

**PERCEIVED QUALITY OF CLINICAL CARE PROVIDED BY
NURSES TO PEOPLE LIVING WITH HIV/AIDS AT FOUR TASO
SITES IN UGANDA**

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Declaration of Originality

This work has not previously been submitted for a degree or diploma in this or any other University or Institution of higher learning.

To the best of my knowledge and belief, the dissertation contains no material previously published or written by another person except where due reference is made in the dissertation itself.

I would therefore like to present this work for the award of the Degree of Master of Public Health of Makerere University Kampala, Uganda.

Witness my hand,

.....

Dr.Kenneth Mugisha

Date

This dissertation has been submitted for examination with the approval of the following academic supervisors:

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Dedication

This piece of work is dedicated to the most important person in my life: my late grandmother **Kasongora Margaret Tibahwerwayo Akiiki**, whose mentoring and spiritual inspiration has brought me this far.

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Acronyms and Abbreviations

| | | |
|-------|-------|---------------------------------------------|
| AIDS | ----- | Acquired Immunodeficiency Syndrome |
| ART | ----- | Antiretroviral therapy |
| CDC | ----- | Centers for Disease Control and Prevention |
| DACM | ----- | Diploma in AIDS Care and Management |
| FGD | ----- | Focus Group Discussion |
| HAART | ----- | Highly Active Antiretroviral therapy |
| HIV | ----- | Human immunodeficiency virus |
| IPH | ----- | Institute of Public Health. |
| KII | ----- | Key Informant Interview |
| MOH | ----- | Ministry of Health |
| OI | ----- | Opportunistic Infections |
| OPD | ----- | Out Patients' Department |
| PLWHA | ----- | People Living with HIV/AIDS |
| SCOT | ----- | Strengthening Counselor Training in Uganda. |
| STDs | ----- | Sexually Transmitted Diseases |
| TASO | ----- | The AIDS Support Organization |
| TB | ----- | Tuberculosis |
| TERC | ----- | TASO Ethics and Research Committee. |

Operational Definitions

Quality:

This is a measure of how good something is. It can be perceived quality, from the client's perspectives; or technical competence as may be assessed by a physician. The quality of technical care consists in the application of medical science and technology in a way that maximizes its benefits to health without correspondingly increasing its risks. The degree of quality is, therefore, the extent to which the care provided is expected to achieve the most favorable balance of risks and benefits.

TASO Management:

In this case refers to the medical coordinators / ART Team leaders, who are in charge of the day- to- day supervision and management of medical services at the TASO centers.

Clerking:

This refers to taking history, conducting a physical examination, making a diagnosis, ordering laboratory investigations, prescribing treatment and following-up of a patient.

Abstract

Introduction

The AIDS Support Organization (TASO), added antiretroviral therapy to the care package it offers to her clients in 2004. With the increasing client load and the acute shortage of medical doctors and clinicians, it was inevitable that clinical care, including antiretroviral therapy, had to be shifted to the nurses, whose primary role was to offer nursing care. This raised interest in the quality of care they provide. This study aimed at assessing the quality of clinical HIV/AIDS care provided by nurses to TASO clients.

Methods

A cross-sectional survey that employed both qualitative and quantitative study designs was conducted at 4 purposively selected TASO sites. Client exit interviews were conducted with 400 clients; 28 self-administered questionnaires filled by the nurses, 56 clinical care sessions observed; 51 medical charts reviewed and 4 key informant interviews conducted with the Medical coordinators. Data was analyzed with the aid of Excel version 2000 and STATA version SE/10 computer packages. Qualitative data was tape-recorded, transcribed, typed in MS word 2003 and analyzed thematically with the aid of Nvivo statistical package.

Results

About 92% of the clients expressed satisfaction with the services received from TASO nurses; and 95% of them said they would recommend these services to other people living with HIV/AIDS. Fifty five percent said they had not been examined by the nurse.

Only two nurses expressed reservations about being involved in clinical care provision. Nurses were found competent to handle general OI care, but needed technical support to manage complex disease conditions.

Only 13% of the medical charts reviewed had a record of physical examination findings. Fifty six percent of the nurses were able to write accurate ARV prescriptions; but 63% could not detect ARV side effects at all.

Key informants noted that TASO nurses have positive attitudes towards people living with HIV/AIDS. They were also satisfied with the clinical skills of the comprehensive nurses. They identified coaching and mentoring in clinical skills, pharmacology and radiology as critical areas which should be focused on.

Conclusions

TASO nurses have positive attitudes and this seems to greatly influence patient satisfaction. Comprehensive nurses have better clinical skills than the other cadres of nurses. However, the overall nurses' technical competence as regards clinical HIV care provision shows significant areas for improvement.

Recommendations

Comprehensive nurses and double-trained nurses should be allowed to participate in clerking of HIV/AIDS patients, provided there is clinical support supervision by a medical officer. The nurses should also be availed with protocols to follow during clinical care sessions. Nursing training schools should incorporate clinical HIV/AIDS care training into their curricula, and develop relevant course content that suits the nurse clinician. Gender biases among clients should be addressed. A national dialogue on task shifting should be held.

CHAPTER ONE

1.0: Introduction and Background

The AIDS pandemic is currently the world's most deadly war that has killed 25 million people since it was first recognized in 1981 (UNAIDS/WHO, 2005), making it one of the most destructive epidemics in recorded history. Despite recent, improved access to antiretroviral therapy and care programs in many parts of the world, the AIDS epidemic claimed 2.1 million lives in 2007 alone.

Today, over 33.2 million people are living with HIV/AIDS worldwide. Of these, over 30.8 million are adults, 15.8 million are women and 2.5 million are children under 15 years. People who were newly infected with HIV in 2007 alone are 2.5 million. A total of 2.1 million deaths due to AIDS were recorded in 2007; of which 1.7 million were adults, and 330,000 were children below 15 years (UNAIDS, 2007).

A little more than one-tenth of the world's population lives in sub-Saharan Africa, which remains hardest hit and is home to 25.8 million people living with HIV, almost one million more than in 2003. Sub-Saharan Africa remains the region most heavily affected by HIV, accounting for 67% of all people living with HIV and for 75% of AIDS deaths in 2007. However, some of the most worrisome increases in new infections are now occurring in populous countries in other regions, such as Indonesia, the Russian Federation, and various high-income countries (UNAIDS, 2008).

In 2005 alone, there were 4.9 million new infections, of who 700,000 were children (UNAIDS, 2005). The adult prevalence of HIV in sub-Saharan Africa is 7.2 % compared with the next highest region – the Caribbean at 1.6%.

Uganda is one of the sub-Saharan African countries worst hit by the HIV/AIDS epidemic, with over 1.2 million people infected and an HIV prevalence rate of about 6.4 %. The burden of disease experienced by Ugandans has long been described by authorities as a national health concern (MOH, 2005).

As the numbers of people living with HIV/AIDS increases, so does the need for quality clinical HIV/ AIDS care, treatment and support services, particularly in resource-limited settings. This calls for adequate, motivated and well trained human resources for health.

Despite grappling with the AIDS epidemic, Africa as a whole, suffers an acute shortage of trained health workers. The few available have left their countries for greener pastures abroad. The remaining has concentrated service provision in the urban areas, leaving over 85% of the national populations untended. A lot of task shifting from medical doctors to nurses and clinical officers has occurred with a resultant effect on the quality of care provided to people living with HIV/AIDS (WHO, 2007).

There is an acute shortage of medical doctors and clinicians to offer clinical care to people living with HIV/AIDS. TASO UGANDA, has failed to attract and retain medical doctors, mainly due to challenges in remunerating them. Over 30% of the doctors and clinicians recruited by TASO leave for better-paying jobs within 6 months (TASO HMIS, 2005). The few doctors who stay on have taken up

leadership and managerial positions at various levels within the organization, causing further scarcity on the numbers of doctors available to provide clinical care for HIV/AIDS patients.

1.1 Clinical HIV/AIDS Care

Clinical HIV/AIDS care is the process of taking a relevant and detailed history of the patient's presenting complaints, doing a thorough physical examination, ordering relevant investigations, making HIV diagnosis, staging of the patient's disease condition, prescribing appropriate medications, follow-up and review of the patient to assess treatment outcome, in order to improve the quality of life and prolong the survival of the patient.

Historically, the nurse's roles in the TASO setting include taking basic parameters at triage e.g. body weight, blood pressure, pulse rate, temperature; conducting health education talks, dispensing of drugs, conducting home visits, follow-up of TB patients, home-based HIV counseling and testing, treatment of minor opportunistic infections, planning and budgeting for clinic activities. The increasing client load has resulted in task shifting, with nurses taking on the added responsibility of providing clinical care, including taking history, examining patients, ordering laboratory investigations and prescribing various HIV medications, including antiretroviral therapy. Given that the staffing, equipment and provisions are standard across TASO centers the main challenge to address is the quality of care.

A nurse working for TASO will attend to over 40 patients per clinic day, in addition to his/ her other tasks of dispensing, triaging, attending to bedridden clients, conducting health talks, and home-based care for very sick clients, as well as supervising community nurses in their catchment areas. This is way above the number of 20 patients per clinic day as recommended in the TASO Quality Assurance manual. Nurses are primary care providers for patients with HIV who present to TASO clinics, but little is known about the quality of care that they provide.

According to Heckman et al (1998), people living with HIV disease, particularly those in small towns and rural areas, face many barriers that prevent them from receiving important life-care services. The need to travel long distances to medical facilities; shortage of adequately trained medical professionals; lack of personal or public transportation; and community residents' stigma toward people living with HIV, are an impediment to access to quality HIV care.

1.2 Background to the Organization

The AIDS Support Organization (TASO) is an indigenous Non Governmental Organization founded in 1987 by a group of 16 volunteers, some of whom were HIV positive. TASO exists to contribute to the process of preventing HIV infection, restoring hope and improving the quality of life of people infected and those affected by HIV/AIDS. It had a humble beginning as an HIV/AIDS Counseling provider. By 1992, it had been realized that in addition to psychosocial support, clients needed medical care in the form of treatment of

opportunistic infections (Sebanja, 2007). Hence the medical department was born, employing nurses as the main care providers till 2002, when the first batch of medical doctors were recruited as medical coordinators. Soon thereafter, these were followed by multiple recruitments of medical officers and clinical officers.

TASO has 11 facility-based clinics and 39 outreach clinics throughout the country. It offers a wide range of services, including counseling and testing for HIV, clinical care, spiritual and emotional support, ART, local and national advocacy, and extensive training in all of these areas for both local and international students. Clients seeking TASO services are predominantly of low socio-economic status, peasant subsistence farmers.

There are over 88,000 active TASO clients today, compared to 6,800 in 1992, without a proportionate increase in the number of service providers (TASO HMIS, 2008). People infected with HIV/AIDS need specialized care to cater for their special medical, psychosocial and other needs. Service providers more often than not find themselves faced with an increasing number of people infected with HIV. To offer this specialized care, there is a need for a dedicated cadre of competent, knowledgeable and skilled health care workers (Donabedian, 1985). Nurses in Uganda have been found to prescribe ART more than clinicians and doctors combined (IDI, 2006 Unpublished). Yet recent advances in HIV/AIDS care especially highly active antiretroviral therapy (ART) have not found their way into the curricula of pre-service training institutions for Nurses, Midwives, Clinicians and Physicians in Africa.

The factors that determine the quality of care provided by nurses to TASO clients had not been studied. The nurses' knowledge, clinical skills and attitudes towards clients was not well documented. The perceptions and experiences of nurses caring for people living with HIV/AIDS in Uganda and TASO had not been studied. Furthermore, there are barriers to access to care and prevention services for TASO clients and their families which needed further research. Hence the aim of this study was to assess the quality of clinical HIV/AIDS care provided by nurses to TASO clients in order to recommend practical interventions to address identified gaps.

This study was conducted at 4 TASO centers of Gulu, Mbale, Mbarara, and Masaka. The latter is in Masaka town and serves a primarily rural population. Gulu is in Northern Uganda, an area that has suffered armed insurgency since 1987. Mbarara and Mbale are found in South-western and Eastern Uganda respectively and serve predominantly rural populations. These centers offer a comprehensive HIV/AIDS care package, including antiretroviral therapy. Each TASO center has at least 7 nurses, who play a pivotal role in the provision of clinical and home-based comprehensive HIV/AIDS care, including ART.

CHAPTER TWO

2.0 Literature Review

2.1 Overview

The primary goal of care is to optimize the quality of life of patients with advanced incurable diseases through control of physical symptoms and attention to the patient's psychological, social and spiritual needs (Omaswa et al, 1999). Consequently, the outcomes of care should be measured in terms of the extent to which this goal is achieved. Quality of care is difficult to define and measure; it is a multidimensional, dynamic and subjective concept (Wilson and McDonald, 1994). Quality of HIV care is therefore a concept relevant to the discipline of nursing.

2.1.1 Quality and its Components

Quality is defined as a measure of how good something is. This could be an object, or a service. In health services, quality can be defined in various ways: either by comparing that service with the standard which has been set; in the way things are done, or it can be considered as doing the best with the resources available.

Quality can be looked at as having many components which are interrelated and will singly or collectively promote quality. Their lack will lead to quality gaps in the services provided. The components of quality include technical competence, efficiency, interpersonal relations, and effectiveness, access to services, continuity and safety (Omaswa et al, 1999).

2.1.2 What Is Quality of Care?

The purpose of all quality assurance efforts is to improve and sustain the quality of healthcare. Quality healthcare is thus the ultimate goal of institutionalized quality assurance activities. There are many different definitions for the term “quality” in the context of healthcare:

“...Proper performance (according to standards) of interventions that are known to be safe, that are affordable to the society in question, and that have the ability to produce an impact on mortality, morbidity, disability, and malnutrition” (Roemer and Montoya-Aguilar 1988).

“The quality of technical care consists in the application of medical science and technology in a way that maximizes its benefits to health without correspondingly increasing its risks. The degree of quality is, therefore, the extent to which the care provided is expected to achieve the most favorable balance of risks and benefits” (Donabedian 1980).

“Quality is doing the right thing, right, the first time, and doing it better the next time, with the resource constraints and to the satisfaction of the community” (Ministry of Health and Population of Malawi 1997).

Quality is multi-dimensional, and nine dimensions of quality that are important to a healthcare delivery system’s various internal and external stakeholders: individual clients, communities, providers, managers, and payers have been identified. Different stakeholders consider those dimensions of diverse importance.

Technical performance, one of the more commonly recognized dimensions of quality, refers to the degree to which tasks carried out by health workers and facilities accord with standards or meet technical expectations.

Access to services reflects a lack of geographic, economic, social, organizational, or linguistic barriers to services.

Effectiveness of care is the degree to which desired results or outcomes are achieved, whereas *efficiency of service delivery* relates to the use of resources to produce those services.

Interpersonal relations refer to effective listening and communication between provider and client; it is based on the development of trust, respect, confidentiality, and responsiveness to client concerns.

Dimensions of Quality

- Technical performance
- Access to services
- Effectiveness of care
- Efficiency of service delivery
- Interpersonal relations
- Continuity of services
- Safety

- Physical infrastructure and comfort
- Choice of services (QA Project 1999).

Continuity of services refers to the delivery of care by the same healthcare provider throughout the course of care (when feasible and appropriate), as well as timely referral and communication between providers when multiple providers are necessary.

Safety, the degree to which the risks of injury, infection, or other harmful side effects are minimized, is a critical dimension of quality care and is receiving increased attention due to the HIV/AIDS epidemic.

The *physical infrastructure and comfort* dimension is sometimes called “amenities”; it includes a facility’s physical appearance and cleanliness, and the comfort and privacy it affords clients.

Choice of services refers to client choice of provider, treatment, or insurance plan, as appropriate and feasible. Inherent in this dimension is client access to information that allows the client to make an informed choice.

Quality of care therefore refers to the degree to which these nine dimensions of quality are present in the healthcare delivered to a client. In this particular study, special focus was placed on interpersonal relations and technical competence

2.1.2 Measuring Quality of Care

The work of Brook et al (1996) raises a lot of interesting issues regarding measuring quality of care. Until recently, we relied primarily on professional

judgment to ensure that patients received high-quality medical care. Monitoring of and improvement in quality were generally left to individual clinicians. Practice patterns and the quality of care vary much more than many people had realized. Our ability to measure quality of care has advanced considerably, and health workers are increasingly interested in having objective information about their practices. More interestingly, patients and clients now want to know more about the quality of care available to them. Efficient methods of measuring quality that can help health workers and institutions improve the quality of medical care they provide are now available (Brook et al, 1996).

According to Brook et al (1997), quality of care can be evaluated on the basis of structure, process, or outcome. Structural data are characteristics of nurses, physicians and hospitals (e.g. a physician's specialty or the ownership of a hospital). Process data are the components of the encounter between a health care provider and a patient (e.g. tests ordered). Outcome data refer to the patient's subsequent health status (e.g. an improvement in symptoms or mobility).

According to Brook et al. (1997), it will never be possible to produce an error-free measure of the quality of care. If poor measures of quality are used, it can unfairly harm institutions and health workers. Brook further asserts that the quality of care can be assessed at several levels, from the care provided by individual health care professionals (e.g. nurses, or physicians) to care provided by a health plan. In this study, quality of care was assessed from the care provided by individual nurses.

Brennan et al (1991), assert that if quality of care criteria based on structural or process data is to be credible, it must be demonstrated that variations in the attribute they measure lead to differences in outcomes. Equally, if outcome criteria are to be credible, it must be demonstrated that differences in outcome will result if the processes of care under the control of health professionals are altered.

According to Ellwood (1988), people who criticize the use of process data to measure the quality of care worry that these measures may not be important predictors of outcomes. These critics argue that if resources were directed toward improving the processes of care represented by these measures, the cost of medical care might increase without producing any corresponding improvement in health.

According to Ashton et al (1994), those who criticize the use of outcome measures believe that most differences in outcomes among patients receiving the same treatment are the result of factors not under the control of health care providers, such as differences in patients' characteristics. Thus they argue that conclusions about quality that are based on outcome may be invalid. When used appropriately, however, both process and outcome measures can provide valid information about the quality of care.

Process data, according to Brook et al (1997), are usually more sensitive measures of quality than outcome data, because a poor outcome does not occur every time there is an error in the provision of care. In this particular study, focus was put on

the process of providing care by direct observation of clinical care sessions and client exit interviews. Structural data was also obtained from patients' and nurses' individual characteristics.

2.2.0 Quality of Care

Available literature widely discusses issues relating to the definition, scope, and measurement of “quality of care” (Donabedian, 1988; Leger et al., 1992; Ellis and Whittington, 1993). Donabedian views quality of care as comprising two components, namely technical and interpersonal. Technical performance depends on the knowledge, judgment, and skill used in arriving at appropriate strategies of care. Interpersonal performance relates to the relationship between the doctor (and any other health care worker) and the patient. Donabedian argues that this process is the “vehicle by which technical care is implemented and on which its success depends.”

Interpersonal performance is just as important as technical performance but is much less predictable in its impact. Patient satisfaction has been the main vehicle through which interpersonal performance has been evaluated.

Some of the key factors influencing patient satisfaction include staff attitudes or inter-personal aspects of care, waiting and consultation times, general perception of different aspects of the health facility, hotel facilities for inpatients, and the outcome of care received (Leger et al., 1994). Despite their widespread use, patient satisfaction surveys have several limitations. Factors such as age, social class, sex, race, level of education, and type of medical insurance influence

satisfaction. This might either be a function of care provided for different social groups, or it might reflect different expectations or different susceptibility to answering questions in a positive way (Ellis and Whittington, 1993). It has also been argued that satisfaction with the interpersonal aspects of care is assessed more frequently than satisfaction with the technical aspects.

Notwithstanding these weaknesses, patient satisfaction surveys have several uses. They serve to identify problems and potential areas for improvement. They also provide an overall estimate of satisfaction with a given service or episode of care. They are sometimes used as part of an initiative in increasing participation in care (Ellis and Whittington, 1993). Also, the inclusion of qualitative analysis can assist in bringing forth issues of a more sensitive nature, especially those relating to stigmatization and discrimination. This is especially important in the context of HIV/AIDS, where people living with HIV/AIDS are continuously marginalized through social isolation and discrimination, particularly where awareness regarding the disease is poor. The implications are that “they are denied some of the basic human rights – like the right to work, access to basic health care, fair labor practices and privacy” (Provincial Administration, 1997). In the context of these issues, patient satisfaction surveys become increasingly important as a tool in identifying barriers to seeking care, in addition to financial and time cost barriers. In this study, the researcher used client exit interviews as one of the data collection tools in assessing the quality of care provided by nurses to clients at four TASO sites in Uganda.

2.2.1 Methods of Quality Assessment

There are five methods by which quality can be assessed on the basis of process data, outcome data, or both. The first three methods are implicit i.e. there are no prior standards or agreements about what reflects good or poor quality, since quality is difficult to measure (Wilson and McDonald, 1994). With each of these methods, a health care professional (usually a physician) reviews a data source (usually a medical record, after care has been provided) and answers one of the following questions:

- Was the process of care adequate (first method)?
- Could better care have improved the outcome (second method)?
- Considering both process and outcome of care, was the overall quality of care acceptable (third method)?

The Training needs assessment conducted by Ministry of health and Infectious Diseases Institute; Makerere University Medical School found that task shifting from medical doctors to clinical officers, nurses and midwives was evident. Nurses and clinical officers spend as much time prescribing ART than Medical Officers. (IDI TNA Report, 2006).

In a study to compare the quality of HIV care provided by nurses and physician assistants to that provided by physicians, Wilson et al (2005) found that nurse practitioners and physician assistants had significantly higher performance scores than generalist non-HIV experts on 6 of the 8 quality measures. However, these results may not be generalizable to care settings where on-site

physician HIV experts are not accessible or to measures of more complex clinical processes. Though this study showed that nurses and clinicians can provide high-quality care for persons with HIV, the preconditions for this level of performance included high levels of experience, focus on a single condition, and either participation in teams or other easy access to physicians and other clinicians with HIV expertise. This study has not been replicated elsewhere, especially in developing countries.

Kemppainen (2001), in a study to determine the predictors of quality of life in AIDS patients, found that although modest, the quality of life for an acutely ill, hospitalized patient with AIDS is enhanced through more active involvement or engagement in the process of nursing care. Furthermore, a pilot study conducted by Brechtel et al (2006), to monitor symptoms in patients with advanced illness in long-term care, found that rapid treatment of symptoms can be an important quality indicator in nursing home patients with advanced illness.

According to Lin (2003), of all Out-Patient Department (OPD) visits with a nurse practitioner service, nurse practitioners saw patients with no presence of a physician in 82 percent of these visits. As the role of the nurse practitioner evolves in the U.S. health care delivery system, further studies on the clinical practice of Nurse practitioners in hospital OPDs can help evaluate the impact of nurse practitioners in providing quality patient care at minimum cost.

In another US study to assess whether nurse practitioners make a difference in provision of health counseling in hospital outpatient departments, Linn et al (2004) found that the presence of a nurse is associated with higher rates of

counseling for diet and HIV/STD prevention provided at patient visits for acute problems. This study indicates an important role nurses can play in providing preventive services. The findings reflect the emphasis of the nurse education on health counseling and patient education in clinical practice.

A study conducted by Smit (2005) on the perceptions and experiences of nurses caring for people living with HIV/ AIDS in the public sector in South Africa found that some nurses reported helplessness, emotional stress and fatigue, fear, anger and frustration, occupational-related concerns, empathy, and self-fulfillment as experiences to deal with at the workplace. This study also shows the importance of providing appropriate pre-registration and continuing education and support for nurses working in HIV/AIDS environments.

A study by Spies et al (2004) in the US has demonstrated that nursing is stressful and that the incidence of occupational stress-related burnout in the profession is high. In a cross-sectional survey to investigate Belgian hospital nurses' perceptions on work environment and workforce issues, quality of care, job satisfaction and professional decision making (Milisen K et al, 2006), several areas of tension were identified in the nursing profession. The commitment to being competent providers of quality care was remarkably strong among the nurses, but they also perceived the barriers in the work environment to be multiple and complex (Clarke and Rao, 2004). In this study, concerns about the quality of leadership and management, insufficient staff, time demands and stressful work environment were experienced as obstacles in providing good nursing care.

Various studies have also proved that empowering nurses is essential for maximizing efficiency at the primary care level. Several other countries, including Malawi and Ethiopia, are now allowing nurse practitioners to prescribe ART (Ashie M et al., 2007; & Thistle et al., 2007).

Some of the key issues that emerge from the above literature review are that as the HIV/AIDS epidemic gains momentum, increasing numbers of HIV-infected people will develop AIDS, and many of them will require expensive tertiary care. This review also highlighted some of the quality of care issues relevant to the study.

On the basis of the above literature review, there appeared to be gaps in knowledge on the quality of clinical HIV/AIDS care provided by nurses, particularly in Uganda. The factors that determine the quality of care provided by nurses to TASO clients had not been studied. The nurses' knowledge, clinical skills and attitudes towards clients were not well documented. The clients' perceptions and experiences of nurses caring for people living with HIV/AIDS in Uganda and TASO were also not clearly understood. Furthermore, there are barriers to access to care and prevention services for TASO clients and their families which needed further research. This study was therefore geared towards addressing some of the gaps.

The assessment was focused on the inputs, process and output components in a systems model approach. Particular attention was paid to the technical competence of the nurses and interpersonal relations.

CHAPTER THREE

3.0 Statement of the Problem

There was inadequate information on the perceived quality of clinical care given by nurses to people living with HIV/AIDS yet the care they give has an impact on the overall outcome of the patient's health.

Over 30% of the doctors and clinicians recruited by TASO leave for better-paying jobs within 6 months (TASO HMIS, 2005). The few doctors who stayed on have taken up leadership and managerial positions at various levels within the organization, further reducing the number of doctors available to offer clinical care.

There has been an increase in the cumulative number of clients served by TASO from 6,800 in 1992 to 193,246 by 2007; without a corresponding increase in the number of service providers. The increased workload has led to task shifting from clinicians to nurses and this invariably has an impact on the quality of clinical care nurses provide to TASO clients.

By virtue of their professional training background, nurses are primarily not expected to offer clinical care. Their mandate is to provide nursing care. The unique function of the nurse is to assist the individual, sick or well, in the performance of those activities which contribute to health, to recovery, or to peaceful death, that would be performed by the patient if the patient had the necessary strength, will or knowledge, and to do this in such a way as to help him gain independence as rapidly as possible (Gladys.E., 1997). Attempts have been made by TASO to train nurses in the clinical management of HIV/AIDS.

However, there has not been any documented follow-up to assess the impact of this training on the quality of care that they provide. Not assessing performance of health workers breeds poor health care practices and increases the burden of disease. Poor quality care reduces the benefit to users of the health care systems, frustrates and demoralizes health care workers, and wastes valuable and often scarce resources (Omaswa et al, 1999).

Senior TASO management did not know the quality of clinical care provided by the nurses they employ, as this could determine the safety of clients under TASO care. The quality of clinical care provided by nurses is of public health importance. It was not known whether nurses can competently handle the clinical tasks performed by doctors and clinical officers in HIV/AIDS care provision. This is even more critical as antiretrovirals, with their complex regimens, have become more available, compared to the earlier years when HIV management was largely focused on opportunistic infections and support services.

3.1 Rationale and Justification for the study

There is a global shortage of medical professionals such as doctors and nurses that is especially severe in resource-limited settings. Doctors are in particularly high demand – too few are being produced, they take longest to train, and they are the most likely to accept positions for better pay in the private sector or move abroad to work in better resourced countries.

In many countries, doctors are the only cadre of health care workers allowed to prescribe antiretroviral therapy (ART). Hence, the virtual absence of doctors in some areas (especially rural settings in poorer countries) makes it difficult or

impossible to provide universal access to ART. Since it takes about six years to produce new doctors, the only way in underserved areas to save potentially millions of lives is to empower cadres with less training to provide ART.

There are no published studies on the quality of clinical HIV care provided by nurses in Uganda. This study will probably be the first of its kind in the Ugandan setting. This study has determined the quality of care nurses provide to TASO clients and the factors responsible for the discrepancy. The study findings could provide a basis for formulating appropriate intervention strategies to improve the quality of HIV care in Uganda, guide national health policy and planning in the context of HIV/AIDS, and inform curriculum development specialists for nursing training. Study findings could also generate information that may guide debate on health care staff recruitment, training, deployment and retention.

This study also generated views from nurses which may contribute to improved workers' health, and address the acute shortage of health care providers, which has been identified as the largest threat to providing HIV/AIDS treatment in sub-Saharan Africa, and to improving quality of care. This may consequently result into better health outcomes for clients receiving clinical HIV care from nurses, improve rational drug use and reduce costs of expenditure on health care for people living with HIV, their households and communities; as well as reduce on the national health care expenditure- hence freeing resources to address other issues of national interest. The findings could also feed into the TASO and National HIV/AIDS strategic plans.

3.2 Conceptual Framework

As shown in Figure 1 below, there are a variety of factors that affect the quality of clinical HIV/AIDS care provided by nurses to TASO clients. Broadly these could be categorized into inputs, processes, outputs, outcomes and impact of the care provided.

The inputs include the health workers (clinicians, counselors and nurses), space, equipment, security, the work environment, and medications among others. Since the infrastructure standards are the same across the TASO centers, the focus of this study will be on the service provider. Academic/professional factors may include the nurses' level of education and professional training, opportunities for continuing education, years of experience working with HIV positive persons and technological advancement. The number of nurses available to provide care, their levels of education, training and experience in HIV / AIDS care could have an impact on the quality of care provided to clients, if they are substandard or inadequate.

The processes encompass such activities as history taking, physical examination of patients, ordering relevant laboratory investigations, making diagnoses, prescribing treatment, counseling, follow-up and/ or referral of the patient. The quality of all these may depend on the technical competence of the provider, which is also greatly influenced by their level of education, pre-service and in-service training as well as experience in providing HIV care.

The output is the treated patients, while the outcome would be the improved patients. Patient-related factors include the client load, attitudes towards nurses, satisfaction and appreciation of the nurses' work, access to the services and affordability of transport costs and meals. The client's perception of the quality of care received has a bearing on whether they adhere to treatment and whether they improve on the prescribed treatment.

The impact of the care provided should be reduced morbidity and mortality from HIV/AIDS and related illnesses, a healthy and economically productive community.

Social factors include HIV –related stigma, emotional stress, and relationship with other colleagues at work. Economic factors may include poverty and the cost of living vis-à-vis the nurses' remuneration package. A poorly remunerated service provider is unlikely to provide good quality care, since their motivation is likely to be low. When this is combined with HIV- related stigma, emotional and work-related stress, the quality of care is bound to be affected.

Hygiene factors include the work environment, among others. It is unlikely that good quality care can be provided in an environment that does not provide privacy and confidentiality during the clinical care sessions. Poor working relations between colleagues and/ or supervisors may also negatively impact on the quality of care a nurse will provide to the client.

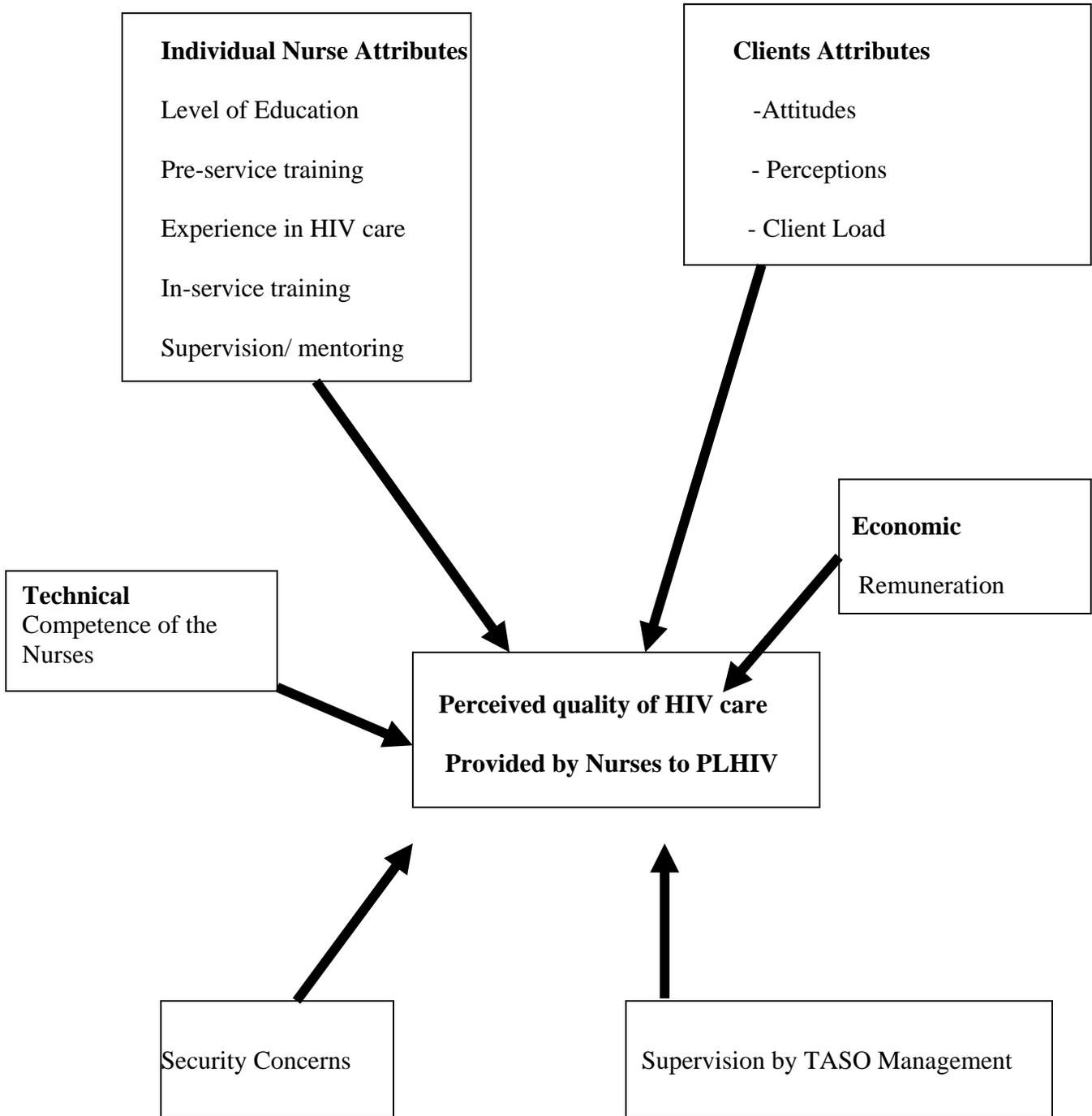
Political factors could include insecurity as in the case of Northern Uganda. Insecurity causes emotional stress to the service providers, in addition to making services inaccessible, since the affected communities get impoverished and hence

may not afford transport costs to the facility. At the same time follow-up of clients at their homes becomes difficult, thereby impacting on the quality of care. The institutional/ structural factors include the number of nursing staff (nurse: client ratio), the quality of leadership and management at the TASO centers, quality of supervision and its frequency, as well as the perceived attitudes by other staff and senior management towards nurses. Where client loads are high, quality of care tends to be poor. When this is combined with poor management practices, particularly inadequate supervision, poor interpersonal relations at the workplace, mentoring and coaching, the quality of care will deteriorate even further. The attitudes of other staff and management towards nurses, when negative, can greatly affect the services they provide, since there will be lack of team work.

3.3 Research Questions

1. What are the perceptions of TASO clients towards the quality of care provided by nurses?
2. What is the level of technical competence of TASO nurses involved in providing clinical HIV/AIDS care?
3. Which factors affect the quality of care provided by nurses to TASO clients in Uganda?
4. What are the perceptions of TASO management on the clinical care services provided by nurses?

Figure I- Conceptual Framework



CHAPTER FOUR

4.0 Study Objectives

4.1 General Objective

The aim of this study was to assess the quality of clinical care provided by TASO nurses to people living with HIV/AIDS at four sites in Uganda in order to recommend practical interventions to address identified gaps.

4.2 Specific Objectives

1. To establish the clients' perceptions of the quality of HIV care provided by TASO nurses in Uganda.
2. To assess the knowledge of TASO nurses in providing quality clinical HIV/AIDS care to people living with HIV/AIDS in Uganda.
3. To assess the quality of clinical skills of nurses involved in the provision of clinical HIV/ AIDS care to TASO clients in Uganda.
4. To investigate management's perceptions of the quality of clinical services provided by TASO nurses in Uganda.

CHAPTER FIVE

5.0 Materials and Methods

5.1 Study Area:

The study was conducted in Uganda at four TASO centers of Masaka, Mbarara, Mbale, and Gulu. TASO Masaka is located within Masaka Regional Referral Hospital complex and serves a predominantly rural population. TASO Mbarara is in South Western Uganda and also serves a predominantly rural population. TASO Mbale is located in the eastern part of Uganda, and serves a predominantly rural population. TASO Gulu is located in the northern part of the country, an area which has suffered armed insurgency for the last 20 years. These sites were purposively selected because they are representative of the variations in culture, level of urbanization, development and social ramifications. These 4 TASO centers provide HIV/AIDS care and support to over 30,000 people living with HIV/AIDS. Hence the study findings can be generalized to other TASO centers in Uganda.

5.2 Study Populations

This study had three study populations: Nurses working in TASO, the Medical Coordinators; and TASO clients at the 4 TASO centers. The nurses were interviewed at their workplace. Medical coordinators were key informants for this study. Registered TASO clients at these 4 centers participated as respondents in this study. These 4 TASO centers provide HIV/AIDS care and support to over 30,000 people living with HIV/AIDS. The respondents (clients) were found at the TASO center clinics and / or outreach clinic sites. About 90% of all TASO

clients are subsistence farmers, living in rural areas. The majority are either semi-illiterate or illiterate.

5.3 Study Design

This study was a cross-sectional survey that employed triangulation of both qualitative and quantitative research methods. Data was collected over a period of 2 months, between April and June 2008.

5.4 Inclusion Criteria

- Nurses who are employed by TASO at the 4 centers on full-time contract basis.
- Registered TASO clients who had received HIV/AIDS care services at the 4 TASO centers, at least 6 months prior to commencement of this study.

5.5 Exclusion Criteria

- Clients who were very sick were excluded from participating in the study.
- Nurses who were absent, or, on leave, during execution of the study.

5.6 Sample Size Determination

A sample size calculation for the clients' population group was done using the Kish Leslie (1965) formula:

$$n = \frac{Z^2 pq}{d^2}$$

$$d^2$$

Where: n is the ideal sample size, Z is the 95% confidence limit, and p is the estimated proportion of clients who were satisfied with the service provided by TASO nurses.

Then q is $(1 - p)$, and d is the precision (permitted error)

$$Z = 1.96$$

$$, p = 0.5$$

$$, q = 0.5$$

$$n = \frac{(1.96)^2 \times 0.5 \times 0.5}{(0.05)^2}$$

$$(0.05)^2$$

$$n = 384.16$$

The adjusted sample size for this study was therefore 400 TASO clients, who participated in the client-exit interviews. The number was increased to cater for non-responses.

Since the number was small, the entire number of 28 nurses at the 4 pre-selected TASO centers of Gulu, Mulago, Mbale and Mbarara was interviewed and at least two (02) clinical care sessions observed for each of the nurses. The medical coordinators of the 4 TASO centers, who were 4 in number served as key informants in this study.

5.7 Sampling Method

Proportional sampling method was used to arrive at the sample size, since the 4 TASO centers had varying numbers of clients as shown in the table below.

Table 1: Proportional Probability Sampling for TASO Clients

| TASO CENTER | Number of nurses (Dec.2006) | Number of Clients (Dec.2006) | Number of clients selected per center |
|--------------------|------------------------------------|-------------------------------------|----------------------------------------------|
| Masaka | 9 | 9,702 | 131 |
| Gulu | 8 | 4,929 | 66 |
| Mbarara | 6 | 7,574 | 102 |
| Mbale | 5 | 7,487 | 101 |
| TOTAL | 28 | 29,692 | 400 |

In order to obtain the required sample size of 400, proportional probability sampling was done as shown in Column 4, table 1 above.

5.8 Sampling Strategy

Since the population of nurses working at the 4 TASO centers was small, the population of nurses served as a study unit. A list of all TASO nurses working at the respective centers was obtained from the Director of Human Resources and Administration, TASO. Informed consent was then sought from the nurses. Those who consented to participate in the study were serially registered and then assigned numerical codes.

Every TASO center runs an out-patient clinic at least 3 days in a week. It was estimated that on average 150 clients receive TASO services on each clinic day. For each study site, the allotted slots for the sample were collected on three separate clinic days. Every alternate client that was attended to by a nurse was

followed and informed consent to an interview sought before conducting the exit interview. If one did not consent to participation in the study, the subsequent client was chosen. This was repeated at each of the study sites until the required sample size proportions were obtained for each site. The respondents' sex was indicated on the questionnaires and this information was used to measure the sex differences.

5.9 Data Collection Techniques

The data for this study was collected using the following techniques:

- Direct observation of the nurses providing clinical care sessions and Chart review
- Client -exit Interviews
- Self-administered questionnaires for the nurses
- Key Informant Interviews with heads of departments at the TASO centers (Medical Coordinators).

5.10 Procedure

Direct observation of nurses providing clinical HIV care was done with the aid of an observation checklist that was developed by the investigator. Using a list of quality performance measures, the investigator carried out extensive medical chart review of clients that had been attended to by nurses. These two data collection techniques/tools were developed by, and enabled the investigator to assess the nurses' competence in knowledge and skills to provide clinical HIV care.

The clients' perceptions, experiences and satisfaction with the quality of HIV care provided by TASO nurses were assessed through exit interviews.

In order to further assess the knowledge and attitudes of TASO nurses towards providing clinical care to TASO clients, self-administered questionnaires were used.

The client exit interview tool was translated in the respective TASO center local language to cater for the respondents who did not know English. All tools were pilot-tested in a mini-survey at a non-participating TASO center of Entebbe.

Permission was sought from the Executive Director of TASO to carry out the study within the TASO centers. After ascertaining the appropriate date and time from the center managers, the respondents were brought into one group and clustered according to language proficiency (vernacular and English). The vernacular speakers were further sub-divided into those who could read and write and those who could not. For those who could not read and write, the questions were read out for each of them and their responses recorded.

Respondents were assured of confidentiality and given an option to opt out in case they did not wish to participate. The instruments were then distributed to the respondents in their clusters, asked to indicate their sex on the questionnaires and responses to the items. All the data collection was done in the usual clinic environment so that the investigator could be able to report accurately on the daily factors affecting quality of care at the TASO centers.

5.11 Qualitative methods

Key informant interviews were conducted with the Medical Coordinators, who are the departmental heads, to assess the nurses' attitudes, perceived technical competences, and challenges encountered in providing quality HIV care. These key informants also provided insight into the perceptions of management towards the quality of clinical care services provided by TASO nurses to people living with HIV/ AIDS. These interviews were tape-recorded and later transcribed. Participants' responses were coded and typed in MS Word. Themes and sub-themes were generated and continuously analyzed before, during and after data collection, with the aid of Nvivo statistical package.

5.12 Quantitative methods

Quantitative data was collected using structured questionnaires and observation checklists, administered by a trained research assistant, who was a doctor working outside the TASO establishment to minimize observer bias. This data was collected over the course of the week on clinic days. The interviews were conducted in the usual clinic environment so that the investigator was enabled to report on the daily factors affecting quality of care at the study sites. The investigator observed 2 patient- nurse clinical sessions per service provider involved in the study.

The clinical care sessions served as the unit of analysis. After the direct observation of clinical sessions conducted by the nurse(s), the investigator conducted an extensive medical chart review of clients' files seen by the individual nurses. These files were identified by the computer codes that were

allocated to each care provider in TASO. The medical chart review was guided by the quality of performance measures list as set out in appendix F. The nurses were interviewed at their workplace.

The research assistants, under the direct supervision of the principal investigator checked for any omissions and errors in recording responses while they were still with the respondents. Data collection went on until the required sample from a particular study site was achieved. Extra interviews were conducted to cater for invalid questionnaires and missing responses.

Participants enrolled once; and to ensure that there was no double participation, their code numbers were recorded and the list always referred to before conducting further interviews.

5.13 Data Management

Study variables were coded before data entry was done using EPI INFO Version 2000 and EXCEL 2003. Computer data cleaning; editing and immediate storage with back-up copies was done on a daily basis. A random sample of the original completed forms was compared with the computer print out to assess the accuracy of entered data. Frequency distributions of all variables were done. The raw data forms were securely kept in lockable filing cabinets to avoid losing them during the course of the study.

5.13.1 Measurements and Study Variables

‘Good quality of clinical HIV/AIDS care’ was the dependent variable. It is a binary variable with “good” and “poor” as the responses.

Independent variables were the nurse characteristics such as: Age, Sex, Nurses' attitudes, Number of years in service, Years of the nurses' professional training, and Level of education of the nurse. Independent variables among the clients' characteristics included age, sex, level of education, employment status, marital status and income level.

5.13.2 Execution of the study in the Field

Five Research Assistants were identified for each study site, one of whom was a medical doctor. The Research Assistants were got from outside the TASO setting so that they were independent of the respondents at any of the study sites. They were involved in conducting the Client exit interviews, administering of questionnaires, interviewing key informants, and conducting observation of nurses' clinical practice sessions and medical chart reviews. They were proficient in the local language in order to ease communication during the data collection exercise.

At the end of each day, the teams reported their experiences to the principal investigator. The principal investigator was responsible for the execution of the study through active participation in data collection and close supervision of the research assistants. He also critically examined all the collected data to ensure its accuracy and completeness.

5.13.3 Instrument Pre-testing

All data collection instruments were pre-tested at TASO Entebbe center to determine their suitability for collecting the required data. After pre-testing, the instruments were refined and the necessary changes made. After this, these

instruments were translated into the local languages as appropriate, in order to facilitate communication during interviews.

5.13.4 Data Quality Control

The principal investigator supervised the data collection. The research assistants underwent a 3-days' training in proper data collection techniques before they set out to work. They were instructed on how to administer the questionnaires, as well as on responsible conduct of research, with emphasis on research ethics. An extensive discussion of the questionnaires was done during training on a question-by-question basis.

The questionnaires were pre-tested on 15 individuals at TASO Entebbe center and accordingly modified to incorporate the changes. At the end of each data collection day, a meeting was held between the data collectors and the Principal investigator to discover and resolve any challenges that could have been encountered during the data collection process.

5.13.5 Quantitative Data Analysis

All the quantitative data collected was edited before leaving the field to ensure consistency of the responses given. The edited data was then classified into categories and coded to reflect the major themes as shown in the conceptual framework. Data master sheets were formulated to cater for all variables of interest. The data was then entered into Excel 2003 and Epi-info version 2000; and analyzed with the aid of the STATA version SE/ 10. Frequencies and percentages were computed. Odds ratios were computed for Bi-variate and multi-variable analysis; p-values and 95% confidence intervals were also computed to

measure the levels of statistical significance and likely relationship between the dependent and independent variables. Any p-value < 0.05 was considered statistically significant.

5.13.6 Qualitative Data Analysis

As described by Mbaaga (2000), qualitative data was analyzed by formulating tentative themes and sub-themes, which were continuously analyzed before and after data collection, with the aid of Nvivo statistical package. The principal investigator cross-checked all data received for completeness, validity, precision and accuracy. Content analysis was used to analyze the qualitative data on the basis of emerging themes and sub-themes in line with the study objectives. Descriptive summaries and quotes were used. A trend analysis of the In-depth-interviews was used for identifying the major issues for each of the study themes and sub-themes. This also facilitated comparisons and contrasts of participants' views within and among the different study sites.

5.13.7 Statistical Analysis

Data analysis was done with the aid of STATA SE 10 computer software. Outcomes were expressed as ratios and percentages. Means, medians, standard deviations, and simple proportions were generated as appropriate to describe the data. Data was summarized in tables, graphs, and pie charts.

'Good quality of care' was the dependent variable, while the nurse characteristics were the independent variables. Clients' demographic characteristics also provided independent variables. Bi-variate analysis was done to determine significant associations between the dependent and the independent variables.

Odds ratios were generated for multi-variable analysis. Variables that were significantly associated with quality of HIV care were identified by computing the 95% confidence intervals and p-values. Any p-values less than 0.05 were considered statistically significant. This generated the outcomes of interest, particularly the factors affecting the quality of HIV care provided by the nurse.

5.13.8 Study Limitations and Remedial actions

- Inter-observer variation might have occurred since there were multiple research assistants at the different study sites. The investigator tried to reduce this by training them before they went out to collect data and using them in the pre-testing of data collection instruments.
- The Hawthorne-effect might have occurred when the nurses' clinical care sessions were being observed by the researcher. Attempts were made to minimize it through blinding the service providers, by telling them a different study aim. In this case they were told that the aim was to assess clients' communication skills during clinical sessions. This blinding by deception was specifically approved by the Institutional Review Board of the School of Public Health. Nevertheless, this did not seem to work, since the nurses were well known to the principal investigator, as one of their supervisors. However, the use of medical officers from outside the TASO setting and observation of more than one session, seemed to substantially reduce this effect.

- Medical chart review was limited by missing data in many cases; in which case the researchers reviewed more files to get a representative sample.

Missing information was also found in some cases due to non-response.

5.13.9 Ethical Considerations

Permission to conduct the research was sought from the Institutional Review Board of the School of Public Health, Makerere University. Written approval was then got from the Executive Director, TASO to proceed with data collection at the centers. Before data collection began, due care was taken to ensure that informed consent was obtained from all respondents. The informed consent included explanations about the purpose and objectives of the study, the procedures to be done, the benefits and risks accruing, and rights of respondents, reimbursement arrangement and reassurance on confidentiality.

This study had no explicit risks to the study subjects, but its findings could inform processes for improving the quality of health care in Uganda. Respondents were free to refuse to participate in the study and this would not affect their right to care, or their relationship with their employer/fellow employees.

All respondents were informed about the study before it started, through health talks. An opportunity was availed to each respondent to ask questions and / or seek further clarification. The study purpose was fully explained to each respondent. Patients who appeared to be very sick were not interviewed.

Unique identification numbers instead of names were indicated on the data collection form. Confidentiality and integrity of all respondents was observed. Any names that were recorded on audio-tapes were changed in the transcriptions

and were also changed in all further use of the material. The audio-tapes were erased at the end of the study. Key informants were not directly linked to the comments made during the study so as to give them freedom to express their views frankly.

Permission was sought from respondents to use audio-recording devices during the Key Informant Interviews. Interviews with nurses were done in the consultation rooms to ensure privacy and confidentiality. Key informants were interviewed in their offices. Clients were interviewed in the counseling rooms or from a private area at the outreach sites. All data records and audio tapes were securely kept for safety and confidentiality during data collection and analysis.

5.13.10 Utilization of Results

Findings from this study will be disseminated to senior TASO management, and Makerere University School of Public Health.

CHAPTER SIX

6.0 Results from the Study

6.1 Introduction:

This study was conducted between April and July 2008 to determine the perceived quality of clinical care provided by nurses to TASO clients. A total of 384 client exit interviews were conducted, 28 nurses' questionnaires administered, 51 clinical care sessions observed, 59 medical charts reviewed, and 4 key informant interviews carried out. Both qualitative and quantitative data collection methods were used. The study findings have been categorized to address each of the specific study objectives. Consequently, they are presented here below in that manner.

6.2 Clients' perceptions of the quality of clinical HIV care provided by TASO nurses.

Socio-demographic Characteristics of Clients

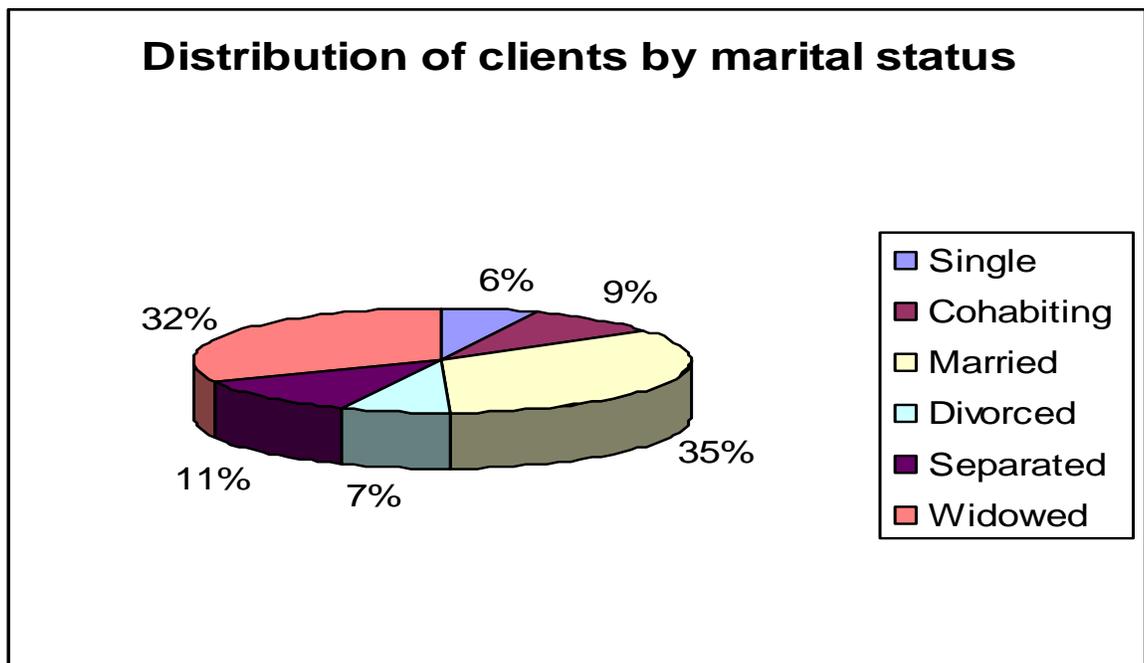
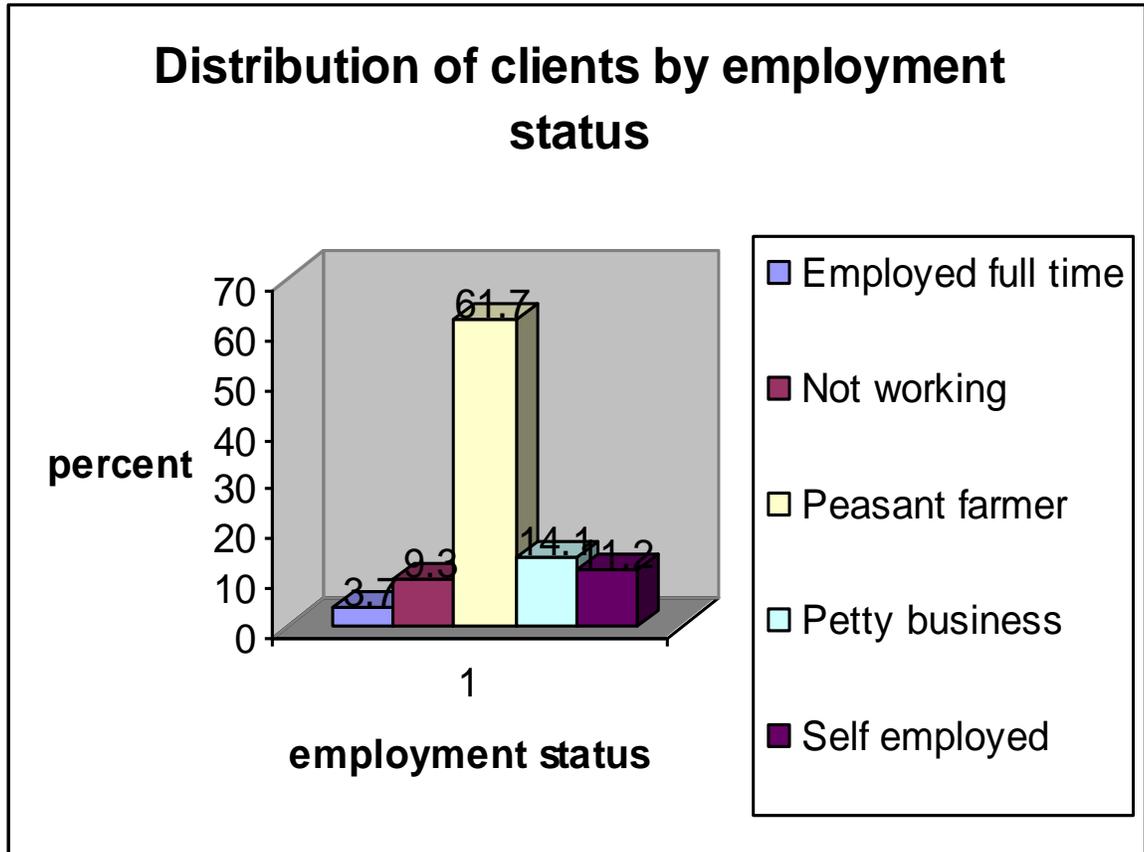
A total of 384 clients at four TASO centers were interviewed to assess their perceptions on the quality of HIV/AIDS care services provided by nurses. About sixty eight percent (67.5%) of the clients were females. The average age of the respondents was 38(± 10.12) years, with the youngest being 8 and the oldest 75 years. Slightly over 60% of the clients had attained primary level of education.

The married made up the biggest proportion of about 35%, followed by the widowed with 32%. The main occupation of the clients was peasant farming with about 62 % (Table 2). Out of 384 clients interviewed 273(71.1%) were earning some income. The average monthly income was approximately Ug.Shs 49,610/= ($\pm 64,190.6$) with a minimum of 1,000/= and maximum of Ug.Shs. 400,000/=.

Table 2: Socio-demographic characteristics of clients interviewed at 4 TASO centers

| Variable | Frequency(n=384) | Percentage |
|-------------------------|-------------------------|-------------------|
| Sex | | |
| Female | 259 | 67.5 |
| Male | 125 | 32.5 |
| Education level | | |
| None | 76 | 19.8 |
| Primary | 239 | 62.2 |
| Secondary | 69 | 18.0 |
| Marital status | | |
| Single | 24 | 6.3 |
| Cohabiting | 33 | 8.6 |
| Married | 133 | 34.6 |
| Divorced | 28 | 7.3 |
| Separated | 44 | 11.5 |
| Widowed | 122 | 31.8 |
| Employment | | |
| Employed full time | 14 | 3.7 |
| Not working(unemployed) | 36 | 9.3 |
| Peasant farmer | 237 | 61.7 |
| Petty business | 54 | 14.1 |
| Self employed | 43 | 11.2 |

Figure 2: Bar Chart showing the distribution of clients by employment status



Waiting time to receive services

Respondents were asked about the waiting time and their satisfaction with the time spent with the nurse while seeking care. Out of the 384 clients interviewed, 149(38.8%) were able to estimate their waiting time before the nurse could attend to them. On average it was estimated to be 25(\pm 11.7) minutes, with a maximum waiting time of 50 minutes. Slightly over half (51.3%) of the clients reported having waited shorter than usual, while 31% reported waiting longer than usual. From the table 3 below it is notable that a significant proportion of patients stay long in the queue.

Table 3: Assessment of time spent with the nurse by the TASO clients

| Variable | Frequency (n=384) | Percentage (%) |
|-----------------------------------------------------|------------------------------|---------------------------|
| Waiting time | | |
| Longer than usual | 119 | 31.0 |
| More or less usual | 55 | 14.3 |
| Shorter than usual | 197 | 51.3 |
| Not sure | 13 | 3.4 |
| Satisfied with the time spent with the nurse | | |
| Yes | 353 | 91.9 |
| No | 31 | 8.1 |

This was also confirmed by one key informant: *“Some are happy that involving nurses in clinical work has reduced their waiting time, so they do not queue for long. There are no direct complaints about nurses. Their main concern is delaying in the queue.”*(Female Key Informant-TASO Gulu)

While 92% of clients who were interviewed expressed satisfaction with the services they received from the nurse during the clinical care sessions (Table 3), only eight percent (8%) said they were not satisfied. In fact, ninety five percent of the clients said they would recommend TASO services to other people living with HIV/AIDS (Table 5).

To assess the socio-demographic characteristics of the clients that may be associated with their satisfaction with various aspects of the services at TASO centers, odds ratios, 95% confidence intervals and p-values were computed. Variables with p-value ≤ 0.05 were considered important in explaining satisfaction of the service. The results are shown in Tables 6 to 9 below.

Clients' perception of the quality of care aspects of the various services offered by nurses at the TASO clinics

From table 4 below, it can be noted that about 62% of clients thought it was easy to understand the nurse, while 87% said privacy was ensured during the clinical care sessions. Only 8% of clients reported being uncomfortable with the language used by the nurse; and 14% said they would have preferred another language.

Ninety two percent of clients reported having been welcomed by the nurse, while only 6% thought the nurse had not paid attention to their complaints. Fifty five percent of clients said they had not been examined by the nurse, while 52% said they had not received any explanation of their disease condition.

Indeed, one key informant had remarked thus:

“Many times they do not examine patients. They depend mainly on history taking to make a diagnosis; and they do not refer patients for laboratory investigations.”

(Key Informant-TASO Mbale)

Perhaps this could also explain a comment made by another key informant:

“Clients’ attitudes are funny, some of them, once they know they are to be seen by a nurse, they will complain. They prefer to see a doctor.”

(Key Informant-TASO Masaka)

Whereas fifty eight percent of clients said that they were not counseled on nutrition and hygiene, 52% reported having been counseled on HIV prevention. About 40% of clients reported that there was another health facility nearer their homes, but they preferred to come to TASO. This is consistent with what one key informant reported:

‘One client told me he prefers to come to TASO because it is relatively cheap. ‘You pay only five hundred shillings and get all the drugs’.’

(Key Informant- TASO Gulu)

Whereas sixty percent of clients said they did not receive any advice on family planning from the nurse, 38% said they had been asked about sexually transmitted diseases. Nevertheless, over 90% of clients reported having been welcomed by the nurse, and that the nurse actually paid attention to their complaints.

Table 4: Clients' perception of the quality of care aspects of the various services offered by nurses at the TASO clinics

| Variable | Percentages (n=384) | | |
|-------------------------------------------|---------------------|------|--------|
| | Yes | No | Unsure |
| Easy to understand the nurse | 61.5 | 38.5 | 0.0 |
| Privacy ensured | 87.0 | 12.0 | 1.0 |
| Comfortable with Language used by nurse | 92.2 | 7.8 | 0.0 |
| Would prefer another language | 14.1 | 84.4 | 1.5 |
| Welcomed by nurse | 91.9 | 5.5 | 2.6 |
| Nurse paid attention to complaint | 93.0 | 5.7 | 1.3 |
| Examined by the nurse | 43.2 | 54.7 | 2.1 |
| Received explanation of disease condition | 45.6 | 52.3 | 2.1 |
| Laboratory investigation requested for | 21.9 | 74.5 | 3.6 |
| Drugs prescribed by the nurse | 47.9 | 49.7 | 2.4 |
| Pharmacy location known by client | 89.6 | 6.3 | 4.1 |
| Accessed all drugs prescribed | 76.0 | 10.9 | 13.1 |
| Nutrition & hygiene counseling received | 42.2 | 57.8 | 0.0 |
| HIV prevention counseling received | 52.1 | 47.9 | 0.0 |
| Has another health facility nearer home | 39.1 | 58.9 | 2.0 |
| Advice on family planning given | 37.8 | 59.9 | 2.3 |
| Screening for STDs done | 38.0 | 62.0 | 0.0 |
| Condoms provided to client | 24.5 | 72.7 | 0.0 |

Would Recommend TASO services to others 95.0 2.1 2.9

Factors associated with satisfaction with staff availability at TASO clinics

The findings in Table 5 below indicate that about 49% of the male clients reported being satisfied with the availability of staff at TASO clinics as compared to 55% of their female counterparts. However, there was no statistically significant relationship between gender and being satisfied with the availability of staff (p-value = 0.268).

It was also found that those who had attained primary education were 1.5 times more likely to be satisfied with staff availability at TASO clinics than their uneducated counterparts (OR = 1.52; 95% CI: 0.91 – 2.55). However, there was no statistically significant relationship (p-value = 0.113).

In addition, only 39% of the unemployed clients were satisfied with availability of staff at TASO clinics as compared to 57% of the peasant farmers. This is probably because the peasant farmers are engaged in gainful activity hence would wish to be attended to faster, while the unemployed could even wish to come to the clinics without an appointment. In fact, the peasant farmers were twice more likely to be satisfied with availability of staff at TASO clinics than their unemployed counterparts (OR= 2.08; 95% CI: 1.01 – 4.26; p-value = 0.046*). This implies that being satisfied with staff availability is dependent on employment status. This emphasizes the need for sustainable livelihoods programming for people living with HIV/AIDS.

Married clients were found to be 3 times more likely to be satisfied with availability of staff than those who were co-habiting perhaps because the latter

may not be emotionally satisfied in their relationships (OR = 2.64; 95%CI: 1.20-5.82; p-value = 0.016*) and this was very statistically significant. This satisfaction was however independent of the clients' age and income (p-value = 0.822; & p-value = 0.067, respectively).

Table 5: Factors associated with satisfaction with staff availability

| Variable | Frequency | Proportion satisfied | Unadjusted odds ratio | 95%CI | p-value |
|------------------------|------------------|-----------------------------|------------------------------|--------------|----------------|
| Sex | | | | | |
| Male | 125 | 61(48.8) | 1.00 | | |
| Female | 259 | 142(54.8) | 1.273 | 0.83-1.95 | 0.268 |
| Education level | | | | | |
| None | 76 | 35(46.1) | 1.00 | | |
| Primary | 239 | 135(56.5) | 1.52 | 0.91-2.55 | 0.113 |
| Secondary | 69 | 33(47.8) | 1.07 | 0.56-2.06 | 0.831 |
| Employment | | | | | |
| Not working | 36 | 14(38.9) | 1.00 | | |
| Peasant farmer | 237 | 135(57.0) | 2.08 | 1.01-4.26 | 0.046* |
| Business | 54 | 22(40.7) | 1.08 | 0.47-2.56 | 0.861 |
| Others | 57 | 32(56.1) | 2.01 | 0.86-4.71 | 0.107 |
| Marital status | | | | | |
| Cohabiting | 33 | 12(36.4) | 1.00 | | |
| Married | 133 | 80(60.2) | 2.64 | 1.20-5.82 | 0.016* |
| Single | 24 | 14(58.3) | 2.45 | 0.83-7.20 | 0.103 |
| Separated/divorced | 72 | 31(43.1) | 1.32 | 0.57-3.09 | 0.518 |
| Widowed | 122 | 66(54.1) | 2.06 | 0.93-4.56 | 0.074 |
| Age | | | 1.002 | 0.95-1.022 | 0.822 |
| Income | | | 0.996 | 0.99-1.00 | 0.067 |

6.3 The knowledge of TASO nurses in providing clinical HIV/AIDS care

Socio-demographic characteristics of the nurses

The average age of the nurses that participated in the study was approximately 35 (± 8.39) years with the youngest being 26 and the oldest 56 years. The sexes of the nurses were equally distributed.

Roman Catholics made up 46.4% of the nurses' population, followed by the Protestants. Most of the nurses (64.3%) had attained advanced level of education with the registered and enrolled comprehensive nurses being most predominant. Most of the nurses (64.2%) had worked for more than four years as nurses and half (50%) had worked with TASO for a period between two to four years (Table 6).

Table 6: Socio-demographic characteristics of the nurses

| Variable | Frequency(n=28) | Percentage |
|--------------------------------------|-----------------|------------|
| Sex | | |
| Female | 14 | 50.0 |
| Male | 14 | 50.0 |
| Religion | | |
| Catholics | 13 | 46.4 |
| Protestants | 10 | 35.7 |
| Others | 5 | 17.9 |
| Education level | | |
| Secondary school | 10 | 35.7 |
| Advanced level and above | 18 | 64.3 |
| Professional Qualification | | |
| Diploma in nursing | 3 | 10.7 |
| Enrolled comprehensive nursing | 8 | 28.6 |
| Enrolled nurse | 6 | 21.4 |
| Midwifery | 3 | 10.7 |
| Registered nurse | 8 | 28.6 |
| Years of experiences as nurse | | |
| 1-3 | 10 | 35.8 |
| 4-9 | 9 | 32.1 |
| 10+ | 9 | 32.1 |
| Duration working with TASO | | |
| One year | 5 | 17.9 |
| 2-4 | 14 | 50.0 |
| 5+ | 9 | 32.1 |
| TASO center | | |
| Gulu | 8 | 28.6 |
| Masaka | 9 | 32.1 |
| Mbale | 5 | 17.9 |

| | | |
|---------|---|------|
| Mbarara | 6 | 21.4 |
|---------|---|------|

It is also worthwhile to note that there was gender balance among the respondents.

This augurs well with what one key informant commented:

“We need to balance gender because maternity leave is now almost 3 months.

Add annual leave: that is 4 months off station!”(Key Informant-TASO Masaka)

One of the key informants made the following observation:

“Some of the clients who are used to clinicians and doctors are not comfortable getting clinical care from nurses; and anyone in a skirt is a nurse.”

(Key Informant-TASO Masaka)

The gender bias comes out even more clearly from the following comment made by one of the clients:

“When you go to “female doctors” they listen but the drugs they give you might not cure you.”(Key Informant-TASO Gulu)

Table 7: HIV/AIDS specialized courses undertaken by TASO nurses

| Variable | Number trained(n=28) | Proportion (%) |
|---------------------------------|----------------------|----------------|
| Clinical management of HIV/AIDS | 20 | 71.4 |
| HIV basic care | 15 | 53.6 |
| WHO basic clinical HIV Care | 9 | 32.1 |
| HIV/AIDS counseling | 15 | 53.6 |
| ART and comprehensive care | 6 | 21.4 |
| HIV education | 10 | 35.7 |
| Principles & Practices of ART | 16 | 57.1 |
| Home-based HIV Management | 4 | 14.3 |
| Community Based HIV/AIDS Care | 3 | 10.7 |

A number of nurses had undergone training in various HIV/AIDS courses. Out of the 28 nurses from the four TASO centers, 71.4% had done training in clinical management of HIV/AIDS, while approximately 54% had done a course in HIV/AIDS counseling and another 54% a course in HIV Basic care. Home-based HIV Management and Community Based HIV/AIDS Care were the least attended courses (Table 11). However, these findings could have been affected by recall bias.

Table 8: Knowledge, attitudes and skills of the TASO nurses

| Variable | Number (n=28) | Proportion (%) |
|-------------------------------------------------------------|----------------------|-----------------------|
| Clinical skills training during pre-service training | 21 | 75 |
| HIV/AIDS care workshops attended | | |
| Never | 3 | 10.7 |
| Occasionally | 15 | 53.6 |
| Often | 2 | 7.1 |
| Rarely | 8 | 28.6 |
| Competence in HIV/AIDS care (Self-ranking) | | |
| Competent | 22 | 78.6 |
| Quite competent | 5 | 17.9 |
| Very competent | 1 | 3.5 |
| Involvement of nurses in clinical care provision | | |
| Disagree | 2 | 7.1 |
| Strongly agree | 26 | 92.9 |
| Reasons why nurses should do clinical work | | |
| They have the experience | 20 | 71.4 |
| Other staff think we are inferior | 7 | 25 |
| Huge numbers of clients | 14 | 50 |
| Barriers in provision of good clinical HIV care | | |
| Lack of consultation rooms | 8 | 28.6 |
| Lack of equipment | 4 | 14.3 |
| Refresher Courses are very rare | 5 | 17.9 |
| Lack of Team spirit | 12 | 42.9 |
| Lack of commitment by some service providers | 5 | 17.9 |

Over 90% of the nurses strongly agreed that they should be involved in the provision of clinical HIV/AIDS care i.e. taking history, examining patients, making diagnoses, requesting for laboratory investigations, and prescribing of HIV medications, including ARVs. One of the reasons advanced for their

involvement is that they thought that they had gained adequate experience in handling HIV/AIDS patients more competently (Table 8). In addition, most of them were also greatly concerned about the increasing client load, which required more service providers. This is reaffirmed by the key informants. When asked as to what they thought was the probable cause of task shifting from doctors to nurses, all the key informants attributed it to the increasing client load at their service centers.

One of the key informants said,

“The task shifting is a deliberate effort actually. The ratio of medical officers to patients is too high. Therefore there was too much work load; so people had to think twice”.

(Key Informant-TASO Masaka)

However, one key informant expressed strong reservations against nurses getting involved in clinical HIV/AIDS care. He had this to say:

*“Based on their training background it is **not** in order for nurses to do this (sic).But if they are trained in clerking and examining patients it would be okay.”*

(Key Informant- TASO Mbale)

On the other hand, one key informant who thought it was okay to implement task shifting had this to say:

“Yes! It is in order because it has helped strengthen service delivery; helped nurses climb from one level to another; and has freed medical officers to zero down on complicated cases and monitoring and follow up of patients especially those on ARVs and this has improved care. So, I think the shift is okay.”

(Key Informant-TASO Gulu)

In order to assess the nurses' clinical skills, they were asked if they had ever undergone clinical skills training prior to joining medical service. Seventy five percent reported having undergone clinical skills training. About 53.6% reported attending HIV/AIDS care workshops occasionally, as part of in-service training.

By self-assessment, all the 28 nurses thought they were competent in terms of knowledge and skills to provide clinical HIV care to TASO clients.

6.4 Clinical skills of TASO nurses in the provision of HIV/ AIDS care

6.4.1 Competence of the nurses in managing HIV/AIDS conditions

To assess the competence of the nurses in managing HIV/AIDS related conditions, nurses were asked to rank themselves on a five point scale. The rating was as follows: Score **1**= if one could not take history relevant to the patient's complaint(s); **2**= if one could take a relevant history; **3**= if they could take a relevant history and conduct a physical examination; **4**= if they could take relevant history, conduct a physical examination and order relevant investigations; and **5**=if they could take a relevant history, conduct a physical examination; order relevant investigations and correctly interpret the results. The summary of the results are shown in Table 9 below.

It is noticeable that conditions which nurses thought they were competent enough to manage included prescribing Septrin for prophylaxis (89.3%), Helminthiasis (85.8%), anemia (85.7%), vaginal candidiasis (85.7%), Urinary tract infections

(78.5%), herpes zoster (75%), chronic diarrhea (75%), Oesophageal candidiasis (71.4%), pulmonary tuberculosis (82.2%) and Cryptococcal meningitis (51.1%).

About 68% of the TASO nurses felt they were good at prescribing and/or switching ARV regimens. The ranking for more complex disease conditions showed that the nurses need to be supported technically by more highly trained medical staff.

Table 9: Nurses' competence in managing HIV/AIDS related conditions

| HIV-related Disease Condition | Self-Ranking Scale (%) (n=28) | | | | |
|-------------------------------------------|--------------------------------------|----------|----------|-------------|----------|
| | 1 | 2 | 3 | 4 | 5 |
| Pulmonary Tuberculosis(PTB) | 0.0 | 3.6 | 14.3 | 53.6 | 28.6 |
| Pneumocystis Jiroveci Pneumonia(PJP) | 0.0 | 28.6 | 42.9 | 17.9 | 10.7 |
| Upper Respiratory Tract Infections(URTI) | 0.0 | 10.7 | 14.3 | 17.9 | 57.1 |
| Oral Candidiasis | 3.6 | 0.0 | 21.4 | 25.0 | 50.0 |
| Esophageal Candidiasis | 0.0 | 0.0 | 28.6 | 39.3 | 32.1 |
| Chronic diarrhea in HIV/AIDS | 3.6 | 3.6 | 17.9 | 50.0 | 25.0 |
| Cryptococcal Meningitis | 0.0 | 21.4 | 25.0 | 42.9 | 10.7 |
| Toxoplasmosis of the brain | 7.1 | 25.0 | 46.4 | 10.7 | 10.7 |
| TB Meningitis | 0.0 | 35.7 | 42.9 | 21.4 | 0.0 |
| Fungal infection of the skin | 0.0 | 0.0 | 32.1 | 35.7 | 32.1 |
| Fungal infection of the nails | 3.6 | 3.6 | 25.0 | 35.7 | 32.1 |
| Depression in HIV/AIDS | 0.0 | 28.6 | 32.1 | 28.6 | 10.7 |
| Kaposi' Sarcoma (KS) | 3.6 | 7.1 | 42.9 | 28.6 | 17.9 |
| Herpes Zoster(KISUPI) | 0.0 | 3.6 | 21.4 | 25.0 | 50.0 |
| Genital Herpes | 0.0 | 7.1 | 39.3 | 28.6 | 25.0 |
| Urinary Tract Infections | 3.6 | 7.1 | 10.7 | 32.1 | 46.4 |
| Cancer pain | 10.7 | 28.6 | 28.6 | 25.0 | 7.1 |
| Skin sepsis | 0.0 | 7.1 | 42.9 | 28.6 | 21.4 |
| Vaginal Candidiasis | 0.0 | 0.0 | 14.3 | 32.1 | 53.6 |
| Pelvic Inflammatory diseases(PID) | 0.0 | 17.9 | 21.4 | 46.4 | 14.3 |
| Anemia | 0.0 | 0.0 | 14.3 | 21.4 | 64.3 |
| Helminthiasis | 7.1 | 3.6 | 3.6 | 17.9 | 67.9 |
| Hepatitis | 0.0 | 21.4 | 50.0 | 21.4 | 7.1 |
| Prescribing Septrin Prophylaxis | 0.0 | 3.6 | 7.1 | 14.3 | 75.0 |
| Prescribing/Switching ARV regimens | 7.1 | 7.1 | 17.9 | 53.6 | 14.3 |
| ARV side effects detection and Management | 7.1 | 0.0 | 35.7 | 50.0 | 7.1 |
| Collapsed Ranking | Poor | | | Good | |

This was also confirmed by the key informants, as can be judged from the following statements:

*“They are not good at handling complicated cases e.g. Toxoplasmosis and Cryptococcal meningitis. They can diagnose but they find a challenge in managing such cases.”***(Key Informant-TASO Mbale)**

“At least those I have been with are competent. But this is only the comprehensive nurses. The registered nurses have a lot of gaps... a lot of gaps! Even supervising them, you would rather leave it to a fellow nurse. They don't appreciate the importance of some programs and record keeping.”

(Key Informant-TASO Mbale)

Study findings also indicated that nurses need more training, mentoring and coaching in the management of complex HIV/AIDS related conditions. Conditions such as PJP, Toxoplasmosis of the brain, Depression in HIV/AIDS, Cancer pain, TB Meningitis, Kaposi sarcoma, Hepatitis, and ARV side effects detection and management.

One of the key informants in this study had this to say:

“They have difficulty handling complicated cases e.g. HIV resistance to ART; and chronic medical conditions especially neurological disorders, cancers and stage 4 disease conditions in HIV/AIDS.”

(Key Informant- TASO Mbarara)

These findings are further reaffirmed by a comment from one key informant, who said:

“Nurses’ involvement in clinical work should be to a certain level. The level of comprehensive nurses or double- trained nurses. But below that, I don’t think it is in order because they tend to have attitude problems. They attach specialization to themselves”. **(Key Informant-TASO Masaka)**

In the same vein, another key informant had this to say:

“Address the polypharmacy challenge: I think during their training they were taught symptomatic treatment; so the management of the prescription process is a challenge.” **(Key Informant- TASO Mbale)**

However, one of the key informants had a different opinion on task shifting:

*“The involvement of nurses in clinical work has brought tension. They now feel they are at the same level as doctors. The hierarchy of referral is diminishing because they see that if they can clerk, why refer? The Medical officers are now complaining. This has killed the team work.”***(Key Informant-TASO Gulu)**

The nurses were also assessed on their ability to interpret laboratory results. They were evaluated on a five point scale where a score of **1=** if one cannot interpret the result at all; **2=** if one needs a lot of guidance and technical support to interpret the result; **3=** if one can partially interpret the result without being guided; **4=** if one can fully interpret the result with technical support; and **5=** if can fully interpret the result without any technical support.

From table 10 below, it is clear that most nurses who were interviewed thought they needed technical support and guidance particularly in interpreting Chest X-ray findings. Indeed 21.4% of nurses could not read and interpret a Chest X-ray at

all. However over 96% could interpret HIV-antibody test results, while over 80% of them reported ability to interpret haemoglobin and pregnancy tests.

Table 14: Ability of TASO nurses to interpret Laboratory results

| LABORATORY RESULT | Self-Ranking Scale(%) (n=28) | | | | |
|----------------------------------------------|------------------------------|------|------|-------------|------|
| | 1 | 2 | 3 | 4 | 5 |
| HIV- antibody test results | - | - | - | 3.7 | 96.3 |
| Haemoglobin(Hb) | 3.6 | 7.1 | - | 7.1 | 82.1 |
| HCG Pregnancy test | - | - | - | 10.7 | 89.3 |
| CD4 results | 7.1 | - | 3.6 | 14.3 | 75.0 |
| B/S for Malaria parasites | - | 3.6 | 3.6 | 17.9 | 75.0 |
| Urinalysis results | 7.1 | - | 14.3 | 53.6 | 25.0 |
| Stool microscopy results | 7.1 | - | 21.4 | 39.3 | 32.1 |
| Liver Function test results | 21.4 | 35.7 | 28.6 | 10.7 | 3.6 |
| Renal Function tests | 17.7 | 39.3 | 25.0 | 14.3 | 3.6 |
| Viral Load test results | 28.6 | 17.9 | 21.4 | 21.4 | 10.7 |
| Reading and interpreting Chest X-Ray results | 21.4 | 42.9 | 17.9 | 17.9 | - |
| Collapsed Ranking | Poor | | | Good | |

These findings could be further elucidated by one key informant’s observation:

“It is because of their mode of training. Initially we did not have comprehensive nurses. These have a lot more knowledge and skills. Registered nurses and other lower cadres are not very good; they are very slow and take long to understand issues.” (Key Informant- TASO Masaka)

Another key informant was even more guarded in his observation:

“They still need regular support from a medical officer. We need to improve on how they manage TB and respiratory tract infections. They do not know how to interpret Chest X-rays and they cannot auscultate.”

(Key Informant-TASO Mbarara)

Another key informant had this to say:

“I give them stethoscopes but they never use them! It seems they need more skills on how to examine patients. They do not examine patients; they do not request for laboratory investigations.” (Key Informant- TASO Mbale)

One of the key informants actually had another opinion on task shifting to the nurses: *“Before they are allowed to see almost every case, we should have an effective triage system which sorts out complex problems to be seen by Medical officers.” (Key Informant- TASO Mbarara)*

In addition, most key informants thought there were glaring gaps in the clinical skills of the nurses and had this to say:

“They need vigorous training in clinical skills. They should be taken through systemic examination like a third year medical student.”

(Key Informant-TASO Mbale)

“They need training in pharmacology. There was one comprehensive nurse who was prescribing Salbutamol for everyone who complained of cough.”

(Key Informant- TASO Mbale)

“With more training they would be very competent. It is easy for a comprehensive nurse to show competence because they are trained in providing clinical care. But as regards enrolled nurses, it will require more vigorous training and confidence building.”(Key Informant-TASO

Mbarara)

When the key informants were asked which disease conditions they felt nurses should not treat single handedly, some had this to say:

“I don’t think there should be a demarcation. A team of nurses providing clinical care should always have a doctor to oversee and provide coaching and mentorship.”(Key Informant-TASO Mbarara)

“Cryptococcal meningitis, HIV-related malignancies, ART toxicities, paediatric illnesses and complications of HIV in pregnancy, since there are multiple contra-indications here.” (Key Informant- TASO Mbarara)

When they were asked about what they thought were the strengths of the nurses working in TASO, the key informants had this to say:

“Comprehensive nurses have the commitment to clerk as part of their work. They are knowledgeable, have good clinical judgment and are more flexible in the TASO context. They can do home care, triage, clerking, dispensing etc unlike clinical officers.”(Key Informant- TASO Mbale)

“They are able to make correct diagnosis and they consult when they encounter problems. They actually provide more comprehensive care that is holistic because they also educate the patient further.” (Key Informant- TASO Masaka)

“This task shifting has helped us evaluate our systems of work. Delegation of duties in clinical care has increased, so nurses can take on other responsibilities like C.M.E.; it has helped us reduce on the workload, improved quality of care and increased their self-esteem.” (Key Informant – TASO Gulu)

The findings in Table 11 below were obtained by the investigator while sitting-in to observe individual nurses’ clinical care sessions with the aid of a checklist. Two clinical care sessions were observed for each nurse to minimize the Hawthorne effect.

Table 11: Direct Observation of nurses' clinical care sessions

| Variable | Ranking(%(n=59) | | |
|-----------------------------------------------------------------------------------------------------------------------|-----------------|-------------|------|
| | 1 | 2 | 3 |
| Neat and Presentable- Dressed in clinical uniform | 33.9 | 27.1 | 39.0 |
| Shows confidence, has organized the clinical setting well | 17.0 | 39.0 | 44.0 |
| Welcomes client and creates rapport | 17.0 | 23.7 | 59.2 |
| Effective communication skills(sitting arrangement, good listening skills, checks understanding, clarifies questions) | 6.8 | 42.4 | 50.9 |
| Takes history that is relevant to the patient's complaint(s) | 5.1 | 42.4 | 52.6 |
| Ensures Privacy and Confidentiality | 20.3 | 47.5 | 32.2 |
| Reviews other systems | 52.5 | 42.4 | 5.1 |
| Reviews past medical history and documents | 40.7 | 33.9 | 25.4 |
| Conducts a thorough physical examination | 56.0 | 36.0 | 8.0 |
| Explains/Discusses findings /diagnosis with client | 45.8 | 33.9 | 18.6 |
| Orders relevant investigations and correctly interprets them | 76.3 | 13.6 | 10.1 |
| Prescribes recommended treatment as per national guidelines/ Refers | 13.6 | 28.8 | 57.6 |
| ARV Prescription is accurate | 44.1 | 25.4 | 30.5 |
| ARV Side effects / toxicities explained/detected/managed appropriately | 66.1 | 28.8 | 5.1 |
| Cotrimoxazole & other OI prophylaxis given | 5.1 | 6.8 | 88.1 |
| HIV medications, Prevention and Nutrition counseling done | 28.8 | 40.7 | 30.5 |
| Collapsed Ranking | Poor | Good | |

Key

- 1- Not done at all
- 2- Demonstrates limited knowledge and skills
- 3- Knowledge, Skills and attitudes demonstrate standard clinical practice.

It was found that only 39% of the nurses were dressed in clinical uniforms and could safely be described as neat and presentable (rank 3). About 45% of them showed confidence and had organized their clinical settings well, even in circumstances like outreach sites where space was a big challenge (rank 3).

However, when ranks 2 and 3 were combined to create a binary variable , with ‘good’ and ‘poor’ as the responses, it was found that about 66% of the nurses could be described as neat and presentable, while 83% of the nurses could be classified as showing confidence and having organized the clinical setting well.

Similarly, it was found that about 83% of the nurses welcomed the client to the session and made efforts to create rapport. In addition, about 93% of them demonstrated effective communication skills during the clinical care session. Eighty percent of the nurses ensured that privacy and confidentiality were observed during their sessions.

It was found that about 95% had taken history that was relevant to the patient’s complaint. However, about 53% of the nurses did not conduct a systemic review at all. Likewise, about 41% of them did not review the past medical history and documents availed to them.

In addition, it was found that 56% of the nurses did not conduct a thorough physical examination. In fact, only 8% of the nurses conducted a thorough physical examination according to standard clinical practice. Only about 53% of the nurses gave an explanation of the treatment, or discussed their clinical findings and diagnosis with the client.

Furthermore, over 76% of nurses did not order for the relevant investigations even when they would have been mandatory. In situations where laboratory tests were ordered, the nurse could not correctly interpret the result. However, about 60% of the nurses were able to prescribe the recommended treatment as per national guidelines, or to appropriately refer clients to other service providers (about 86.4%, if ranks 2 and 3 are collapsed).

For those nurses who prescribed antiretroviral therapy, 56% of them were able to write accurate prescriptions. However, only 5% could correctly detect, explain, or appropriately manage ARV-related side effects. This is perhaps because ART management is a new yet complicated component of HIV care which TASO nurses have not yet adequately mastered.

Never the less, it was interesting to find that only 5% of the nurses did not prescribe Cotrimoxazole or other OI Prophylaxis. These could have been cases of clients who either did not consent to taking the prophylaxis, or were allergic to sulphur-containing drugs. It was also found that over 70% of the nurses actually provided counseling on HIV medications, HIV prevention and Nutrition, according to standard clinical practice.

Extensive medical chart review of the clients' files that had been seen by the nurse practitioners showed that 60% of the nurses were able to take relevant clinical history from the client. However, only 13% of the medical charts had a record of physical examination findings. About 45% of the nurses had made accurate diagnoses and requested for the relevant laboratory investigations.

Table 12: Quality of Care Performance Measures Checklist

| Quality of care performance measure | Rating (%) (n=51) | | | | |
|--------------------------------------------------------------------------------------------------------------------------|-------------------|------|------|-------------|-------------|
| | 1 | 2 | 3 | 4 | 5 |
| Relevant history taken | 2.0 | 15.7 | 21.6 | 31.4 | 29.4 |
| Physical examination of relevant systems done | 49.0 | 11.8 | 25.5 | 9.8 | 3.9 |
| Diagnosis made and accurate; Relevant Laboratory Investigations requested. | 7.8 | 19.6 | 25.5 | 37.3 | 9.8 |
| Cotrimoxazole and other OI Prophylaxis Prescribed and correctly | - | 7.8 | 9.8 | 21.6 | 60.8 |
| STI Screening done, correctly | 3.9 | 11.8 | 19.6 | 21.6 | 43.1 |
| TB screening done by history, examination and/or investigation. | - | 7.8 | 19.6 | 29.4 | 43.1 |
| HIV Medications prescribed are accurate in dosage, frequency, and duration, and appropriate for the diagnosed condition. | - | 9.8 | 15.7 | 29.4 | 45.1 |
| ARV prescription is accurate in dosages, frequency, and duration; and free of drug interactions/contraindications. | 41.2 | 9.8 | 15.7 | 31.4 | 2.0 |
| ARV side effects and toxicities detected, explained and / or appropriately managed. | 62.8 | 11.8 | 19.6 | 3.9 | 2.0 |
| HIV Prevention & Nutrition counseling done | 29.4 | 2.0 | 21.6 | 29.4 | 17.7 |
| Collapsed Rating | | | | Poor | Good |

Key

- 1- Not done at all
- 2- Manifests glaring performance gaps
- 3- Demonstrates limited knowledge and skills
- 4- Demonstrates adequate knowledge and skills in that area

5- Knowledge, skills and attitudes demonstrate standard clinical practice.

Similarly, it was found that screening for STIs was done correctly by 65% of the nurse practitioners, while 70% of them actually screened clients for TB through history, examination and / or investigations.

About 75% of the nurses accurately prescribed HIV medications for OI management in dosage, frequency and duration; and the medications given were appropriate for the diagnosed condition. However, only 33% of the nurses were able to make an accurate ARV prescription, while only 6% accurately detected ARV related side effects, explained and or appropriately managed them. Nearly 63% of them could not detect side effects at all. Nevertheless, about half of the nurses were in position to provide prevention and nutrition counseling to the clients.

6.5 Management's perceptions of the quality of clinical services provided by TASO nurses.

The key informants were also asked whether they thought that the practice of nurses doing clinical work hitherto reserved for doctors and clinicians was acceptable. Only one out of the four key informants had strong reservations.

Furthermore, when asked what barriers they thought TASO clients face in accessing clinical care provided by nurses, they had this to say:

✚ *“Some nurses fear accidental blood exposure. Actually, some injectables expire because of that fear.”*(Key Informant-TASO Gulu)

✚ *“Some clients complain that nurses use bad language and shout at them. But this is rarely. Otherwise nurses are more available and more willing to do work than doctors, who are busy with academics.”(KI-Mbarara)*

When the key informants were asked about the nurses’ attitudes towards people living with HIV/AIDS, they had this to say:

✚ *“I think it is good, especially those who have stayed for sometime and those who have been trained in HIV/AIDS counseling. What seems to be affecting them is the salary issue.”(Key Informant-TASO Masaka)*

✚ *“Ninety percent have good attitudes. They are not discriminatory, but they fear to do the nursing care e.g. setting up IV lines, treating wounds.....that attitude is not good. Sometimes if a patient coughs openly at their face, they become very rude and this is because of the high incidence of needle stick injuries. So the fear of ARV side effects is too much.”(Key Informant-TASO Gulu)*

✚ *“They really manifest empathy, so the attitude is positive. They follow up patients and they go an extra mile.”(Key Informant- TASO Mbale)*

The above responses re-affirm the finding that over 90% of TASO clients were satisfied with the services they receive from the nurses.

Furthermore, the key informants were asked about what they thought were the key factors affecting the nurses’ motivation to participate in clinical care provision, and they had this to say:

✚ *“The remuneration aspect. They don’t want a big difference. They are doing doctors’ work, yet they are paid less.”(Key Informant- Masaka)*

- ✚ *“Improvement in the client’s well being on treatment that they have prescribed. When they manage a condition and the patient comes back when he has improved they feel motivated and want to continue clerking.”*
- ✚ *“How they are treated by colleagues at the workplace; people regarding them as low cadres, and the human resource practices.”*
- ✚ *“Recognition that they work a lot. They want appreciation from their supervisors and more opportunities for training.”* **(Key Informant-Mbale)**

Furthermore, the key informants made the following recommendations in order to improve the quality of clinical HIV/AIDS care provided by nurses:

- ✚ *They should undergo pre-service training in HIV/AIDS care and receive regular updates on HIV/AIDS.’* **(Key Informant- TASO Mbarara)**
- ✚ *‘We need to intensify support supervision and avail them with protocols to follow during clinical care sessions.’* **(Key Informant-TASO Masaka)**
- ✚ *‘We need to access their pre-service training curriculum to enable us compare what they do with what they study so that we can fill in the gaps.’*
(Key Informant-TASO Mbale)

CHAPTER SEVEN

7.0 Discussion

7.1 Introduction

For people living with HIV, in 94% of the cases, the first contact with health systems is not with a doctor but with a nurse, or a social worker or a community health worker (Dr. Fabienne Shumbuko, 2008). So the question becomes how to empower these cadres provide good quality services and to make sure that the service users are safe and the health workers protected.

Non-physician clinicians and nurses can take over many of the tasks in providing HIV care and treatment (including ART) in some resource-limited settings- and shifting to them can free up doctor's time, and reduce the impact of HIV/AIDS programs on the health system as a whole.

7.2 Clients' perception of the quality of clinical HIV/AIDS care received from TASO nurses

In this study, it was found that over 90% of the clients expressed satisfaction with the quality of care they receive from TASO nurses. This could be explained by the positive attitudes that are exhibited by the TASO nurses, as evidenced by the key informants' testimonies. Nursing is a dynamic process of action, coordination and interaction between the nurse and patients such that the basic needs of daily living and the ability to cope with health and illness at a particular point in life is enhanced(Laoye.A.M.,1988). Nurses' friendliness, demonstrable empathy and

understanding of the patient as a unique individual have been found to be conducive in the therapeutic relationship. Positive encouragement and reassurance is of great value to the patient since many HIV/AIDS patients see their diagnosis as a death sentence (Beedham and Wilson-Barnett, 1995). It gives them some kind of hope, which is a factor in maintaining and regaining health and accepting illness limitations and even death. Hope is present in all stages of life including dying (Stephenson, 1991). Nurses should therefore accept HIV/AIDS patients for what they are and not attribute characteristics to them based on their illness or its source because the majority of HIV/AIDS patients are usually abandoned by family and friends, with the patient often left to rely on the nurse for care and support. This contrasts sharply with the findings by Deetlefs et al in a study conducted in South Africa (2003). According to their study about the attitudes of nurses towards HIV positive patients, they concluded that the attitudes of nurses towards the HIV positive patients are mostly negative. They go on to comment that nurses cope with the resulting discomfort by using defence and coping mechanisms, which hamper the development of a therapeutic relationship between them and HIV positive patients. However, I concur regarding the perceived risk when they say that ‘nurses entertain a biased view of their own risks, considering risks only from occupational exposure.’ Indeed, the fear of accidental exposure was mentioned as an impediment to good quality care by one key informant in this study.

In the same vein, according to Michael Polgar’s 1995 US study: Nurses and AIDS care: Occupational risk perception and the social construction of HIV’ he found

that multiple indicators of risk perception are consistently associated with AIDS care experience, knowledge and training, attitudes toward groups most affected by AIDS, and a nurse's organizational environment. He re-echoes what the key informants affirmed that nurses who are experienced in AIDS care, knowledgeable, tolerant, and are under less stress perceived a lower degree of risk from occupational infection. Hence organizational reform, nurse education and experience may help temper elevated perceptions of occupational HIV risk and thus enhance the quality of care.

Assessment of the patients' perceptions of the quality of care is vital especially in circumstances where there is an acute shortage of human resources for health. In this study, 92% of TASO clients said they were satisfied with the quality of care received, while 95% of them said they would recommend TASO services to other people living with HIV/AIDS. These findings are in agreement with Baldursdottir et al's 2002 study in Australia, regarding the importance of nursing care behaviors as perceived by patients receiving care. They found that patients considered clinical competence to be the most important nurse caring behaviour, which further emphasizes the notion of caring as a moral stance integral to all interactions with patients.

Similarly, Laura S. Thorsteinsson, in a 2002 study conducted in Iceland on the quality of nursing care as perceived by individuals with chronic illnesses concluded that professional caring is the most important part of quality of care. This was reaffirmed by one key informant.

According to Heckman et al (1998), people living with HIV disease, particularly those in small towns and rural areas face many barriers that prevent them from receiving important life care services. The need to travel long distances to medical facilities; shortage of adequately trained medical professionals; lack of personal or public transportation; and community residents' stigma toward people living with HIV, are an impediment to access to quality HIV care. But findings from this particular study indicate that over 40% of clients who have other health facilities nearer to their homes, preferred to travel to TASO centers for care and treatment, probably due to the good quality of services available.

The study findings are in agreement with Donabedian's observation that to offer this specialized care; there is a need for a dedicated cadre of competent, knowledgeable and skilled health care workers (Donabedian, 1985). However, the key informants in this study were of the opinion that there are glaring gaps in the nurses' competence to provide clinical HIV/AIDS care. Perhaps what determines the client's satisfaction with the quality of care is more to do with the providers' attitudes than the technical competences. But this requires further study.

Furthermore, whereas the training needs assessment survey conducted by the Infectious Diseases Institute and the Uganda Ministry of health in 2006, found that nurses prescribe ART more than clinicians and doctors combined, this study found that only 68% of the nurses in TASO considered themselves competent enough to prescribe ART, as well as detect and manage ART-related side effects.

This study finding further confirms the assertion by Omaswa et al (1999) that quality has many components which are interrelated and will singly or

collectively promote quality. Their lack will lead to quality gaps in the services provided. This was particularly noted in the gaps in clinical competence manifested by TASO nurses during the clinical care sessions. Most nurses did not examine their clients at all, and majority confessed to not being able to interpret Chest X-ray findings. Yet, given the well known relationship between TB and HIV, it would be unfortunate to find that nurse practitioners are not in position to gainfully utilize one of the key diagnostic tools for TB disease.

Omaswa et al, (1999) lists technical competence, efficiency, interpersonal relations, and effectiveness, access to services, continuity and safety as key components of quality. Whereas the technical competence of the TASO nurses was found to be limited in some areas, assessment of their attitudes towards TASO clients showed that they are empathetic; indicating that they scored highly in terms of interpersonal relations.

According to Brook et al (1997), quality of care can be evaluated on the basis of structure, process or outcome. This study evaluated process data, which incorporated the components of the encounter between the nurse practitioner and the TASO client. The investigator found that largely, the quality of clinical care provided by the nurses was good. However, this study could not demonstrate whether there could be differences in outcome, if the processes of care under the control of the nurses were altered by training in clinical skills. None the less, evidence showed that comprehensive nurses were more competent clinical HIV/AIDS care providers compared to the registered and enrolled nurses. This difference is best attributed to their pre-service training. This is agreement with

Dr. Francesca Celletti's observation at the 2008 International AIDS Conference in Mexico: 'Good health service provision and coverage depends on having an adequate number of people, adequately trained to provide services'.

This study finding is also in line with Brennan et al (1999)'s assertion that if quality of care criteria based on structural or process data is to be credible, it must be demonstrated that variations in the attribute they measure lead to differences in outcome. Given that triangulation of methods was used during data collection, it lends further credence to these study findings.

Whereas the use of process data to measure the quality of care may not be important predictors of outcomes (Ellwood, 1998), the perceived quality of care as measured by the client exit interviews showed that over 90% of TASO clients expressed satisfaction with the clinical care provided by the nurses; and 95% of them said they would recommend these services to other people living with HIV/AIDS. However, this particular study could not independently verify whether if resources were directed towards improving the processes of care represented by these measures, the cost of medical care for people living with HIV/AIDS would not increase, without producing a corresponding improvement in the health of the patient.

According to Ashton et al (1994), those who criticize the use of outcome measures believe that most differences in outcomes among patients receiving the same treatment are the result of factors not under the control of health care providers, such as differences in patients' characteristics. However, findings from this study indicated that patient satisfaction was independent of most of the

client's characteristics (p-values > 0.05). This finding was also obtained by Sullivan et al (2001) in their study on the doctor- patient relationship and HIV-infected patients' satisfaction with primary care physicians. They found that satisfaction among HIV-infected patients was not associated with the patients' socio-demographic characteristics, HIV risk characteristics, alcohol and drug abuse, health status, quality of life, or concordant patient- physician gender and racial matching. The investigator only differs with them on the gender aspect, since in this particular study it was found that there is a statistically significant relationship between gender and patients' satisfaction.

Findings from this study also indicate that the key factors influencing patient satisfaction include staff attitudes or interpersonal aspects of care, waiting and consultation times; and general perception of different aspects of the health facility, such as staff availability. This is in agreement with similar findings obtained by Leger et al in 1994.

This study also confirms the findings that inclusion of qualitative analysis can bring forth issues of a more sensitive nature, as espoused by Ellis and Willington (1993). In this study one of the key informants quoted a client's comment on female service providers. This reveals the gender biases that could affect the perceived quality of care. Probably, future studies should focus on which gender actually provides better clinical care as measured by technical competence and interpersonal relations or client perceptions.

According to one of the key informants in the study, each team of nurses who are providing clinical HIV care should have a medical doctor to oversee their practice

as well as offer coaching and clinical mentoring. This is in agreement with Wilson et al (2005), who found that for nurse practitioners to have good clinical performance, the preconditions include high levels of experience, focus on a single condition, and either participation in teams or other easy access to physicians and other clinicians with HIV expertise. This is further supported by an observation made by Dr. Fabienne Shumbuko of Family Health International at the HIV Implementers' meeting 2008 in Kampala where she asserted that nurses can effectively perform when optimal conditions are met in terms of good preparation, better tools, and consistent support. She described a successful pilot program in rural Rwanda in which nurses were trained and mentored by medical doctors to prescribe first-line ART for treatment-naïve adult patients at primary health centers.

Furthermore, findings from this study are similar to what Linn et al (2004) concluded in a US study to assess whether nurse practitioners make a difference in provision of health counseling in hospital outpatient departments. Like in this study where 72% of nurses were found to have offered HIV prevention and nutrition counseling, Linn et al noted that the presence of a nurse is associated with higher rates of counseling for diet and HIV/STD prevention at patient visits for acute problems. This study therefore also indicates an important role nurses can play in providing preventive services. The findings reflect the emphasis of the nurse education on health counseling and patient education in clinical HIV care practice.

Finally, the nurse: patient ratio in TASO was found to be close to that recommended by the World Health Organization. The four study sites, with a patient population of 30,000 clients; who are served by 28 nurses. WHO recommends a nurse: patient ratio of 100 per 100,000 of the population.

CHAPTER EIGHT

8.0 Conclusions

- ✚ Manifesting positive attitudes towards people living with HIV/AIDS by the nurses seems to greatly influence patient satisfaction.
- ✚ Comprehensive nurses tend to have better clinical skills than the other cadres of nurses and can take over many of the tasks in providing HIV care and treatment, including antiretroviral therapy. However, the overall nurses' technical competence in regards to clinical HIV care provision shows significant areas for improvement, particularly in the field of clinical skills, pharmacology and radiology.
- ✚ The management of TASO is positive about the shifting of tasks to nurses, although they set vigorous clinical skills training, mentoring and continuous support by a medical doctor as preconditions.
- ✚ Gender biases, income levels and employment status of people living with HIV/AIDS may have a role to play in determining their satisfaction with the services they receive.

Therefore, it is possible to achieve universal access to AIDS treatment by improving the clinical skills of nurses to their full capacity and potential.

8.1 Recommendations

In view of the findings from this study, the investigator would like to make the following recommendations:

- Comprehensive nurses and double-trained nurses should be allowed to participate in clinical care for HIV/AIDS patients in TASO Uganda. This should be accompanied by intensified clinical support supervision by a medical officer. The nurses should also be availed with protocols to follow during clinical care sessions and a mechanism of periodically evaluating their competencies established.
- National institutions for nursing training should incorporate Clinical HIV/AIDS care training into their curricula, as well as develop relevant course content that suits the nurse clinician. Focus should be put on pharmacology, radiology and clinical skills.
- Gender biases among clients which affect their perception of the quality of care received need to be addressed through vigorous sensitization campaigns.
- The national leadership should provide the necessary political support and favourable regulatory policy framework that allows nurses to take on some clinical tasks as well as permit new cadres, such as social workers, to take on some tasks of existing health workers.
- A national dialogue among the stakeholders to determine the way forward regarding shifting of tasks from one echelon to another, and its implications on pre-service training should be held.

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Appendices
Appendix A : Client Exit Interview Questionnaire

[A1] Questionnaire number: _____

[A2] Name of TASO Center _____

Client Exit Interview

Instructions to interviewer: Obtain the consent of the patient before proceeding to interview him/her.

Read greeting:

Hello. I am from the TASO Training Center, Kanyanya, Kampala-Uganda. We are trying to assess the quality of care you receive from nurses at this TASO center.

I would like to ask you some questions about the visit you have just had with the nurse, and some questions of a personal nature.

I will not write down your name, and everything that you tell me will be kept secret.

You do not have to take part in this study. You stand no risk by participating in this study. No re-imburements will be made to you for participating in this study. If you do take part, you do not have to answer any question or group of questions, and you may stop the interview at any time. The information that you provide is strictly confidential and will be used for the purposes of this study only. If you have any questions about the study, I will be happy to answer them. If you decide not to take part, I assure you that this will not affect the quality of care that you receive here.

May I continue?

[A3] Name of Interviewer _____

[A4] Interview Date _____ (dd/mm/yy)

[A5] Time interview started: _____ [A6] Time interview ended: _____

Introduction: I would like to ask you questions about yourself, where you live and whom you live with.

B Socioeconomic/demographic Client Information

Perceived Quality of Care for People with HIV/AIDS in TASO Uganda.

B1 Gender of respondent (cross the appropriate box)

Male 1

Female 2

B2. How old are you? _____

B3. Where do you live? _____

Physical Address

Village.....

Sub-County.....

County.....

District.....

B4. What is your marital status?

Marital status. Cross (X) the appropriate box

Married 0 Living with partner 1 Single 2 Divorced 3

Widowed 4 Separated 5 Do not know 98

B5 How many people live with you in your home?

Household members' Number

Children.....

Adults.....

B6. What kind of work do you do?

Employment status. Cross (X) the appropriate box

Employed full-time 0 Employed part-time 1

Self employed 2 Pensioner/ Retired 3

Peasant farmer 4 Petty business 5

Still at school 6 Not working at all 7

Do not know 98

B7. What is the highest level of education you ever attained?

Level of Education. Cross (X) the appropriate box

No schooling 0 Primary school [P1-P7] 1

Secondary school (S 1- S4,) 2 Advanced Level 3

Degree/ diploma 4 Do not know 98

B8. What is *your* average monthly income?

Uganda shillings.....

B9. What is the estimated household/family monthly income? (Excluding respondent's Income)

Uganda shillings.....

B10 How many people depend on this household income? _____

Interviewer: I would like to ask you about your visit to the TASO center clinic today.

C. Patient's Perception of Quality of Services

C1. How long did you wait before seeing the nurse/health worker?

_____Hour(s) and / or _____minutes

C2. Is this more or less how long you normally wait to see the doctor/health worker, or do you normally wait for a longer or shorter time?

Waiting time. Cross (X) the appropriate box

More or less the same time as usual 1 Shorter than usual 2

Longer than usual 3 Not sure 98

C3. Were you satisfied with the time that the nurse spent with you?

Yes 1 No 2 Unsure 98

C4. During the consultation, did you feel that the nurse was easy to understand when explaining things to you, or did you feel that he/she was difficult to understand?

Cross (X) the appropriate box

Easy to understand 1 Difficult to understand 2 Do not know 98

C5. In your opinion, did you have enough privacy during your consultation with the nurse?

Yes 1 No 2 Unsure 98

C6. Were you comfortable with the language that the nurse used?

Yes 1 No 2 Unsure 98

C7. Would you have preferred another language?

Yes 1 No 2 Unsure 98

C 8. When you entered the consultation room, did the nurse welcome you?

Yes 1 No 2 Unsure 98

C 9. Did the nurse pay attention to your complaints today?

Yes 1 No 2 Unsure 98

C 10. Did the nurse examine you?

Yes 1 No 2 Unsure 98

C 11. Did the nurse explain to you what you could be suffering from?

Yes 1 No 2 Unsure 98

C 12. Did the nurse send you to the laboratory for any investigations?

Yes 1 No 2 Unsure 98

C 13. Did the nurse explain to you which drugs he/ she had prescribed for you, if any?

Yes 1 No 2 Unsure 98

C 14. Did the nurse explain to you how to take the drugs?

Yes 1 No 2 Unsure 98

C 15. Did you know where the pharmacy is located?

Yes 1 No 2 Unsure 98

C 16. Did you get all the drugs that were prescribed for your sickness today?

Yes 1 No 2 Unsure 98

C 17. Did the nurse counsel you on nutrition and hygiene?

Yes 1 No 2 Unsure 98

C 18. Did the nurse counsel you on HIV prevention?

Yes 1 No 2 Unsure 98

C 19. Did the nurse educate you on family planning choices?

Yes 1 No 2 Unsure 98

C 20. Did the nurse ask you any questions concerning TB?

Yes 1 No 2 Unsure 98

C 21. Did the nurse ask you any questions concerning STD's?

Yes 1 No 2 Unsure 98

C 22. Did the nurse provide you with condoms?

Yes 1 No 2 Unsure 98

C 23. Would you recommend the service you received from the nurse today to other people living with HIV/ AIDS?

Yes 1 No 2 Unsure 98

C 24. *If the respondent answered NO to Q.C8, what are the reasons?*

C.25. How would you rate the following aspects of this TASO clinic?

Cross (X) the appropriate box.

Poor 1 **Fair 2** **Good 3** **Very Good 4** **Excellent 5**

1 Drug availability 2 Doctor's attitude 3 Nurse's attitude

4 Counselor's attitude 5 Availability of staff 6 Cleanliness of facility

7 Overall perceptions of services at facility

C26. How do you think the services at this TASO Clinic can be improved?

C27. Is there another facility that is nearer to your home/work where you could have gone for the same HIV/AIDS services?

Yes 1 No 2 Unsure 98

C28. If YES, why did you visit TASO and not the other health facilities?

Thank you for answering these questions. Have a good day.

Appendix B: Consent Form

An assessment of the quality of clinical HIV care provided by TASO nurses to people living with HIV/AIDS at four sites in Uganda.

Principal Investigator:

Mugisha Kenneth, M.B.Ch.B, Makerere University, Kampala; DACM, University of Manchester, UK. Telephone contact: 077-2309809 E-mail: kengmug@yahoo.com

The interviewer reads and explains the following to the study participant.

Study Purpose

The biggest threat to provision of quality HIV care is acute shortage of human resources for health. TASO nurses have taken on added responsibilities to offer clinical HIV care, including history taking, examining patients, ordering investigations, making diagnoses, and prescribing various HIV medications, including antiretroviral drugs. This is in addition to the nursing care roles they execute. This is in a bid to meet the human resource challenges caused by lack of doctors and clinicians. Ultimately; this task shifting may have an impact on the quality of care. This study sets out to assess the quality of clinical HIV care provided by nurses to TASO clients in order to recommend practical interventions to address any performance gaps.

Study Procedure

If you agree to participate in the study, you will be asked to complete an interview with a trained interviewer. This interviewer will record your answers with utmost confidentiality. You therefore required to be as truthful as possible in your responses.

The interviewer will ask about clinical HIV care and those factors that affect the quality of care provided by nurses to TASO clients in Uganda.

Benefits

You will benefit from this study by getting to critically analyze the factors that affect the quality of clinical HIV care provided by nurses, and any practical interventions that may be put in place to improve care to TASO clients.

Risks

No risks will be posed to your life or your job as a result of participating in this study. The interviewer will ask some sensitive questions about you and/ or your work. No samples from any part of your body will be taken.

Reimbursement

You will not be paid for participating in the study.

Right to Refuse or Withdraw From the Study

Your participation in this study is entirely voluntary, and you are free to take part or withdraw at anytime without jeopardizing your care or your job. You are also at liberty to answer all or some of the questions posed.

Confidentiality

The results of the study will be kept strictly confidential, and used only for research/academic purposes. Your identity will be kept confidential in so far as the law allows. All information will be kept on coded forms; your names will not appear on these forms. Tape recorded messages will be erased immediately after data analysis and interpretation.

The interviewer has discussed this information with me and offered to answer my questions. If I have further questions, I may contact Mugisha Kenneth Tel.0772309809.

Statement of Consent

----- has described for me what is going to be done during this study, the risks, the benefits involved and I will be available for questions at -----.

I understand that my decision to participate in this study will not alter my usual working relations with my colleagues and employer(s), or any care that I may need from TASO. During the utilization of any information obtained from this study, my identity will remain anonymous.

I am aware that I may withdraw from this study at any time. I understand that by signing this consent form, I do not waive any of my legal and/ human rights but merely indicate that I have been informed about the research study in which I am voluntarily agreeing to participate.

A copy of this consent form will be provided to me.

Signature of participant----- Age-----

Date-----

Signature of Interviewer-----

Date-----.

Appendix C: Key Informant Interview Question Guide

Question Guide for Key Informant Interview on assessment of the quality of Clinical Care provided by TASO nurses to people living with HIV/AIDS in Uganda.

Introduction

Good morning sir/madam.

I am Dr. Mugisha Kenneth, from the TASO Training Center, Kanyanya .Kampala. I am a student of Master of Public Health at Makerere University, School of Public Health.

I am here to conduct a research study on the quality of clinical care provided by TASO nurses to people living with HIV/AIDS in Uganda in order to recommend appropriate interventions to address any gaps that may be identified.

Your opinion is vital regarding this study topic and therefore I request for your participation by responding to a few questions that I will pose to you shortly.

The information you will provide will be treated with utmost confidentiality. I request that I write down and /or tape-record this interview to enable me remember correctly what we are about to discuss.

Date.....

TASO Center.....

Position / Job Title.....

Age.....

Sex.....

Academic qualifications.....

Duration of service among people living with HIV/AIDS.....

Question Guides

1. A few years ago it was not common for a nurse to prescribe drugs to sick persons. This was the preserve of doctors and medical assistants (clinical officers).The situation seems to be changing. What do you think is the cause of this change?
2. In your opinion is it in order for nurses to make diagnosis and prescribe treatment for people living with HIV/AIDS?
3. In your opinion what are the strengths and weaknesses of nurses working for TASO?
4. What would you wish to be improved regarding the clinical care provided by nurses to TASO clients?
5. What barriers do you think TASO clients face in accessing clinical HIV/AIDS care provided by nurses at TASO clinics?
6. What is the opinion of TASO clients on the quality of clinical care they receive from nurses?

7. Comment about the nurses' competence in providing clinical HIV care.
8. What is your opinion about the attitudes of TASO nurses towards people living with HIV/AIDS?
9. In your opinion, what factors affect the motivation of TASO nurses to participate in clinical care provision?
10. Which disease conditions would you wish to be treated by a doctor or clinical officer only, and not a nurse alone?
11. Please make any comment(s) about what you would like to be addressed regarding the quality of Clinical HIV/AIDS care provided by nurses to TASO clients.

We have come to the end of this interview. I would like to thank you for the free and frank discussion. Have a good day.

Appendix D: Quality of Care Performance Measures List

This is a checklist on quality of clinical HIV/AIDS Care for use during medical chart review/ clinical sessions by the physician research assistant and the principal investigator using the grading as shown at the bottom of the table.

Nurse Code:

| Quality of care performance measure | 1 | 2 | 3 | 4 | 5 |
|--------------------------------------------------------------------------------|---|---|---|---|---|
| Relevant history taken | | | | | |
| Physical examination of relevant systems done | | | | | |
| Diagnosis made and accurate; Relevant Lab. Investigations requested. | | | | | |
| Cotrimoxazole and other OI Prophylaxis Prescribed and correctly | | | | | |
| STI Screening done, correctly | | | | | |
| TB screening done by history, examination and/or investigation. | | | | | |
| HIV Medications prescribed accurate (dosage, frequency, duration). | | | | | |
| ARV prescription accurate (dosage, frequency, duration; no drug interactions). | | | | | |
| ARV side effects detected, explained and appropriately managed. | | | | | |
| HIV Prevention & Nutrition counseling done | | | | | |
| Other remarks | | | | | |

KEY:

- 1- Not done at all
- 2- Manifests glaring performance gaps
- 3- Demonstrates limited knowledge and skills
- 4- Demonstrates adequate knowledge and skills in that area
- 5- Knowledge, skills and attitudes demonstrate standard clinical practice.

Appendix E: Direct Observation Checklist

This Check list is for use during the Direct Observation of the nurse-client encounter. To be used by a medical officer using the grading at the bottom. Nurse Code.....

| Observation | 1 | 2 | 3 | Comments on observation |
|------------------------------------------------------------------------------------------------------------------------------------------------------|----------|----------|----------|--------------------------------|
| Total time taken for consultation:.....minutes | | | | |
| Neat and Presentable- Dressed in clinical uniform | | | | |
| Shows confidence, organized clinical setting well | | | | |
| Welcomes client and creates rapport | | | | |
| Effective communication skills(sitting arrangement, good listening skills, checks understanding, clarifies questions, uses open ended questions etc) | | | | |
| Takes history relevant to the patient's complaint(s) | | | | |
| Ensures Privacy and Confidentiality | | | | |
| Reviews other systems | | | | |
| Reviews past medical history and / documents | | | | |
| Conducts a thorough physical examination(General | | | | |

| | | | | |
|-----------------------------------------------------------------------------------------------|--|--|--|--|
| and systemic) | | | | |
| Explains/Discusses findings /diagnosis with client | | | | |
| Orders relevant investigations & correctly interprets them | | | | |
| Prescribes recommended treatment as per national guidelines/ Refers | | | | |
| ARV Prescription accurate (dose, frequency, duration, no interactions/contra indications etc) | | | | |
| ARV Side effects toxicities explained/detected/managed appropriately | | | | |
| Cotrimoxazole & other OI prophylaxis given | | | | |
| HIV medications, Prevention and Nutrition counseling done | | | | |
| Other remarks | | | | |

KEY:

- 1-Not done at all.
- 2- Demonstrates limited knowledge and skills.
- 3- Knowledge, skills and attitudes demonstrate standard clinical practice.

APPENDIX F : Questionnaire For TASO Nurses

A study is being conducted to assess the quality of clinical HIV/AIDS care provided by nurses to TASO clients in order to recommend appropriate interventions to further improve the care for people living with HIV/AIDS. You are hereby requested to respond to the following questions as honestly as possible. The information you provide will be handled with utmost confidentiality. Thank you.

Section A: Demographic Characteristics

Staff Code.....

Age.....

Sex.....

Religion.....

TASO Center.....

Level of Education.....

What Professional Qualifications do you hold?

.....

Which specialized HIV/AIDS Care courses have you attended and when?

Course

Year

.....

.....

.....

Which year did you start working with TASO as a full-time staff?

.....

How long have you worked as a nurse?

.....

Section B: Knowledge, Attitudes and Skills

(Tick where appropriate).

1) Did you undergo clinical skills training during your pre-service training?

Yes No.....

2) How often do you attend HIV/AIDS care training workshops/conferences in a year?

Often..... Occasionally..... Rarely..... Never.....

3) In your opinion, to what extent are you competent in knowledge and skills to provide clinical HIV care to TASO clients? (Tick one appropriate response).

Not Competent Quite Competent.....Competent.....
Very competent.....

4) In your opinion, do you think nurses should be involved in the provision of clinical HIV/AIDS care?

Strongly Agree..... Disagree..... Strongly Disagree.....

5) Give reasons for your opinion

.....

6) In your opinion, what would you identify as the main barriers to providing good clinical and nursing care to TASO clients?

.....

7) What factors affect the provision of Clinical HIV care at this TASO center?

.....

What motivates you to provide quality care to TASO clients?

.....

8) How do clinicians and doctors support you in providing clinical HIV/AIDS care to TASO clients?

.....

9) Which HIV-related disease conditions would you feel uncomfortable treating single handedly?

.....

10) Which HIV-related disease conditions do you usually refer to doctors?

.....

11) Why do you think you should refer clients with those disease conditions?

.....

12) How would you rank your competence in managing the following conditions?

Tick the appropriate box according to the grades below.

| Condition | 1 | 2 | 3 | 4 | 5 |
|------------------------------------------|----------|----------|----------|----------|----------|
| Pulmonary Tuberculosis(PTB) | | | | | |
| Pneumocystis Jiroveci Pneumonia(PJP) | | | | | |
| Upper Respiratory Tract Infections(URTI) | | | | | |
| Oral Candidiasis | | | | | |
| Esophageal Candidiasis | | | | | |
| Chronic diarrhea in HIV/AIDS | | | | | |
| Cryptococcal Meningitis | | | | | |
| Toxoplasmosis of the brain | | | | | |

| | | | | | |
|-------------------------------------------|--|--|--|--|--|
| TB Meningitis | | | | | |
| Fungal infection of the skin | | | | | |
| Fungal infection of the nails | | | | | |
| Depression in HIV/AIDS | | | | | |
| Kaposi' Sarcoma (KS) | | | | | |
| Herpes Zoster(KISUPI) | | | | | |
| Genital Herpes | | | | | |
| Urinary Tract Infections | | | | | |
| Cancer pain | | | | | |
| Skin sepsis | | | | | |
| Vaginal Candidiasis | | | | | |
| Pelvic Inflammatory diseases(PID) | | | | | |
| Anemia | | | | | |
| Helminthiasis | | | | | |
| Hepatitis | | | | | |
| Prescribing Septrin Prophylaxis | | | | | |
| Prescribing/Switching ARV regimens | | | | | |
| ARV side effects detection and Management | | | | | |

Key: **1** Cannot take relevant history **2** Can take relevant history **3** Can take relevant history and conduct a physical examination **4** Can take relevant history, conduct a physical examination and order relevant investigations. **5** Can take relevant history, conduct a physical examination; order relevant investigations and correctly interpret the results.

13) How would you assess your ability to interpret the following laboratory test results? Tick the appropriate box according to the grades below.

| Laboratory Result | 1 | 2 | 3 | 4 | 5 |
|----------------------------------------------|----------|----------|----------|----------|----------|
| HIV- antibody test results | | | | | |
| Haemoglobin(Hb) | | | | | |
| HCG Pregnancy test | | | | | |
| CD4 results | | | | | |
| B/S for Malaria parasites | | | | | |
| Urinalysis results | | | | | |
| Stool microscopy results | | | | | |
| Liver Function test results | | | | | |
| Renal Function tests | | | | | |
| Viral Load test results | | | | | |
| Reading and interpreting Chest X-Ray results | | | | | |

Key: **1** Cannot interpret the result at all **2** Needs a lot of guidance and technical support to interpret the result **3** Can partially interpret the result if not guided **4** Can fully interpret the result with technical support **5** Can fully interpret the result without any technical support.

14) Have you ever been occupationally exposed to HIV or taken a short course of PEP to prevent HIV infection?

Yes..... No..... Do Not remember.....

15) Do you suffer any form of stigma as a result of being a TASO employee?

Yes.....No..... Do not remember.....

16) If YES, describe your lived experiences.

.....

17) If you were to get an opportunity, would you choose nursing again as a career?

Yes..... No.....

18) Give reasons for your answer above.

.....

19) Have you ever contemplated leaving the nursing profession at some point in time?

Yes..... No

20) If YES, give reasons why.

.....

21) What challenges do you encounter during provision of HIV/AIDS care services to TASO clients?

.....

22) How would you describe the nurse-clients relationship at your TASO center?

.....

23) How would you describe the attitude of other TASO employees towards nurses working in TASO?

.....

24) In your opinion, what is the attitude of TASO management towards nurses?

.....

25) Please comment on how you think the quality of clinical HIV/AIDS care provided by nurses could be improved.

.....

Appendix G: Map of Uganda Showing the Current TASO Regions, Service Centers and Their Catchment Areas



Appendix H: Content Validity Index Measurement

Criteria for Measuring Content Validity Index (CVI)

1. Relevance

1 = not relevant

2 = item need some revision

3 =relevant but need minor revision

4 = very relevant

2. Clarity

1=not clear

2 = item need some revision

3 =clear but need minor revision

4 = very clear

3. Simplicity

1 = not simple

2 = item need some revision

3 = simple but need minor revision

4 = very simple

4. Ambiguity

1= doubtful.

2 =item need some revision

3 = no doubt but need minor revision

4 = meaning is clear