contact Eunice at 0772603452, or Mr. Tom Rubaale at the Health Department in Fort Portal 0777912866.

Your consent and legal rights:

Your signature on the consent form means that you understand the information in this letter. It also means you agree to participate in the study.

Please keep these pages in case you need them in the future.

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APPENDIX III: Consent Form for Nurses

Title of Project: Assessing Work Stress of Rural Nurses from HIV/AIDS Care in Kabarole District, Uganda

Part 1: Research information

Name of supervisor: Dr. L. Duncan Saunders
Affiliation: University of Alberta
Contact information: +17804926814

Name of principal investigator: Harmony McRae
Affiliation: University of Alberta
Contact information: 0788448888

Part 2: Consent of Subject

	Yes	No
Do you understand you have been asked to participate in a study?		
Have you read and received a copy of the information sheet?		
Do you know the risks and benefits of participating in the study?		
Have you been able to ask questions and discuss the study?		
Do you know that you can withdraw anytime without an explanation? You have the right to refuse to participate.		
Do you understand confidentiality?		
Do you know who has access to your personal information?		

Part 3: Signatures

The study was explained by: _____ Date: _____
I agree to take part in this study: Signature of participant: _____ Date: _____ Printed name: _____ I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate. Signature of investigator: _____

The appropriate information sheet must be attached to this consent form and a copy given to the research subject.