University of Alberta

Herbal Medicine Considerations in the Treatment of HIV Patients: A Study in Western Uganda

by

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For Cherie,
Who awakened me through her passion
and pursuit of global justice.
Her encouragement, unyielding support and spark not
only contributed to the completion of this thesis,
but to my own personal growth.

And

For my parents, Edmund and Darlene,
Who provided love and stability throughout my life
and who fostered a spirit of self-confidence, independence,
and tenacity in me.

ABSTRACT

This cross-sectional study collected information on the behaviours and perceptions of HIV-infected adults in Kabarole District, Uganda, with respect to the use of traditional herbal medicine (THM) in the treatment of HIV/AIDS. Quantitative and qualitative data was gathered through the administration of semi-structured interviews (n=137) and group discussions (n=4) with persons living with HIV/AIDS (PLWAs). Half of the study sample was composed of persons receiving antiretroviral therapy (ART). Additional information was collected from interviews with traditional healers (n=7). The findings indicated that THM use is widespread in PLWAs regardless of the use of ART or gender. PLWAs on ART also revealed high concurrent THM-ARV use. Despite the common use of THM and the potential for harmful herb-pharmaceutical drug interactions, there is minimal communication between PLWAs and conventional medical practitioners about THM use. A mitigation strategy is recommended to reduce the potential frequency of THM-ARV drug concomitant use among ART recipients.

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AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
ARV(s)	Antiretroviral Drug(s)
BHS	Basic Health Services
CMC	Conventional Medical Care
CMP(s)	Conventional Medical Practitioner(s)
GDP	Gross Domestic Product
GNP	Gross National Product
HDI	Human Development Index
Healer(s)	Traditional Healers
HPI	Human Poverty Index
HIV	Human Immunodeficiency Virus
JCRC	Joint Clinical Research Centre
MACA	Multi-Sectoral Approach to the Control of AIDS
NGOs	Non-Governmental Organizations
PLWA(s)	Person(s) Living with HIV/AIDS

PLWA-ART	Persons Living with HIV/AIDS on Antiretroviral Therapy
PLWA-Rtn	Persons Living with HIV/AIDS on Routine Care (i.e. not on ART)
PMTCT	Prevention of Mother to Child Transmission of HIV
SPSS	Statistical Package for the Social Sciences
STD	Sexually Transmitted Disease
TH	Traditional Healer
THETA	Traditional and Modern Health Practitioners Together Against AIDS
THM	Traditional Herbal Medicine
OAU	Organization of African Unity
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations' Development Programme
UNMHCP	Uganda National Minimum Health Care Package
WHO	World Health Organization

CHAPTER 1 - INTRODUCTION

For some, the term *traditional medicine* is associated with thoughts of exotic and mysterious medical practices. Prior to the 20th century however, one aspect of traditional medicine[1] in particular was anything but exotic – the use of medicinal remedies made from naturally occurring botanical resources was a common and respected medical practice. Each botanical medicine was discovered through trial and error, and information about success and failures was relayed orally, with little or no written record. Lacking measurement systems (Okpako, 1986) and written instructions, consistency in preparation and standardized dosages were unachievable.

> *"Traditional: the handing down of information, beliefs, and customs by word of mouth or by example from one generation to another without written instruction." Merriam-Webster, 2005*

> *"Medicine: 1 a: a substance or preparation used in treating disease b: something that affects well-being; 2 a: the science and art dealing with the maintenance of health and the prevention, alleviation, or cure of disease b: the branch of medicine concerned with the non-surgical treatment of disease; 3: a substance (as a drug or potion) used to treat something other than disease; 4: an object held in traditional American Indian belief to give control over natural or magical forces; also: magical power or a magical rite." Merriam-Webster, 2005*

Medicine changed significantly in the 20th century as technological advancements in medicine made it possible to identify and synthesize some of the active ingredients within medicinal plants (Angell & Kassirer, 1998). Measurement systems and pharmacological processes were developed; clinical trials identified standard dosages, medical benefits and unwanted side effects. Science replaced trial and error, and oral

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[1] The World Health Organization uses the term '*traditional medicine*' in reference to the various forms of indigenous medicine used in Africa, South-East Asia, Latin America, and/or the Western Pacific. In the regions of North America, Europe and Australia, the terms '*complementary and alternative medicine*' and/or '*non-conventional medicine*' are used to describe the various therapeutic interventions that are provided within the national health care systems (WHO, 2002).

tradition was replaced by scientific publications and regulatory procedures such as labelling and prescriptions. Today, approximately 25% of prescription pharmaceuticals were discovered through herbal medicine studies and continue to be directly derived from botanical resources (Weiner, 2004; WHO, 2003).

Angell and Kassirer (1998) state that, along with improvements in sanitation and living conditions, the scientifically approved medicines of the 20th century have led to dramatic improvements in life expectancy in "all countries affluent enough to afford it" (p. 840). The significant caveat of this perspective is the requirement of *affluence*; a socio-economic state that escapes the majority of residents living throughout Africa and renders conventional medicine a luxury experienced by few (Bodeker, 2001). Even when allopathic medicines[2] are physically available, and despite government subsidies, the majority of Africans lack the financial means to afford a consistent supply (Pecoul, Chirac, Trouiller, & Pinel, 1999). Further, many people are unable to sacrifice money on transport costs in order to attend conventional health facilities to acquire the medicine (Morris, 2001). As a result, traditional medicine remains as a system of medicine that is suited to the resources of its recipients (Green, 1994).

In many instances, persons living with the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) may rely on herbal medicine[3] for the treatment of their HIV-related illnesses - as access to essential conventional drugs, including anti-retroviral drugs (ARV drugs), is beyond their means (Sebit, Chandiwana, Latif, Gomo, Acuda, Makoni & Vushe, 2002; Giarelli & Jacobs, 2001; Bodeker, Kabatesi, King & Homsy, 2000). Several HIV-related illnesses (e.g. fever, diarrhea, sexually transmitted diseases and skin-disorders) also present as the *same symptoms* that have been commonly treated with herbal medicine for generations (UNAIDS, 2000; Homsy, Katabira, Kabatesi, Mubiru, Kwamya, Tusaba, Kasolo, Mwebe, Ssentamu, Okello &

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[2] "The term allopathic medicine is used by adherents of alternative medicine to refer to any form of mainstream medicine" (Wikipedia, 2005). The terms *allopathic medicine, conventional medicine, modern medicine,* and *pharmaceutical drugs* have been used interchangeably throughout this study.

[3] "Herbal medicines include herbs, herbal materials, herbal preparations and finished herbal products, that contain as active ingredients parts of plants, or plant materials, or combinations thereof" (WHO, 2002, p. 1).

King, 1999). Therefore, with or without a formal diagnosis of the underlying pathology responsible for these symptoms, it is a logical extension for many persons living with HIV/AIDS (PLWAs) to manage these and other HIV-related symptoms the same way that they would have prior to HIV infection.

Morris (2001) notes that many authorities on HIV/AIDS in Africa have concluded that the traditional herbal medicine (THM) system, rather than the conventional health care system, is providing the majority of PLWAs with care and support. Although there is widespread use of herbal medicine, there has been a dearth of rigorous scientific testing of herbal remedies to-date. This has resulted in many of the THMs' potential therapeutic benefits, risks and pharmacological basis remaining unknown (Homsy, 1999). Despite this overall lack of empirical evidence and scientific understanding related to herbal medicine, herbal plants have been evaluated since the early 1990s for potential antiviral properties (Bodeker, 2003) and some studies have found herbal remedies to be associated with improvements in PLWAs' clinical conditions and quality of life (WHO/AFRO, 2001a; Sebit, Chandiwana, Latif, Gomo, Acuda, Makoni & Vushe, 2000).

As traditional and conventional medical care (CMC) systems co-exist in many regions of the world, people may use the medicine from each system exclusively, simultaneously, or sequentially. As noted by King and Homsy (1997), patients often decide to use traditional and conventional medicines concurrently and/or serially (i.e. *medical pluralism*) and this can be "interpreted as a means of survival which is all the more compelling when disease pressure is high and health resources are scarce or ineffective" (p. S223). The difficulty that arises in association with medical pluralism is that very few of the pharmacological interactions between herbs and conventional medicines have been investigated to-date, with many of the potential risks and benefits remaining unknown (Fugh-Berman, 2000). Concerns related to medical pluralism have been raised and preliminary empirical evidence has substantiated some of the concerns about herb-ARV interactions (Piscitelli, Burstein, Welden, Gallicano, & Falloon, 2002; Piscitelli, Burstein, Chaitt, Alfaro & Falloon, 2000; Clevenbergh, Durant, Chaillou, & Dellamonica, 1999).

As recently as the end of 2002, there was minimal cause for concern about potential interactions between herbal remedies and ARV drugs in sub-Saharan Africa, as access

to ARV drugs were available to less than 1% of PLWAs who were in need of such treatment (AfroAIDSinfo, 2003). It is anticipated however, that substantial improvements in the accessibility of anti-retroviral therapy (ART) in Africa (as well as in other impoverished HIV epidemic regions) will gradually be realized. This may largely occur as a result of combined international efforts, including: international trade law revisions and generic ARV manufacturing leading to reduced drug costs; enhanced and sustainable access to ARV drugs through public-private partnerships such as the Accelerated Access Initiative (AVERT, 2003); increased international health financing, for example through the Global Fund to Fight AIDS, Tuberculosis and Malaria; and non-governmental organizations (NGOs). As access to ARV drugs increases in geographic regions known for high herbal medicine prevalence, so does the potential for herb-ARV interactions.

Given that a sparse recognition of cultural factors has been implicated in the overall poor response to HIV prevention activities in Africa (Mann, Tarantola & Netter, 1992), it is imperative that this significant cultural factor – herbal medicine – be considered during the development and implementation of ARV programmes in sub-Saharan Africa. Failure to do so may culminate in ART failure and drug resistance via detrimental herb-ARV interactions (Piscitelli et al., 2002; Piscitelli et al., 2000; Clevenbergh et al., 1999). Within sub-Saharan Africa, identifying the role of THM in the treatment of HIV-related symptoms is a necessary first step in order to begin to understand the potential impact that herbal medicine may have on ARV programmes.

> *"An understanding of health-related indigenous knowledge is also essential for health planners and program implementers, if plans and programs are to be culturally appropriate and therefore effective."* E.C. Green (1994).

CHAPTER 2 - PURPOSE AND OBJECTIVES

In sub-Saharan Africa, two of the constants that co-exist within communities are HIV and the use of traditional herbal medicines. The recognition of the reliance on herbal medicine by the majority of the SSA population has led to the generally accepted conclusion that THM was (and continues to be) used for the treatment of HIV-related symptoms (Bodeker, 2003; Burford, Bodeker, Kabatesi, Gemmill, & Rukangira, 2000). Until recently, this general assumption alone appears to have been accepted as adequate with regards to a sufficient level of knowledge on the issue of THM use by PLWAs. Consequently, investigations designed to acquire detailed information about such treatment behaviours have been rare, resulting in the current paucity of published literature.

Now, however, general assumptions may no longer suffice. The devastating and constantly rising impact of HIV/AIDS in sub-Saharan Africa is capturing increasing international attention. Due in part to mounting public pressure, the disbursement of long-overdue financial assistance and reduced ARV drug prices are slowly coming to fruition. For the first time, wide-scale, publicly funded ART programmes are being developed and implemented in resource poor areas. These developments bring with them the heightened probability that a growing number of ART recipients will use herbal medicine and ARV drugs concomitantly. This may especially be the case as ART programs reach deeper into rural regions where there is a higher reliance on THM. Within this context, the potential ability of active compounds within herbal remedies to alter the clinical effectiveness of ARV drugs must soon be considered.

The current investigation sought to move beyond general assumptions about herbal medicine use by PLWAs; it sought to identify and deepen the understanding of the role of THM in the treatment of HIV/AIDS in Uganda, one country in sub-Saharan Africa that is actively pursuing ARV program expansion. Specifically, the primary objectives of this research study were:

- Identification of the frequency of herbal medicine use amongst PLWAs currently receiving ART and PLWAs who were on routine care (i.e. not receiving ARV drugs);

- Identification of the common reasons of PLWAs for the use of herbal remedies in the treatment of HIV-related symptoms;

- Identification of the frequency of concurrent herbal medicine and pharmaceutical drug use, especially the co-use of herbs and ARV drugs;

- Identification of the willingness of HIV-infected persons to disclose their use of herbal medicine to their conventional medical practitioners (CMPs);

- Identification of the willingness of PLWAs to follow CMPs' advice about the concurrent use of herbal medicine and pharmaceuticals (including ARV drugs); and

- Preliminary identification of the names of herbal medicines commonly used for the treatment of HIV-related symptoms.

The author asserts that the results of this research can be used to advance knowledge about herbal medicine use by PLWAs from general assumptions to realistic estimates. This includes establishing an accurate estimate for the probability of herbal medicine and ARV drug co-use, for both the currently existing ARV population and the population composed of likely future beneficiaries of ART programs. Additionally, armed with knowledge about communication patterns and treatment seeking behaviours related to herbal medicine use in the treatment of HIV/AIDS, program planners and implementers may be able to proactively design mitigation strategies to minimize the concomitant use of herbs and ARV drugs by HIV-infected persons.

CHAPTER 3 - BACKGROUND INFORMATION

Commonly referred to as *The Pearl of Africa*[4], Uganda is host to ecological and cultural riches that are as plentiful as they are diverse. This title, however, does not reflect the developmental, socio-economic and health hardships that the majority of Ugandans have to contend with.

3.1 Governance

Prior to the establishment of Uganda's formal borders and its current name, the region of the African continent on which Uganda lies was home to numerous ethnic groups who formed societies based on the extended family unit (Gakwandi, 1999). Several of these ethnic groups practiced ancestor worship and much of their time was occupied by subsistence agriculture and pastoral practices. Inter-tribal trading was eventually established to supplement the range of goods available within specific societies, and new social and sometimes familial relations developed. Given the various tribal ethnicities and numerous societal groupings, several political systems were established with monarchical kingdoms in the south and west (most notably the Buganda, Toro, Bunyoro and Nkoro kingdoms). Chiefdoms or principalities dominated the east and north, and were characterized by a 'Council of Elders,' who scrutinized the decisions of the respective political figureheads. These Ugandan societies exhibited tremendous political and cultural diversity and, with the exception of trading activities, had surprisingly little interaction with each other. These societies were also largely isolated from foreigners up to the 19th Century due in part to Uganda's land-locked location.

Between the arrival of the first foreigner in the region in 1844 (an Arab trader named Amhed bin Ibrahim) and the establishment of Uganda as a British Protectorate in 1894, Uganda was subject to considerable conflict (Gakwandi, 1999). Much of the conflict during this period was created by the competition for political influence and power between the four main religious contingents in the area – namely Traditionalists, Muslims, Protestants and Catholics.

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[4] Winston Churchill is credited with originally coining the phrase *The Pearl of Africa* to describe Uganda (Finlay, Fitzpatrick, Fletcher & Ray, 2000).

The strife in Uganda continued during British rule and domination. These conflicts arose for a variety of reasons: the attempts of Ugandan monarchical and tribal leaders to regain lost territories; continued hostilities between Catholics and Protestants; the opposition of tribal and/or societal leaders to the positions of subservience they occupied under British rule; and the resentment of many societies towards the posting of Bugandan chiefs and clerks as colonial government administrative agents throughout the country (Gakwandi, 1999). The favouritism extended to the powerful Buganda people by the British colonial government also assisted the Bugandans in establishing dominance in the commercial sector. Seeking alternate ways to be incorporated into the new society, many northern tribesmen joined the military and became the military's tribal majority – a situation that would have a significant impact in the post-colonial period (Finlay et al., 2000).

Tribal lines remained strong and well defined during the time of British governance - to the point that the Buganda considered a separatist movement during the period preceding Independence (Finlay et al., 2000). When independence was achieved in 1962 under a new coalition government, a compromise was achieved in which the Buganda enjoyed significant autonomy. Their leader was to serve as the President, while Milton Obote, leader of coalition formed between the Uganda People's Congress and the Kabaka Yekka party, would take the position of the Prime Minister of Uganda (Gakwandi, 1999). This compromise never materialized, however, and in 1966 Milton Obote staged a coup against the Bugandan leader, declared himself as Executive President, and suspended the Constitution of 1962 (Finlay et al., 2000; Gakwandi, 1999). Furthermore, Obote declared Uganda to be a Republic in 1967 that would exist under a unitary Constitution, an action that eliminated the former kingdoms.

Between 1962 and 1986, Uganda was characterized by numerous political and armed conflicts. The most notorious and heinous leader during this period was Idi Amin, who staged a coup against Obote in 1971 and was in power until 1979 (Finlay et al., 2000; Gakwandi, 1999). Amin's era was marked by the suspension of all political activities; empowerment of the military to kill on-sight anyone suspected of opposing the Amin regime; the obliteration of complete villages; and the torture and massacre of approximately 300,000 Ugandans. Amin also sanctioned the murder of professionals (including doctors, lawyers, business people and government and military officers) within

Ugandan society whom Amin believed posed a threat to his reign, and 70,000 members of the settled Asian community were banished from Uganda (Finlay et al., 2000). The industrial and economic collapse that ensued resulted in the systemic disintegration of the existing infrastructure, including: the closure of hospitals and health clinics; deterioration of the road system; weakening of the education system; and decline of the provision of basic utilities. Amin's army annihilated the people and wildlife throughout Uganda and his provincial governors were provided with indisputable power and authority. This resulted in many Ugandans seeking refuge in neighbouring countries.

Amin's reign of terror ended in 1979 when a coalition of Ugandan exiles and the Tanzanian army liberated Uganda (Fact, 2005; Finlay et al., 2000; Gakwandi, 1999). However, Uganda's struggles were not resolved and a succession of interim administrations continued to keep Uganda fraught with despair and destitution.

In 1986, stability was largely established in Uganda through the leadership of Yoweri Museveni and the National Resistance Army, whose philosophy was one of Ugandan self-sufficiency and anti-corruption (Fact, 2005). The National Resistance Movement (formerly the National Resistance Army) is slowly and progressively working to improve the conditions in Uganda. The situation, although markedly improved, remains less than ideal with many human rights violations continuing (AI, 2002) and the Lord's Resistance Army has wreaked havoc in northern Uganda for 18 years thus far. The actions of the Lord's Resistance Army has resulted in the displacement of approximately 1.5 million people, the abduction of 8,000 to 10,000 children, and innumerable deaths (Fact, 2005).

3.2 Uganda's Struggling Health Care System

The British Imperial East Africa Company first introduced allopathic (i.e. western or conventional) medicine to the Uganda Protectorate in the 1880s. In 1894 the British Colonial Office developed a medical care system in the Protectorate (Okuonzi, Owor & Jeppsson, 2001). This medical system was established to: provide care to civil servants and Indian labourers working on the Uganda Railway; reduce illnesses in the indigenous populations in order to minimize the risk of disease transmission to colonial staff; and ensure that ill health did not disrupt the productivity of indigenous labourers in cash crop industries. Health centres were also established by missionaries, an act that has been viewed primarily as a method of evangelization rather than as a genuinely altruistic

humanitarian effort (Okuonzi, Owor & Jeppsson, 2001; Okuonzi & Macrae, 1995). Regardless of the motivation behind these developments and the fact that the actual benefits to the indigenous population may not have been central to their original intent, Uganda had received the benefit of a respectable health infrastructure by the time of independence.

From 1971 to 1986, the health care infrastructure eroded amid on-going political and armed conflicts and the resultant cessation of international aid (Okuonzi, Owor & Jeppsson, 2001). Massive population displacements and the breakdown of health care services led to a proliferation of vector-borne diseases and malnutrition. International emergency assistance was provided in Uganda in the early 1980s by various NGOs but resulted in further fragmentation of the health system as the NGOs sought to achieve their own objectives rather than establishing a cohesive health care system (Okuonzi & Macrae, 1995).

Even after the installation of the National Resistance Movement as the Ugandan government, the magnitude of the health financing crisis continued to go unrecognized, and this failure resulted in the delayed development and implementation of a national health plan (Okuonzi, Owor & Jeppsson, 2001). Finally, in 1992 and with the assistance of the World Bank, the Ministry of Health developed a three-year national health plan. Some key recommendations included encouraging a swift response to the AIDS crisis; financing the health care system by way of user's fees; and the cessation of health care infrastructure expansion. However, for the most part, this 1993-1996 national health plan never came to fruition due to deficient donor funding (Okuonzi, Owor & Jeppsson, 2001).

In 2000, it was recognized that 51% of households in Uganda did not have access to health care facilities due to limited health infrastructure, which was especially the case in rural regions where the majority of the population resided (WHO/AFRO, 2001b). In recognition of this fact and in an effort to reduce the impact of major diseases in Uganda, the Ministry of Health, in collaboration with other government ministries, key stakeholders and development partners, implemented the National Health Policy and the Health Sector Strategic Plan (MOH, 2001; WHO/AFRO, 2001b). The Uganda National Minimum Health Care Package (UNMHCP) and the Health Care Delivery System

continue to constitute two of the five program outputs of the Health Sector Strategic Plan. Within the UNMHCP, the Sexually Transmitted Disease (STD)/HIV/AIDS Programme is categorized as a technical health care programme. In its Annual Health Sector Performance Report, the Uganda Ministry of Health (2001) acknowledged that the health sector continued to suffer from understaffing at all health sector levels. Combined with continued funding insufficiencies, this meant that the health sector also possessed an operational capacity of less than 50% of the minimum required to deliver its UNMHCP.

Recent evaluations indicate that the Ugandan government is spending 3.4% of its gross domestic product (GDP) on health expenditures (of note, 2.5% GDP is directed towards public education and 2.4% GDP is military expenditure), an amount that equates to approximately 57.5% of the total health expenditures in Uganda (WHO, 2004a; UNDP, 2003a). The remaining health expenditures are accounted for by NGOs and private organizations. In part, these expenditures are used to operate Uganda's national health service outlets which consist of 104 hospitals, 250 health centres, 2 palliative care facilities, and a combination of 1,382 maternity units, dispensaries, sub-dispensaries, and dispensary-maternity units. The Government of Uganda manages 66.7% of the hospitals and health centres (54.8% of hospitals and 71.6% of health centres) while 31.6% are managed by NGOs and 1.7% by private organizations (MOH, 2003a).

The per capita expenditure on health in Uganda, estimated at USD $38-57, is grossly insufficient to meet the health needs of the general public (WHO, 2004a; UNDP 2003a; UNDP 2003b). Accessing physician care remains difficult in Uganda with only one physician per 20,000 population and 21-50% of Ugandans remain without sustainable access to affordable essential drugs (UNDP, 2003a).

3.3 The People

Uganda is home to a population of 26.7 million (UAC, 2003a), with approximately 359,000 to 497,422 people living in Kabarole District (MOH, 2003b; UCC, 2003). Uganda's population is composed of numerous tribes with the largest being the Baganda, the Banyankore, the Basoga, and the Bakiga (UBOS, 2002). The tribal languages are broadly defined into five language categories but several dialects or variations are present within each category due to varying tribal ethnicities. Despite the

common use of tribal languages, English is the official language of Uganda (Finlay et al., 2000).

Religion is a large part of life for many Ugandans and the introduction of the Christian faith occurred in the late 1870's under the influence of the British and missionary workers (Gakwandi, 1999). Today, Christianity is the largest religion in Uganda with 41.9% of the population identifying as Catholic and 39.5% identifying as Anglican (UBOS, 2002). Of the remaining population, 12.1% are Muslim (UBOS, 2002) and one to18% practice indigenous beliefs (CIA, 2005; UBOS, 2002).

Approximately 46% of Ugandans aged ten years and older are engaged in economic activity (UBOS, 2002). The majority of the labour force (77-82%) works in the agricultural sector, and subsistence agriculture is the main occupation for 71% of the working population (Fact, 2005; UBOS, 2002). The largest cash crops in Uganda are tea, coffee, cotton, cassava (tapioca), tobacco, and potatoes (Fact, 2005). The industrial sector (consisting mainly of sugar, brewing, tobacco, cotton textiles and cement) is managed by 5% of the labour force and 8-13% are employed in the service sector (Fact, 2005; UBOS, 2002).

3.3.1 Human Development

With a noted interdependency between health status and economic development, Tulchinsky and Varavikova (2000) suggested that economic development measured by factors such as life expectancy, educational attainment, nutritional status, income and gross national product (GNP) were more accurate and revealing than measurement by GNP alone. This perspective coincides with that of the human development index (HDI) developed by the United Nations Development Programme (UNDP). The HDI utilizes the primary measurements of life expectancy, literacy, school enrolment and income to provide a more extensive perspective on a country's development status than that reflected by income in isolation (UNDP, 2004). The Human Development Reports produced by the UNDP provide insight into these measurements and, in its 2004 report, classified Uganda as a nation of 'low human development' based on its HDI value of 0.493. The HDI value, which is an overall indicator of a nation's human development progress, placed Uganda at a 146th place ranking out of 177 countries (UNDP, 2004).

Mortality rates, in conjunction with life expectancy, are frequently used as indicators of a country's overall health status. In Uganda, life expectancy at birth is startling, at 46.2 to 49.3 years and the under 5-mortality rate ranges from 124 to 147 per 1,000 live births. Similarly, Uganda has a high infant mortality rate of 79-89 deaths per 1,000 live births and a high maternal mortality ratio of 510-800 per 100,000 lives births (WHO, 2004a; UNDP, 2004; UNDP, 2003a; UNDP, 2003b). AIDS mortality is a major cause of death in the population.

In 2001/2002 in Uganda, 71% of the student population[5] was enrolled in primary, secondary or tertiary education in 2001/2002 (UNDP, 2004). In youth literacy (aged 15 to 24 years), Uganda is making positive gains with an increase of 3.9% since 1990 and a current rate of 79.4%. This positive trend in literacy is also revealed when youth literacy rates are compared with the literacy rate of 68% for the whole population 15 years or older. Unfortunately, gender inequities in education and literacy persist as evidenced by an overall female to male literacy ratio of 0.85. With recent indications of a female to male ratio of 0.75 for secondary school and 0.52 for tertiary schools in 2000/2001, it appears that educational inequities continue presently (UNDP, 2003b). As noted by Buvé, Bishikwabo-Nsarhaza and Mutangadura (2002), education provides essential skills that can improve an individual's capacity to access sex-related information.

A staggering 82.2% of Ugandans live on less than US$1 per day and 96.4% live on less than US$2 per day (UNDP, 2003b). To indicate the distribution of human development progress within a population, the human poverty index (HPI) was developed in 1997 by the UNDP to 'humanize poverty' – and is a measurement of human development deprivation as a result of the multifaceted aspects of poverty (WHOSEA, 2003). In 2004, the UNDP Human Development Report recognized Uganda as having a 36.4% HPI-1 value, which is equivalent to a 60th place ranking out of the 95 developing countries monitored. A further indication of income or consumption inequality is reflected by the Gini index, wherein a value of zero means perfect equality (i.e. the members of the

[5] The combined primary, secondary and tertiary gross enrolment ratio expressed by the UNDP is the total number of pupils (regardless of pupil age) enrolled in primary, secondary and tertiary education expressed as a percentage of the population composed of age groups that would theoretically attend those educational levels (UNESCO, 2005).

population all have the same income) and conversely, a value of 100% reflects perfect inequality (i.e. one person has all the income and the remaining members have no income) (Wikipedia, 2005). In the last survey year of 1996, Uganda had a Gini index of 37.4% as compared to most developed European nations having index values of 24% to 36% and an American index value of 41% (UNDP, 2003b; Wikipedia, 2005).

The impact of poverty on nutritional status appears to be buffered somewhat by the agricultural attributes of Uganda, as demonstrated by a population under-nourishment rate that rests at approximately 21% (UNDP, 2003b). Although agricultural activities consist mainly of subsistence farming, any amount of surplus crop is taken to the market as a small means of income generation. As a result, more than 80% of Uganda's population is directly or indirectly dependent on the agricultural sector (Gakwandi, 1999). This high agricultural involvement is supported by 85.5% to 87% of the total population living in rural areas, although only 47% of the rural population has sustainable access to a safe water source (UAC, 2003a; UNDP, 2003b).

3.4 HIV/AIDS

At the end of 2004, global estimates indicated that 39.4 million people were living with HIV (UNAIDS, 2004a). Approximately three million lives were lost to AIDS in 2004 and there were another 4.9 million new HIV infections. To date, it is estimated that AIDS has claimed over 20 million people worldwide, a number that continues to rise despite global prevention, education and relief efforts.

Although only ten percent of the world's population resides in sub-Saharan Africa, the region is burdened with over 60% of global HIV infections (UNAIDS, 2004b). In 2004, this meant that over 25.4 million persons in sub-Saharan Africa were infected with HIV and 3.1 million new infections occurred. The tragic reality of HIV in sub-Saharan is AIDS mortality - the region lost more 2.3 million citizens in 2004 alone. Epidemiological trend evaluations confirm that feminization of HIV/AIDS is occurring in sub-Saharan Africa, a development that will have a significant impact within the household as females have also become the most predominant heads of household (UNAIDS, 2004c). Women now represent 57-60% of infected adults and the highest rates of new HIV infections are noted in young women between 15 and 24 years of age (UNAIDS, 2004b; UNAIDS, 2004c). For every ten young men infected with HIV in sub-Saharan Africa, the

Joint United Nations Programme on HIV/AIDS (2004b) estimates that there are 36 HIV-infected young women.

The Government of Uganda's willingness to publicly discuss HIV/AIDS and its consistent programming and policy efforts has partially contributed to the 8.9% decrease[6] in HIV prevalence, with Uganda having a current prevalence rate of 4.1% (UNAIDS, 2004a). These efforts and results have received global recognition and praise. Despite a reduction in the HIV prevalence rate, HIV/AIDS continues to have a catastrophic impact on Uganda with between 500,000 and 1,000,000 persons living with HIV infection (UNAIDS, 2004c; UAC, 2003a; UAC, 2003b). There were over 940,000 accumulated AIDS deaths at the end of 2001 (UAC, 2003a) and, in 2003 alone, there was an additional 78,000 AIDS deaths (UNAIDS, 2004c). The orphan population in Uganda has surged, with approximately 50% of Uganda's 2 million orphans resulting from the deaths of parents as a result of AIDS.

3.4.1 Uganda's Response to HIV/AIDS

The world changed in 1981 with recognition of the first AIDS case. Although first noted in the United States, AIDS diagnoses rapidly emerged around the globe. Uganda first recognized 'slim disease' in 1982 and did not confirm this as being synonymous with AIDS until 1984 (Okware, Opio, Musinguzi, & Waibale, 2001; MOH, 1999). Rapidly and progressively, AIDS reached epidemic levels throughout sub-Saharan Africa predominantly through heterosexual transmission. One decade after the first case was reported, Uganda's national AIDS prevalence rate[7] had reached 18.3% and prevalence rates of up to 30% were recorded in some regions (UAC, 2003a).

AIDS was shrouded in mystery in Africa and rumours spread rampant that AIDS was a witch's curse because it caused the untimely deaths of adults who seemed otherwise healthy (Okware et al., 2001; Van Dyk, 2001). People readily turned to traditional healers to remove the curse spread by AIDS (Van Dyk, 2001). After an initial delay and

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[6] Decreased HIV prevalence also results from AIDS mortality (Hennekens & Buring, 1987).

[7] Prior to 2002, HIV sentinel surveillance in Uganda consisted of 19 antenatal clinics in hospitals and one surveillance site at a referral STD clinic. Five additional antenatal sentinel surveillance sites were added in 2002 (STD/AIDS, 2003).

much to Uganda's credit, Uganda's National Resistance Movement government responded to the HIV/AIDS epidemic with unprecedented political commitment and openness. The Ministry of Health's AIDS Control Program was implemented in 1986 to provide education, counselling, and patient care activities for HIV/AIDS and other sexually transmitted infections (MOH, 2003a). The Multi-Sectoral Approach to the Control of AIDS (MACA) was adopted in 1990/91 to facilitate the collective responsibility and management of HIV/AIDS by government levels, community groups, agencies, NGOs and individuals (MOH, 2003a). The MACA was supported further in 1992 through a parliamentary act that established the Uganda AIDS Commission, an organization designed to coordinate the national response to HIV/AIDS and ensure common goals were achieved (UAC, 2003a). The achievement of common goals was also assisted by the National Operational Plan for HIV/AIDS Prevention (1994-1998) which served to guide the activities of various HIV/AIDS agencies (MOH, 2003a). The Strategic Framework for HIV/AIDS was implemented for the period of 1998-2002 and was designed for the purpose of: reducing HIV infection rates; strengthening the national response capacity; and minimizing the socio-economic and health impacts of HIV/AIDS at all levels.

In an effort to improve access to HIV/AIDS care and access to ART, Uganda entered into the Drug Access Initiative in 1997 in partnership with the Joint United Nations Programme on HIV/AIDS (Okero, Aceng, Madraa, Namagala, & Serutoke, 2003). Uganda began independently managing its ARV drug access initiative by 2000 and, supported by the World Health Organization (WHO), set forth with expansion plans for the period of 2001 to 2006 under the National Strategic Framework for Expansion of HIV/AIDS Care and Support. In 2001, Uganda secured a US$50 million loan from the World Bank in order to support its HIV/AIDS activities (UAC, 2003a) and also successfully negotiated with drug companies to receive an 80-90% reduction in ARV drug purchase costs (MOH, 2001). These efforts – in combination with reduced costs of ARV drugs internationally; increased distribution of AIDS resources and funds from donor countries and agencies; the World Health Organization's '3 by 5 Initiative'; and many other programmes and developments – resulted in 20,000 Ugandans receiving ART by June 2004 (WHO, 2005; WHO, 2004b). Unfortunately, access to ART programmes remains limited and fails to assist the 110,000 HIV-infected persons in Uganda who are in critical need of ARV drugs (WHO, 2004b).

Uganda is continuing with its efforts to mitigate the impact of HIV/AIDS at all levels. The National Strategic Framework for Expansion of HIV/AIDS Care and Support is a tremendous step forward and one that needs to expand further to meet the ever growing needs of Uganda's HIV-infected citizens. ART, although not a cure for HIV/AIDS, is currently the most effective form of treatment for decreasing HIV morbidity and mortality and the lives of almost one million Ugandans are dependent on its successful management.

3.5 Physical Environment and Climate

Uganda is a small landlocked country of approximately 235,000 square kilometres located within sub-Saharan Africa (Gakwandi, 1999). Straddling the equator, Uganda shares its border with no less than five neighbours: Sudan in the north; Kenya on the east; Tanzania on the south, Rwanda in the southwest; and the Democratic Republic of Congo on the west. Despite this equatorial location, Uganda enjoys a temperate tropical climate with average daytime and nighttime temperatures of 26 and 16 degrees Celsius, respectively (Finlay et al., 2000). These temperatures are a result of Uganda's elevated position on the African plateau, with 82% of the surface area resting between 900 and 1500 meters above sea level. The altitude has also contributed to 78% of Uganda's total surface area being classified as land area, while 18% of the remaining surface area is composed of open water and four percent of swamps (Gakwandi, 1999).

A history of volcanic activity and successive earth movement has created a spectacular landscape with a topographical diversity that is almost indescribable from one border to the next (Finlay et al., 2000). In part, volcanic activity moulded the landscape around the central plateau, resulting in mountains in the extreme east and west portions of Uganda as well as innumerable features such as crater lakes, geysers, and springs (Gakwandi, 1999). The topography of the plateau is also heterogeneous, with the southern aspect of the plateau being covered by flat-topped hills that are separated by valleys and the north-eastern aspects turning to semi-desert. The mineral rich volcanic soils of the western and southern portions of Uganda are supported by generous rainfall during the rainy seasons, creating optimal conditions for lush vegetation. Uganda also possesses tremendous diversity in flora and fauna with more than 1000 different bird species and one of the highest primate densities in the world (Finlay et al., 2000).

The lush tropical climate that typifies western Uganda provides a wide-diversity of botanical resources that are readily available to the majority of people. Although the practice of traditional medicine was suppressed during times of colonial power, most countries in Africa returned to widespread traditional medicine practices after independence (Kasilo, 2001).

CHAPTER 4 - LITERATURE REVIEW

Rooted in spirituality, traditional medicine in Africa has been described by Okpako (1986) as being an effective social welfare and health care system that is contingent on shared beliefs amongst its providers and recipients. Central to traditional medicine is the belief that poor health and other calamities are experienced when the equilibrium between the individual and their internal, social and/or spiritual environment(s) is disturbed (Bodeker, 2003; Okapako, 1986). Okpako (1999) further explains that within an African cultural context, it is believed ancestral spirits become angered by the 'immoral' acts of an individual and, in turn, cast illness upon the individual. To restore harmony and reinstate favourable health, various forms of traditional medicine may be used to counteract these supernatural forces (Okpako, 1986).

Green (1994) has identified two broad categories of traditional healers in sub-Saharan Africa: herbalists (including traditional birth attendants, bonesetters, and infertility/impotence specialists) and diviner-mediums (including shaman, witch identifiers, oracles, and spirit mediums). Typically, herbalists use *materia medica* - naturally and locally available botanical resources to produce medicines. Conversely, diviner-mediums have "cultivated a relationship with ancestor and other spirits believed to assist in divination and healing" (Green, 1994, p.17). It is important to note that, rather than limiting their treatment regimes to these defined categories, traditional healers (healers) often use more than one method of treatment in their practice (Homsy et al., 1999).

For centuries, the botanical resources used by herbalists in Africa have represented one form of traditional medicine used to remedy illnesses of varying physical and/or psychological manifestations. Today, traditional treatments exist in most African countries for nearly all illnesses with the exception of those requiring major surgical interventions (Bandeira, Gaspar, & Pagula, 2001). The wide diversity of illnesses that are treated with herbal medicine can in part be explained by the enormity of the naturally occurring botanical resources - throughout the world, approximately 34,000 of the 250,000 plant species are used as a form of medicine (Weiner, 2004). In Africa, an estimated 80% of the population rely on indigenous and botanical medicines for primary

health care (WHO, 2002; Morris, 2001; Hamill, Apio, Mubiru, Mosango, Bukenya-Ziraba, Maganyi & Soejarto, 2000).

Although traditional medicine and CMC co-exist in many sub-Saharan Africa communities, traditional medicine continues to be highly utilized because of its cultural appropriateness, accessibility, and affordability in comparison to allopathic treatments in the CMC system (WHO, 2002; Burnett, Baggaley, Ndovi-MacMillan, Sulwe, Hang'Omba, & Bennett, 1999). For these reasons, traditional medicine continues to be the initial form of health care sought by urban and rural sub-Saharan Africa populations (Homsy et al., 1999) and medical pluralism results in many cases (Bodeker, 2001; Obbo, 1996). In Uganda, there is an approximate traditional healer to population ratio of 1:100 to 1:400 (Bodeker et al., 2000; Burford et al., 2000; Homsy et al., 1999) compared to the estimated CMC physician to population ratio of 1:20,000 (WHO, 2002; Morris, 2001; Bodeker et al., 2000; Burford et al., 2000; Green, 1994). The even smaller numbers of physicians in rural areas further impede accessibility to CMC, resulting in even higher reliance on traditional medicine (WHO, 2002). For example, in the rural district of Kabarole, Uganda, the CMC physician to population ratio is 1:30,000 (W. Kipp, personal communication, April 7, 2004).

The absence of affordable and accessible CMC for HIV-infected persons – namely anti-retroviral therapy – inevitably contributes to a reliance on traditional medicine for the management of HIV-related illnesses in sub-Saharan Africa (Bodeker, 2003; Sebit et al., 2002; Giarelli & Jacobs, 2001; Burford et al., 2000). Conditions commonly associated with AIDS - fever, diarrhea, sexually transmitted infections and skin irritations — have been treated by traditional medicine herbalists for generations (Hamill et al., 2000; Sibanda, 2000; Green, 1994). According to Green (1994), healers in several sub-Saharan Africa countries also believe that traditional medicine is better suited than CMC for the treatment of such conditions and this has likely contributed to the increasing number of HIV-related symptoms treated by healers in Uganda (Homsy, 1999).

Despite considerable dependence on traditional medicine in sub-Saharan Africa countries, there is limited information about the use of herbal medicine by PLWAs in Africa. Additionally, minimal data is currently available pertaining to the physiological benefits, risks and limitations derived from the bioactivity of traditional herbal treatments

in sub-Saharan Africa (Carter, Elion, Kuebel, Mindes, Nambiar, Shull, Silenzio & Wootton, 2002; Bandeira et al., 2001). Of the published scientific studies focusing on African THM, the vast majority have focused on ethnobotany and phytochemistry. This has resulted in a paucity (if not complete absence) of published research regarding the impact of sub-Saharan Africa herbal remedies on the efficacy and effectiveness of ARV drug treatments during concomitant medicine use. Notwithstanding the lack of scientific data, Neema reports that over 50% of patients eligible for ARV programme participation receive some form of THM in southwest Uganda (S. Neema, personal communication to W. Kipp, November, 2003).

Outside of sub-Saharan Africa, the use of unconventional therapies – including herbal medicine – is common, especially amongst PLWAs and other special populations (Bica, Tang, Skinner, Spiegelman, Knox, Gorbach & Wilson, 2003; Furler, Einarson, Walmsley, Millson & Bendayan, 2003; WHO, 2002; Aruna, 1999; Astin, 1998; and Winslow & Kroll, 1998). Although the concomitant use of herbal remedies and conventional medicine has been consistently demonstrated, herb-drug interactions have been under-researched despite the recognition that such interactions may potentially result in serious consequences (Bica et al., 2003; Furler et al., 2003; Wilasrusmee, Siddiqui, Bruch, Wilasrusmee, Kittur, & Kittur, 2002; Nelson & Perrone, 2000; Angell & Kassirer, 1998; Ernst, 1998; Miller, 1998; Winslow & Kroll, 1998). The potential for harmful herb-drug interactions is particularly high when ingested forms of complementary or alternative medicine are used (Bica et al, 2002; Nelson & Perrone, 2000; Slifman, Obermeyer, Aloi, Musser, Correll, Cichowicz, Betz & Love, 1998). Herb-drug interactions may also have undesirable effects that overlap with anti-retroviral toxicities (Ernst, 1998) and some herbs have been noted to alter the metabolism of prescription pharmaceuticals (Nelson & Perrone, 2000; Winslow & Kroll, 1998).

With respect to the concomitant use of herbal medicine and ARV drugs, seemingly harmless herbal remedies that are commonly used in North America been shown to alter the blood plasma concentrations of ARV drugs. Piscitelli and colleagues (2000) demonstrated that the plasma concentration of the HIV-1 protease inhibitor indinavir was significantly reduced in the presence of St John's wort (*Hypericum perforatum).* Specifically, the area under the indinavir plasma concentration curve (from time zero to five hours after the dose) decreased by 57% in the presence of St John's wort while the

concentration of indinavir eight hours after dosing was reduced by 81% when used concurrently with St John's wort (Piscitelli et al., 2000). Prompted by the findings of the initial study and in recognition of the high use of garlic supplements within the HIV-infected population, Piscitelli and colleagues (2002) completed a similar study in 2002 to evaluate the interactions between garlic supplements (i.e. garlic caplets) and the protease inhibitor saquinavir. The investigation found that garlic supplements reduced the area under the eight-hour dosing interval curve for saquinavir plasma concentration by 51% and the mean maximum concentration of saquinavir decreased by 54% (Piscitelli et al., 2002).

The findings from Piscitelli and colleagues (2002; 2000) are of exceptional importance as lower protease inhibitor concentrations have been associated with higher levels of HIV ribonucleic acid, ARV drug resistance and HIV treatment failure (Clevenbergh et al., 1999). As herbal supplements have strong pharmacological effects that can alter the metabolism of pharmaceutical agents, herbal remedies can no longer be viewed as benign or harmless treatments. Until conclusive data is provided about specific herb-ARV drug interactions, it has been recommended that the concomitant use of some herbal remedies with protease inhibitors and non-nucleoside reverse transcriptase inhibitors be avoided (Williamson, 2003; Piscitelli, 2000).

Empirical evidence has indicated that some herbal remedies can have modulatory effects on the immune system and therefore, herbs with immunosuppressive properties could be harmful in immuno-compromised patients (Wilasrusmee et al., 2002). Scientific literature has also noted that some ingested botanical remedies can result in toxicities, often in relation to the inherent chemical properties of the botanical compound (Nelson & Perrone, 2000; Angell & Kassirer, 1998; Slifman et al 1998). Additionally, herbal medicine toxicities may also result from the use of an incorrect dosage. Dosage issues may arise from the sentiment that 'more is better' and/or as a result of deficient quality control and regulation mechanisms (Nelson & Perrone, 2000; Angell & Kassirer, 1998; and Winslow & Kroll, 1998). It has been suggested that anecdotal testimonials may propagate the use of herbal medicine without providing potential users with accurate information about the potential toxicities associated with specific herbs (Nelson & Perrone, 2000; Winslow & Kroll, 1998; Mudar, 1996).

The potential development of negative herb-drug interactions is more likely when CMC physicians are unaware of patients' use of herbal medicine (Aruna, 1999; Burnett et al., 1999). Poor communication between patients and physicians with regards to herbal medicine and unconventional therapy use has been noted in several North America studies, with a range of 25-89% of patients discussing complementary and alternative therapy use with physicians (Furler et al., 2003; Eisenberg, Kessler, Van Rompay, Kaptchuk, Wilkey, Appel & Davis, 2001; Eisenberg, Kessler, Foster, Norlock, Calkins, & Delbanco, 1993; Nelson, 2000). In view of poor communication patterns and the potential for clinically significant herb-drug interactions and herb toxicities, several studies have indicated that appropriate patient care is contingent on adequate physician knowledge about the potential hazards associated with herb-drug interactions as well as adequate knowledge about patient herbal medicine use as obtained through the patient history (Bica et al., 2003; Chang, Van Servellen, & Lombardi, 2003; Furler et al., 2003; Wynia, Eisenberg, & Wilson, 1999; Miller, 1998; Winslow & Kroll, 1998; and Eisenberg et al., 1993) .

Two factors have been identified as essential components of the WHO Traditional Medicine Strategy (2002), namely the need for improved cooperation between herbal medicine practitioners and CMC physicians and enhanced treatment communication between caregivers and patients. Winslow and Kroll (1998) have suggested that enhanced communication may occur when physicians are able to nurture an environment in which patient disclosure about herbal medicine is facilitated. Physicians demonstrating an understanding of both conventional and herbal medicines are better positioned to achieve this task. A study completed by Wynia, Eisenberg and Wilson (1999) provided evidence that such a strategy should be successful, as the study indicated that physicians who perceived unconventional therapy as beneficial were more likely to discuss such treatment with their HIV-positive patients. At the same time, it is equally important to recognize that in actuality, many CMC physicians view herbal medicine as an invalid form of treatment. This opinion often stems from inadequate research knowledge about herbal medicine as well as recognition of the lack of regulation and standardization pertaining to herbal medicine practices (Klasser, Blanc & Greenblatt, 1991). Regardless of a physician's personal perspectives on the merits and/or detriments of herbal medicine, it is important that physicians understand and accept that patients do use herbal medicine (Winslow & Kroll, 1998).

Dean's (1981) perspective that self-diagnosis and self-treatment are used for an overwhelming majority of medical symptoms may partially explain the high utilization of herbal and unconventional therapies within developed and undeveloped countries alike. The individual capability that people have to perform self-treatment, however, is dependent on socio-demographic characteristics such as income, education, culture and religion (Orem, 1991). Within North America, higher levels of education and income have been frequently associated with increased use of unconventional therapies while no consistent findings have been noted in relation to gender-based differences in unconventional therapy use (Bica et al., 2003; Chang et al., 2003; Furler et al., 2003; Astin, 1998; and Ostrow, Cornelisse, Heath, Craib, Schechter, O'Shaughnessy, Montaner & Hogg, 1997).

It has also been suggested that patient attitude and learned behaviours are determinants of the type of medical care used by a patient (Druss, 1999). Astin (1998) has noted three possible explanations for patient use of unconventional therapies: (1) the belief that conventional medical care is ineffective; (2) unconventional therapies may provide patients with a sense of control and autonomy with respect to their health; and (3) the use of unconventional therapies is compatible with a patient's values and life perspectives. Research has indicated, however, that dissatisfaction with conventional medical care does not fully account for unconventional therapy utilization rates (Eisenberg et al., 2001).

There has been increasing support in Uganda, as well as several other sub-Saharan Africa countries, for the use of traditional medicine in the care of PLWAs. In 1987, the Ugandan Health Policy Review Commission recommended open referral between healers and CMC physicians (Hamill et al., 2000). A Ugandan NGO, *Traditional and Modern Health Practitioners Together Against AIDS and Other Diseases (THETA),* organized a regional task force on traditional medicine and HIV/AIDS in eastern and southern Africa in 2000 (THETA, 2003). Supported by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the task force was formed to coordinate the activities of traditional medicine related to HIV/AIDS and promote collaboration between healers and CMC physicians. The Organization of African Unity (OAU) declared 2000 to 2010 as the 'Decade for African Traditional Medicine' and resolved to make traditional medicine a priority (WHO/AFRO, 2002).

CHAPTER 5 - METHODOLOGY

5.1 General

The investigation was completed in Fort Portal, which is a small municipality situated in Kabarole District, western Uganda (Appendix 1). The data collection period was from September 1, 2004 to November 30, 2004. The study site was selected because of the on-going collaborative relationship between the researcher's graduate studies supervisor, Dr. W. Kipp, Department of Public Health Sciences, University of Alberta and Dr. G. Kabagambe-Rugamba, Kabarole District Direct of Medical Services and Mr. T. Rubaale, Team Leader, Basic Health Services (BHS) in Kabarole District.

On the recommendation of the BHS Team Leader, three recruitment sites for PLWAs were identified for this study: (1) the Prevention of Mother-to-Child Transmission of AIDS (PMTCT) Programme at the Fort Portal Referral Hospital; (2) the Joint Clinic Research Centre (JCRC) at the Fort Portal Referral Hospital; and (3) the AIDS Clinic at Virika Hospital. Site selection was based on the key criteria that the subjects at the sites would have both a known HIV sero-positive status and a known ARV drug treatment status. The PMTCT and JCRC sites were used primarily for the recruitment of subjects receiving ART (PLWA-ART), as the vast majority of PLWAs within Kabarole District on ART received treatment from one of these two programmes. Conversely, several diagnosed HIV sero-positive adults who were receiving routine medical care that did not include ART (PLWA-Rtn) attended the AIDS Clinic operated by Virika Hospital. The Virika Hospital also provided outreach clinics once per month at two rural health units - Kitojo Health Unit and Yerya Health Unit - in order to provide services to rural PLWAs who could not regularly access Fort Portal.

Although the recruitment sites were located within Fort Portal municipality (with the exception of the outreach clinics operated by Virika Hospital's AIDS Clinic), BHS personnel were confident that subjects obtained through the identified recruitment sites would be representative of PLWAs within Kabarole District as a whole. This assumption was based on the knowledge that a large number of patients travelled to Fort Portal from rural areas to access conventional medicine care. It was believed that the study might also be representative of PLWAs in Kabarole's neighbouring districts (namely

Bundibugyo, Kamwenge, Kasese and Kyenjojo) as many patients from these districts relied on the medical facilities and programmes in Fort Portal.

5.2 Sampling

HIV-infected persons between the ages of 18 and 55 were eligible for study participation (Sebit et al., 2002). Eligible PLWAs also had to be outpatients at one of the HIV programmes used for subject recruitment and all subjects had to have a confirmed HIV sero-positive status. The PLWAs were stratified into two subgroups based on their ARV treatment status at the time of subject recruitment: PLWA-ART and PLWA-Rtn. This stratification was important to ensure sufficient sample sizes in both subgroups were obtained, thereby permitting an in-depth comparison of the two groups. The PLWA-ART subgroup was of particular importance for identification of THM use by ARV recipients, including the possibility of direct herb-ARV interactions. The PLWA-Rtn subgroup was of no less importance, as information from this group was anticipated to provide insight into patterns of THM use that might be commonly associated with future ARV recipients.

To determine the sample size for this investigation, the proportion of the Ugandan population using traditional medicine was deemed to be 80% (Morris, 2001; WHO, 2002). It was desired to estimate the true proportion of the population using traditional medicine to within 10% (i.e. plus/minus 10%) with 95% confidence. The calculation provided a sample size of 61.5 and this was increased slightly to 68 to ensure ample subjects had been entered into the study in the event that some subjects were unable or unwilling to complete the full interview and/or if some subjects subsequently decided to withdraw from the study. Additionally, as two subgroups of PLWAs were being investigated, the sample size of 68 was sought for each subgroup, yielding a total desired PLWAs sample size of 136.

Clinical personnel at each recruitment site were instructed to complete systematic sampling[8] on each day that the HIV programme was providing services to adult PLWAs. Specifically, clinical personnel asked every second male and every second female meeting the inclusion criteria if he/she would be interested in participating in a research

[8] Systematic sampling is a form of probability sampling wherein a sample of every *n*th element is chosen and a random start is used (Palys, 1992).

study about HIV/AIDS. The research team was unable to monitor or confirm if this sampling methodology was consistently adhered to throughout the course of the investigation. If an eligible subject expressed an interest in study participation, they were directed to a research team member. The research team then provided the eligible subject with an information letter in the subject's preferred language of English or Rutooro and, if necessary, the research assistant would read the subject the information letter (Appendix 2). The research assistants were trained to thoroughly explain the study to eligible subjects and address subject concerns, including framing information in a manner that was culturally appropriate and comprehensible. Informed consent was either obtained or refused after the subject expressed an understanding of the study information, with the subject's inked thumbprint serving as a signature if the subject consented to study participation but was unable to sign his or her name (Appendix 3). The appropriate clinical personnel were advised to discontinue subject recruitment for each PLWA subgroup once the sample size had been obtained.

Systematic sampling was felt to be the most efficacious and ethical sampling methodology for this investigation for two key reasons. First, HIV/AIDS is associated with a high degree of discrimination and stigmatization in sub-Saharan Africa. With this in mind, systematic sampling was deemed to maximize patient confidentiality by ensuring that subject identity was not revealed to the research team without the eligible subject's knowledge and expressed interest in study participation. Systematic sampling was also appropriate due to logistical and ethical difficulties that would be encountered in attempts to contact subjects outside of the clinical programme sites. Specifically, the levels of poverty in the study area (and Uganda as a whole) meant that the majority of citizens did not have access to fixed line or mobile phones; the vast majority of residential dwellings did not have identifiable addresses; and, most importantly, efforts to identify and contact potential subjects outside of the clinical programme sites could place the potential subjects at risk by unintentionally drawing the attention of community and/or family members to the subjects and/or the subjects' medical condition.

The methodology used in this investigation ensured that the informed consent process was completed with a research team member and not in the presence of HIV programme personnel. This methodology component was designed to ensure that clinical personnel were not aware of which potential subjects actually entered the study

and hence there was no potential or actual coercion in relation to subject recruitment by clinical personnel. Additionally, it was speculated that PLWAs – regardless of their ARV treatment status - might have concerns about sharing accurate information about their THM use. There was the conjecture that PLWA-Rtn might fear being disqualified as candidates for future enrolment in an ARV drug treatment programme if their disclosure was exposed. Similarly, PLWA-ART could perceive the disclosure of their concurrent THM-ARV use as potentially jeopardizing to their continued enrolment in the ART programmes. By ensuring that clinical personnel were not aware of the identity of study participants, these concerns were minimized.

Once a subject had provided consent for study participation, the subject was assigned a four-digit subject number. The subject number was used in place of subject names on all study documents with the exception of the subject number assignment sheet, the consent form, and the group discussion roster (i.e. to ensure that only subjects that had be recruited into the study were present at the appropriate group discussion session). Furthermore, subject numbers were utilized within the study's Statistical Package for the Social Sciences (SPSS) dataset to assist with ensuring subject anonymity.

To track the PLWA subject participation rate at the time of subject sampling and recruitment, the clinical personnel and research assistants were asked to complete a tracking sheet for each subject contact. The tracking sheets collected the following information: programme name and/or site; recruiter's name; the date of subject contact; the subject's gender; and whether or not the subject agreed to proceed with the recruitment process (clinical personnel tracking sheet) or whether consent was obtained (research assistant tracking sheet). The clinical personnel tracking sheet is provided in Appendix 4.

This investigation used convenience sampling for the identification of traditional healers. This methodology was used due to the limited number of healers near Fort Portal, the limited use of healers reported by PLWAs during the field component of this study, and perceived logistical difficulties in identifying and contacting healers. The Chairman of the *Kabarole Traditional Healer and Herbalist Association* completed convenience sampling for healers who were members of his association, all of whom were located in rural areas of Kabarole district. This was necessary as the researcher had no other means of

identifying and/or sampling these traditional healers. As per the primary investigator's request, the Chairman identified three traditional healers for participation in the study and also acquired their permission for the primary investigator to meet with them on an individual basis.

Healers operating herbal clinics within Fort Portal were also identified via convenience sampling, with the research team identifying only three herbal clinics within the municipality. It was determined that the research team would contact the healers at each of these clinics to ascertain their willingness to participate in the study based on the minimal number of clinics. As well, a healer who had a collaborative relationship with one of the Virika AIDS Clinic outreach programmes expressed a willingness to meet with the researcher at the researcher's request. The researcher gladly accepted this offer and a meeting was established.

A total sample size of six to eight healers was sought for this study. The healers were all provided with information letters about the study in their preferred language of English or Rutooro. As well, informed consent was obtained from all healers prior to study participation. In a similar strategy as that employed with PLWAs, an identification number was assigned to each healer after their consent had been obtained. This number was used on all documents to identify information provided by the participant and to ensure preservation of healer anonymity.

5.3 Data Collection

The investigation utilized both quantitative and qualitative study techniques to acquire information about issues related to the use of traditional herbal medicine by persons living with HIV/AIDS. Data from PLWAs was primarily collected using a semi-structured questionnaire with closed and open questions during a face-to-face interview (Hamill et al., 2000; Sebit et al., 2000; Burnett et al., 1999; Phillips, 1996). The interview questions were asked sequentially as outlined in the PLWAs' questionnaire (Appendix 5). Open-ended questions were purposively incorporated into the questionnaire to collect data that was unsuitable for closed-question design due to the broad spectrum of answers that could have been provided (e.g. symptoms for which medicine is used; names of THM used) and/or when more detailed information was desired (i.e. qualitative responses).

Questionnaire pre-testing within the study area was completed prior to the initiation of actual subject interviews (Sparber, Wootton, Bauer, Curt, Eisenberg, Levin & Steinberg, 2000). The BHS Team Leader identified two male and two female HIV-infected persons who were willing to volunteer for questionnaire pre-testing. The volunteers were provided with an information letter and informed consent was obtained from each volunteer for participation in the pre-testing activities. Each research assistant conducted one English and one Rutooro interview and also interviewed one male and one female volunteer.

At the conclusion of each pre-test, the volunteer and research assistant were asked to comment on the questionnaire terminology, sequence of the interview questions, and general concerns related to the interview process. Minor revisions were made to the interview questionnaire based on the comments and suggestions received. The primary investigator also provided the research assistants with constructive feedback based on the research assistants' observed interviewer skills and techniques. The small number of questionnaire pre-tests did not permit a thorough assessment of document reliability or potential interviewer biases. The information that was available, however, did not reflect an obvious bias in relation to interviewer gender or interview technique.

Interviews with PLWAs were conducted in privacy in rooms or offices within each HIV programme site. It was anticipated that this would best ensure that the subjects were in a familiar environment where they would feel at ease. These arrangements also permitted data to be collected in a manner that avoided unnecessary travel or other inconvenience for both the subjects and the research team. In the event that the subject was not comfortable with the location and/or timing of the interview, the subject could request that the interview be completed at an alternate location with consideration for subject confidentiality, comfort, and time and/or transportation constraints.

Based on the consideration of language and cultural barriers, all PLWAs' interviews were completed by the primary research assistants. The presence of language barriers were a complicating factor for the data collection phase of this investigation as the vast majority of Kabarole residents are unable to communicate in English and the primary investigator was unfamiliar with the Rutooro language. As a result, it was imperative that communication with subjects be completed in the subjects' preferred language. (Burnett

et al.,1999). It was also speculated that study participants would be more willing to share accurate information about THM with a member from their own culture than with a 'muzungu' (i.e. a Caucasian or European). In order to promote the greatest openness and forthrightness of study participants, it was deemed best that the research assistants conduct the interviews with PLWAs.

PLWAs' questionnaire responses were recorded directly on the study questionnaire at the time of information delivery. The same questionnaire, consisting of 41 primary questions, was utilized with the PLWA-ART and PLWA-Rtn subgroups with 10 supplementary questions that were related specifically PLWA-ART being intentionally omitted during PLWA-Rtn interviews. The PLWA interviews were approximately 75 minutes in duration due, as mentioned previously, to the inclusion of several open-ended questions and also to the willingness of subjects to provide comprehensive explanations. The interview duration was decreased to approximately 40 minutes when interviewees indicated that they did not use THM.

The interviews with PLWAs were designed to assess the general use of THM by PLWAs, as well as their use of THM specifically for symptoms that they believed were related to their HIV/AIDS status. Information about the perceived effectiveness of THM and modern medicine was sought, as was information related to PLWAs' communication about THM use with their CMPs. Questions were included to determine the potential influence of CMC practitioner advice and dialogue with patients on PLWAs' health care behaviours.

As information was being obtained from PLWAs about their use of THM for the treatment of HIV-related symptoms, it was important to first identify what subjects considered to be HIV/AIDS symptoms. These *culturally defined* HIV/AIDS symptoms represented the cultural domain or semantic of HIV/AIDS in this study and free-listing techniques were used during the interviews to generate symptom lists (Brewer, Garrett, & Rinaldi, 2002; Robbins & Nolan, 1997; Weller & Romney, 1988). To establish the HIV-symptom domain, PLWAs were asked, "what kinds of illness (symptoms) have you experienced that are caused by AIDS?" The answers were recorded in the order provided by the PLWA and interviewers prompted the subjects to further expand the list by reading the

list back to the subject and asking, "what other symptoms do you have?" Free-listing was also used to identify the types of THM used by HIV-infected persons.

Previous traditional medicine studies revealed that subject characteristics such as gender, age, and educational attainment were variables that impacted the use of traditional medicine (Sebit et al., 2002; Sparber et al., 2000). As such, this demographic information was included on the questionnaire for this investigation. The additional variables of tribal ethnicity and marriage status were also included to assist in further defining the characteristics of PLWAs who participated in this investigation.

The cultural appropriateness of traditional medicine has been cited as a reason for its frequent use in sub-Saharan Africa societies (WHO, 2002; Burnett et al., 1999). To ascertain if the perceived cultural acceptance of THM impacts its use by PLWAs, participants were asked about their perception of their communities' acceptance of THM in comparison to CMC. As well, individual acceptance of THM was addressed by asking PLWAs about their preferred form of medicine use (i.e. THM or pharmaceuticals). It was anticipated, however, that subjects might not use their preferred form of medicine due to factors such as socio-economic constraints and/or convenience. Thus, it was equally important to identify the first medicine used by PLWAs when an illness episode was experienced as well as their secondary health care behaviours.

It was speculated that perceived medicine effectiveness and the perceived effects of concomitant medicine use could potentially influence PLWAs' medicine preferences and health seeking behaviours. Thus, interview questions addressed perceived medicine effectiveness in general as well as in relation to specific symptoms for which medicine was used. Additionally, subject perceptions about the benefits and risks of concurrent THM-CMC use were recorded, with the PLWA-ART subgroup also providing perceptions specifically about THM-ARV co-use.

Further insight into the role of THM in the treatment of PLWAs was derived from data about PLWAs' willingness to modify their medicine use based on health provider advice, especially in relation to concurrent medicine use. Information of this nature was deemed valuable to predict PLWAs' health seeking and medicine use behaviours in the event

that future pharmacological research provides information related to the benefits or contraindications of concurrent THM-ARV use.

Group discussions with PLWAs were completed in the later part of the data collection period. These discussions provided the researcher with an opportunity to expand and/or clarify her understanding of information and local terminology acquired from the interviews with PLWAs. Additionally, it was speculated that subjects might disclose more accurate and detailed information about THM use in a group discussion format as compared to individual interviews; subjects could construe groups as affording a higher degree of anonymity and hence less personal risk with respect to information disclosure. Thus, the group discussions also provided an opportunity to verify the general accuracy of interview data.

To enhance participation and information sharing amongst the participants, four separate group discussions were conducted on the basis of both PLWAs' gender and ARV treatment status. A maximum of 26 participants were invited to each group discussion as it was anticipated that at least 40-50% of invited subjects would not attend due to: forgetfulness resulting from the length of time between the invitation and the group discussion; unpredictable personal circumstances such as illness and workload; and transportation constraints. The first 26 male and female PLWAs interviewed in each subgroup were invited to participate in a group discussion and provided with the information about the group discussion. This approach was necessary as the majority of subjects were difficult to locate and/or contact outside of the clinic setting, i.e. street addresses are rare and there is a general lack of access to telephones. All group discussions took place in the privacy of a shelter at the Fort Portal Referral Hospital.

To ensure only study participants were in attendance at the group discussions, subject attendance by name was verified on a roster indicating the names of the individuals who had been invited to the group discussion. This process was completed by a research assistant as the subject entered the room and was conducted in a discrete manner in order to maintain confidentiality of subjects' names. Once their attendance was verified, participants were given a numbered card that did *not* correspond to the subject number assigned at the time of informed consent. The purpose of the numbered card was to assist in preventing participants from interrupting each other during the discussion and to

enable the research team to identify and/or call upon the subject without using the individual's name.

The group discussions were co-facilitated by the primary investigator and a research assistant who was of the same gender as the participants. Gender consistency between the participants and the research assistant was identified as a culturally appropriate practice that would promote a more comfortable environment for the participants. At the beginning of each group discussion, subjects were informed of the 'ground rules' (Appendix 6) and the need for confidentiality and respectful conduct towards other participants was reinforced. Participants were also reminded that the group discussions were being audio taped using a small and unobtrusive tape recorder. Subject concerns and/or questions were addressed prior to tape recording. At the end of each group discussion, subjects were thanked for their participation and candour. As an expression of appreciation for the participants' time and effort, sodas and a culturally appropriate snack were provided at the conclusion of the group discussions.

To supplement the information provided by PLWAs, semi-structured interviews were completed with traditional healers within the study's geographic area. These interviews provided an opportunity to acquire insight into the potential impact that traditional healers have in relation to the use of THM by some PLWAs. Interviews with traditional healers also yielded information regarding: the treatments provided by healers; advice they share with clients about THM use; and their opinions about concurrent traditional and modern medicine use. Interviews with the traditional healers took place individually at the healer's convenience, either at their herbal clinics or at their homes. Responses were recorded with pen and paper and the sequential order of the questions as outlined in Appendix 7 was not adhered to during all of the interviews. That is, the order of the questions was altered to permit an uninterrupted flow of conversation based on the leading information provided by the healer.

5.4 Analysis

Two-way document translation was completed for the information letters, consent form and PLWA interview questionnaire. The first phase of the translation process involved translation of the original English documents to Rutooro; the second phase consisted of re-translating the Rutooro documents to English. To achieve an unbiased translation of

the written materials, different research assistants were used for each phase of the translation process. Revisions were made to the documents based on research assistant recommendations to make certain that the terminology and wording of the documents was culturally appropriate. The primary investigator completed document analysis and validation to ensure that the contextual meanings of the documents were unaltered through the translation process.

Within this study, validation of PLWAs' interview responses and the questionnaire reliability were assessed with a *test–retest* procedure. A random sample of PLWAs who had provided the research team with contact information was selected through Statistical Package for the Social Sciences (SPSS) Version 11.5 for Windows after completion of all PLWAs' interviews. In total, retesting was completed with 10.2% (n=14) of PLWAs enrolled in the investigation.[9] Review of the test-retest data revealed very high levels of correlation in subject responses between the first and second interview. The differences that were noted involved a slight variance in the recall of specific symptoms for which medicine was used, the order of symptom recall, and the names of medicines used. When questioned about the differences, subjects indicated that they either had forgotten about a certain symptom or medicine and/or they had developed a new symptom since the time of the initial interview. Based on the test-retest findings, the researcher has confidence in the reliability of the questionnaire and the validity of subject responses.

SPSS served as the statistical software for this investigation and the primary investigator assumed sole responsibility for data entry into SPSS. A data codebook was also created in Microsoft Excel to assist with the transformation of data from the questionnaire into SPSS (Bernard, 1988). Data entry for the closed-ended questions was coded according to the outlined responses on the questionnaire. The qualitative information derived from open-ended questions was broadly categorized and coded into SPSS to permit descriptive and comparative analysis within and between PLWA subgroups.

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[9] Thirty-three PLWAs had provided the research team with contact information and retesting was therefore completed with 42.4% (n=14) of these subjects. Of the retests, 57.1% (n=8) were completed with PLWA-ART subjects.

Several different methods were employed in the study for the analysis of PLWAs' data. The qualitative responses were analyzed with surface analysis[10] to identify the themes (Rothe, 2000). The relative importance of both reported herbal remedies and reported symptoms identified with free-listing tasks was determined via informant consensus (Phillips, 1996). Statistical analysis was completed with a variety of parametric and nonparametric tests with a five percent level of significance used for all statistical analysis. Additionally, missing cases for each variable (i.e. respondent did not provide a response; the question was 'not applicable'; and/or the question was missed by interviewer) were not included in the calculations. The independent samples t-test (i.e. parametric test) was used for continuous variables that were normally distributed. Nonparametric tests were used for the analysis of continuous data with a skewed distribution and also for variables that were measured on an ordinal scale. The nonparametric test that was used was the Mann-Whitney U test. The Pearson Chi-square test (χ^2) and the Fisher's Exact Test were used for the analysis of categorical variables.

As the group discussions were primarily completed in Rutooro, Rutooro transcriptions of the audiotapes were completed. To ensure validity of the original transcription, an alternate research assistant compared the Rutooro transcription with the corresponding audiotape. In doing so, it was noted that the transcriptions were a summary of participant responses and not a verbatim account of the group discussions. The primary research assistants completed a verbatim re-transcription of the audiotapes to make certain that full information from the group discussion was available. An alternate research assistant verified randomly selected sections of the transcripts with the original audiotape. Once completed, all transcripts were translated into English and randomly selected sections of the English transcripts were compared with the Rutooro transcripts for translation verification. Comparison of the original transcriptions and the verbatim transcriptions revealed no discrepancies in the overall meaning of the information and

[10] Surface analysis consisted of grouping the qualitative responses into major categories based on the similarity of the explanations and/or information within the responses. The categories were then synthesized into broad themes which identified patterns of PLWA behaviour (Rothe, 2000).

the researcher was confident that full and accurate group discussion information was transcribed and translated.

Analysis of information generated through the group discussions with PLWAs was not specifically analyzed. Rather, as the information from the group discussion was used for verification and clarification purposes, it was incorporated directly into the study during data entry. For example, the term "loss of blood" was coded as anaemia based on clarifying information provided during the group discussions.

Analysis of traditional healer information was limited to surface analysis and response frequency due to the small sample size and qualitative nature of the interviews.

5.5 Ethics and Approvals

Dr. Walter Kipp, Department of Public Health Sciences, University of Alberta and members of the local health authorities in Kabarole District, Uganda devised the premise of this study. Dr. G. Kabagambe-Rugamba, Kabarole District Director of Health Services, Uganda Ministry of Health and Mr. T. Rubaale, Team Leader of Basic Health Services (BHS) in Kabarole District, Uganda provided support and approval for this investigation as it was deemed to be of importance for anti-retroviral programmes in the district. This investigation also was sanctioned at a national level within Uganda through approval from the Uganda National Council of Science and Technology.

The University of Alberta's *Standards for the Protection of Human Research Participants* were fulfilled as study approval was received from the University of Alberta's Health Research Ethics Board.

In adherence with cultural protocols, formal introductions between the researcher and the Medical Superintendents and/or senior HIV programme staff at each study recruitment site were completed (either by a BHS staff member or by a letter of introduction written by the BHS Team Leader). The introductory meetings provided a forum in which to explain the investigation and obtain senior level support for the study. Additionally, permission was attained at such meetings to access each facility, acquire the assistance of HIV programme staff and recruit potential subjects. The researcher provided the appropriate clinical personnel with a comprehensive study briefing and an

explanation of their role in the study. These personnel generally expressed support for the study and a willingness to participate.

The Chairman of the *Kabarole Traditional Healers and Herbalists Association* also expressed his support for the investigation and agreed to discuss the study with the association members. The Chairman agreed to act as a liaison for the researcher, and coordinate interviews with any traditional healers who expressed an interest in participating in the study. However, the Chairman was unable to assist the researcher in contacting traditional healers who were not members of the Kabarole Traditional Healers and Herbalists Association.

5.6 Research Team

To overcome numerous cultural and language barriers, BHS Team Leader Mr. T. Rubaale identified two local residents to act as primary research assistants during the course of this investigation. The research assistants were required to be bilingual in Rutooro and English, and to possess strong oral and written skills in each language. They were both familiar with the local culture, residents of Fort Portal, and personable. To minimize the chance of gender-based interviewer bias, one male and one female research assistant were engaged.

The primary investigator provided each primary research assistant with comprehensive information about the investigation and his or her roles and responsibilities. Particular attention was focused on subject confidentiality, respect, equality and open communication. Training for the research assistants included (a non-exhaustive list): education about HIV/AIDS; information about the study design and methodology; procedures to be employed during subject information sessions; procedures of obtaining signed consent including the emphasis on subject confidentiality and anonymity; how to address subject concerns and questions; and interview skills (e.g. neutral reaction to subject responses; qualitative skills such as probing questioning; etc). Several interviewer-subject role playing exercises and mock interviews were incorporated into the training sessions and repeated as necessary to achieve the both the desired level of competence required for this investigation.

Throughout the data collection period, daily debriefings were completed with the primary research assistants and the researcher reviewed the completed questionnaires with the research assistants. Areas of strength and those needing improvement (e.g. depth of probing) were reviewed and shared with the research assistants in an effort to maximize the quality of quantitative and qualitative information collected and to minimize potential interviewer bias with respect to the generation of qualitative data.

Additional research assistance was needed to successfully complete the study. Three individuals with varying botanical knowledge were used to identify the botanical names of herbal resources used by PLWAs. This was necessary as the PLWAs had provided the local Rutooro plant names and the primary research assistants were not knowledgeable of botanical plant names. Two of these botany research assistants were local residents; the first was an herbalist with extensive experience and training from the Natural Medicine Development Organization, Uganda. The other had extensive experience as a field assistant in the nearby Kibale National Forest, where his main duties were plant identification and cataloguing by local and botanical name. A third botany research assistant - a Makerere University student with botany experience and familiarity with the Rutooro language – was used to verify some of the botanical names.

One BHS staff member also assisted with the transcription of the group discussion tapes, as she possessed the necessary clerical skills and equipment to complete this task efficiently.

Completion of this study would have been much more difficult without the support and skills of all the research assistants. They provided endless and enriching insights into the local language, culture, beliefs, and customs that assisted this researcher's understanding not only of the data, but of the people and their environment. Samples of local medicinal plants were frequently collected and shared with the researcher and numerous 'field trips' enhanced the primary investigator's understanding of the accessibility and abundance of many herbal plants. With the lack of written resources pertaining to Rutooro THM names, the assistance with the translation of the medical plants identified in this study was invaluable.

CHAPTER 6 - RESULTS: PERSONS LIVING WITH HIV/AIDS

6.1 Subject Recruitment and Participation Rates

Data related to the recruitment of HIV-infected persons are presented in Table 6.1. Slightly more than half of the PLWA-ART sample (53.6%) was recruited from the PMTCT programme, with the balance of the ART subjects being recruited from the JCRC programme. As expected, no PLWA-ART subjects were recruited through the Virika Hospital's AIDS Clinic or its out-reach clinics (at Yerya Health Unit and Kitojo Health Unit) as the AIDS Clinic did not provide ARV drugs at the time of the investigation.

Table 6.1 Recruitment of PLWA subjects by study site and HIV/AIDS programme

Hospital Site ***Programme***	**HIV-Infected Persons n(%)**				**Total**
	Receiving Routine Treatment		**Receiving Antiretroviral Treatment**		
	Females	Males	Females	Males	
Fort Portal Hospital	11 (22.9)	2 (10.0)	48(100.0)	21(100.0)	82 (59.9)
PMTCT	4 (8.3)	0 (0.0)	28 (58.3)	9 (42.9)	41 (29.9)
JCRC	7 (14.6)	2 (10.0)	20 (41.7)	12 (57.1)	41 (29.9)
Virika Hospital	37 (77.1)	18 (90.0)	0 (0.0)	0 (0.0)	55 (40.1)
Virika AIDS Clinic	25 (51.1)	15 (75.0)	n/a	n/a	40 (29.2)
Yerya Health Unit	9 (18.8)	1 (5.0)	n/a	n/a	10 (7.3)
Kitojo Health Unit	3 (6.3)	2 (10.0)	n/a	n/a	5 (3.6)
Total	48 (35.0)	20 (14.6)	48 (35.0)	21 (15.3)	137 (100.0)

It was not possible to accurately calculate the overall participation rate at the first contact point for this investigation as the clinical personnel tracking sheets were not consistently completed at all recruitment sites. In response to inquiries about the incomplete tracking sheets, clinical personnel explained that they endured excessive workloads in the clinics and could not be burdened with the additional task of completing the tracking sheet. The personnel at the Virika Hospital's AIDS Clinic had consistently tracked subject recruitment and a 100% participation rate was reported. The participation rate for

PLWAs at the second contact point – phase of informed consent with a research assistant – was 99.3%.

A total of 137 PLWAs who met the inclusion criteria were recruited into the study and interviewed. Sixty-nine subjects were on ART and the remaining 68 subjects were receiving routine treatment that did not include ART. The calculated sample size of 68 subjects per PLWA subgroup was exceeded with one additional PLWA-ART being recruited. The extra subject was inadvertently recruited into the study when the last two PLWA-ART subjects were independently and simultaneously recruited and enrolled into the study. The researcher made the determination not to exclude the additional subject's data from the study in order to compensate for an incomplete PLWA-ART interview[11] that occurred earlier in the investigation.

Rutooro was the most frequently used language during PLWA interviews, with 91.2% of the interviews being completed in Rutooro. There was evidence of a significant difference in language preference based on PLWAs' gender (Fisher's Exact Test $p=0.007$) and ART treatment status ($\chi^2=5.718$, $df=1$, $p=0.017$). Specifically, males and ART recipients more commonly used English.

There was a substantial variation in the number of participants in the PLWAs' group discussions (Table 6.2). Although it was desired to invite 26 participants to each group discussion, this was not achieved due to the low number of males recruited into the study. Additionally, some HIV-infected males were recruited into the study after the group discussion sessions had been completed. One less female PLWA-ART was invited due to a tracking error on the part of the research team.

The group discussion sessions averaged 60 minutes in length. Three of the four group discussions were conducted exclusively in Rutooro. The fourth group discussion session was composed of male subjects on ART who expressed themselves in English throughout the majority of the session.

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[11] The subject, due to time and transportation constraints, discontinued the interview.

Table 6.2 Group discussions with PLWAs: Descriptive statistics

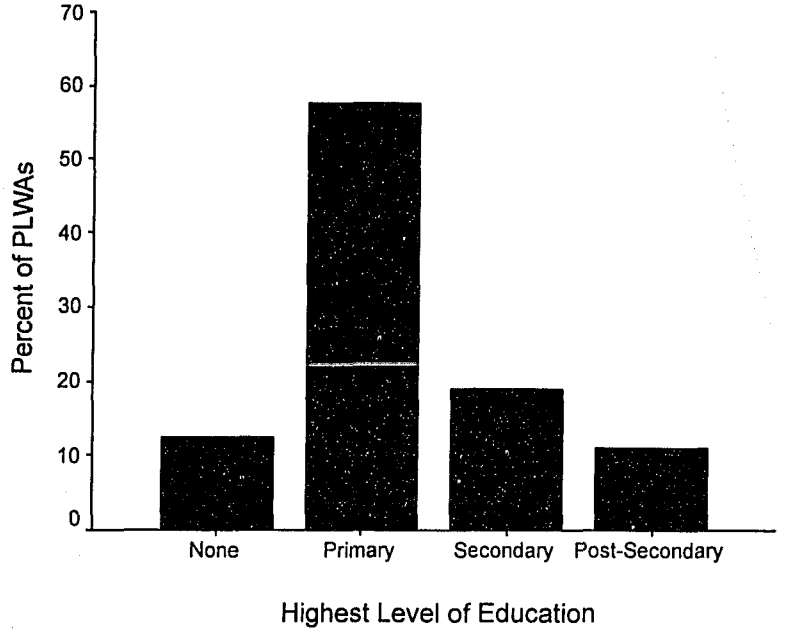
Group		Number of Invitations	Number of Group Discussion Participants
PLWA-Rtn	Females	25	6
	Males	18	2
PLWA-ART	Females	26	17
	Males	17	8
Total		86	33

6.2 Socio-Demographic Characteristics

Of the PLWAs who volunteered for participation in the study, 70.1% of the total sample consisted of female participants. Additionally, the number of female and male participants in each PLWA subgroup was almost identical (Table 6.1). Clinical personnel at the PMTCT programme and the Virika Hospital's AIDS Clinic believed that the proportion of female participants in the study was representative of the gender distribution amongst HIV programme patients in general.

The mean age of HIV-infected persons within the investigation was 36.28 years (minimum=20, maximum=53) with a standard deviation of 7.25 years. Low levels of educational attainment were reported with 70.1% of PLWAs having less than a secondary level of education (Figure 6.1). The vast majority of PLWA subjects resided within Kabarole District (84.7%) and had a tribal ethnicity of Batooro (78.8%). Forty-six percent of all HIV-infected persons were separated, divorced or widowed (13.9% were either separated or divorced and 32.1% were widowed), 42.3% were married and 11.7% were single.

Figure 6.1 PLWAs' highest level of educational attainment (n=137)



Socio-demographic data, stratified by ARV status and gender, has been provided in Table 6.3. Compared on the basis of ART treatment status, subjects receiving ART had significantly higher levels of education attainment than PLWA-Rtn (χ^2=10.736, df=3, p=0.013). Additionally, the PLWA subgroups varied significantly with respect to reported marital status (χ^2=17.306, df=3, p=0.001) with the PLWA-ART subgroup having the highest rates of marriage and the PLWA-Rtn enduring the highest rates of separation, divorce and widowhood. The mean age (t=0.302, df=132, p=0.763), tribal ethnicity (χ^2=0.089, df=2, p=0.957) and district of residence (χ^2=1.321, df=1, p=0.250) were not significantly different between PLWA-ART and PLWA-Rtn.

When gender comparisons were completed (Table 6.3), significant differences were noted in marital status (χ^2=11.756, df=3, p=0.008). There was borderline evidence of males having significantly higher levels of education than females (χ^2=7.792, df=3, p=0.051). Males and females were statistically similar for the traits of tribal ethnicity (χ^2=5.538, df=2, p=0.063) and district of residence (χ^2=3.702, df=1, p=0.054).

Table 6.3 PLWA demographic information: age; marital status; educational attainment; district of residence; and tribal ethnicity (n=137)

Variable		ARV Status		Gender	
		PLWA-Rtn	PLWA-ART	Females	Males
Age (years)	Mean	36.09	36.47	35.26	38.61
	+/- SD	+/- 7.57	+/- 6.98	+/- 7.28	+/- 6.70
Marital Status n (%*)	Single	7 (10.3)	9 (13.0)	13 (13.5)	3 (7.3)
	Married	18 (26.5)	40 (58.0)	33 (34.4)	25 (61.0)
	Divorced/ Separated	14 (20.6)	5 (7.2)	12 (12.5)	7 (17.1)
	Widowed	29 (42.6)	15 (21.7)	38 (39.6)	6 (14.6)
Education n (%*)	None	10 (14.7)	7 (10.1)	14 (14.6)	3 (7.3)
	Primary	45 (66.2)	34 (49.3)	60 (62.5)	19 (46.3)
	Secondary	11 (16.2)	15 (21.7)	14 (14.6)	12 (29.3)
	Post Secondary	2 (2.9)	13 (18.8)	8 (8.3)	7 (17.1)
District of Residence n (%*)	Kabarole	60 (88.2)	56 (81.2)	85 (88.5)	31 (75.6)
	Other[12]	8 (11.8)	13 (18.8)	11 (11.5)	10 (24.4)
Tribal Ethnicity n (%*)	Batooro	53 (77.9)	55 (79.7)	78 (81.3)	30 (73.2)
	Bakiga	6 (8.8)	6 (8.7)	10 (10.4)	2 (4.9)
	Other[13]	9 (13.2)	8 (11.6)	8 (8.3)	9 (22.0)

*Note: % are the percentages within the ARV grouping or gender grouping, respectively.

6.3 Time Since Diagnosis and Time Since Initiation of ART

The median time between HIV diagnosis and individual PLWA interviews during the study was 13 months, with minimum of zero months and a maximum of 216 months[14] (Figure 6.2). A high proportion of subjects (48.9%) had been diagnosed with HIV less than one year before the interview. With the median time since HIV diagnosis being 8.5 months for PLWA-Rtn and 15.0 months for ART subjects, there was evidence of a significant difference between the PLWA subgroups (Mann-Whitney U test z= -2.529, p=0.011). Males and females did not vary significantly for median time since HIV diagnosis (Mann-Whitney U test z= -1.787, p=0.074).

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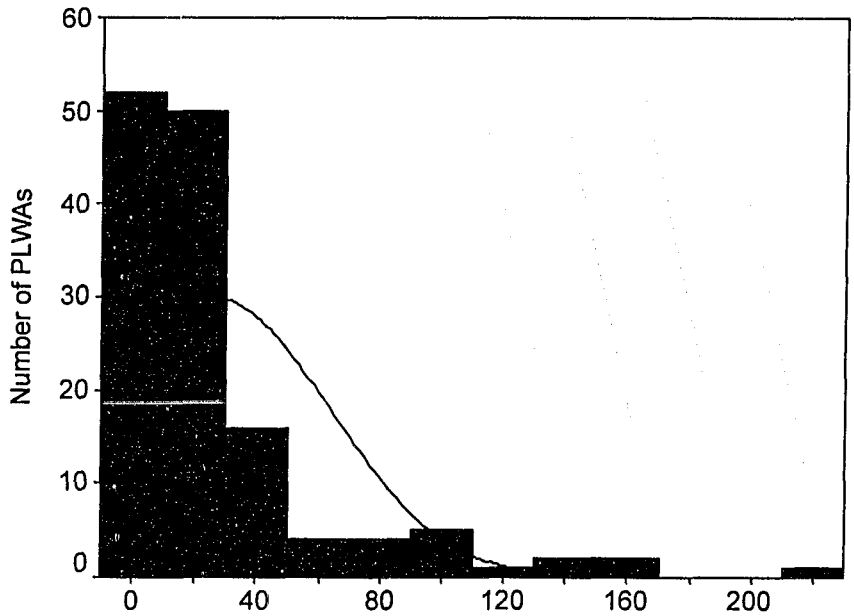
[12] 'Other' included the Districts of Kyenjojo, Kamwenge, Bundibugyo, and Kasese.

[13] 'Other' included the tribal ethnicities of: Banyankole, Banyoro, Bakonjo, Baganda, Kumanu, Mufumbiira, Musoga, Alur and Langi.

[14] The category of 'zero' months was used to denote subjects who were diagnosed less than two weeks before the interview.

Figure 6.2 Length of time between HIV diagnosis and study interview (n=137)



Of the PLWA-ART who participated in this study, the median length of time on ARV treatment was 7.0 months (minimum=0.1, maximum=56.0). Although there was a difference in the median length of time on ART between females (median=9.0 months, minimum=0.5, maximum=56.0) and males (median=4.0 months, minimum=0.1, maximum=34.0), this difference was not statistically significant (Mann-Whitney U test z= -1.831, p=0.067).

6.4 Symptomology

6.4.1 General Symptoms

PLWAs reported using pharmaceutical drugs for the treatment of 49 different symptoms (Appendix 8), with the ten most frequently reported symptoms listed in Table 6.4. On average, each subject reported 5.6 symptoms (minimum=1, maximum=13) and there was no significant difference in the number of reported symptoms based on subject gender (t=0.284, df=135, p=0.777) or ART treatment status (t=-1.124, df=135, p=0.263).

Forty different symptoms were treated with THM by HIV-infected persons (Appendix 8) and the ten most frequently mentioned symptoms are outlined in Table 6.4. Each PLWA

used THM for an average of 3.2 different symptoms (minimum=1, maximum=10). Males and females used THM to treat a similar number of symptoms (t=1.087, df=127, p=0.279). Statistical analysis did provide evidence of a significant difference in the number of symptoms treated by THM in the PLWA subgroups (t=-2.050, df=127, p=0.042) with PLWA-Rtn demonstrating a broader use of THM ($\bar{x}$=3.6 symptoms) compared to ART recipients ($\bar{x}$=2.9 symptoms).

Table 6.4 Ten most common symptoms treated with pharmaceutical drugs and/or traditional herbal medicine

Pharmaceutical Drugs		Traditional Herbal Medicine	
Symptom Treated	**Frequency of Mention**	**Symptom Treated**	**Frequency of Mention**
Fever (general)	119	Cough	67
Headache	99	Fever (general)	62
Cough	93	Stomach/Abdominal Pain	34
Stomach/Abdominal Pain	63	Diarrhea	32
Flu	42	Yellow Fever[15]	27
Diarrhea	41	Rash	22
Rash	30	Herpes Zoster	21
Other Pain	29	Headache	16
Back Pain	21	Parasites	14
Chest Pain	21	Other Pain	10

6.4.2 Culturally-Defined HIV Symptoms

PLWAs reported experiencing a diverse array of symptoms and/or illnesses that they considered to be caused by HIV (Appendix 9). Within the study population, the cultural domain for HIV/AIDS consisted of 50 symptoms and Table 6.5 outlines the 10 most

[15] *Yellow fever* was a self-diagnosed and commonly reported symptom of PLWAs. In actuality, the symptom described by PLWAs is likely jaundice caused by acute infectious hepatitis (personal communication with W. Kipp, 2005). Based on this, the reported symptom of *yellow* fever has been reported as jaundice throughout this investigation.

frequently reported symptoms. HIV-infected persons reported experiencing an average of 5.2 HIV-related symptoms (minimum=0, maximum=13) and significant differences were not present between subject on the basis of ART treatment status (t=-0.034, df=135, p=0.973) or gender (t=0.199, df=135, p=0.842).

Table 6.5 Ten most frequently reported HIV-related symptoms by PLWAs (n=137)

HIV-Related Symptoms	Frequency of Mention
Fever (General)	89
Cough	72
Rash	63
Headache	62
Diarrhea	46
Stomach/Abdominal Pain	36
Herpes Zoster	33
Loss of Appetite/Weight Loss	25
Sores in Mouth	23
Flu	19

PLWA-ART identified a total of 38 different symptoms that were viewed as being the reason for which ART was initiated, with the 10 most frequently mention symptoms outlined in Table 6.6. Subjects on ART reported experiencing an average of 3.4 symptoms (minimum=0, maximum=11) when treatment with ARV drugs was begun and 15.9% of ART subjects stated that ART was started before they experienced any HIV-related symptoms. In relation to the number of symptoms that subjects were experiencing when placed on ART, there were marked differences (t=-2.357, df=66, p=0.021) in the number of symptoms reported by males ($\bar{x}$=4.4 symptoms) and females ($\bar{x}$=2.9 symptoms).

Table 6.6 Ten most common symptoms experienced when ART was initiated (n=68)

Symptoms	Frequency of Mention
Fever (general)	30
Cough	29
Rash	28
Headache	19
Diarrhea	14
Weakness	12
Loss of Appetite/Weight Loss	9
Stomach/Abdominal Pain	8
Sores in Mouth	7
Vomiting	7

6.5 Frequency of THM Use

6.5.1 General THM Use

In total, 94.2% of PLWAs indicated that they had used traditional herbal medicine at one time or another. Of the PLWAs who reported that they did not use herbal medicine, the primary reason was related to a lack of knowledge about THM. As well, some subjects indicated that the use of THM was prohibited on the basis of religious or tribal beliefs:

> *"I do not have any knowledge about herbs; I do not know anything concerning the herb."* (Male PLWA-ART, age 44)

> *"My parents are Saved and don't believe in herbal medicine. They stopped me from using herbs."* (Male PLWA-ART, age 33)

> *"I am from the Obumu cult of Owobusubozi Bisaka[16]. We do not use traditional medicine; it is against our cult requirements."* (Male PLWA-ART, age 42)

[16] In 1992, participation in the Bisaka cult was banned by the government because its members were forbidden to seek medical care by cult leaders. The ban was later lifted when Bisaka cult leaders agreed to stay the obstruction of medical care. (Worthynews, 2000)

"According to my tribal origin[17] *and clan, they don't use herbs."* (Male PLWA-Rtn, age 52)

Herbal remedies were the most common form of traditional medicine used by HIV-infected persons in the study and represented the only form of traditional medicine used by 76.5% of PLWAs. Amongst subjects who used alternate forms of traditional medicine, the use of a Traditional Birth Attendant was the most frequent[18] (12.5%) and only a very small number of subjects had consulted with a traditional healer for divining (2.2%) and/or bone setting (2.9%). Accurate statistical analysis could not be completed due to the small number of subjects using alternate forms of traditional medicine.

6.5.2 THM Use Before HIV Diagnosis

A large portion of subjects (90.4%) indicated that THM had been used prior to being diagnosed with HIV[19]. As demonstrated in Figure 6.3, similar frequencies of pre-diagnosis THM use were noted between subjects on ART and those on routine treatment (χ^2=0.102, df=1, p=0.749). Although statistical analysis of THM use prior to the HIV diagnosis could not be accurately completed for gender comparisons[20], females were noted to be more frequent users of THM than males (93.6% and 82.9%, respectively) as illustrated in Figure 6.4. Additionally, the use of herbal remedies prior to HIV diagnosis was similar regardless of the subject age[21] (χ^2=0.763, df=3, p=0.858).

6.5.3 THM Use After Diagnosis

Herbal medicines were used after HIV diagnosis by a large portion of subjects (63.5%) for a variety of symptoms, not all of which were classified as being HIV-related

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[17] Tribal ethnicity was Alur

[18] One male PLWA who was not receiving ARV indicated that he had acquired the services of a TBA. This is plausible as TBAs sometimes perform dual roles (i.e. TBA and herbal medicine). However, it is possible that this subject interpreted the question incorrectly and the response may reflect services that the subject acquired for his wife.

[19] HIV diagnosis was defined as the first HIV sero-positive test result received by the subject

[20] Accurate statistical analysis was not possible as more than 20% of cells had an expected count of less than 5.

[21] Categorized age groups used during analysis were: 20-29 years; 30-39 years; 40-49 years; and 50-55 years.

symptoms. THM was used after diagnosis by 59.4% of PLWA-ART and by 67.6% of subjects on routine treatment (Figure 6.3). The frequencies of post-diagnosis use of THM were similar between subjects, whether on the basis of gender (χ^2=0.623, df=1, p=0.430), ART treatment status (χ^2 =1.000, df=1, p=0.317) or subject age (χ=3.227, df=3, p=0.358).

Compared to the general post-diagnostic use of THM, the reported use of THM after HIV diagnosis decreased slightly when confined to the treatment of *HIV-related symptoms* (58.1%). Specifically, 52.9% of PLWA-ART and 63.2% of PLWA-Rtn used THM for the treatment of HIV-related symptoms (Figure 6.3). PLWAs' use of THM for HIV-related symptoms was not significantly different between PLWA-ART and PLWA-Rtn (χ^2=1.480, df=1, p=0.224) or between males and females (χ=0.096, df=1, p=0.757; Figure 6.4).

Figure 6.3 Use of THM by HIV-infected persons: Comparison based on ART treatment status

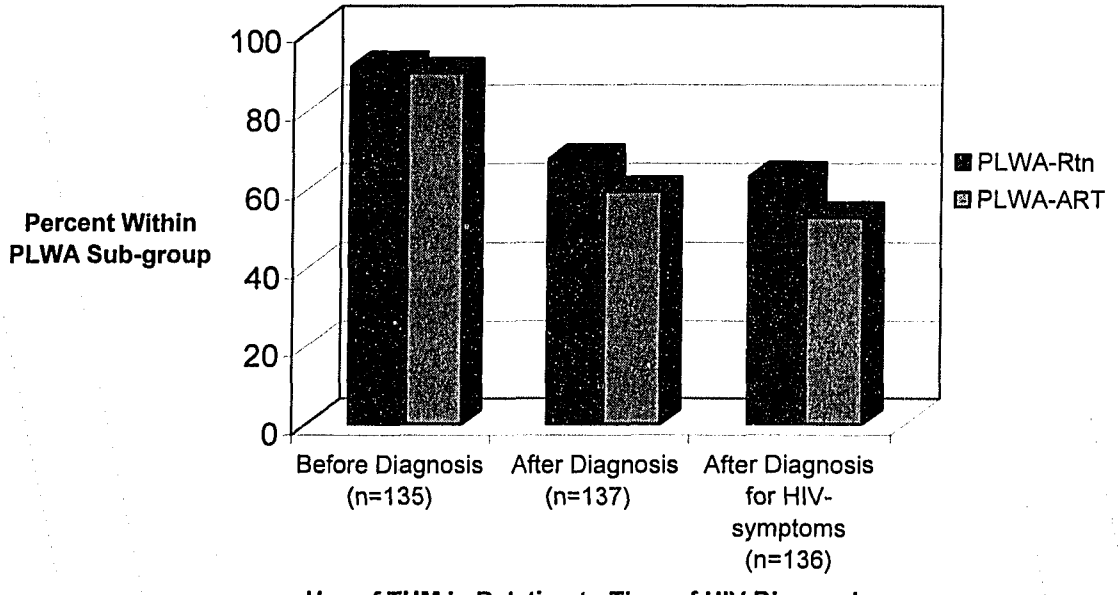
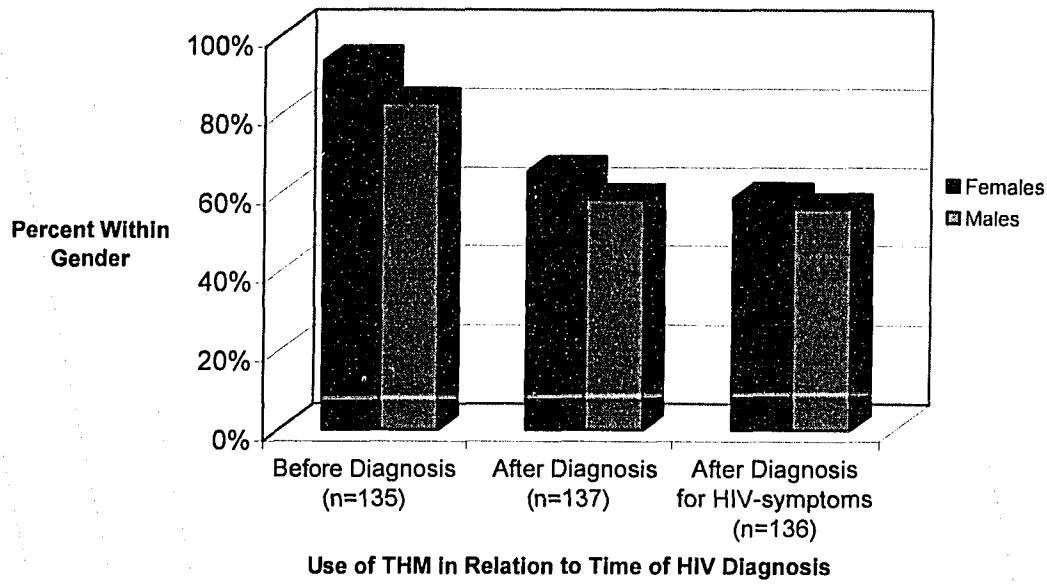


Figure 6.4 Use of THM by HIV-infected persons: Gender comparison



Persons living with HIV/AIDS reported using THM for the treatment of 33 HIV-related symptoms (Table 6.7 and Appendix 10). Among PLWAs who reported using THM for the treatment of HIV-related symptoms, each subject treated a mean of three different symptoms. No statistically significant differences were noted in the number of HIV-related symptoms that were treated with THM when subjects were compared on the basis of gender ($t=0.520$, $df=77$, $p=0.604$) or ARV treatment status ($t=-0.871$, $df=77$, $p=0.386$).

Table 6.7 Ten most frequently mentioned HIV-related symptoms for which PLWAs used herbal medicine (n=79)

Symptom	Frequency of Mention
Fever (General)	40
Cough	37
Diarrhea	23
Rash	20
Herpes Zoster	18
Stomach/Abdominal Pain	17
Headache	9
Genital Itching	7
Itchiness (Non-genital)	7
Boils	7

HIV-infected persons reported the use of 98 different medicinal plants for the treatment of culturally defined HIV-related symptoms (Appendix 11). Table 6.8 provides the 10 most frequently mentioned Rutooro THM names and the corresponding botanical names, as translated by members of the research team. Additionally, there were 45 responses in which THM was used for the treatment of HIV-related symptoms but the name of the THM was unknown[22]. An average of 4.8 different herbal remedies were used by each subject who used THM for the treatment of HIV-related symptoms and the number of herbal remedies used was similar when compared by subject gender ($t=1.156$, $df=76$, $p=0.251$) and treatment status ($t=-1.410$, $df=76$, $p=0.163$).

Herbal remedies were administered in several different ways for the treatment of HIV-related symptoms. The most common methods of THM administration were ingestion of a liquid (74.0%) and the topical application of THM (19.0%) such as smearing an herbal balm on the skin or applying a poultice. Ingestion of a solid form of THM (i.e. chewing the leaves, roots or bark of the herbal plant) constituted 6.1% of subject responses and inhalation of THM (0.8%) was rarely used by PLWAs.

[22] The name of the THM was unknown as the subject either had not learned the name of the THM, could not recall the name of the THM, or provided a THM name that did not coincide with any known THM in Kabarole district.

Table 6.8 THM used by PLWA for the treatment of culturally defined HIV-related symptoms (n=79)

Rutooro THM Name	Botanical Name***	Frequency of Mention
Ekibirizi * / Omubirizi ** / Ekyesembya	Vernonia amygdalina	42
Enkoko Rutanga	Barbadensis (i.e. Aloe vera)	24
Omwihura	Vernonia turbinata (possibly Momordica foetida)	14
Omuyembe / Amababi G'emiyembe	Mangifera indica (i.e. Mango bark/Mango leaves)	11
Ekijaja * / Omujaja **	Ocimum Suave	10
Omusikamooli	Eurphorbia spp.	10
Kalitunsi	Eucalyptus spp.	9
Ekinyamunsunga	Plectranthus langinosus (possibly Solenostemon latifolius)	9
Amapera	Psidium guajava (i.e. Guava)	9
Omweya	Cythula spp.	8
Omwani / Amababi G'omwani	Coffea sp. (i.e. Coffee/coffee leaves)	7
Moringa	Moringa oliefera	7

In some instances, there is more than one name for the THM was provided:
** Singular name of the THM in Rutooro*
*** Plural name of the THM in Rutooro*
**** In some instances, the research team provided more than one botanical name for the specific Rutooro THM. As the primary investigator was unable to determine the exact nature of the THM in question, both botanical names have been provided.*

To verify the reported frequency of THM use for the treatment of HIV-related symptoms amongst only those subjects receiving ART, a similar question was incorporated into the later stages of PLWA-ART interviews. Although similar frequencies of THM use for HIV-related symptoms remained between males and females (χ^2=0.515, p=0.473) on the verification question, comparison of the responses to the original question indicated an decrease in the overall frequency of THM use (39.7%). The qualitative responses to the

verification question provided evidence that some ART recipients had interpreted this question as meaning 'the direct treatment of the human immunodeficiency *virus and/or AIDS'* and not the 'treatment of HIV-related symptoms':

> *"I have never seen any or know any herbal medicine that helps treat HIV/AIDS."* (Male PLWA-ART, age 31)
>
> *"I have not yet heard of a particular herb that treats AIDS."* (Female PLWA-ART, age 27)

Qualitative data collected with the verification question also highlighted four main themes that explained why PLWA-ART did not use THM for the treatment of HIV-related symptoms: subjects were satisfied with the treatment results provided by ARV drugs; the ART programme personnel had advised against using THM when using ARV drugs; subjects believed that there was no herbal medicine that could treat or cure HIV/AIDS; and/or subjects lacked the knowledge about what herbs to use for the treatment of HIV/AIDS[23]. Of these explanations, the lack of a specific THM treatment for HIV/AIDS and/or lack of knowledge about such an herb were the predominant themes.

Qualitative data was also collected to help understand why PLWA-ART used THM for the treatment of HIV-related symptoms. The most predominant theme that emerged in the qualitative data was that ART recipients simply wanted to relieve the symptom being experienced. Several different responses categories were present with the predominant theme: the belief that pharmaceutical drugs had failed to treat the symptom adequately; the desire by PLWA-ART to have rapid symptoms relief; and that family and/or friends had advised subjects that THM could be of benefit.

The majority of PLWAs (80.8%) who used THM for the treatment of culturally defined HIV-related symptoms indicated that THM would be used again if the symptoms returned and/or persisted. The potential future use of THM for the treatment of HIV-

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[23] Some HIV-infected persons believed that herbal medicine could treat HIV/AIDS but the subjects themselves did not know the types of THM to use.

related symptoms was similar between when PLWAs were compared by treatment subgroups (χ^2=3.376, df=1, p=0.066) and gender (Fisher's Exact Test p=0.747).

6.6 Medical Pluralism

6.6.1 THM and Pharmaceutical Drugs in General

To capture the overall pattern of concomitant medicine use, PLWAs were asked if they ever used THM and pharmaceuticals together in the same day[24]. The response to this question revealed that 29.4% of all HIV-infected persons in the investigation practiced medical pluralism. Although there was no evidence of a statistically significant difference in the frequency of medical pluralism between the PLWA subgroups based on ART treatment status (χ^2=2.267, df=1, p=0.132), it may be clinically significant to note that PLWA-ART had higher rates of THM-pharmaceutical medical pluralism than PLWA-Rtn (35.3% and 23.5%, respectively). Significant differences in co-therapy practices were noted between males and females (χ^2=4.304, df=1, p=0.038), with females reporting a higher frequency of concurrent medicine use than males (34.7% and 17.1%, respectively).

When THM and pharmaceutical drugs were co-used within the same day, the majority of PLWAs were diligent about taking the different forms of medicine at different times:

> *"I use the medicines in the same day but not at the same time. I take the modern medicine in the morning and herbs at around 11:00 a.m. I have heard from people that when you take them together it becomes poison."* (Female PLWA-ART, age 26)

Facilitation of rapid symptom relief, pain reduction, and the simultaneous treatment of two or more co-morbid symptoms were the most common explanations for the concurrent use of THM and pharmaceuticals. These explanations coincided with the perceived benefits of co-therapy that were reported by the proportion of the PLWA sample (33.0%) that believed medical pluralism did have benefits. There was no

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[24] To assist in establishing the overall practice of medical pluralism, the question was not confined to the treatment of HIV-related symptoms and/or the concurrent use of THM and ARV drugs.

evidence of a significant gender difference in the perceived benefits of THM and pharmaceutical co-use (χ^2=0.110, df=1, p=0.740) or a difference between PLWAs when stratified by ART treatment status (χ^2=0.556, df=1, p=0.456).

> *"I wanted to get cured very fast as I was badly off."* (Female PLWA-ART, age 20)

> *"I took the medicines in the same day and the same time. I had too much pain and that the modern I knew would treat my illness and herbal medicine would reduce the pain."* (Female PLWA-Rtn, age 25)

> *"I take the medicines together to cure different illnesses. For example, modern medicine for headache and herbal medicine for stomach ache. But, I don't take herbal medicine and modern medicine for one type of illness at the same time."* (Male PLWA-Rtn, age 35)

> *"You may be better since you are treating different symptoms or viruses. The medicines help to cure you very fast."* (Female PLWA-ART, age 36)

Two main themes (Table 6.9) emerged from the qualitative data that explained why some PLWAs refrained from medical pluralism with THM and pharmaceutical drugs: the belief that co-use of THM and pharmaceuticals was unsafe (39.4%) and the advice from others[25] that the two forms of medicine should not be mixed (29.4%). The explanation of co-therapy as being 'unsafe' correlated with the belief held by the majority of PLWAs (84.4%) that medical pluralism was a risky behaviour. The risk perception associated with co-therapy was held similarly between the PLWA treatment subgroups (χ^2=0.561, df=1, p=0.454) and between females and males (χ^2=0.452, df=1, p=0.501).

[25] 'Others' referred to conventional medical practitioners, family members, friends, traditional healers, and drug shop attendants.

Table 6.9 PLWAs' rationale for abstaining from THM and pharmaceutical drug co-therapy (n=109 responses)

Rationale	PLWA Group: Routine Treatment n	(%)	Receiving ART n	(%)	Total Responses n	(%)
Belief that co-therapy is unsafe	29	(47.5)	14	(29.2)	43	(39.4)
Advice from CMP	6	(9.8)	10	(20.8)	16	(14.7)
Advice from others*	11	(18.0)	5	(10.4)	16	(14.7)
THM was not used	3	(4.9)	9	(18.8)	12	(11.0)
Preference not to mix medicine	6	(9.8)	6	(12.5)	12	(11.0)
Other	6	(9.8)	4	(8.3)	10	(9.2)
Total Responses	61	(99.8**)	48	(100.0)	109	(100.0)

**'Others' refer to family members, friends, traditional healers and drug shop attendants.*
***Total is less than 100% due to rounding of the percentages to one decimal point.*

The qualitative categories that emerged about the safety concerns and perceived risks associated with medical pluralism were the beliefs that: the herbal medicine could reduce the effectiveness of pharmaceutical drugs; the medicine mixture would be a poison; sickness would develop; an overdose could occur; and/or death would result. Additionally, some PLWAs felt that it was unsafe to mix herbal medicines and pharmaceutical drugs because of inherent differences in the properties of each form of medicine such as differences in the method of production, *strength* of the medicine, and/or source of the medicine (i.e. local versus foreign):

> *"I heard from people that if you use the two medicines together, you die."* (Female PLWA-Rtn, age 33)

> *"The HIV doctor stopped me from using herbal medicine. The doctor explained at the beginning of ARV treatment about not using herbs with ARV. The doctor explained to me that there is harm in using them together; using the ARV with herbs will cause harm to my body and may even cause death."* (Female PLWA-ART, age 27)

"The modern medicine ingredients are not known and it could be having the same herb as I am taking as one of the ingredients. Someone may take an overdose; you may take more medicine which will outweigh the body." (Female PLWA-Rtn, age 47)

"Every medicine has its intensity in working. So, the mixture may cause too much intensity in the body, leading to harm." (Female PLWA-ART, age 31)

"One medicine can easily destroy the other and cause harm." (Female PLWA-ART, age 42)

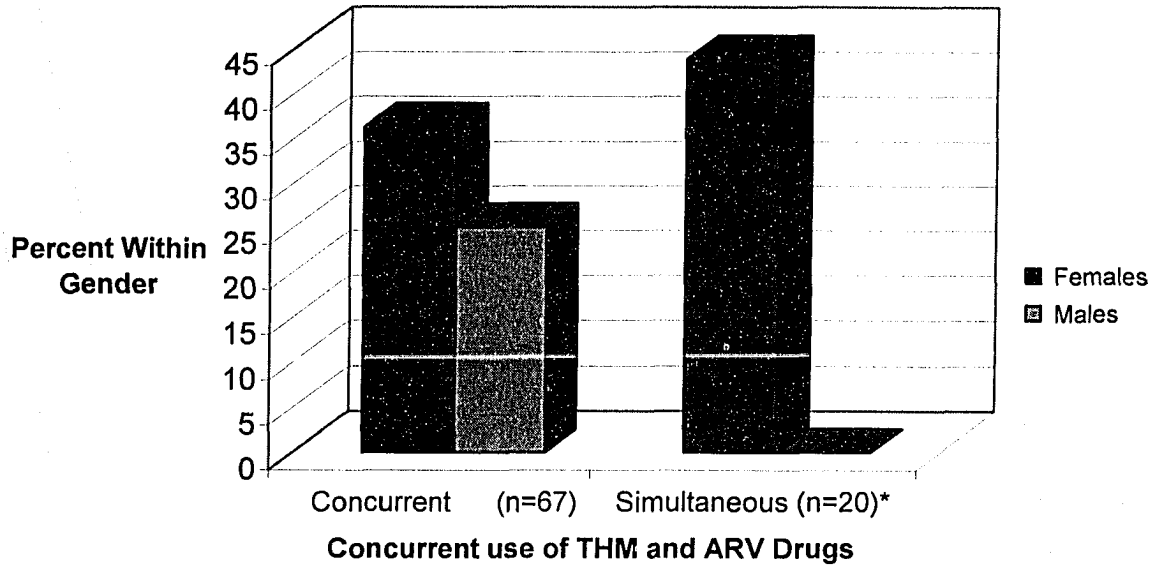
"The medicines are different and must not be used together. Modern medicine is purified unlike herbal medicine which is an un-purified mixture and could be harmful." (Female PLWA-Rtn, age 43)

6.6.2 THM and ARV Drugs

In this investigation, 32.8% of ART subjects stated that THM was used concurrently with ARV drugs (Figure 6.5) and the frequency of THM-ARV drug co-use was similar based on gender comparisons (χ^2=0.794, df=1, p=0.373). It should be noted that 6.0% of these PLWA-ART advised that the herbal medicine was only used topically. Antiretroviral drugs were administered simultaneously[26] with THM by 10.4% of the *total* PLWA-ART study sample, a value that corresponds to 31.8% of the ART recipients who had reported concurrent THM-ARV drug practices (Figure 6.5). Only female PLWA-ART reported the simultaneous use of herbal medicine and ARV drugs and accurate statistical analysis could not be completed due to the small number of subjects who practiced simultaneous traditional and modern medicine use.

[26] 'Simultaneous' administration of herbal medicine and ARV drugs refers to taking each form of at the same time (i.e. together) whereas 'concurrent' administration has been used to mean the taking each form of medicine within the same day.

Figure 6.5 Concurrent use and simultaneous administration of herbal medicine and antiretroviral drugs by PLWA-ART



*The number of subjects was based on the number of PLWA-ART who reported concurrent THM and ARV drug use and who provided a response to this variable (i.e. 2 missing cases).

HIV-infected persons who were receiving ART were asked about their perceptions of the benefits and risks associated with THM and ARV drug co-therapy. A fair proportion (43.6%) of PLWA-ART felt that there were benefits obtained from concurrent THM and ARV drug use (Figure 6.6), with males perceiving there to be benefits to a significantly larger extent than females (χ^2=4.441, df=1, p=0.035). Qualitatively, the majority of these ART subjects felt that benefits in co-therapy between ARV drugs and herbal remedies were derived from the independent ability of each form of medicine to treat symptoms and/or the ability of the medicine combination to provide rapid symptom relief. Some ART recipients valued co-therapy based on the nutritious benefits of THM, viewing the role of THM as a dietary supplement that could complement the treatment provided through ARV drugs (as opposed to considering THM as a medicine designed for treatment).

> *"Each medicine will be taken to do its role for the reason being taken."* (Female PLWA-ART, age 40)

"Herbs assist in reducing the pain and ARVs assist in boosting the white blood cells." (Female PLWA-ART, age 27)

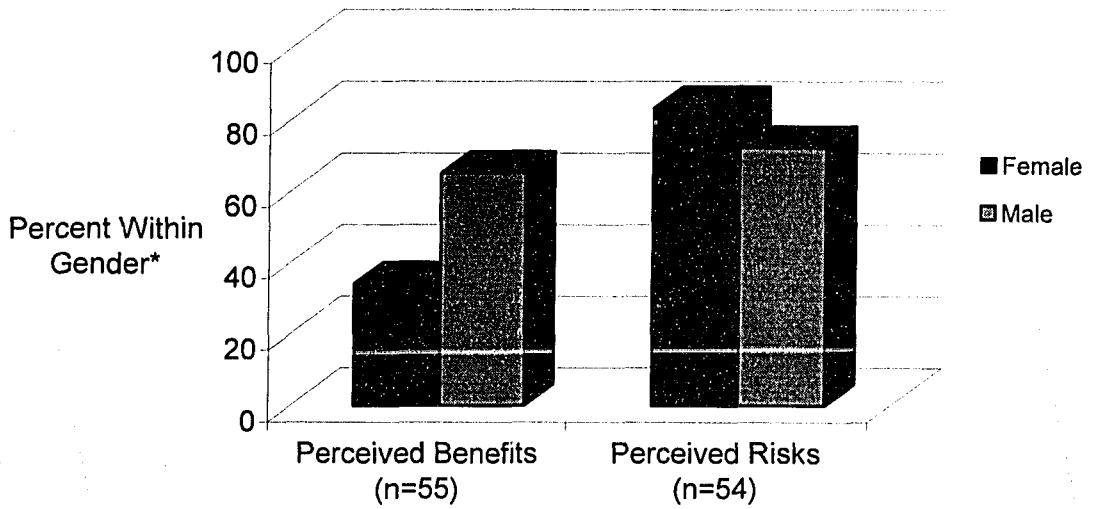
"I think herbal medicine has some nutrients which could help in treating me." (Male PLWA-ART, age 35)

The concurrent use of THM and ARV drugs was associated with more risks than benefits, a perception maintained by 79.6% of ART recipients (Figure 6.6). There was a similar proportion of male and female PLWA-ART who reported there to be risks associated with THM-ARV drug medical pluralism (Fisher's Exact Test p=0.475). The main risk themes reported by ART subjects in relation to the concurrent use of herbal medicine and ARV drugs were the development of harmful effects (i.e. medicine overdose and/or death) and the potential for decreased ARV drug effectiveness due to drug-herb interactions. Importantly, some subjects indicated that administrating the medicines at different times within the same day could mitigate the risks of THM-ARV drug co-therapy. This staggered administration of THM and ARV drugs was supported by some ART programme staff, as per the reports of PLWA-ART subjects.

"The ARVs alone are very strong so using herbal medicine and ARVs will be an overdose. Because the ARVs makes you weak, if you add in the herbal medicine you may even die." (Female PLWA-ART, age 29)

"*Herbal medicine can spoil the ARVs if taken at the same time. But, if it's in the same day but at different times, there are no risks because nothing has happened to me."* (Female PLWA-ART, age 35)

Figure 6.6 Concurrent THM and ARV drug use: Perceived benefits and risks by PLWA-ART



6.7 Perceived Treatment Effectiveness

6.7.1 Overall Effectiveness: THM Compared to Pharmaceutical Drugs

HIV-infected persons were asked to provide their perception of the overall treatment effectiveness of herbal medicine in comparison to pharmaceuticals based on forced-choice responses: more effective, equally effective or less effective. THM was perceived to be more effective than pharmaceuticals by 9.1% of PLWAs and 17.4% of the respondents felt that traditional and modern medicines were equally effective. The majority of PLWAs (73.6%), however, perceived THM as being less effective than pharmaceutical agents. No difference in the ratings of THM in comparison to pharmaceutical drugs was noted between subjects when compared by ART treatment status (Mann-Whitney U test z= -1.430, p=0.153) or gender (Mann-Whitney U test z= -0.397, p=0.692). Qualitative themes provided insight into the reasons why THM was generally rated as having lower levels of treatment effectiveness than pharmaceuticals: pharmaceuticals reduced symptoms more rapidly than THM; pharmaceuticals had better curative abilities and provided effects that were more sustained than herbal medicine; pharmaceuticals could treat more serious illnesses and/or illnesses that were unresponsive to herbal treatment; and the pharmaceutical drugs were matched to a specific illness based on medical diagnosis.

"Modern medicine always cures my diseases. Modern medicine truly – health wise – improves people's status." (Female PLWA-ART, age 44)

"The herbal medicine only stops the disease for sometime and then it comes up again and modern medicine heals it completely. Modern medicine treats me well." (Female PLWA-Rtn, age 34)

"The modern medicine is given to the exact disease through blood test knowledge – unlike herbal medicine done in guesswork." (Female PLWA-ART, age 51)

6.7.2 Perceived Effectiveness for General Symptoms

To generate a more detailed evaluation of perceived treatment effectiveness, PLWAs were asked to rate the treatment effectiveness of traditional and herbal medicines based on the symptoms for which medicine had been used (note: the symptoms were not specified as being HIV-related symptoms). This provided symptom specific ratings of perceived treatment effectiveness ("effectiveness ratings") for each form of medicine independently (i.e. traditional and modern medicine) without asking subjects to directly compare one form of medicine to the other. When the effectiveness ratings of herbal medicine were compared to those of pharmaceuticals, the results indicated that pharmaceuticals were not associated with higher rates of treatment effectiveness than herbs (Mann-Whitney U test z=-1.583, p=0.113). Stratified by ART treatment status, a closer analysis revealed that ART recipients had assigned similar effectiveness ratings to THM and pharmaceuticals (Mann-Whitney U test z=-1.153, p=0.249) and subjects on routine HIV treatment also perceived a similarity in the effectiveness of THM and pharmaceuticals (Mann-Whitney U test z=-0.926, p=0.354).

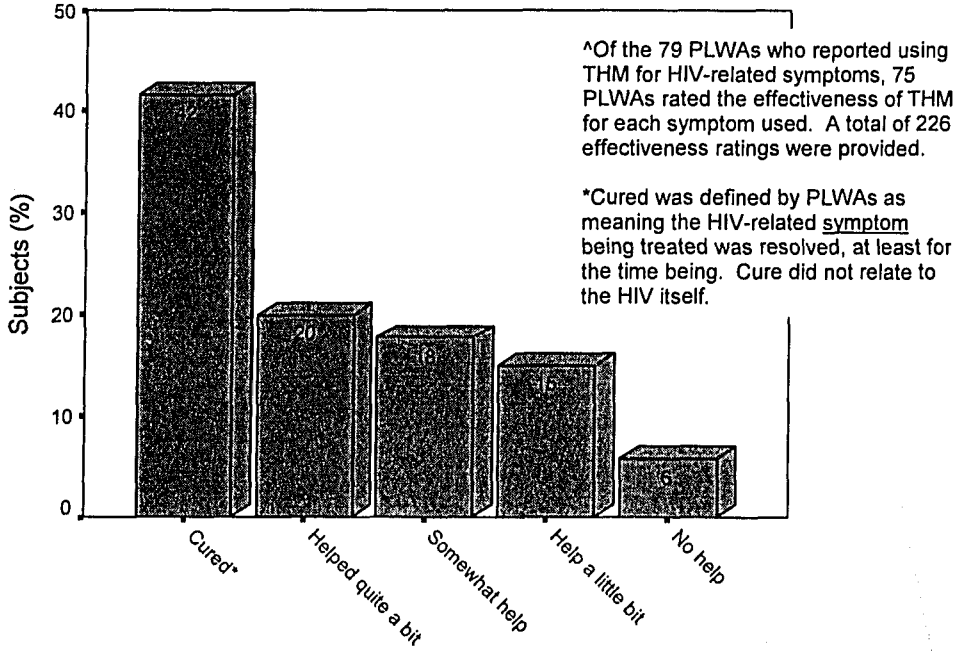
Evaluation of the symptom specific effectiveness ratings for pharmaceutical drugs in isolation indicated significant differences in the ratings provided by the PLWA subgroups (Mann-Whitney U test z = -3.341, p=0.001). Specifically, ART recipients perceived pharmaceutical drugs to be more effective than PLWA-Rtn. Male and female subjects reported similar effectiveness ratings for pharmaceutical agents (Mann-Whitney U test z = -1.143, p=0.253).

As compared to the effectiveness ratings for pharmaceuticals, the opposite pattern emerged when the symptom specific effectiveness ratings for herbal medicines were analyzed. In the case of THM, there was no evidence of a difference in the effectiveness ratings reported by PLWA-ART and PLWA-Rtn (Mann-Whitney U test z= -1.489, p=0.136). There was a significant difference, however, in the THM effectiveness ratings reported by males and females (Mann-Whitney U test z= -2.874, p=0.004), with females assigning higher ratings of effectiveness to THM than males.

6.7.3 Perceived Effectiveness of THM for HIV-Related Symptoms

HIV-infected persons were also asked to rate the effectiveness of THM when used for the treatment of HIV-related symptoms. Overall, 61.5% of PLWAs felt that THM treatments either resolved the HIV-related symptom(s) or helped quite a bit (Figure 6.7). ART subjects more frequently assigned higher levels of treatment effectiveness to THM for HIV-related symptoms than the PLWA-Rtn subgroup; statistical analysis provided borderline evidence that the difference in PLWA subgroup effectiveness ratings was not significant (Mann-Whitney U test z= -1.928, p=0.054). Additionally, females and males rated THM treatment effectiveness at similar levels for HIV-related symptoms (Mann-Whitney U test z= -0.233, p=0.816).

Figure 6.7 Perceived treatment effectiveness of THM for HIV-related symptoms (n=75^)

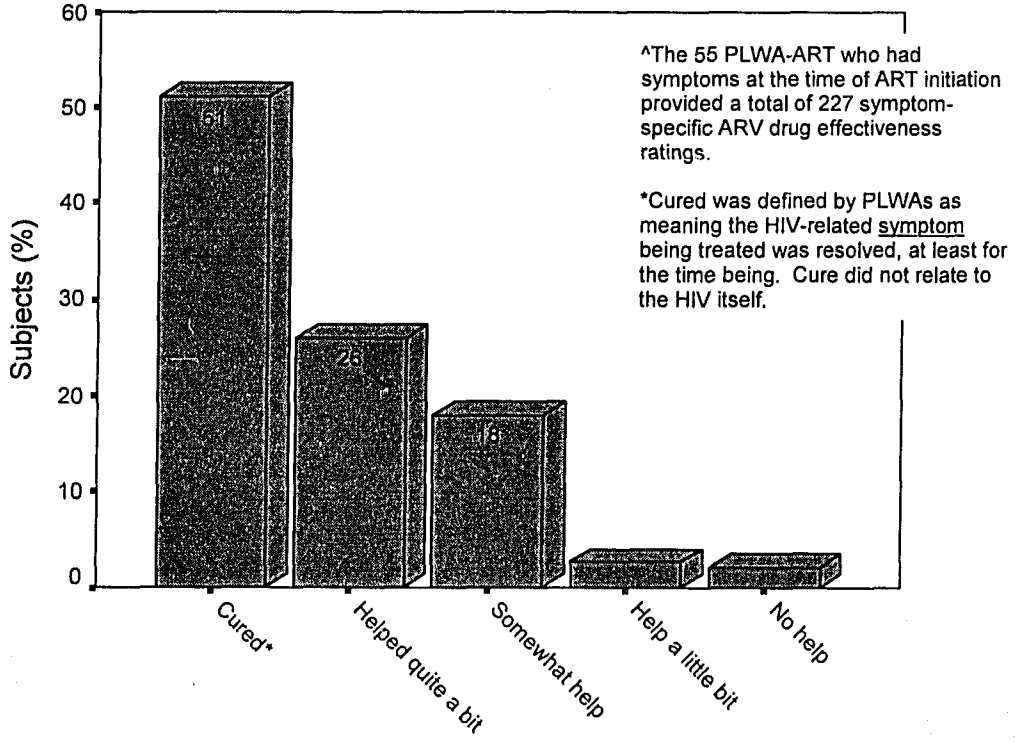


The perceived treatment effectiveness ratings of THM for HIV-related symptoms were compared to the ratings assigned to THM for the treatment of symptoms in general. Overall and within the total sample of PLWAs who used herbal medicine, the THM effectiveness ratings assigned to general symptoms and HIV-related symptoms were similar (Mann-Whitney U test z=-0.626, p=0.531). The THM effectiveness ratings that were assigned to the two groups of symptoms (i.e. general symptoms and HIV-related symptoms) were also similar within the PLWA-ART subgroup (Mann-Whitney U test z=-0.133, p=0.894) and the PLWA-Rtn subgroup (Mann-Whitney U test z=-0.725, p=0.469).

6.7.4 Perceived Effectiveness of ARV Drugs

The majority of subjects receiving ART (77.1%) felt that ARV drugs either resolved their HIV-related symptom(s) or helped quite a bit (Figure 6.8). There was no evidence of a significant difference in the ratings of ARV drug treatment effectiveness between females and males (Mann-Whitney U test z= -0.779, p=0.436).

Figure 6.8 Perceived treatment effectiveness of ARV drugs for the treatment of HIV-related symptoms by PLWA-ART (n=55^)



Of particular interest was the comparison of effectiveness ratings assigned to herbal medicines and ARV drugs. Specifically, there was no evidence of a statistically

significant difference in the effectiveness ratings of ARV drugs and THM for the treatment of HIV-related symptoms (Mann-Whitney U test z=-0.177, p=0.860).

6.8 Acquisition of THM

As illustrated in Figure 6.9, the majority of subjects (53.8%) gathered[27] and prepared herbal medicines on their own; it was indicated that this was their sole source of herbal medicine. Along with making their own herbal remedies, some HIV-infected persons also obtained assistance from other persons[28,29] who were knowledgeable about THM (27.7%) and/or PLWAs purchased herbal medicines from traditional healers (18.5%). Although female and male PLWAs obtained herbal medicine from similar sources (χ^2=1.819, df=2, p=0.403), a difference in THM acquisition patterns was evident between ART recipients and those on routine treatment (χ^2=10.443, df=2, p=0.005). Specifically, PLWA-ART more frequently acquired THM from a traditional healer (14.3% compared to 4.2% of PLWA-Rtn) while subjects on routine treatment more frequently gathered and prepared herbal medicines on their own (33.6% compared to 20.2% of PLWA-ART).

> *"The herbal medicine was given to me by a friend who is also positive; my friend only asked for 1000 Ugandan shillings from me to go and look for the herb in the bush. The same friend also advised me to come and test for HIV."*

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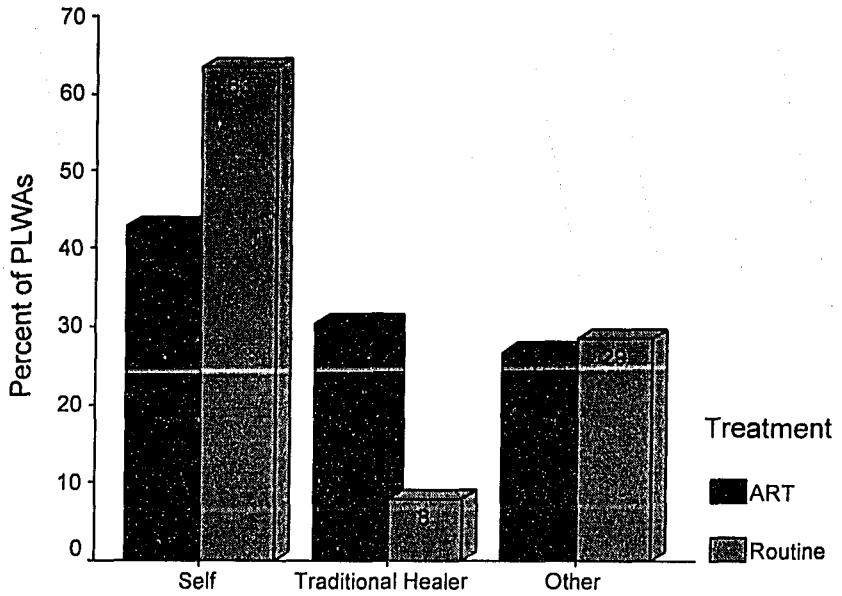
[27] Leaves, bark and/or roots of botanical plants were collected either from PLWAs' own gardens or from nearby bushes.

[28] 'Others' included family members, friends, neighbours and/or acquaintances. The most frequent 'other' from whom assistance was obtained was the mother of the PLWA.

[29] Assistance was provided in gathering the botanical resources and/or preparing the medicine. Some PLWAs who were usually self-sufficient in the gathering and preparation of THM would acquire assistance when they were too ill to prepare the medicine on their own.

Figure 6.9 Sources of THM used by HIV-infected persons (n=119)



Sources of Herbal Medicine

Qualitative data analysis indicated two main pathways by which PLWAs acquired knowledge about THM: relatives and friends/neighbours. The vast majority of subjects who obtained THM knowledge from relatives identified their parents (predominantly the mother) and grandmothers as key resources. In a small number of cases, PLWAs acquired knowledge about the use of herbal medicine for the treatment of HIV-related symptoms from other PLWAs, with information occasionally being shared within the waiting rooms of HIV treatment programmes.

> *"I get the knowledge from my mother or neighbours who have used the herbs before."* (Female PLWA-Rtn, age 26)

> *"When we come to the AIDS clinic with other HIV positive people, we share information about the use of herbs and even bring samples. I even got samples of herbal plants from my HIV positive friends and I have planted them."* (Female PLWA-Rtn, age 31)

6.9 Factors Influencing the Type of Medicine Used

HIV-infected study participants reported several different reasons for their use of THM and pharmaceutical drugs (Table 6.10). ART recipients and subjects on routine treatment reported similar reasons for the use of herbal medicines (χ^2=0.409, df=1, p=0.523), as did male and female subjects (χ^2=0.293, df=1, p=0.588). Significant variations in the reasons provided for pharmaceutical drug use were also not present when PLWAs' responses were compared on the basis of ART status (χ^2 =0.009, df=1, p=0.924) and subject gender (χ^2=1.493, df=1, p=0.222).

Table 6.10 Factors influencing HIV-infected persons' use of herbal medicines (n=129) and pharmaceutical drugs (n=137)

Reason	Type of Medicine	
	Pharmaceutical Drugs n (%)	Herbal Medicine n (%)
Accessibility		
• Affordability	10 (7.3)	12 (9.3)
• Proximity	13 (9.5)	21 (16.3)
• Good Availability	38 (27.7)	42 (32.6)
Other		
• Familiarity with the Medicine	40 (29.2)	14 (10.9)
• Failure of Medicine		
o THM Failed	5 (3.6)	
o Pharmaceuticals Failed		9 (7.0)
• Medicine Effectiveness	26 (19.0)	19 (14.6)
• Miscellaneous	5 (3.6)	12 (9.3)
Total	137 (100.0)	129* (100.0)

* 8 subjects reported no THM use

Qualitative data provided additional insight into the reasons for PLWAs' medicine selection. The reported *affordability* of pharmaceutical drugs appears to be related to subject participation in the HIV treatment programmes from which subjects were recruited. Additionally, some subjects stated that herbal medicines acquired from traditional healers were expensive:

> *"The nurses give us the medicine from the Fort Portal Hospital and Mugusu Health Unit and Kasingo."* (Female PLWA-ART, age 32)

"Modern medicine is given free of charge." (Female PLWA-ART, age 35)

"I have no money to buy herbal medicine from the healers as they are expensive." (Female PLWA-Rtn, age 40)

Of *other* reasons provided for pharmaceutical drug use, some persons living with HIV/AIDS reported experiencing negative reactions after using THM:

"I failed with herbs whereby I vomited the herbs whenever I used them." (Female PLWA-Rtn, age 40)

"Recent herbal medicine that I used caused stomach pain." (Female PLWA-ART, age 31)

A common theme in favour of herbal medicine was the belief held by some PLWAs that some symptoms were unresponsive to pharmaceuticals and/or THM was known to be effective for specific symptoms. This was said to be especially true for the symptoms of Yellow Fever, parasites, Herpes Zoster, tonsillitis, cough, ulcers and boils.

Occasionally, HIV-infected persons indicated that THM was used because of external influences such as parents. To a lesser extent, PLWAs were also persuaded to use THM by friends and/or the radio advertisements of healers:

"Because of our parents influence; they tell us to use herbs and to use them on our kids." (Female PLWA-ART, age 32)

"I heard an advertisement over the radio that a traditional healer's medicine works and since I had stayed with this itching and gonorrhoea for so long, I went for medication at the herbalist's store." (Female PLWA-ART, age 31)

The accessibility of medicine was also noted to be a factor that could influence the type of medicine used by PLWAs. Qualitative responses indicated that herbal remedies were used when pharmaceuticals could not be easily accessed and/or when herbal medicines were very easily accessed:

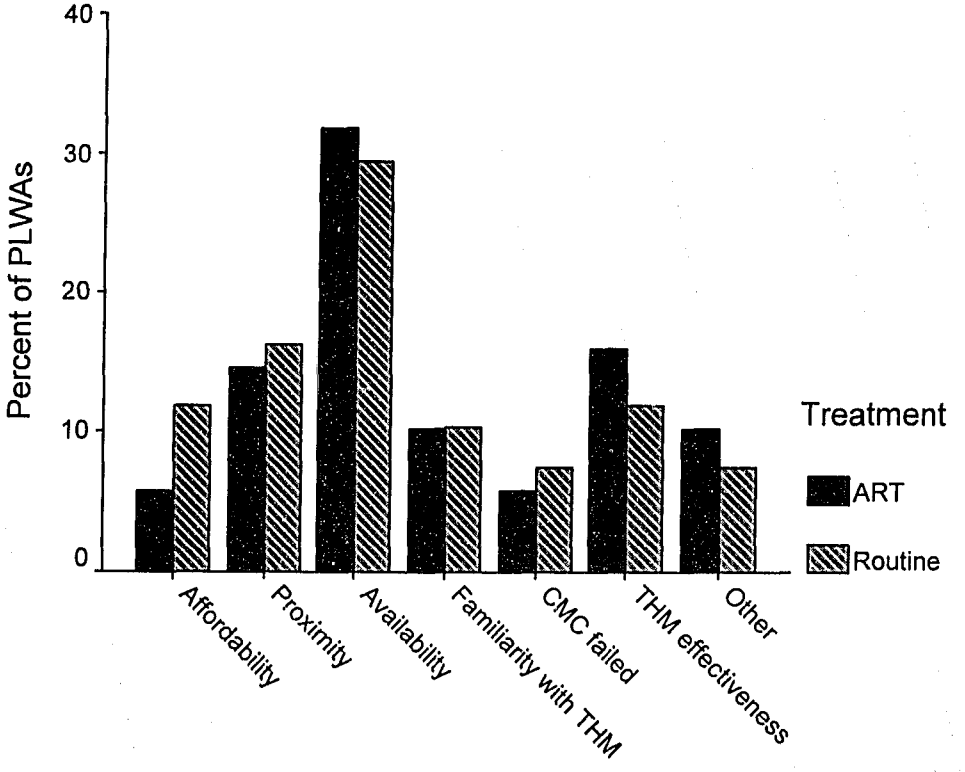
"My days of coming to the HIV clinic are every other one month. Because of the long period between HIV clinics, I use herbs for illnesses that I get before the clinic opens." (Female PLWA-Rtn, age 43)

"Most of the illnesses find me when I have no money so the first choice is to use herbal medicine." (Male PLWA-Rtn, age 50)

"Herbal medicine is from the gardens." (Female PLWA-ART, age 35)

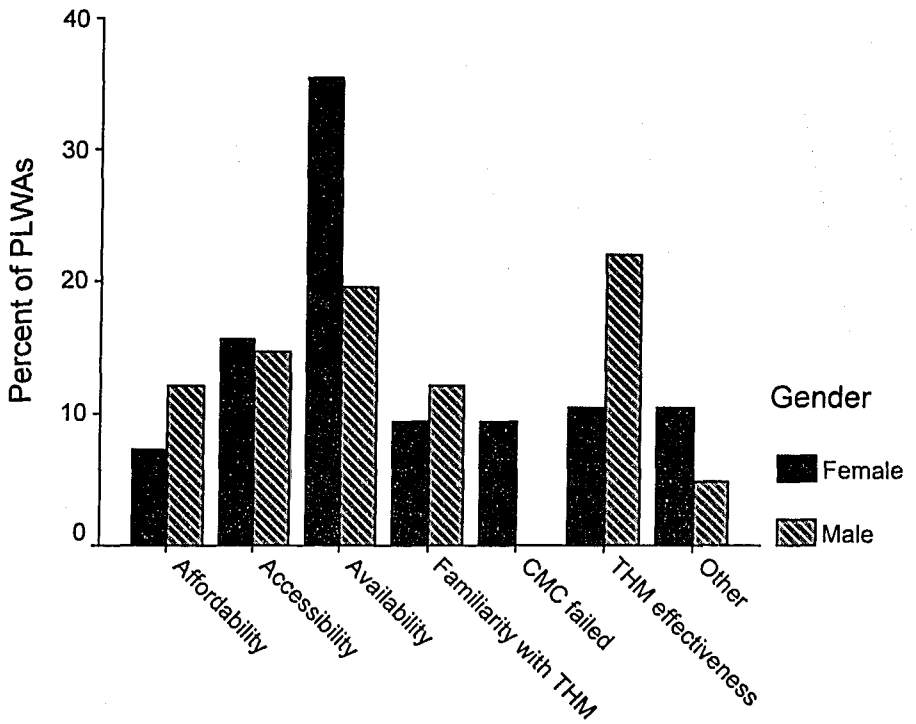
The reasons for THM use reported by PLWA-ART and PLWA-Rtn were very similar (Figure 6.10). One of the differences present was that THM treatment effectiveness was more frequently reported as a factor related to THM use by PLWA-ART than by PLWAs on routine treatment. Another difference was the more frequent reporting of THM affordability as a reason for THM use by PLWA-Rtn than subjects receiving ART.

Figure 6.10 Factors influencing the use of herbal medicine by HIV-infected persons: Stratified by ART status (n=129)



Differences in the reasons reported for herbal medicine use were more pronounced when subjects were compared on the basis of gender[30]. As illustrated in Figure 6.11, female PLWAs reported the good availability (35.4%) and close proximity (15.6%) of herbal resources as a reason for THM use more frequently than males. Conversely, males more frequently reported that THM use was related to THM treatment effectiveness (22.0%) and good availability (19.5%).

Figure 6.11 Factors influencing HIV-infected persons' use of THM: Stratified by gender (n=129)



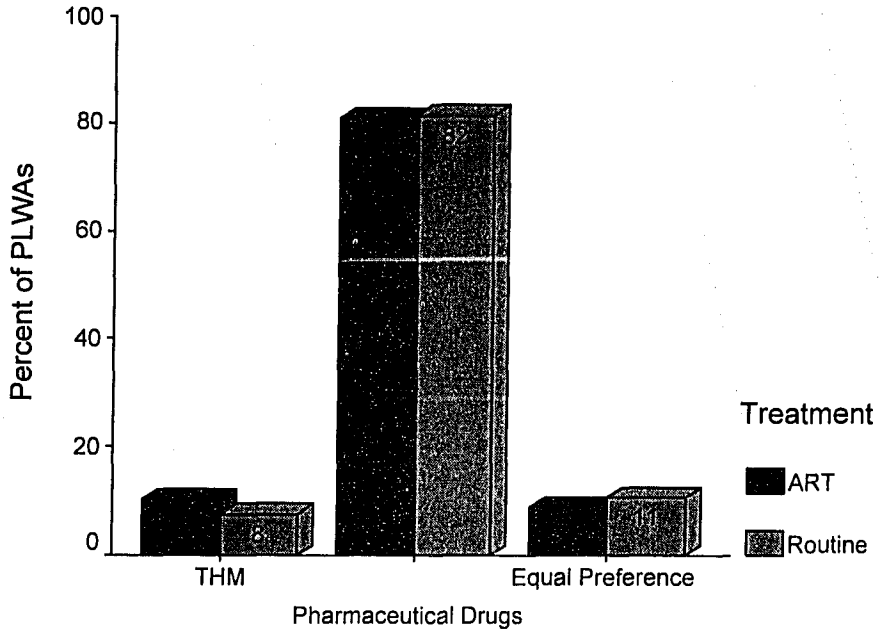
6.10 Medicine Preferences

With respect to the type of medicine that PLWAs would prefer to use when ill, a considerable number of subjects (81.2%) reported a preference for pharmaceuticals (Figure 6.12). Additionally, an equal preference for traditional and modern medicine was voiced by 9.8% of study participants. Statistical analysis did not provide evidence of a significant difference in PLWAs' medicine preference when compared by subject ART

[30] Given the substantial difference in the participation rate of males and females in the study, the comparison was based on the response frequency within each respective gender category

status (χ^2=0.380, df=2, p=0.827). An accurate comparison of male and female medicine preferences could not be completed[31].

Figure 6.12 PLWAs' preferred type of medicine to use (n=133)



Preferred Medicine Use

A number of themes and categories emerged from qualitative data analysis that provided insight into PLWAs' preference for pharmaceutical drugs. Pharmaceuticals were believed to provide better treatment effectiveness than THM based on the perception that pharmaceuticals took effect more rapidly and provided a higher level of symptom relief than herbal remedies:

> *"Modern medicine works better than herbal medicine in curing and treating my illnesses."* (Female PLWA-Rtn, age 30)

> *"Modern medicine cures me very fast – faster than the herbs."* (Female PLWA-ART, age 20)

[31] Statistical analysis could not be completed as more than 20% of cells had expected counts of less than 5.

Pharmaceutical drugs were also preferred more than herbal medicine by PLWAs because pharmaceuticals were subject to government regulation, prescribed by qualified medical personnel and administered according to standardized doses. Additionally, PLWAs favoured pharmaceutical drugs due to their international approval, recognition and use:

> *"With modern medicine, you can get the right measurement, right prescription and right dose. With herbal medicine, you just take it by trial and error."* (Male PLWA-ART, age 45)

> *"Modern medicine is more hygienic – its prepared in the best and safest ways. It is clean. It's even recommended by the world."* (Male PLWA-ART, age 42)

> *"The modern medicine is approved to improve my health. Modern medicine is accepted worldwide."* (Male PLWA-ART, age 38)

Several HIV-infected persons found pharmaceutical drugs to be more accessible than THM in terms of both cost and distance:

> *"Modern medicine can be easily accessed due to the increased number of health centres, clinics and drug shops."* (Female PLWA-ART, age 32)

> *"I can easily get them or I can access them very fast from the hospital free of charge."* (Female PLWA-Rtn, age 45)

Another reason provided by subjects for the high preference for pharmaceuticals was familiarity with the medicine:

> *"Modern medicine is what we have been using ever since I was a kid."* (Female PLWA-Rtn, age 35)

> *"I am familiar with modern medicine and that is what I normally use whenever I am sick."* (Female PLWA-Rtn, age 29)

Finally, pharmaceuticals were the preferred medicine of PLWAs because of its easy administration and the perception that modern medicine had few side effects:

> *"Modern medicine is easier to swallow. It is less sour than herbs. Modern medicine has no side effects as the herbs do like vomiting and dizziness."* (Female PLWA-Rtn, age 26)

> *"Modern medicine is quick and faster to use."* (Female PLWA-ART, age 41)

When herbal medicine was identified as the preferred form of medicine to use, most PLWAs explained that the partiality for THM was a result of its good accessibility (i.e. close at hand and affordable):

> "*I can easily get the herbs – I can get it myself from the bush if I am told what to get. It is not expensive to get it."* (Male PLWA-ART, age 42)

Subjects who did not have a clear preference for either THM or pharmaceutical drugs felt that medicine selection should be dependent on the illness and/or symptoms being experienced. Specifically, the medicine with the best-known effectiveness for a particular symptom would be the preferred medicine to use regardless of whether it was a herbal medicine or a pharmaceutical agent:

> *"Medicines all have specific illnesses that they treat. That is, each has what it treats and is better than the other type of medicine."* (Female PLWA-Rtn, age 40)

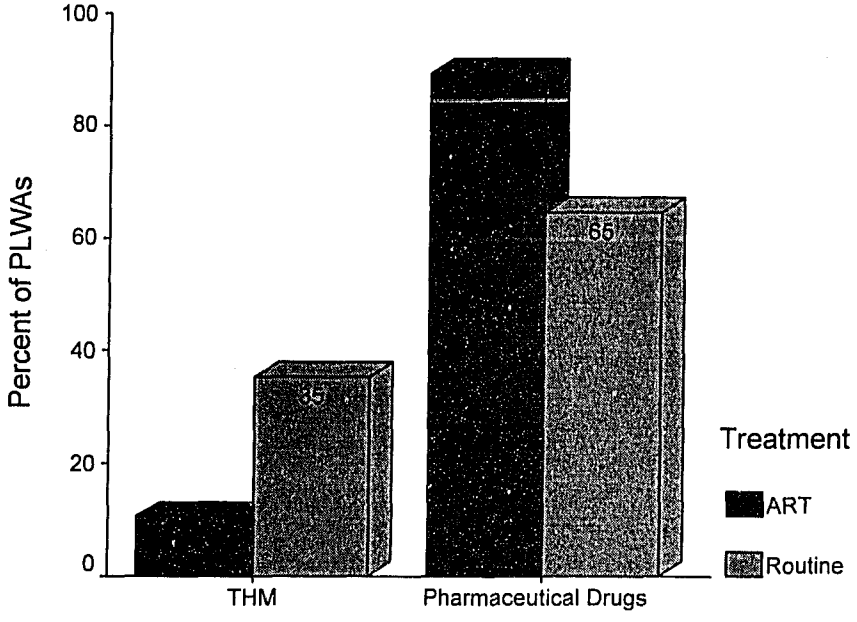
6.11 Health Care Behaviours

6.11.1 First Type of Medicine Used

The investigation took into consideration the possible difference between the type of medicine that PLWAs preferred to use first and the type of medicine that PLWAs actually resorted to using first, possibly as a result of economic factors and other constraints. The data revealed that THM was the first type of medicine used by 22.9% of subjects (although only 9.0% of PLWAs identified THM as their medicine preferred). There was a significant difference in the type of medicine that was used first by ART recipients and PLWAs receiving routine treatment (χ^2=11.388, df=1, p=0.001), with PLWA-Rtn subjects

using THM more frequently than ART subjects (Figure 6.13). Statistically, the gender of PLWAs was not implicated in relation to differences in the type of medicine used first (χ^2=3.423, df=1, p= 0.064). It should be noted, however, that herbal medicine represented the first form of medicine used more frequently for males (33.3%) than females (18.5%).

Figure 6.13 First type of medicine used by HIV-infected persons (n=131)



6.11.2 Initial Health Care Behaviours

To identify PLWAs' health care behaviours and the potential impact of this on THM use, subjects were asked what they did first when experiencing illness: rely on self-treatment; consult with a traditional healer; or acquire treatment from a conventional medical practitioner. Based on the data collected, the initial health care behaviours of HIV-infected persons were equally divided between self-treatment (50.0%) and obtaining treatment from CMPs (50.0%). There were distinct differences in the initial health care behaviours of PLWA-ART and PLWA-Rtn (χ^2=7.529, df=1, p=0.006). Specifically, subjects on ART consulted more frequently with CMPs and PLWA-Rtn relied more heavily on self-care as first level health care behaviours. Males and females had similar patterns of initial health care behaviours (χ^2=0.314, df=1, p=0.575).

Qualitatively, a major theme reported by PLWAs for seeking the care of CMPs as an initial health care behaviour was to obtain accurate diagnoses and proper treatment. Additional themes related to consultations with CMPs as a first level health care behaviour were good accessibility to the CMC system and the qualifications and/or experience of CMPs:

> *"I want to know what I am suffering from through the blood test and then get the correct treatment."* (Female PLWA-ART, age 36)

> *"I go to the hospital because in the first case I do not know what I am suffering from – not until I am told by the medical workers."* (Female PLWA-Rtn, age 28)

> *"The health unit is near our home. The medicine is free of charge at the health unit."* (Female, PLWA-Rtn, age 30)

> *"I have no medicine so I come to the doctor since we get free medicine. I do not know what to use."* (Female PLWA-ART, age 44)

> *"The doctor will treat you well as he is qualified."* (Female PLWA-ART, age 42)

Herbal medicine (36.9%) and pharmaceutical drugs (38.2%) were used almost equally by PLWAs who reported self-treatment as an initial health care behaviour. A small number of subjects (7.2%) indicated that both pharmaceuticals and THM were used for self-treatment and the remaining subjects (17.7%) did not specify which form of medicine was used. The main reason for the reliance on self-treatment as a first level health care behaviour was the need to reduce treatment costs; HIV-infected persons expressed an inability to pay for pharmaceutical drugs as well as a lack of financial resources for transportation costs to and/or from conventional health care facilities. The good availability of both pharmaceutical drugs and herbal medicines was also a theme related to the use of self-treatment as an initial health care behaviour. Finally, self-treatment was used by PLWAs' as a form of first aid for the treatment of minor symptoms and/or to reduce symptoms while awaiting an opportunity to access CMC facilities.

"I am poor. In most cases, illness finds me without any money." (Male PLWA-Rtn, age 42)

"When I treat myself then I am giving myself first aid since the distance is big to the next health unit." (Male PLWA-ART, age 36)

"*I use herbal medicine in most cases because I do not have the money to buy the modern medicine* when *I am ill. I can easily access herbs both in the gardens and bush."* (Female PLWA-Rtn, age 31)

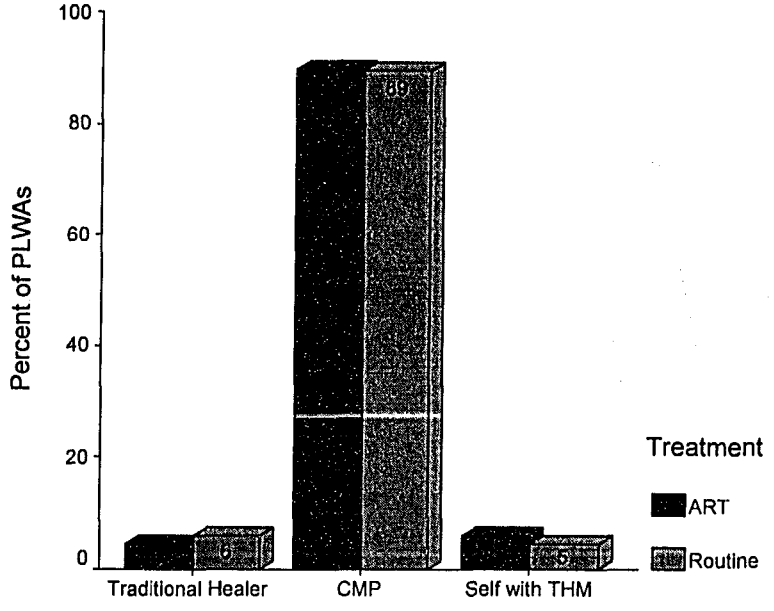
"Since the hospital is far, I treat myself to reduce on transport costs." (Female, PLWA-Rtn, age 45)

6.11.3 Secondary Health Care Behaviours

The vast majority of PLWAs (89.6%) indicated that the care of CMPs would be sought if their symptom(s) were not reduced by the treatment implemented through the first level health care behaviour (Figure 6.14). One hundred percent of HIV-infected persons who started with self-treatment reported that conventional medical practitioners were consulted as a second level health care behaviour. More diversity was reported in the secondary health care behaviours among PLWAs who started with treatment through CMPs: 77.9% of subjects continued care with CMPs; 11.8% of PLWAs switched to self-treatment; and 10.3% of HIV-infected persons sought consultations with traditional healers. Accurate statistical analysis of differences in the second level health care behaviours between PLWA subgroups and gender groups could not be completed[32].

[32] More than 20% of cells had expected counts of less than 5.

Figure 6.14 Second level health care behaviours of HIV-infected persons (n=134)



Qualitative data analysis provided insight into PLWAs' second level health care behaviours. After using self-treatment as an initial health care behaviour, HIV-infected persons would switch to consultations with CMPs if self-treatment had failed and/or the subject acquired sufficient funds to pay for CMC treatments and/or transportation costs. Conversely, the majority of subjects who started with treatment through conventional medical practitioners indicated that they would continue to consult with CMPs because: alternate types of pharmaceutical drugs could be tried; the physician could consult with a specialist to improve the treatment; further diagnostic testing could be completed; the physician would be able to provide proper treatment; and/or an alternate CMP could be consulted directly by the subject.

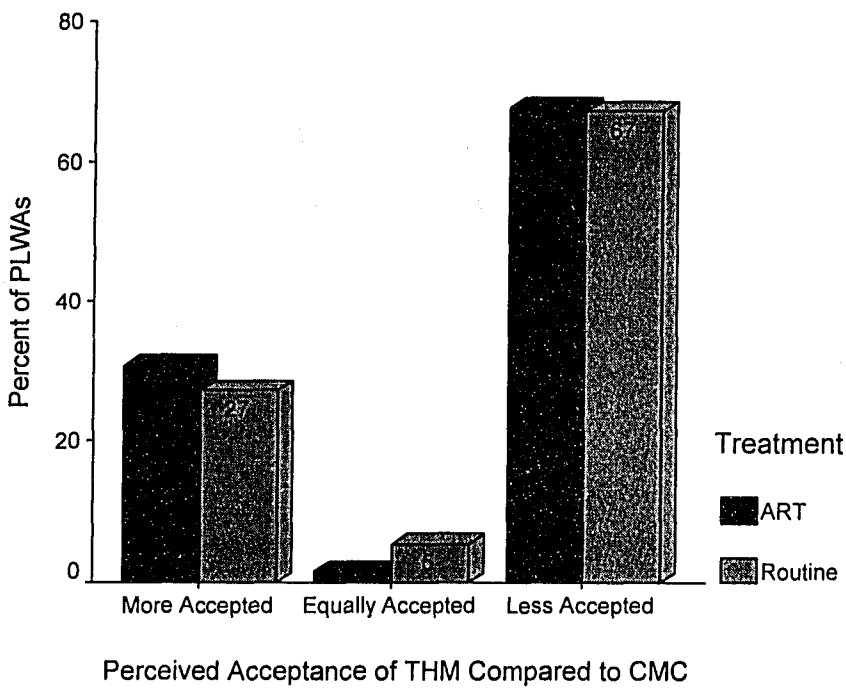
In the event that adequate system relief was not initially achieved through the CMC system, some PLWAs reported consultations with healers or self-treatment as secondary health care behaviours. One subject explained that the failure of pharmaceuticals might indicate that the illness was demonic in nature and thus would require treatment from a traditional healer.

"Since modern medicine has not helped me than I would use trial and error on the traditional medicine (i.e. self-treatment with herbal medicine), which also sometimes does not help me." (Female PLWA-ART, age 35)

6.12 Perceived Community Acceptance of THM

To develop an understanding of the potential influence of perceived community acceptance on PLWAs' use of THM, subjects were asked if the use of THM was more, equally or less accepted in their respective communities than conventional medical care. Several PLWAs (29.2%) perceived herbal medicine as being more accepted in their community than CMC and 3.3% felt that the two forms of medicine were equally accepted (Figure 6.15). The majority (67.5%) however, perceived THM as having less community acceptance than CMC. Statistical analysis did not indicate a significant difference in perceived community acceptance of THM between PLWA-ART and PLWA-Rtn (Mann-Whitney U test z= -0.097, p=0.923) or between males and females (Mann-Whitney U test z= -0.316, p=0.752).

Figure 6.15 Perceived community acceptance of herbal medicine in comparison to conventional medical care (n=120)



Thematically, THM was perceived as having higher community acceptance than CMC based on the perception that community members relied on herbal self-treatment as the initial health care behaviour:

> *"Most of them, when they get sick, they first use herbs and when that fails they switch to modern medicine but some get treated with herbs."* (Female PLWA-ART, age 30)

> *"Because of the lack of money they first use herbal medicine and then modern after they have sold some of their property. Most people use herbs because they don't have money for modern medicine."* (Female PLWA-ART, age 26)

PLWAs indicated that in times of poor health, many community members would go to hospitals or health clinics for treatment. This observation was interrupted by many PLWAs to mean that herbal medicine was less accepted within the community than modern medicine. Many HIV-infected persons felt that the CMC system was frequently used by community members either as a result of inadequate THM knowledge and/or the proximity of CMC facilities. The theme that there were very few or no traditional healers available within or near some communities also emerged as a reason for the perceived frequent use (and hence acceptance) of CMC.

> *"They do not have any knowledge in regards to herbal medicine, on how it works, and what to use. Most people in my village go to hospitals and even get better."* (Female PLWA-Rtn, age 29)

> *"I am near town and people are well informed or have a bit of education and are near to modern medicine services."* (Female PLWA-ART, age 37)

> *"I see many people going to the health unit and I have not seen many using herbal medicine. Many people go to hospitals for treatment compared to those going to traditional healers for treatment."* (Female PLWA-ART, age 41)

> *"Because you can easily access the medical people since they are everywhere unlike the traditional healers."* (Female PLWA-ART, age 32)

6.13 Medicine and Communication

6.13.1 Current Communication with Conventional Medical Practitioners

Of the HIV-infected persons who used THM after being diagnosed with HIV, only a small number (16.3%) indicated that they had informed CMPs about their use of THM. PLWAs' disclosure rate about herbal medicine use was similar between subjects when compared by ART status (χ^2=0.784, df=1, p=0.376) and gender (Fisher's Exact Test p=1.000).

Information acquired from PLWAs indicated that 17.9% of all subjects had been directly asked about THM use by their CMPs, with similar rates reported by male and females PLWAs (χ^2=0.969, df=1, p=0.325) and between ART subgroups (χ^2=0.203, df=1, p=0.652). Importantly, if conventional medical practitioners were to directly inquire about THM use, 67.6% of PLWAs indicated that they would disclose such information. The willingness to disclose information about THM use to CMPs' was similar in between subjects on ART and those on routine treatment (χ^2=0.115, df=1, p=0.734) and by subject gender (χ^2=0.000, df=1, p=0.991). HIV-infected persons were willing to disclose THM information to their conventional medical providers to ensure that CMPs considered the implications of THM when prescribing treatment and providing advice. By doing so, PLWAs felt that the negative effects associated with medical pluralism could be avoided.

> *"To get safe and proper treatment. In order for the doctor to know if I use herbs and put it into consideration."* (Female PLWA-Rtn, age 40)

> *"In order to give me the correct treatment. I will only tell the doctor if he asked or he suspected me to be using herbal medicine. But, if the doctor does not ask, then there is no need to tell about herbs."* (Female PLWA-ART, age 41)

> *"To let the doctor know about my use of herbs and advise me if to continue or not."* (Female PLWA-Rtn, age 45)

Qualitative data analysis also provided insights into PLWAs' unwillingness to disclose THM information to conventional medical practitioners, even if CMPs directly inquired

about THM use. The predominant theme that emerged was the perception of PLWAs' that CMPs do not support the use of THM by patients. Based on this perception, PLWAs anticipated that CMPs would not actually want information about THM or the CMPs would react negatively towards the subject once the use of THM was disclosed.

> *"I fear telling my doctor about using herbs since he does not support them. I fear that the doctor would accuse me because he doesn't deal with herbs."* (Female PLWA-Rtn, age 29)

> *"Doctors do not allow the use of herbal medicine so the doctor's reaction wouldn't be good."* (Male PLWA-Rtn, age 40)

> *"The doctor may decline to give me modern medicine if I told him (about using herbs)."* (Female PLWA-Rtn, age 40)

Subjects receiving ART were asked if they consulted with their ART practitioners about using THM and ARV drugs concurrently. A small percentage of respondents (13.2%) indicated that they had asked their CMPs about THM and ARV drug co-therapy and there was no significant difference in the responses of males and females (Fisher's Exact Test p=0.442). Of the PLWA-ART who did consult with their CMPs, qualitative analysis revealed that subjects wanted to be informed about the potential risks and/or benefits of medical pluralism. Additionally, some ART recipients had hoped that the concurrent use of herbal medicine and ARV drugs would be approved by CMPs in order to reduce their out-of-pocket treatment costs.

> *"I wanted to know if there are effects on using ARVs with herbal medicine. I want to find out if it's bad when you use both medicines."* (Male PLWA-ART, age 42)

> *"I thought maybe the herbs could help and so I could reduce my costs. The HIV doctor stopped me from using herbs."* (Male PLWA-ART, age 44)

Several themes explained why PLWA-ART had not inquired about THM and ARV drug co-therapy with their CMPs. Many PLWA-ART felt that THM treatments were not necessary because ART was an effective treatment. Other ART recipients indicated that

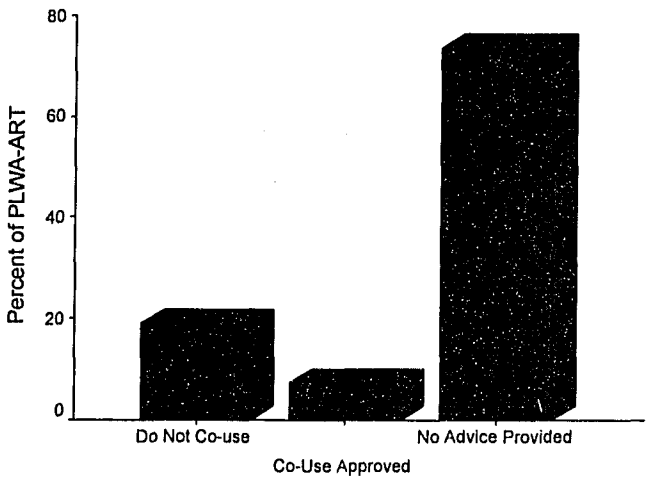
there was no need to inquire about co-therapy since no herbal remedies were available for the treatment of HIV. As well, many PLWA-ART explained that they simply did not think about asking their CMPs about concurrent THM and ARV drug use. The qualitative responses also indicated that PLWA-ART perceived conventional medical practitioners as being unsupportive of THM use and/or that CMPs lacked knowledgeable about herbal medicine.

> *"The modern medicine I get from the doctor helps me so asking whether herbs can be used with modern medicine is surely of no importance. I think that doctors only use modern medicine and there is no need of asking about herbal medicine because the doctors do not know it and they do not know how it works."* (Female PLWA-ART, age 44)

> *"The doctors have given me modern medicine and I think that they work for me without herbal medicine. The doctors are more of modern medicine and they do not require any information about herbal medicine."* (Male PLWA-ART, age 38)

Of the PLWAs on ART, 73.5% of subjects indicated that their CMPs did not provide any advice about medical pluralism (Figure 6.16). Of the PLWA-ART who did received advice from conventional medical practitioners, 27.8% of subjects indicated that their CMPs supported the concurrent use of THM and ARV drugs.

Figure 6.16 Concurrent THM-ARV drug use: Conventional medical practitioner advice to PLWAs (n=68)



6.13.2 Current Communication with Traditional Healers

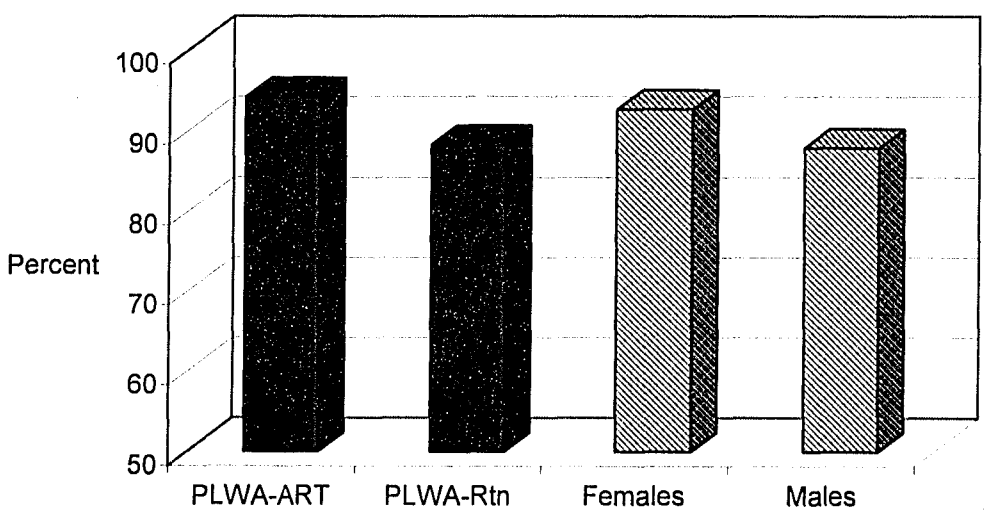
In all, 77.8% (n=17) of PLWAs who consulted with traditional healers had disclosed information about pharmaceutical drug use to their healers. Direct healer inquiry about pharmaceutical use was reported by 38.9% (n=8) of these subjects. Due to the limited number of subjects who acquired herbal medicine from healers, accurate statistical analysis could not be completed. Importantly, the response received from one ART recipient indicated that ARV drug adherence was reduced based on a discussion with a traditional healer:

> *"I thought herbal medicine could help as I heard it on the radio. I didn't take the herb from an herbalist for a specific symptom but was told that it could help to fight HIV in general. I left the herbalist's medicine because it didn't help me and he told me to leave ARVs but I got worse."* (Female PLWA-ART, age 32)

6.13.3 Potential Impact of Conventional Medical Practitioner Advice on THM Use

The majority of HIV-infected persons (91.2%) reported that they would refrain from using herbal medicines if advised to do so by a conventional health practitioner. As demonstrated in Figure 6.17, this response was similar between PLWA-ART and PLWA-Rtn (χ^2=1.462, df=1. p=0.227) and significant differences were also not present in the responses of females and males (Fisher's Exact Test p=0.347).

Figure 6.17 Predicted cessation of herbal medicine use in response to CMPs' advice to stop herbal medicine use (n=136)



Qualitatively, many PLWAs explained that they were willing to discontinue the use of herbal medicine and follow CMPs' advice because of the medical qualifications held by CMPs. Given these medical qualifications, HIV-infected persons recognized that the CMPs were more apt at managing health issues than PLWAs through self-directed care. Additionally, CMPs were viewed as having specialized and sound knowledge about the appropriate and safe use of medicines. CMPs were also highly trusted and respected by PLWAs and were considered to be honest practitioners.

> *"The doctors are well informed about the use of these medicines and the bad things associated with them."* (Female PLWA-ART, age 20)

> *"The doctor knows what is good and bad for my body. The doctor can never tell lies."* (Male PLWA-Rtn, age 36)

> *"The doctor has studied medicines and so I need direction from him about the use of the medicines."* (Male PLWA-ART, age 42)

> *"The doctor will have seen that the herbs are not good to be used. I trust the doctor with my life since I know that any mistake (means) I can die."* (Female PLWA-ART, age 44)

> *"The doctor knows my life better than I do."* (Male PLWA-ART, age 36)

In response to CMP advice, HIV-infected persons were also willing to discontinue the use of THM as a result of pharmaceutical drug effectiveness. Many PLWAs indicated that pharmaceutical drugs had provided better symptom resolution than herbal medicine and that pharmaceuticals were the preferred form of treatment.

> "It is the modern medicine that has treated most of my symptoms." (Female PLWA-Rtn, age 31)

> "The medicine the doctor gives me helps me in the treatment of my symptoms." (Male PLWA-ART, age 50)

Subjects who indicated that they would not stop using THM based on CMPs' advice primarily explained that herbal medicine was an effective form of treatment for their symptoms. A few subjects also indicated that herbal medicine could not be discontinued because of its accessibility and affordability, especially when money was not available to purchase pharmaceutical drugs.

> *"If I can get treated by herbs, I can not allow stopping them. I cannot tell the doctor that I use them."* (Female PLWA-ART, age 26)

A large percentage of PLWAs (86.8%) indicated that they would use THM and ARV drugs concurrently if CMPs advised that such a practice was beneficial. This response was similar between subjects on ART and those on routine treatment (χ^2=0.000, df=1, p=1.000) as well as between gender groups (χ^2=0.100, df=1, p=0.752). HIV-infected persons considered CMPs' advice to be reliable because of CMPs' medical training and qualifications. PLWAs continued to express a high degree of trust in the opinions and advice provided by CMPs due to their qualifications. To a lesser extent, some subjects felt obligated to follow CMPs' orders because of the knowledge and qualifications held by CMPs.

> *"The doctor is qualified. The doctor can never tell lies about someone's life and the use of these medicines."* (Male PLWA-ART, age 32)

> *"The doctor will have tested the co-use. Doctors can never lie like traditional healers."* (Male PLWA-Rtn, age 38)

> *"The doctor is qualified. The doctor will not tell me lies so I believe that whatever he says about my life is true."* (Male PLWA-Rtn, age 30)

> *"The doctor will have seen that the two (medicines) can treat me. Since the doctor is informed, I cannot refuse his advice."* (Female PLWA-ART, age 36)

PLWAs who indicated that they would not participate in medial pluralism with THM and ARV drugs, even if advised of the benefits by a CMP, expressed safety concerns. That

is, PLWAs maintained the position that co-therapy would lead to harmful reactions in the body (e.g. poison or overdose).

> *"I know that the medicines can never be used together and no doctor can say such a thing."* (Female PLWA-Rtn, age 30)

The vast majority of PLWAs (95.6%) indicated that they would not use THM and ARV drugs concurrently if their CMPs advised that co-therapy was harmful. An additional 1.5% of subjects stated that the concurrent use of THM and ARV drugs would be stopped if the CMP clearly instructed them to discontinue co-therapy. Accurate statistical analysis could not be completed to determine the presence of differences between PLWA subgroups or males and females[33]. In keeping with previous qualitative themes that emerged about PLWAs' willingness to follow CMPs' advice, PLWAs expressed trust and confidence in the accuracy of the advice. This was attributed to the general recognition of CMPs' qualifications, training, and knowledge. The theme of PLWAs' obligation to follow CMPs' advice also emerged during qualitative analysis. Some HIV-infected persons also expressed a desire to avoid medical pluralism based on their personal beliefs about the harms of co-therapy (e.g. poisoning, overdose, etc.).

> "*The doctor is qualified in this field. Whatever the doctor says is actually the truth."* (Male PLWA-ART, age 50)

> *"Since the doctor is qualified in medicines, he will see harm in using the medicines together so I would stop immediately."* (Female PLWA-Rtn, age 40)

> *"You have to follow the orders of the doctor since he has the knowledge about the drugs."* (Male PLWA-ART, age 36)

> "Since the *doctor is more informed about medicine than me, than I have to follow his advice."* (Male PLWA-Rtn, age 38)

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[33] More than 20% of the cells had an expected count of less than 5.

To avoid the use of co-therapy, 85.4% of PLWAs reported that they would choose to continue with ARV drugs rather an herbal medicine. An additional 10.0% of PLWAs stated that they would continue with the form of medicine recommended by their CMPs. A very small percentage of subjects (0.7%) advised that they would continue with the form of medicine that was perceived as offering the most benefit, regardless of whether it was THM or ARV drugs. Finally, 0.7% of PLWAs – all of whom were subjects receiving routine treatment - indicated that they would continue with THM and ARV drug co-therapy, taking each form of medicine on alternate days so as to avoid THM-ARV drug interactions.

Qualitative analysis revealed that most PLWAs were willing to discontinue the use of herbal medicine (in order to avoid THM and ARV drug co-therapy) because a herbal remedy for HIV was not available. Additionally, many PLWAs perceived pharmaceutical drugs as being generally more effective than THM through their ability to provide faster and more prolonged symptom relief. This perception led some PLWAs to the conclusion that ARV drugs would therefore be more effective than THM in the treatment of HIV. Less frequently mentioned themes were: THM was not appropriately processed, tested or approved; pharmaceutical drugs should be continued as they are used by CMPs; pharmaceuticals could be easily accessed; and ART had to be adhered to once it was started.

> *"The modern medicine has helped me on many symptoms compared to herbal medicine so I would give out on the herbal medicine."* (Female PLWA-ART, age 44)

> *"The herbal medicine does not treat me very fast – not as fast as modern medicine does."* (Female PLWA-ART, age 20)

> *"The doctor who would have told me this deals in modern medicine and I have to go with this and drop the herbs."* (Female PLWA-Rtn, age 35)

> *"The modern medicine is easily got from doctors but herbal may require having some knowledge about it or it may require going to healers who are scarce."* (Female PLWA-ART, age 31)

"According to ARVs, once you start on them you are not supposed to stop its use unless you want negative effects." (Female PLWA-Rtn, age 26)

One additional theme was also noted specifically amongst PLWA-ART: ARV drugs are more effective than herbal medicine in the treatment of HIV and/or HIV-related symptoms:

"ARVs are meant to sustain life but the herbal medicine may be meant to treat a specific symptom." (Male PLWA-ART, age 35)

"I had all along used ARVs that have helped quite a bit so I wouldn't go for herbs as they just reduce the illness." (Female PLWA-ART, age 40)

Of note, one qualitative response also indicated the potential impact of ART programmes in encouraging individuals who may be infected with HIV to seek testing:

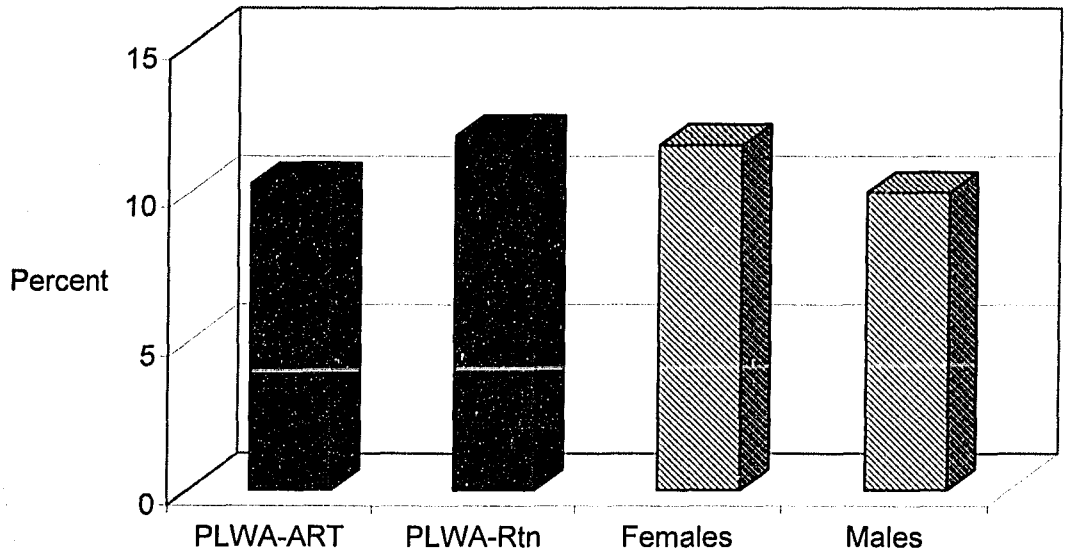
"I have seen many people take HIV medicine and live longer. I got tested so that I might begin on ARVs." (Female PLWA-Rtn, age 31)

6.13.4 Potential Impact of Traditional Healer Advice on Pharmaceutical Drug Use

If advised to do so by healers, 11.1% of PLWAs indicated that they would stop using pharmaceutical drugs. As illustrated in Figure 6.18, significant differences in the responses of the PLWA groups were not evident either by ARV status (χ^2=0.093, df=1, p=0.761) or by gender stratification (Fisher's Exact Test p=1.000). Two main qualitative themes related to the willingness of PLWAs to discontinue pharmaceutical drugs based on healers' advice emerged during data analysis: that the herbal medicine being used was actually improving the subjects' health and the need to avoid concurrent medicine use.

"If the healer gives me medicines that helps improve my health, I would go by her word." (Female PLWA-ART, age 31)

Figure 6.18 Predicted cessation of pharmaceutical drug use in response to traditional healer advice to stop pharmaceutical drug use (n=135)



Several qualitative themes were also evident in association with PLWAs' aversion to discontinuing pharmaceutical agents based on healer advice. The most frequent theme was that PLWAs perceived pharmaceuticals as a more effective treatment modality than THM, thus pharmaceuticals would be continued. Another theme was broadly related to the perceived lack of traditional healers' qualifications and training. In the absence of recognized qualifications, PLWAs viewed healers as: being dishonest and/or untrustworthy; prescribing medicine through guesswork rather on sound diagnosis of the illness; and witchdoctors who participated in demonic practices. Additionally, the continuation of pharmaceutical drugs was preferred by HIV-infected persons because of the lack of regulations and approvals associated with THM.

> *"Modern medicine works better. Through experience, when I left ARVs (based on healer's advice) I regretted it because of the terrible sickness I got."* (Female PLWA-ART, age 32)

> *"Healers are just people like me – without any qualifications. Healers just want to deceive people."* (Male PLWA-Rtn, age 31)

"I don't trust traditional healers. They are not qualified. They tell lies and use imaginations." (Male PLWA-ART, age 36)

"Healers are just thieves whose motive is to just to make money and put bad spells on people that we are against." (Male PLWA-ART, age 42)

"The healer does not diagnose and he just gives you whatever he finds. So, he is not sure of what he is treating." (Female PLWA-ART, age 26)

"I know the herbal medicine is not processed the right way so I have to continue with modern medicine since it is used worldwide, unlike herbs which are used only in Uganda." (Male PLWA-Rtn, age 33)

CHAPTER 7 - RESULTS: TRADITIONAL HEALER INTERVIEWS

7.1 Healer Participation

In total, seven traditional medicine practitioners[34] were included in the study: four provided treatments from their homes and three operated herbal clinics in Fort Portal. All but two of the healers interviewed were males.

Initially, the Chairman of the Kabarole Traditional Healers and Herbalists Association indicated study participants (i.e. members of his association) would be recruited through a general announcement at one of the Association meetings. However, this sampling methodology was altered by the Chairman and instead he approached individual healers working within a reasonable proximity of Fort Portal to ascertain their willingness to participate in the study. As a result, the investigator was unable to track the overall healer participation rate.

Of the traditional healers who were recruited into the study and who were not members of the Kabarole Traditional Healers and Herbalists Association, a 100% participation rate was achieved. That is, all of the individuals approached to participate in the study gave their informed consent and were registered as participants. Interviews with healers were approximately 30-45 minutes in duration. Following the interviews, two of the subjects toured the researcher through their medicinal herb gardens, although specific plant names were not disclosed.

7.2 Healer Behaviours and Perspectives

As only a small number of healers were interviewed, the accuracy or validity of the information cannot be determined. Rather, this information serves only to provide insight into the beliefs and behaviours of some healers and to highlight the advice that they may give to PLWAs about medical pluralism and THM use.

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[34] One interview session was conducted jointly with two traditional healers who did not operate an herbal clinic. These traditional healers were a husband and wife team who shared their knowledge and clients with each other and indicated a preference to be interviewed together. This joint interview was considered equivalent to one interview with one subject.

Of the healers interviewed, three were Catholic and three were Muslim; the religion of the remaining healer is unknown. The terminology used by the practitioners to identify themselves varied greatly, with some preferring to be called an 'herbalist' while others called themselves 'healer' or 'doctor'. None of the healers interviewed reported using spirits, charms, etc. in their treatment practices.

All of the healers indicated that they had acquired basic knowledge about herbal medicine from their parents and had used herbal remedies as children. In adulthood, additional expertise was gained either by apprenticing with an individual herbalist or by garnering knowledge from several different practitioners over time. In all but one case, the herbalists' knowledge about THM was kept secret and specific botanical ingredients were not shared with clients. A single herbalist taught clients "what plants to use" and "how to use them." She explained that this enabled continued access to THM for clients with transportation and financial constraints. After being taught which medicines to use, the clients were then asked by the herbalist to return a short time later to ensure that they were using the medicine appropriately. If the medicinal preparation was complex or a botanical ingredient was difficult to find (or not available locally), this herbalist would prepare and prescribe the medicine for her patient.

Healers indicated that they were not usually aware of clients' HIV status as the majority of clients only informed healers about the specific symptoms for which treatment was being sought. Healers would then develop the treatment plan based on the clients' reported symptomology. None of the healers interviewed indicated that they inquired specifically about their clients' HIV status.

The payment for treatment varied between the healers. The primary investigator observed that two herbalists, each of whom operated a herbal clinic, sold a combination of various medicines to clients for prices ranging from 20,000 to 45,000 Ugandan shillings (approximately US$11.40 to $25.70). Another herbalist did not request any money from clients at the time of treatment but explained that clients who were helped by the medicine would return later to thank the healer with money or other commodities.

Additionally, one herbalist (i.e. the same one who taught clients to make herbal remedies) provided treatment either for free or for a small fee[35].

Healers' responses varied on their self-proclaimed ability to treat HIV. Four healers indicated that herbal medicines can only be used to treat symptoms and therefore can't be used to cure or treat HIV. Two healers believed that their medicines would result in HIV sero-conversion (i.e. after using the medicine, a repeat HIV blood test would yield a negative result) but were unsure if the medicines cured HIV completely. One of these practitioners believed and advised clients (in-person and on the radio) that, as long as the medicine use continued, the HIV would cause "no more problems" and would no longer be transmitted because it was in a dormant state. Finally, one healer felt that his medicines could cure HIV but indicated that none of his patients had been re-tested to confirm this.

The majority of healers felt that THM was more effective than pharmaceuticals, although two healers believed that both forms of medicine had their strengths. For some healers, THM effectiveness was related to its perceived ability to treat illnesses in which CMC treatment had failed and/or its ability to treat chronic illnesses like epilepsy and diabetes. One healer felt that this was especially true if a client sought herbal remedies early in the course of an illness before it had progressed significantly. Additionally, THM was also deemed to be more effective as pharmaceuticals were considered toxic or believed to be processed with harmful chemicals (as was thought to be indicated by the side effects that they caused). One healer explained that pharmaceuticals might appear to work faster because they are prescribed for specific illnesses based on known diagnoses, whereas healers necessarily take a more general approach to illness management due to the lack of specific diagnostic information. Similarly, it was stated that healers can only make treatment modifications in response to the treatment outcomes progressively observed.

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[35] This herbalist (who was a resident in a faith-based organization) used all the money acquired through the sale of THM to pay for the transportation costs incurred in providing treatments to clients in rural areas.

Healers (n=6; one missing response) were equally divided on the safety of medical pluralism. The belief that pharmaceuticals are herbal in origin was one reason given for the perception that herb-drug co-therapy is safe. Another explanation was that co-therapy is safe if several hours are allowed between the ingestion of the two types of medicine. One herbalist indicated that co-therapy was safe as long as only topical THM was used. Those opposed to concurrent administration felt that poisoning and/or death could result because each medicine has its own power and/or pharmaceuticals contain unknown ingredients. Another made an analogy to food, indicating that as a stomach ache results from mixing different foods, a similar reaction would occur from mixing medicines.

When asked specifically about the co-use of THM and ARV drugs, one healer indicated that he had not heard of ARV drugs. Of those practitioners familiar with ARV drugs, there was no consistency in response. Some indicated that co-therapy was dangerous, some believed it to be safe, and others specified that to ensure safety, only topical THM could concurrently be used. Of particular note was the belief articulated by one healer that ARV drugs could be discontinued without any detrimental effects as long as this was immediately followed by the initiation of THM treatment.

There was considerable variation in the healers' perceptions with respect to the level of THM acceptance by the community. As many healers acquire clients on a 'word-of-mouth' referral basis, some assumed that THM must be generally accepted and that people were aware of its benefits. One healer felt that CMC was generally more accepted in the community because of influential religious beliefs, as demonstrated by the fact that his herbal gardens were occasionally destroyed by community members adhering to tenets that forbade herbal medicines. This healer went onto explain that many of his clients come from distant villages to ensure that their local community members do not see them with a healer. Another healer indicated that people who are known to seek the services of healers are considered by community members to be uneducated, which deters individuals from attending treatments with healers. Additionally, one healer felt that community acceptance of THM was associated with the clients' area of residence - in town, pharmaceuticals were preferred because of their high availability and relatively low costs while THM was preferred in villages because of the abundance of herbs in rural areas.

All but one of the healers interviewed indicated that they encourage clients to seek conventional medical care if they do not respond favourably to herbal medicine. As well, some healers try to persuade clients to go for HIV tests based on a client's presenting symptomology. In addition, two healers indicated that CMPs also would refer clients for herbal treatment if the clients were not benefiting from conventional medical care.

CHAPTER 8 - KEY FINDINGS

In order to comprehensively understand the role of THM in the treatment of HIV-infected persons, a wide array of information was gathered during the course of this investigation. The key findings of this study are:

- Herbal medicine use is widespread in HIV-infected persons;
- The use of HIV antiretroviral drugs does not reduce the frequency of herbal medicine use;
- As per the literature review, there are potential harms associated with the use of herbal treatments and antiretroviral drugs;
- HIV-infected persons have a preference for pharmaceutical drugs;
- Self-treatment with herbal medicine and/or pharmaceutical drugs is common among PLWAs;
- Traditional healers are not often consulted by HIV-infected persons who attend HIV treatment programmes;
- There is minimal communication between PLWAs and conventional medical practitioners about herbal medicine;
- Conventional medical practitioners are highly trusted by HIV-infected persons;
- Herbal medicine use, treatment behaviours, and communication with medical providers are very similar between PLWAs regardless of ART treatment status and gender; and
- Herbal medicine knowledge is freely shared with family members, friends and other PLWAs.

CHAPTER 9 - DISCUSSION AND RECOMMENDATIONS

Sociodemographic Variations

By in large, the two subgroups of HIV-infected persons in this investigation (i.e. PLWA-ART and PLWA-Rtn) were highly alike based on sociodemographic characteristics, as significant differences were only noted for marital status and educational attainment. Similar to the reported association between poor education and diminished access to sex-related information (Buvé et al, 2002), this author extrapolates that a parallel relationship exists between poor education and reduced access to information about ART programmes. Therefore it is unsurprising that higher levels of education were found in the PLWA-ART sub-group as HIV-infected persons with higher educational levels are more likely to access and understand information about ART (e.g. through posters, newspapers, etc.) and subsequently seek enrolment in ART programmes. The majority of children in Africa currently do not complete primary education despite improvements in access to basic education (Mulinge, 2002). Thus, the poor overall levels of education noted amongst PLWAs can be expected in the future and may continue to impede the enrolment of less educated PLWAs into ART programmes. As HIV continues to infiltrate all aspects of Ugandan and sub-Saharan African societies, it is essential that HIV/AIDS programme developers and implementers – whether focusing on prevention or treatment – recognize the need to reach those with poor access to information.

It is asserted that an improved capacity to understand and respond to illness generally corresponds with increases in education and income (Orem, 1991). In consideration of Lynch and Kaplan's (2000) observation that educational level determines the types of employment and hence economic returns that are achievable by an individual, a strong argument exists for the indirect impact that increased education has on PLWAs' ability to access ARV programmes. The more advanced levels of education noted amongst PLWA-ART in this study likely result in higher household incomes and, in turn, improved capacities to pay for transportation and other costs associated with ART programmes participation.

The results of this study indicated a difference in PLWAs' educational attainment based on gender, with females possessing slightly less education than their male counterparts. This is consistent with findings throughout Uganda and sub-Saharan Africa. As a result of gender inequities, the ratio of literate females to males in Uganda was 0.74 in 2001 (UNDP, 2003b). The difference in educational levels noted between male and female PLWAs is unlikely to change as girls continue to suffer from poorer access to education in most developing countries (UNICEF, 2000).

Substantial differences were noted in marital status, with males and PLWA-ART reporting the highest rates of marriage within the study. This difference may in part be a reflection of subject recruitment from the PMTCT programme. The PMTCT programme is offered free of charge to women who test HIV-positive in *antenatal clinics*, with their spouse/partner and children being provided access to the PMTCT programme if they are also HIV sero-positive. As the majority of women presenting at antenatal clinics are married, it is a logical inference that the majority of women in the PMTCT programme are married. Additionally, the PMTCT programme promotes partner referral through the removal of treatment costs; the ability of ART to reduce the complications of HIV; and increased public awareness of HIV and the benefits of ART through promotional campaigns (Nuwaha, Faxelid, Neema, Eriksson, & Höjer, 2000). Increased partner referral to the PMTCT by pregnant women likely facilitates an increased enrollment of married males into the program.

The stimulus for HIV testing may also account for the differences in reported marital status between subjects based on gender and ART treatment status. Several PLWA-Rtn mentioned to the research team that they went for voluntary HIV testing and counselling after the passing of their spouse, as they suspected HIV may have been the cause of death. This is a substantial contrast to the way in which subjects recruited into the PMTCT programme learned of their HIV status; that is, through HIV testing at an antenatal clinic and partner referral.

Herbal Medicine: A Common Treatment for HIV-Infected Persons

Within this investigation, the frequency of *herbal medicine* use prior to HIV diagnosis is notably higher than previously cited estimates of traditional medicine use (defined as including both *medication and non-medication therapies*) in the African population and in

Uganda specifically (WHO, 2002; Hamill et al, 2000). Deficient and inequitable access to conventional health services, as well as the often prohibitive costs of conventional health care which impede frequent and/or sustained use, may explain the continued and potentially increasing use of THM amongst PLWAs (Geissler et al., 2000; Tsey, 1997). Manfredi and Chiodo (2000) also suggest that unconventional therapies remain popular with PLWAs due to the conventional health care system's inability to provide a definitive cure for HIV.

Burford and colleagues (2000) advise that most PLWAs in Africa use THM for the treatment of opportunistic infections and other HIV-related symptoms because of the costly and insufficient supply of essential and ARV drugs. Thus, it could be surmised that reduced costs and improved access to pharmaceuticals would result in reduced dependency on THM. This is a proposition consistent with the current study's finding that THM use by PLWAs decreased 26.9% after HIV diagnosis. Improved accessibility and affordability of pharmaceuticals was facilitated by the HIV treatment programmes through which the PLWAs were recruited, with the programmes providing subsidized and/or free essential pharmaceuticals to assist in the management of opportunistic infections and other symptoms. In the absence reduced pharmaceutical costs within HIV treatment programmes, it is highly probable that PLWAs' pre- and post-diagnostic use of THM would remain essentially unchanged.

Overall, 63.5% of PLWAs indicated that herbal medicine had been used after HIV diagnosis. This frequency reduced to 58.1%, however, when PLWAs were asked about the post-test use of THM specifically for what they considered to be their HIV-related illnesses. This demonstrates that PLWAs do not restrict their herbal medicine use to treating HIV-related illnesses alone. Thus, it is important for CMPs and researchers to inquire about herbal treatments for both HIV-related illnesses and other co-morbid conditions. Failure to do so may inadvertently overlook the full spectrum of potential herb-drug interactions that may be experienced by a patient.

A consistency check[36] in the PLWA-ART interviews exposed an inconsistency in the reported frequency of THM use for HIV-related symptoms. The qualitative responses to

[36] The consistency check involved comparing the responses to two similar interview questions.

the questions suggested that some subjects misinterpreted one of the questions. Specifically, one question was correctly understood as the use of THM for the treatment of *HIV-related symptoms* and the other question was interpreted as the use of THM for the treatment of the *HIV directly.* Although this identified inconsistency reduced the overall validity of the responses to these particular questions, it did reveal important information, namely that several PLWA-ART believe that there is no herbal medicine that can directly treat or cure HIV.

The overall frequency of reported THM use by PLWAs was higher than could be explained by the number of PLWAs who reported using THM either as the first type of medicine used for an illness episode and/or THM treatments as a first or second level health care behaviour. In part, this finding may be attributed to the prophylactic use of THM – a behaviour that may be considered by PLWAs to be irrelevant in relation to 'treatment' oriented questions. Additionally, the chronic and progressive nature of HIV-related illnesses may result in PLWAs consulting CMPs numerous times before resorting to THM. This treatment pattern would not have been captured within this investigation as inquiries were made only about first and second level health care behaviours.

Within this investigation, there was a noticeable similarity between the nature of symptoms for which pharmaceutical drugs and THM were most commonly used: fever; cough; stomach and/or abdominal pain; diarrhea; rash; and headache. Consistent with the findings of Geissler et al. (2000), there was a distinct preference for modern analgesics in the treatment of symptoms such as flu, back pain, and chest pain. Conversely, THM was the preferential treatment for jaundice, herpes zoster, and parasites. THM was also used to treat these symptoms regardless of whether the symptoms were considered as individual disease states or symptoms related to HIV. A further finding was that treatment with THM was more prevalent for itching (genital and non-genital) and boils than for jaundice and parasites. The use of THM by PLWAs for the treatment of herpes zoster has been previously noted in Uganda. Based on their preliminary investigation, Homsy and colleagues (1999) suggest that herbal treatments may be as effective as pharmacological treatments (including acyclovir) for the treatment of herpes zoster.

Similar to the findings of Geissler and colleagues (2000), PLWAs commonly expressed that THM was slow acting. HIV-infected persons also felt that THM was effective for short term symptom relief and not the curing of underlying disease states. Thus, when asked to comment on the relative effectiveness of herbal medicine *compared* to pharmacological agents, it was not unforeseen that PLWAs considered THM to be generally less effective than allopathic drugs; a finding consistent with that of Tabuti, Dhillion and Lye (2003). Yet when PLWAs rated the perceived effectiveness of each form of medicine in isolation and on a symptom-by-symptom basis, a different pattern emerged when traditional herbal medicine was compared to pharmaceutical drugs. Specifically, the statistical analysis of these ratings (regarding the perceived effectiveness of THM and pharmaceutical drugs) indicated that both PLWA-Rtn and PLWAs receiving ART no longer perceived a difference between the effectiveness of THM and pharmaceutical drugs for *general symptoms.* When framed in reference to *HIV-related symptoms*, perceived effectiveness ratings reported by the PLWA-ART subgroup continued to indicate that there was no significant difference in the perceived effectiveness of THM and ARV drugs.

It must be emphasized that THM is largely selected based on its ability to treat a specific *symptom* and not for its ability to directly treat the underlying illness. The specific THM treatment does not change, for example, because fever is believed to be associated with the flu, HIV, or another sickness; it will simply be treated as 'fever.' As noted by Geissler et al. (2000), "local herbal practice is based on experimental treatment of single symptoms of illness, trying out one or several of the many available herbs...a definite cure is not expected from the treatment, but a temporary mitigation" (p. 1781). This insight assists in explaining the consistency in reported THM effectiveness between THM treatment for general symptoms and HIV-related symptoms, a finding that was also consistent between the ARV subgroups.

Females consider THM to be generally more effective than males, a finding that may reflect a higher degree of THM knowledge and competency held by females. In African society, adolescent girls spend more of their day in or near the home assisting their mothers and/or grandmothers with domestic tasks. As children acquire their basic knowledge about THM within the domestic domain through the teachings of their mothers and grandmothers (Geissler et al., 2000), it is reasonable to conclude that

females would acquire more THM knowledge than males. With children viewing THM as a female domain (Geissler et al., 2000), it is also anticipated that girls more readily seek and accept information about THM from their female elders. Based on these perspectives, it is suggested that females have higher skills than males for correctly identifying botanical resources and accurately preparing and administering them - skills which may lead to improved THM outcomes.

Medical Pluralism

PLWAs use a large variety of herbal plants for the treatment of their HIV-related symptoms. Ninety-eight different herbal plants were named within this study for the treatment of 33 culturally defined HIV-related illnesses, and each PLWA who used THM did so for an average of three different HIV-related illnesses. As several PLWAs did not know the specific names of the herbal treatments that they used, it is possible that the actual array of botanical treatments may have been slightly broader than that reported. Even though some THM names were unknown, the author is confident that the names of the most commonly used herbal medicines for the treatment of HIV-related symptoms were identified in order of most frequent use. Confidence in the data is based on the relative stability of THM names during the later stages of data entry, with few additional THM names and little variation in the order of frequency being noted with data obtained using a free-listing technique (Martin, 1995; Weller & Romney, 1988).

Given the wide range of symptoms that THM is used for and its frequency of use as reported in this study, medical pluralism was likely to arise. The HIV-infected persons within this investigation demonstrated a moderate tendency (29.4%) to concomitantly use herbal medicine and pharmaceutical drugs. This practice was predominantly used for the treatment of different symptoms simultaneously and/or to achieve more rapid resolution of individual symptoms. As this investigation asked about the concurrent use of THM and pharmaceuticals in general, it is unknown whether the reported frequencies represent co-therapy behaviours before HIV diagnosis, after HIV diagnosis or a combination thereof.

Geissler and colleagues (2000) found that girls and boys use both THM and pharmaceutical agents in childhood but with increasing age, females relied more heavily on THM than boys as boys more frequently accessed pharmaceutical drugs. A similar

finding was noted within this investigation as females used THM more frequently than males. It is speculated that the higher rates of medical pluralism noted with female PLWAs (as compared to male PLWAs) is related to the more frequent use of THM amongst females.

The majority of PLWAs perceived concurrent medicine use as a high risk behaviour that could lead to outcomes such as poisoning, overdose, and death. However, some PLWAs also simultaneously held opposing views about the outcomes of medical pluralism, feeling that it was associated with both risks and benefits. These PLWAs felt that cautious and appropriate co-administration would minimize the risks while allowing the benefits of co-therapy to be experienced. One of the most popular ways to minimize the perceived risks was to use the medicines on different days or, at a minimum, with several hours between each treatment.

HIV-infected persons receiving ART were the most frequent users of co-therapy and 32.8% confirmed the concomitant use of herbal medicine and ARV drugs. Similar to studies in North America and Europe, this finding indicates that herbal medicine is used to complement ARV drugs (Bica et al., 2003; Manfredi & Chiodo, 2000) although the frequency of doing so is less in Uganda. This elevated use of concomitant treatment by PLWA-ART (as compared to PLWA-Rtn) is explained by adherence to ARV treatment protocols, with PLWAs possibly perceiving interruption of their ARV therapy as being more detrimental or harmful than medicine co-administration. Furthermore, as PLWA-ART considered THM to be *equally effective* as ARV drugs in the treatment of HIV-related symptoms, it is understandable that an alternate form of treatment would be used if the desired level of symptom relief was not achieved using ART alone. Certainly, this perspective is supported by PLWA-ARTs' explanation that THM was used to achieve more rapid relief of their symptoms or because pharmacological treatment was perceived to have failed. Satisfaction with ART effectiveness was also provided as a reason for not using THM. Chang and colleagues (2003) have also indicated that PLWA-ART use alternative therapies to alleviate some of the negative side effects of ARV drugs such as nausea and diarrhea. Overall, the suggestion from Sparber and colleagues (2000) that PLWAs are increasingly aware of the incurability of HIV and therefore seek unconventional medicine to assist in the management of symptoms or side effects appears to be equally applicable to PLWAs in Uganda.

HIV-infected persons on ART reported there to be more benefits and less risks associated with concurrent THM and ARV drug use than that of co-therapy with THM and pharmaceutical drugs in general. However, the majority of PLWA-ART considered medical pluralism with THM and ARV drugs as still having substantial risks. While some of the most frequently perceived risks were similar to the concerns expressed regarding general pharmaceutical drug and THM concurrent use (i.e. overdose and death), concerns also focused on the potential interference with ARV drug effectiveness. The beliefs regarding the benefits of THM and ARV drug co-use also closely resembled those involving herbal and modern medicine combinations in general, namely, that medicine co-administration could provide more rapid symptom relief and/or simultaneously treat different symptoms. Males more frequently perceived concurrent THM and ARV drug use as being beneficial than females. As this gender difference was present specifically in relation to THM and ARV drug co-use and not the concurrent use of THM and pharmaceuticals in general, one possible explanation is a greater understanding of ART by males, possibly due to a generally higher educational level. Males may more readily understand that ARV drugs directly combat the HIV and thus are not a treatment designed to directly alleviate common symptoms. Males may consequently perceive the complementary use of THM as a way to treat common HIV-related symptoms.

The method of THM administration must be taken into consideration as the potential for herbal toxicities and herb-drug interactions are greatest when the medicines are ingested (Bica et al., 2002; Nelson & Perrone, 2000; Angell & Kassirer, 1998). Within this investigation, ingestion (80.1%) was the most frequent method of herbal medicine administration for HIV-related symptoms and approximately 25% of PLWA-ART used ingested THM while on ART. This finding highlights the critical need for future pharmacological herb-ARV drug interaction studies, as it is currently unknown if the herbal remedies used by PLWA-ART in Uganda and sub-Saharan African have an impact on ARV drug plasma concentrations (Piscitelli et al., 2002; Piscitelli et al, 2000) and ARV resistance (Clevenbergh et al., 1999). Specifically, current literature does not provide evidence that pharmacokinetic and/or pharmacodynamic studies have been completed with ARV drugs and the herbal remedies reported within this investigation.

Health Care Behaviours and Influences

In general, Africans trust modern medicine more than herbal medicine (Tabuti et al., 2003; Obbo, 1996) and find pharmaceutical drugs easier to administer than THM (Tabuti et al., 2003). Similar findings were noted within the current study and assist in explaining why the majority of PLWAs indicated a clear preference for pharmaceutical agents. However, it was also noted within this investigation that several PLWAs were unable to act on their medicine preference when initially treating an illness, as evidenced by PLWAs resorting to the use of natural botanical resources before manufactured pharmaceuticals. This difference is not explained by choice but by necessity; THM is a convenient and accessible treatment option for people struggling with extreme poverty, poor health and transportation challenges. The influence of family on THM use must also be considered, as family members often determine the type of treatment that is provided when someone falls ill (Tabuti et al., 2003).

Similar to another regional Ugandan population (Tabuti et al., 2003), HIV-infected persons in Kabarole district reported less familiarity with herbal remedies than with pharmaceutical drugs. This lack of familiarity with THM may also contribute to PLWAs' preference for pharmaceuticals over herbal medicine, and may explain PLWAs' perception that community members frequently use conventional health care facilities rather than THM. Finally, poor knowledge about THM may also explain why fewer symptoms were managed with THM than with pharmaceutical drugs on an individual basis.

In the current study, PLWAs seldom reported using healers for any form of treatment other than for the provision of herbal remedies. Of PLWAs who used THM, the vast majority (81.5%) acquired THM on their own or with the assistance of family members or friends (i.e. home-produced herbal remedies). The tendency to use home-produced herbal remedies and self-care rather than treatments provided by traditional healers corresponds with the results of a literature review completed by McCombie (1996) in relation to malaria treatment-seeking behaviours. These findings suggest that people do not consult with traditional healers for common and/or familiar symptoms.
Within this study, the author hypothesizes that the lower use of healers by PLWAs may result from the perception that healers are unable to amend the physiological and/or underlying supernatural causes of HIV infection (Tabuti et al., 2003; Okpako, 1986).

This perception may be related to a general understanding amongst HIV-infected persons that HIV/AIDS is a serious and life-threatening illness with no known cure – an understanding derived from information provided by HIV education programmes, HIV counselling sessions, and personal experiences. Additionally, PLWAs may feel that their knowledge of THM is comparable to that of traditional healers and that naturally growing botanical resources are equally accessible to all community members. In a previous study, Geissler and colleagues' (2002) did not find a clear distinction between the level of THM knowledge held by healers and members of the community at large. Indeed, in some cases, mothers and grandmothers were the most experienced THM practitioners (Geissler et al., 2002). It is highly probable that this situation exists in Kabarole district, the result being a reduced need to consult with healers for THM.

Treatment costs, religious beliefs, and trust were also factors implicated in the finding within this study that PLWAs did not frequently access the services of traditional healers. PLWAs reported that access to traditional healers was cost-prohibitive, and observations by the author substantiated these reports. Other studies have also noted that healer treatments are generally more expensive than conventional medical care (Liddell, Barrett & Bydawell, 2005; Tabuti et al., 2003; Leonard, 2001; Obbo, 1996). Of note, HIV-infected persons receiving ART were found to visit traditional healers to a significantly larger extent than PLWA-Rtn. It can be speculated that PLWA-ART have greater financial capacities than PLWA-Rtn given differences in educational attainment, a factor that may correspond to an improved ability to afford the fees charged by traditional healers.

Some PLWAs in this investigation also mentioned that they did not use traditional healers and/or traditional medicine because of their religious beliefs. A similar finding was previously noted with born-again Christians and fundamentalists in Uganda (Tabuti et al., 2003). Although some religions in Uganda do permit the use of herbal medicine[37], the use of indigenous or ancestral spirits is forbidden. As healers have been known to be both herbalists and diviners (Okpako, 1986), this may deter people

[37] For example, one traditional medicine practitioner of strong Catholic faith explained that Catholics were permitted to use herbal medicine based on scripture (Sirach 38: Sickness and Medicine).

from acquiring herbal remedies from healers. Finally, the low use of traditional healers may be accounted for by PLWAs' expressed concerns about the honesty, training, and integrity of healers – sentiments that have also been expressed by other Ugandan communities (Tabuti et al., 2003).

A large proportion of research and scientific commentary on African traditional medicine has focused on the role of traditional healers in terms of the treatments healers provide, healers' knowledge of medicinal plants, and the potential for collaboration between traditional and conventional health practitioners in the delivery of HIV/AIDS programmes. Comparatively, few studies have focused on the use of home-produced herbal medicines. Cocks and Dold (2000) feel that the common practice of self-treatment has been overshadowed by the focus of anthropological studies on the later stages of illness when specialist services have been sought. In the current study, this author is not questioning the importance of traditional healers in African societies or the services that they provide. However, the findings of this investigation strongly suggest that traditional healers have a much smaller role in the treatment of HIV/AIDS than would have been expected based on a review of previous literature commenting on Africa traditional medicine. Based on the findings of this study, it is strongly recommended that future investigations related to traditional herbal medicine – especially those focused on HIV/AIDS – not overlook the importance of home-produced medicines and common knowledge.

Self-treatment with non-prescription pharmaceuticals and/or home remedies made from herbs has been found to be a common practice in Africa (Tabuti et al., 2003; Cocks & Dold, 2000; Geissler et al., 2000; Tsey, 1997; Obbo, 1996). The findings of this study provide further evidence about the common use of self-treatment, as self-treatment constituted the first health care behaviour for half of the HIV-infected persons. As with other studies (Cocks & Dold, 2000; Geissler et al., 2000), this investigation also demonstrated that self-treatment represents a sustainable, convenient and cost effective form of care that can be used to spare the expense of consultations with traditional and conventional health practitioners in regions where people are frequently ill and finances are sparse. Self-treatment was also found to be an indispensable form of care in the midst of impoverished socio-economic conditions and a struggling public health care system. Although the use of herbs by PLWAs as an early form of treatment is more

pronounced than in general populations (Nyamongo, 2002), self-treatment is not solely confined to the use of home-produced herbal remedies. This was evidenced by the finding that pharmaceutical agents were used to an almost equal extent as herbs in PLWAs' self-treatment practices within this study. This integration of pharmaceuticals into self-treatment practices has been previously noted within the African population (Nyamongo, 2002; Prince, Geissler, Nokes, Maende, Okatcha, Gringorenko & Sternberg, 2001; Geissler et al, 2000; Obbo, 1996).

The common health care behaviour pattern in Africa generally begins with self-treatment. It is not until the illness fails to resolve or worsens that health care behaviours progress to consultations with CMPs, with traditional healers often only being consulted as a 'third' level health care behaviour (Tabuti et al., 2003; Nyamongo, 2002; Geissler et al., 2000). Within this study, however, there was an equal division between HIV-infected persons who sought the care of CMPs as the initial health care behaviour and those who relied on self-treatment. Similar to health switching behaviours noted in previous studies (Tabuti et al., 2003; Nyamongo, 2002), there was a very high tendency for PLWAs who started with self-treatment to switch to conventional medical practitioners as a second level health care behaviour. Within this investigation, the change in PLWA treatment behaviour from self-treatment to CMP consultation was prompted primarily by a poor response to self-treatment and the collection of enough money to facilitate access to CMPs. It is also possible, however, that PLWAs' culturally learned behaviours and attitudes were equally responsible for the reported pattern of health care behaviours (Druss & Rosenheck, 1999).

The author suggests that the higher frequency of CMP consultations as a first level heath care behaviour stems from PLWAs' knowledge of their HIV positive status and its imminent threat to their health and well-being. The PLWAs in this study depended on conventional health practitioners to provide accurate diagnoses and treatments for their symptoms rather than resorting to autonomous self-diagnosis, a common feature in African populations (Tabuti et al., 2003; Cocks & Dold, 2000; Geissler et al., 2000). It is important to note that the reduced dependency on self-treatment in this investigation may be related to the recruitment methodology used, whereby all subjects were patients of HIV treatment programmes at conventional medical care facilities. Given this factor, it is not unexpected that several PLWAs would return to the HIV treatment programmes for

further diagnosis and treatment of opportunistic infections. Additionally, several PLWA-ART reported that they had been advised by ART programme staff to return to the clinic immediately upon the appearance of secondary symptoms in order to obtain immediate and appropriate treatment and to ensure that the ART was still effective.

The evidence generated by this investigation indicates that the role of THM in the treatment of HIV/AIDS is *highly consistent* between PLWA-ART and PLWA-Rtn. It is believed, however, that the services provided by the HIV treatment programmes themselves may influence the health care behaviours of PLWAs and thus may explain some of the significant differences noted between the PLWA subgroups. Within the study population, it is believed that lower reliance on THM and more timely clinical consultations occurred when the HIV treatment programme featured regular and convenient hours of operation throughout the week; shorter waiting periods; and, most importantly, provided free clinical evaluations and essential drugs for the management of opportunistic infections and other symptoms. These programme attributes were more commonly observed by the author at the ART programmes than at the Virika AIDS clinic (probably due to greater financial and staffing resources as well as lower patient numbers). When clinical evaluations and essential drugs are provided at no cost, PLWAs can more reasonably justify and afford the transportation costs that are needed to attend the HIV clinic. Without these provisions, the majority of people in Uganda are unable to afford the cumulative out-of-pocket expenses for transportation, pharmaceutical drugs, and programme fees on as regular and/or sustained basis as is needed with a disease such as HIV/AIDS.

It is also speculated that PLWAs are more motivated to maintain their participation in ART programmes than general HIV treatment programmes that do not feature ART. Due to programme counselling and education sessions, it is likely that PLWA-ART are aware both of the benefits of ART and the necessity of the consistent and monitored management of their therapy. Furthermore, PLWA-ART are required to attend the programme site on a regular basis in order to acquire additional supplies of ARV drugs and to have their treatment appropriately monitored and adjusted to ensure the maximal effectiveness of ART is achieved.

It is suggested that the perceptions of PLWA-ART that pharmaceuticals more effectively treat various symptoms than THM may have been biased by their use of ARV drugs. This bias may be responsible for the significant difference found between the reporting of PLWA subgroups with respect to the subjective effectiveness of pharmaceutical agents. First, it is probable that the majority of HIV-infected persons on ART have stronger immune systems and lower viral loads as a direct result of their ART than PLWAs on routine treatment. It is likely that this would correspond to a lower frequency of secondary infections and less severe symptomologies overall for PLWA-ART as compared to PLWA-Rtn. Accordingly, it is predicted that the two PLWA subgroups would have different treatment responses and outcomes when using modern medicines. The earlier and more appropriate use of pharmaceuticals by PLWA-ART (due to seeking the assistance of conventional medicine practitioners as an initial rather than subsequent health care behaviour) may also help account for the significant variation in the perceived effectiveness of pharmaceuticals between the PLWA subgroups. That is, pharmacological treatments are more likely to be effective when first administered in the more acute stages of disease rather than in the chronic stage.

Herbal Medicine Communication: Sharing and Withholding Information

During the field component of this investigation, BHS staff felt that THM use might vary substantially with the age of PLWAs. Specifically, it was believed that younger PLWAs would use THM less than their older counterparts due to lack of knowledge about THM, disbelief in THM, and/or higher trust in conventional medicine. Quantitative analysis, however, provided no evidence of a significant difference in THM use – before or after diagnosis – in relation to PLWAs' age. As the majority of subjects acquired knowledge about herbal medicine from relatives, friends and/or neighbours, the data strongly suggests that the oral tradition of relaying herbal medicine knowledge from one generation to the next has continued in recent times despite the increased presence of conventional medicine in rural Uganda.

Soaring rates of AIDS-related mortality and drastic increases in the number of orphans may jeopardize the continued transfer of indigenous herbal medicine knowledge to future generations. Children acquire basic knowledge about herbal medicine primarily during late childhood and youth from their female caregivers (Geissler et al., 2000). Thus, it is highly probable that many HIV-infected parents will not have the opportunity to

share their knowledge about THM with their children prior to succumbing to AIDS and other diseases. With estimates of sub-Saharan Africa being home to 25 to 40 million orphans by 2010 (AfroAIDSinfo, 2003; World Bank, 2003) and exceptionally high HIV prevalence rates in young women (UNAIDS, 2004a; Glynn, Carael, Auvert, Kahindo, Chege, Musonda, Kaona & Buvé, 2001), the future use of herbal remedies is uncertain.

Throughout this study, communication was commonly noted to either encourage or discourage the use of THM by PLWAs. Positive communication about THM – sharing knowledge about botanical resources, medicine preparation and the uses and benefits of THM – appears to have been received throughout the life-course of PLWAs. This result corroborates with the findings of other researchers that have noted THM education often starts in childhood with knowledge transfer from parents and/or grandparents (Geissler et al., 2002; Prince et al., 2001). PLWAs also acquired knowledge about THM through other relatives, friends and/or neighbours and PLWAs would employ the assistance of others in medicine gathering and preparation when necessary. As well, PLWAs also shared their THM knowledge with each other while in the waiting rooms of the HIV/AIDS clinics and, in some instances, distributed herbal plant samples to facilitate self-treatment. There appears to be more communal sharing of THM knowledge with PLWAs than has been commonly noted within the general African population, where personal knowledge about THM is often a well-kept secret that may only be shared with young family members (Prince et al., 2001; Whyte, 1997). These basic patterns of THM knowledge acquisition affirm the importance of the oral tradition of herbal medicine and confirm that THM is a shared and valuable resource (Geissler et al., 2002; Prince, 2001; Geissler et al., 2000).

With lack of THM familiarity and knowledge cited in this study as key reasons for not using herbal medicine, it is highly probable that increases in positive THM communication would result in a corresponding increase in THM use among PLWAs. Certainly, the evidence within this investigation suggests that the overall impact of positive THM communication is an increased use of herbal medicine, with some people selecting an herbal remedy based on the subjective reports of others. This later finding is also consistent with that of Winslow and Kroll, 1998 and was especially true for HIV-infected persons on ART as it was frequently reported that THM was used based on the advice of family and/or friends. It is postulated that knowledge shared between HIV-

infected persons may carry additional weight since the information and its relatedness to HIV-related symptoms may be perceived to be more convincing and accurate coming from someone who shares the same disease and health problems. It also raises some concerns about the increased use of THM within the HIV-infected population based on anecdotal information with the potential users receiving inaccurate or incomplete information. Other authors have expressed similar concerns (Nelson & Perrone, 2000; Winslow & Kroll, 1998). Following the advice of others, the potential exists for PLWAs to search for the herbal plant on their own, an activity which can lead to misidentification of the plant or result in the wrong part of the plant being used (Winslow & Kroll, 1998).

Conversely, evidence also indicates that some persons living with HIV/AIDS refrain from using THM based on the teachings and advice of others. Some PLWAs' religious beliefs not only deter individual THM use but also prohibit the transfer of knowledge about indigenous medicine to an individual's children. Conventional medical practitioners, family members and others have also deterred PLWAs from using THM for HIV-related symptoms because of perceived harmful outcomes, for example, overdosing, poisoning, and death.

All in all, PLWAs are likely to be exposed to conflicting advice about herbal medicine use depending on who they talk to. The diverse perspectives of staff within the conventional medical care system about patients' herbal medicine use are evidenced by the recommendations provided to PLWA-ART. The majority of PLWA-ART reported that no advice was received from ART programme staff about concurrent herbal and ARV drug use. When guidance was obtained from clinical personnel, PLWAs were advised that ARV drugs should be used in isolation of THM, although approximately 28% were advised that medical pluralism with herbs was acceptable. This finding suggests that the HIV treatment programmes involved in the study do not have a formal, consistent policy in place with respect to staff advice regarding THM use. With most inquiries about THM-ARV drug co-use being managed on an ad-hoc basis, there is an increased likelihood that the advice provided will be a reflection of the conventional medical practitioners' personal views rather than information based on sound pharmacological and scientific evidence. It is recommended that specific policies be developed within HIV treatment programmes to ensure that patient inquiries about concurrent THM-ARV drug use are answered in a consistent and open manner at all times by clinical personnel.

Nyamongo (2002) indicates that some patients (herbal medicine users in particular) adhere to specific health care choices because of their subjective beliefs about the effectiveness of those particular choices. Thus, it is likely that some PLWAs will make the decision to continue to use herbal medicine despite receiving advice, including professional advice, to the contrary. The findings of this study support the notion that this may be especially true for ART recipients as they perceived herbal medicine and ARV drugs to be equally effectiveness in the treatment of HIV-related symptoms. In consideration of this, it is important that clinical personnel alert PLWAs to the potential harms of THM-ARV drug concomitant use in order to facilitate informed decision making on the part of PLWAs.

Public announcements on radio talk-shows represent another form of communication that can influence PLWAs' health care behaviours. It was observed by the researcher that some traditional health practitioners who operated herbal clinics within the study area participated in weekly radio talk-shows. This served as a subtle form of advertising for their products. Some HIV-infected persons within the study indicated that they had been motivated to seek the services of a traditional health practitioner as a direct result of the radio announcement. Without actual data pertaining to the influence of radio announcements on THM use, it is difficult to surmise how influential this aspect of communication might be within Kabarole district. In India, however, concerns about practitioner induced demands for THM through promotional public advertising campaigns were significant enough that India amended its drug act to include a THM herbal medicine advertising ban in relation to diseases such as HIV/AIDS (Mudar, 1996).

PLWAs indicated that their conventional medical practitioners only occasionally inquired about patient THM use. Study findings indicated that the frequency of such physician inquiries was less than those reported by Wynia and colleagues (1999) regarding physicians in North America. Due to concerns about potential herb-drug interactions and important toxicities arising from the use of herbal remedies alone (Bica et al., 2003; Furler et al. 2003; Piscitelli et al., 2002; Wilasrusmee et al., 2002; Nelson & Perrone, 2000; Piscitelli et al., 2000; Clevenbergh et al., 1999; Angell & Kassirer, 1998; Ernst, 1998; Miller, 1998; Winslow & Kroll, 1998; Slifman et al., 1998), physicians in North America have been encouraged to obtain a detailed herbal medicine history from

patients (Bica et al., 2003; Chang et al., 2003; Furler et al., 2003; Manfredi & Chiodo, 2000; Wynia et al., 1999; Miller, 1998; Winslow & Kroll, 1998; Eisenberg et al., 1993). Based on the evidence generated by this investigation, it is recommended that CMPs in Uganda and sub-Saharan Africa also include a detail herbal medicine history in initial and follow-up patient evaluations, especially for patients receiving antiretroviral therapy. Although the actual propensity for ARV drug and African herbal medicine interactions is currently unknown, completion of herbal medicine histories serves two primary purposes. First, case reports about adverse events in ART recipients that potentially develop as a result of concomitant THM use could be reported to a regulatory body (e.g. a Ministry of Health department). This could assist in identifying research priorities related to THM-ARV drug interactions. Second, knowledge about patients' herbal medicine use would provide a means of rapidly identifying patients at risk should evidence emerge about specific ARV drug and THM interactions. The current evidence indicates that PLWAs in western Uganda would willingly provide such information if requested by conventional medical practitioners. This willingness was based on participating PLWAs general understanding that CMPs are better able to provide appropriate and beneficial treatment when they are fully aware of the patient's medicine history.

As spontaneous reporting of herbal medicine use by PLWAs to conventional medical practitioners was found to be rare, it is suggested that prudence requires these practitioners to initiate conversations on the topic. Within this investigation, the frequency of THM disclosure was considerably less than that noted within North America (Furler et al., 2003; Eisenberg et al., 2001; Eisenberg et al., 1993; Nelson, 2000). Similar to HIV-infected persons in North America (Bica et al., 2003; Eisenberg et al., 2001; Ostrow et al., 1997), low THM disclosure rates are partially related to PLWAs' perception that CMPs are fundamentally opposed to the use of traditional medicine. Based on this perception, some PLWAs fear that disclosure may jeopardize their access to conventional medical care services. PLWAs' perception that CMPs are uninterested in herbal medicine information was noted within this study as well as previous studies in developed nations (Kemper, 2003; Eisenberg et al., 2001). However, by asking patients about THM use in an understanding, informed and non-judgmental manner, conventional medical practitioners could encourage HIV-infected persons to share information about their herbal medicine use (Fugh-Burman, 2000; Manfredi & Chiodo,

2000; Winslow & Kroll, 1998). Knowledge of THM use would assist CMPs in identifying potentially harmful patient health care practices such as medical pluralism and the un-hygienic preparation of medicines (Tabuti et al., 2003) and, if warranted, health practitioners could discourage such practices. Encouraging disclosure could also assist in revealing potentially beneficial THM practices (Giarelli & Jacobs, 2001).

Conventional medical practitioners should advise patients about any known risks and the current lack of information pertaining to herb-drug interactions (Fugh-Berman, 2000). To ensure adequate patient care is provided, it is recommended that CMPs become knowledgeable about herbal medicine toxicities and any herb-drug interactions that are likely to occur within their patient populations (Bica et al., 2003; Miller, 1998; Winslow & Kroll, 1998). At all times, it is important that conventional medical practitioners base their THM advice solely on empirical or reasonable evidence, rather than on any existing personal prejudices.

Communication as a Mitigation Strategy

Amidst entrenched poverty, low levels of human development, and meagre health and transportation infrastructures, it is foreseeable that herbal medicine will continue to be a highly accessible and affordable form of treatment for the vast majority of people in Uganda well into the future. Certainly the data collected in this study indicates a high likelihood of the on-going use of THM by subjects for the treatment of their HIV-related symptoms. Additionally, though the expansion of ART programmes is anticipated, it is highly unlikely that the capacity of such programmes will be sufficient to meet the needs of the majority of HIV-infected persons in Uganda. Importantly, the evidence in this study, as well as the evidence reported in previous studies (Bica et al., 2003; Manfredi & Chiodo, 2000), indicates that the initiation of treatment with ARV drugs does not necessarily correlate with a termination of herbal medicine use by PLWAs. Herbal medicine use endures, serving as a complementary treatment to supplement the effects of ARV drugs.

Failure to recognize local cultural factors and make the necessary adjustments to western-based AIDS education and prevention programmes have been implicated in the limited effectiveness of such programmes (Van Dyk, 2001). In order for history not to be repeated, the risks associated with the concomitant use of herbal medicines and ARV drugs (Piscitelli et al., 2002; Piscitelli et al., 2000; Clevenbergh et al., 1999) must be

recognized. Further, it is recommended that the risks of concurrent herbal medicine and ARV drug use be taken into serious consideration by ART programme developers, implementers, and clinicians. If traditional herbal medicine practices are not duly recognized, it is this author's opinion that the effectiveness of antiretroviral therapy and the overall success of ART programmes may be jeopardized.

Given the vast array of herbal medicines used by PLWAs, as well as the lack of standardization of THM practices (i.e. varying preparation techniques, inconsistent concentrations of the herbal remedy; non-standardized dosages), it is very difficult to complete rigorous scientific testing on THM and/or herb-drug interactions. Despite the absence of empirical evidence regarding potential interactions between ARV drugs and commonly used THM within various African communities, it is essential that the implementation of ART programmes still proceed expeditiously in order to minimize the impact of AIDS on individuals, families and communities to the greatest extent possible. However, the need to further investigate the concomitant use of THM and ARV drugs - in the interest of mitigating potentially harmful herb-ARV drug interactions - remains.

> *"In the absence of full and timely evidence of impending danger, it is necessary to judge incomplete and inadequate evidence, often with an inadequate understanding of how all of the critical causal processes function."*
> *(S. Hrudey, Risk Management Lecture, Department of Public Health Sciences, University of Alberta, October 30, 2003)*

This investigation revealed a timely and cost effective risk management strategy that can be employed to minimize the potential hazards of medical pluralism with herbal medicines and ARV drugs, namely, communication between conventional medical practitioners and PLWAs. In response to a series of hypothetical questions, an overwhelming majority of subjects indicated that they would discontinue using herbal medicines if their CMPs indicated that such use was harmful and/or should be stopped. Of particular importance, PLWA-ART and PLWA-Rtn both indicated that THM use would be discontinued in favour of ARV drugs if CMPs informed them that co-therapy with herbal medicines and ARV drugs was harmful.

HIV-infected persons exhibit a high level of trust and respect for conventional medical practitioners due to their formal training, qualifications and perceived integrity. In many cases, this explains the willingness of PLWAs to accept and/or adhere to instructions provided by CMPs about potentially harmful health practices. It also makes PLWAs more amenable to the advice provided by CMPs as compared to that provided by traditional healers. Additionally, PLWAs indicated that they would *initiate* herbal medicine and ARV drug co-therapy if a CMP indicated that it would be beneficial. This willingness to overcome their expressed concerns or perceived risks about medicine co-use emphasizes the level of trust that PLWAs place in CMPs.

PLWAs recognize pharmaceutical drugs as being government approved, regulated, and standardized. These traits make pharmaceuticals more appealing to PLWAs than THM and, as a result, PLWAs expressed a readiness to discontinue herbal medicines. Concerns about the risks of concurrent medicine practices (i.e. overdosing and poisoning) were also highlighted by PLWAs as a reason to discontinue or refrain from herbal medicine use in relation to antiretroviral therapy.

Potential Communication Issues with Traditional Healers

Due to the limited utilization of traditional healers by persons living with HIV/AIDS in this investigation, conclusive evidence is not available about communication patterns between PLWAs and healers. The collected data suggests that healers and PLWAs discuss medicine use (in this case, the use of pharmaceuticals) more frequently than do PLWAs and CMPs. In the author's estimation, this may be related to the greater acceptance of pharmaceuticals within Uganda society when compared with THM. Similarly, the use of conventional medicine is a practice that does not appear to be associated with any negative community perceptions, unlike the use of THM. Several of the healers interviewed in this study indicated that they encourage subjects to seek conventional medical care if herbal remedies fail to be of assistance.

Traditional healers indicated that they were usually unaware of clients' HIV status and it stands to reason that healers may also be unaware of clients' use of ARV drugs. Without such information, healers might provide ingestible herbal remedies even if they were not supportive of co-therapy practices. As healers and CMPs alike may be unaware of PLWAs' full spectrum of medicine use, PLWAs ultimately bear the

responsibility for informing their various care-givers of any medical pluralism behaviours. However, all practitioners must endeavour to provide clients with relevant information regarding these behaviours. To that end, it is recommended that CMPs work collaboratively with the healers in their communities to ensure that healers are adequately informed about the known and potential dangers of THM-ARV drug concurrent use. It is anticipated that African healers and CMPs would be willing to work collaboratively in activities related to HIV-infected persons based on previous literature.(THETA, 2003; UNAIDS, 2000; Burnett et al., 1999; King & Homsy, 1997) However, just as CMPs need to create an open and supportive environment in which to discuss THM with patients, so too must they with healers - as professional conflicts can develop if one medical system is perceived as attempting to dominate the other (Bodeker, 2001; Morris, 2001; King & Homsy, 1997; Green, 1994). The author suggests that more collaborative relationships between healers and CMPs could develop if CMPs remain open to the benefits of some THM treatments, for example, topical herbal medicine for herpes zoster (Homsy et al., 1999) and referred patients for the same.

Finally, it is recommended that authorities from both the traditional and conventional medical systems work collaboratively to ensure that patient adherence to ART is not interrupted because of the unsubstantiated advice of some healers that THM can replace ARV drugs with no detrimental effects. Based on information obtained in this study and a previous investigation (Chaudhury, 2001), it is equally important to recognize and mitigate other harmful healer practices such as advising patients that THM can result in sero-conversion, render HIV non-transmittable, and/or cure HIV.

CHAPTER 10 - STUDY LIMITATIONS AND STRENGTHS, FUTURE RESEARCH DIRECTIONS, AND CONCLUSION

10.1 Limitations

Cross-sectional study designs are commonly used to explore the use and knowledge of unconventional medicines by the general population and HIV-infected populations – whether it be 'herbal medicine' in developing countries or 'complementary and alternative medicine' in developed countries (Bica et al., 2003; Chang et al., 2003; Furler et al., 2003; Geissler et al., 2002; Eisenberg et al., 2001; Prince et al., 2001; Astin, 1998). However, the inherent limitation of this and other prevalence studies is the inability to provide information about time trends and casual relationships.

Differences in herbal medicine and allopathic medicine use between rural and urban populations have been previously observed (Bodeker, 2003; McCombie, 1996). This is important in two key ways. First, the frequencies of THM use in this investigation likely under-estimate the frequencies of THM use by PLWAs in more rural regions where access to pharmaceutical agents and conventional medical care remain very limited (McCombie, 1996). Secondly, this investigation was based within a semi-urban centre with no other urban or semi-urban municipalities within a reasonable distance (i.e. by local standards) of the study site. Additionally, the majority of subjects resided outside of the semi-urban municipality itself. In recognition of these factors, it is suggested that the findings from this investigation are most likely only generalizable to PLWA populations in Uganda and sub-Saharan Africa that reside in or near a semi-urbanized centre and have limited access to alternate urban or semi-urban municipalities.

Selection bias may be present in the study. Although it is believed that the systematic sampling procedures that were outlined with HIV/AIDS clinical personnel were adhered to, the primary investigator had no means of confirming if the attempted consistency of sampling was actualized. Additionally, the systematic sampling procedures necessarily resulted in the exclusion of PLWAs who were not patients at HIV treatment programmes due to ethical and logistical concerns. Thus, the PLWA sampling methodology used in this study may be implicated in the high frequency of pharmaceutical use reported by PLWAs. While the high demand for and use of pharmaceutical drugs in Africa is

growing (Geissler et al, 2000; McCombie, 1996), it is suggested that the frequency of conventional medicine use found in this study may be an overestimation given that PLWAs were recruited from HIV treatment programmes at conventional medical care facilities. It is also possible that PLWAs' self-selection during subject recruitment (i.e. at the time of first study contact with clinical personnel) may have resulted in an over-reporting of THM use. Additionally, the frequency of pharmaceutical drug and herbal medicine use may be higher in PLWA populations (as compared to non-HIV-infected populations) due to poorer levels of overall health with HIV. As a result of the potential sampling bias related to PLWAs, the findings of this investigation may again only be generalizable to populations of HIV-infected persons in Uganda and sub-Saharan African who have been tested as HIV positive, are participating in HIV treatment programmes, and have similar sociodemographic characteristics.

Convenience sampling of traditional healers may also have resulted in selection bias. As the primary investigator had very limited access to traditional healers, it was not possible to influence the procedures by which rural traditional healers (i.e. those that were not operating herbal shops within Fort Portal municipality) were identified.

As a result of language barriers, the use of research assistants for independent completion of PLWA interviews was unavoidable. The staff at Basic Health Services confirmed that the use of local research assistants was a culturally appropriate research methodology. Indeed, the employ of similar assistants did not have a negative impact on previous research efforts in the region. Basic Health Services staff also agreed with the primary investigator that local research assistants would be able to acquire more accurate responses from study participants than a 'western' interviewer given the cultural nature of traditional medicine. However, the use of research assistants may have contributed to interviewer bias within this investigation. It is possible that the individual research assistants may have conducted the interviews in slightly different manners despite receiving standardized training. For example, there may have been differences in the depth of probing used during the questioning of subjects. Additionally, different personality traits and social skills could impact the research assistants' abilities to develop rapport with subjects and instil a sense of trust in them regarding conditions of confidentiality and anonymity – factors that could either promote or deter subject sharing.

Gender differences can also add to interviewer bias. Fortunately, this investigation was able to acquire both a male and a female research assistant for subject interviews and both completed interviews with male and female subjects. The research assistants were also consistently rotated between the interview sites to ensure that each research assistant completed near equal amounts of both male and female PLWA-ART and PLWA-Rtn interviews.

The potential presence of response bias must be taken into consideration. HIV-infected persons were advised during the informed consent process that the investigation was being facilitated by a foreigner from a 'western' university. Because of this 'western' affiliation, PLWAs may have viewed the research team as being prejudiced against traditional medicine. Subjects may also have been concerned that the research team would disapprove of their THM behaviours, judging them as inappropriate or unacceptable. As a result, subjects may have been reluctant to disclose information about traditional medicine – in whole or in part – in order to protect themselves from potential negative reactions or perceptions. It is also possible that inaccurate or incomplete information could have been provided during the interviews in order to keep THM information secret. However, the author feels that the disclosure rates were very high overall, based on the reported rates of THM use, diversity of THM names received, and the depth of qualitative information. Therefore, potential underestimations of THM use due to response bias are believed to be minimal.

Response bias may also have impacted PLWAs' responses about CMC and pharmaceuticals. This is especially probable if PLWAs perceived the research assistants as being employees of the CMC facilities. This perception could have prompted PLWAs to provide favourable responses about CMC and pharmaceutical drugs (e.g. preferred medicine use, community acceptance, treatment effectiveness, etc).

Questions pertaining to PLWAs' THM use were worded in the broad terms of 'before' and 'after' HIV diagnosis. Eisenberg and colleagues (2001) have indicated that the degree of recall bias is contingent on the most recent episode of use and, in this study, a broad time reference could certainly increase the likelihood of recall bias. Recall bias in this investigation may be reflected not only in the frequency of THM use, but in the types

of symptoms THM was used for; the names of THM used; and the effectiveness ratings assigned to THM treatments. More precisely defined timeframes (e.g. in the last 3 months, in the last six months, etc) for these questions may have reduced recall bias but during the piloting of the questionnaire such references resulted in confusion for the test subjects. As a result, the questionnaire was modified to reflect less restrictive timeframes in order to facilitate PLWAs' ability to answer such questions.

The clinical records of study subjects were not accessed by the research team during this investigation. Obviously, this limited the ability to verify some of the information acquired from PLWAs. Information acquired directly from these records would have provided an accurate date of HIV diagnosis (i.e. compared with patient self-reporting due to potential recall bias). As well, clinical records may have been able to validate and/or provide more accurate information about CMP inquiries about THM use. However, the rationale for not accessing clinical records was to ensure that clinic personnel were not aware of which patients had been recruited into the study. Additionally, clinic personnel had exceptionally high time constraints (as evidenced by the lack of compliance in completing the recruitment tracking sheets). It was reasonable to assume that clinic personnel would have resisted assisting the research team in acquiring information from clinical records based on their current workloads and time constraints.

In retrospect, information should have been acquired from PLWAs with respect to their occupation and current employment status. This information could have provided substantial insight into any association between household income and PLWAs' ability to afford transportation costs, healer fees, etc.

A previously validated questionnaire was not used in this investigation simply because an appropriate one did not exist. Although several complementary and alternative medicine research studies have been completed in developed nations, the author determined that the use of the research instruments from these studies would not be valid in Uganda. This decision was based on the knowledge that the socio-economic and cultural differences between these PLWA populations (i.e. in developed and developing nations) are extensive. As well, there are profound differences associated with the respective conventional medical care systems within Uganda and developed nations (for example: availability, proximity, level of care, physician to population ratios,

accessibility issues, etc.). For example, previous studies within developed countries have indicated that the higher use of alternative (as well as conventional) therapies are associated with higher income levels (Bica et al., 2003; Ostrow, 1997) whereas in Africa, the use of traditional medicine is seen to be related to poverty and lack of accessibility to CMC (WHO, 2002; Bodeker, 2001; Burnett, et al., 1999). Further, the use of herbal medicine tends to be assessed alongside numerous other treatment options (e.g. massage, acupuncture, chiropractor, yoga, etc) in studies evaluating conventional and alternative medicine within developed nations. These other forms of treatment are either non-existent or uncommon within the African context, an issue that further reduces the validity of such instruments in relation to the specifics of this investigation.

Several limitations of this exploratory investigation were associated with the lack of botanical knowledge held by the research team. Without such knowledge, it was not possible to verify the types of botanical resources used by PLWAs (i.e. achieved either through field visits or via samples brought by PLWAs). Although best efforts were used to identify the Latin botanical names based on the Rutooro names provided, the primary researcher is unable to substantiate the validity of such information and therefore cautions against the use of such information without further investigation. Furthermore, the active chemical ingredients of the herbal medicines reported in this investigation have not been identified. Based on this and the researcher lack of advanced pharmacological knowledge, a judgement about the actual dangers of THM use within this investigation cannot be provided and further investigations are required.

10.2 Strengths

This study collected quantitative and qualitative information from HIV-infected persons regarding their basic use of THM and related factors. Based on a thorough literature review, it appears to be the *first and largest* investigation of its type in Uganda and very possibly sub-Saharan African. The information collected confirms the belief that PLWAs use herbal medicine for many of the same reasons that the non-HIV-infected population in Africa does, namely, accessibility, familiarity, and necessity. It also comprehensively identifies many elements of herbal medicine use as they relate specifically to HIV-infected persons.

One of the strength of this study is its contribution to previous research efforts focusing on HIV/AIDS in Uganda. This investigation was completed as part of an on-going, collaborative relationship between Basic Health Services in Uganda, and the Department of Public Health Sciences, University of Alberta, as facilitated by Dr. W. Kipp. This study aligns with a larger study led by Dr. Kipp at the University of Alberta entitled *Options for the implementation of anti-retroviral treatment in rural Uganda*, a proposal that has received substantial funding from the Canadian Institute of Health Research (CIHR) Global Health Research Pilot Project Grants.

The main purpose of this investigation was conceptualized by Basic Health Services and Dr. W. Kipp. As such, the study was deemed to be of value by the local partner, Basic Health Services, since its initial conception. Additionally, the local ownership of this study is apparent in that it was completed at the request of Basic Health Services. Thus, it is anticipated that there will be an increased willingness on the part of the Uganda collaborators to access this information in order to better meet the needs of HIV-infected persons and to augment local ART programming considerations and subsequent development plans.

The concerted efforts of the staff at Basic Health Services and the research assistants are to be heartily commended. The personnel at Basic Health Services greatly assisted the researcher with achieving the cooperation of the participating HIV treatment programmes and the Chairman of the Kabarole Traditional Healers and Herbalists Association. Without the research assistants, data collection would not have been possible due to language barriers and lack of familiarity with local botany. Also key to the success of this project were the efforts of all team members to communicate as effectively as possible. Good communication strategies enabled our team to mitigate potential research complications as soon as they were identified. Both Basic Health Services and the research assistants provided tremendous insight into local culture and customs, and ensured that all study documents and approaches were culturally sensitive and appropriate. Without the efforts of these individuals, the primary investigator is certain that the success of the study would have been compromised.

The sample size for this investigation was only achieved through the efforts of HIV clinical personnel at the Virika AIDS Clinic, the PMTCT programme and the JCRC

programme. Without the assistance of these personnel, logistical difficulties in identifying and contacting PLWAs outside of the clinical programme areas would have hindered the ability of the researcher to attain the desired sample size. Thankfully, the systematic sampling methodology employed proved to be successful not only to achieve subject confidentiality and anonymity but also to minimize disruption to the already burdensome workload of clinical personnel.

A large amount of qualitative information was gathered during interviews with PLWAs. As this investigation did not have the benefit of modelling off of previously conducted studies, it was difficult to anticipate subject responses and design a questionnaire with a multitude of forced-choice or categorical responses. Inclusion of open-ended questions provided PLWAs with the opportunity to spontaneously express their thoughts and beliefs in relation to many of the questions during the interview. Although this resulted in a lengthy interview, the responses provided a wealth of information and insight into the treatment behaviours of PLWAs that were not anticipated (e.g. fears related to medical pluralism, the impact of religion, etc). It is also believed that the inclusion of open-ended questions increased the interaction between the research assistants and the PLWAs which may have relaxed the subject and encourage more information sharing.

Importantly, communication issues relating to conventional medical providers were identified by the PLWAs involved in the study. These findings provide insight into how CMP communication may impact the future of herbal medicine use by PLWAs. It is recommended that this information be incorporated into ART staff training in order to increase patient awareness of the potential harms of herb-ARV drug co-therapy. Information from this study can also be used in ART staff training to improve practitioner-patient communication and ensure a more welcoming environment in which THM can be discussed is created.

10.3 Future Research Directions

It is inevitable that some HIV-infected persons will continue to use herbal medicine for the treatment of HIV-related symptoms once they are on antiretroviral therapy. Due to potential errors in translation and/or subject misidentification (either in the gathering or in the naming) of the botanicals they use for THM, this study was unable to verify with any accuracy the specific botanical resources used by PLWAs for THM treatment. However,

this study has preliminarily identified numerous plants that are potentially used in THM self-treatment by PLWAs. Thus, to maximize cost-effectiveness, it is recommended that a follow-up study be completed to determine the consistency and accuracy of PLWAs' plant identification before any specific herb-drug pharmacokinetic and pharmacodynamic interaction studies are undertaken. Such a study would require the assistance of a highly skilled botanist who is familiar with Uganda's flora.

In the interests of public safety, herb-ARV drug interaction studies should be completed (Miller, 1998). Once the accurate identification of botanical sources is accomplished, it is recommended that pharmacokinetic and pharmacodynamic studies explore any interactions between the botanical resources most frequently used by PLWAs and the ARV drugs provided through Uganda's HIV treatment programmes. These studies would determine the benefits and risks associated with herb-ARV medical pluralism. Information from such studies could be used to provide CMPs with adequate knowledge about THM-ARV interactions so as to counsel patients appropriately.

The HIV-infected subjects in this study have indicated their anticipated behaviours in response to advice or information from CMPs regarding herbal medicine. As these responses are speculative in nature, further investigation is warranted to determine the actual outcomes of CMP communications on PLWAs herb-ARV drug co-therapy behaviours.

To ensure the on-going effectiveness of ART treatment, it is recommended that future studies investigating antiretroviral therapy compliance include some questions about THM use. Specifically, it is important to determine if poor adherence to a therapy regimen is more pronounced when there is increased reliance on THM. It appears that advice received from traditional healers and herbalists may encourage poor adherence to ARV drugs. This concern may also warrant further study.

McCombie (1996) has indicated that reliance on self-treatment can delay people from seeking appropriate care. Based on the high reliance that PLWAs have on self-treatment as a first level health care behaviour, it may be important to determine the possible delays that this has on HIV treatment programmes attendance for patients already enrolled in such programmes. If treatment at conventional medical facilities is

indeed delayed, it would be important to investigate any possible adverse effects on viral load and CD4 levels amongst PLWA-ART and also in comparison of PLWA-ART and PLWA-Rtn.

Though not the focus of this investigation, it was noted that the JCRC programme and the Virika AIDS clinic have children/orphan clinics. Due to the growing orphan population in Uganda and sub-Saharan Africa, it is likely of interest to acquire more knowledge about medical pluralism using ARV drugs and self-prescribed medicines within child and adolescent populations. This is especially relevant given the extensive use of herbal medicines and self-treatment within the young population and the potential impact on THM knowledge and use when a child is left motherless (Geissler et al., 2002; Prince et al., 2001; Geissler et al., 2000).

10.4 Conclusion

The results of this study confirm that at least one aspect of traditional medicine - herbal remedies – has a large role in the treatment of HIV-infected adults regardless of their gender, age or participation in antiretroviral therapy. Herbal medicine is an important self-treatment resource that is used as an initial health care behaviour, largely because of socio-economic deprivation impeding early or frequent access to conventional medical care facilities. The role of herbal medicine is very diverse within the HIV-infected population, with a multitude of botanical resources being used for a variety of different symptoms. HIV-infected persons consider THM to be an effective for the treatment of individual symptoms. Crucially, PLWAs receiving antiretroviral therapy view herbal medicine and ARV drugs as being equally effective in the treatment of HIV-related symptoms.

Approximately 60% of HIV-infected adults who access HIV treatment programmes continue to use herbal medicine after being diagnosed with HIV. This, combined with the finding that one third of PLWAs participate in medical pluralism, demands that the use of traditional herbal medicine be taken into consideration when PLWAs access health care from the conventional medical care system. This is especially true with respect to HIV-infected persons on antiretroviral therapy as the empirical evidence about detrimental herb-ARV drug interactions (Piscitelli et al, 2002; Piscitelli et al., 2000) highlights the risks that can develop from the use of seemingly harmless herbal

remedies. The benefits and toxicities of many herbal plants and their interactions with antiretroviral drugs currently remain unknown. Therefore, in the interests of maximizing both patient safety and ART effectiveness, this author advocates for the cessation of herbal medicine use once antiretroviral therapy is started.

As Uganda and other countries in sub-Sahara Africa develop and expand HIV treatment programmes which include ART, it is suggested that clinical programme staff be trained to discuss PLWAs' use of herbal medicine in an open and supportive manner and take a herbal medicine inventory during initial patient evaluations and follow-up sessions. It is crucial that the *potential* adverse consequences of herb-ARV drug interactions (such as reduced effectiveness of ARV drugs) be clearly explained to patients. Until research emerges to indicate otherwise, this author asserts that it is critically important that ART programme staff are vigilant about cautioning patients that *ingested herbal remedies may reduce the treatment effectiveness of ARV drugs.* The evidence of this study indicates that such advice would likely be followed by the overwhelming majority of HIV-infected adults.

It is equally important to recognize that research related to ARV drug and herbal medicine interactions may reveal non-harmful and/or beneficial effects related to medical pluralism. In this event, HIV clinical personnel should promote the appropriate combinations of ARV drugs and herbal medicines to maximize treatment effectiveness and patient health. The inclusion of THM as a complementary medicine in the treatment of HIV/AIDS (if proven beneficial and safe) may provide an affordable and accessible option for the majority of PLWAs.

This author is not attempting to undermine the importance of traditional herbal medicine or the benefits that it provides to innumerable Africans. At the same time, antiretroviral therapy represents the best clinical treatment for HIV to-date. It is imperative that every effort be taken to maximize the effectiveness of antiretroviral therapy effectiveness as HIV/AIDS continues to devastate individuals, families, communities and society as a whole.

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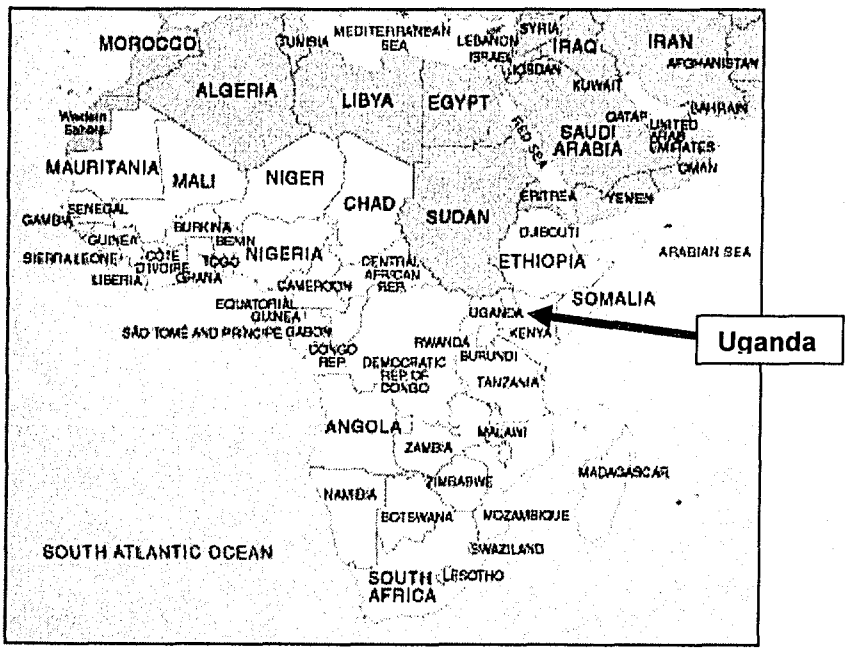
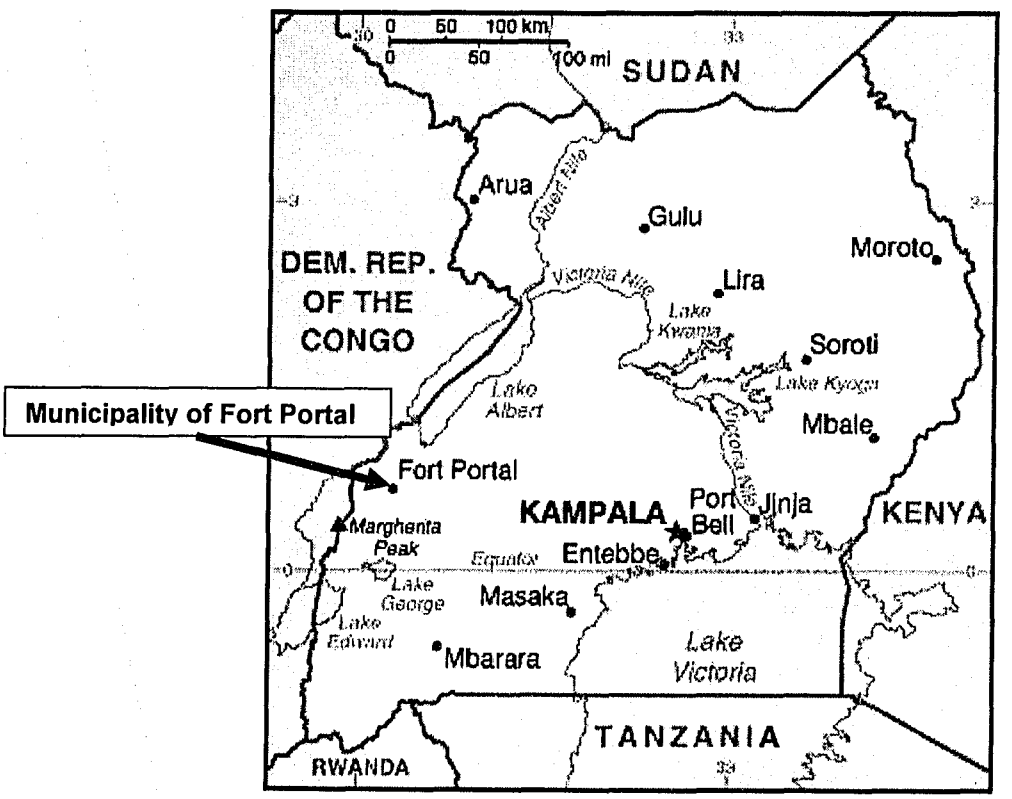
Appendix 1: Maps of Uganda

UGANDA AND SUB-SAHARAN AFRICA



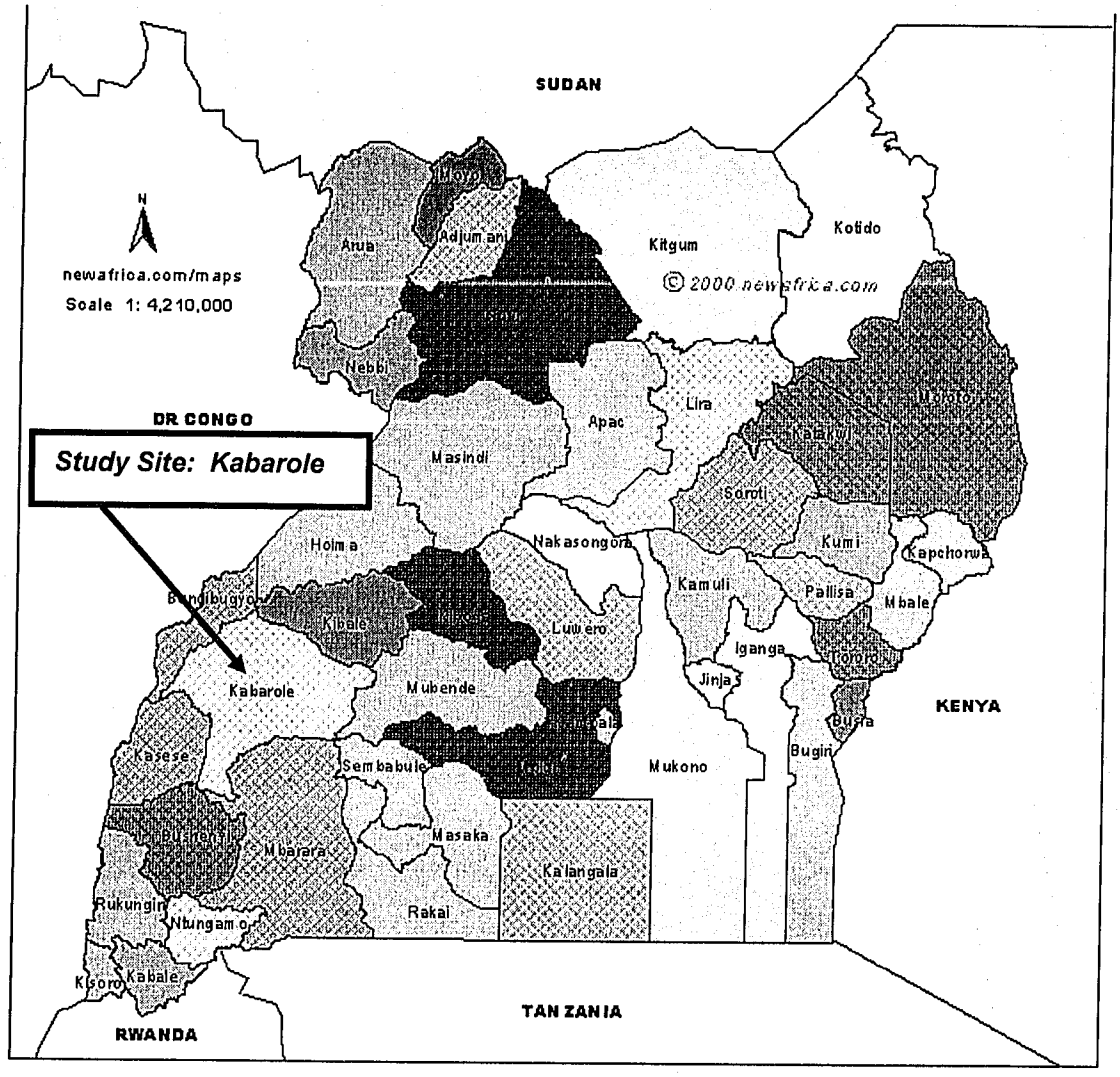
Source: Maps, 2005

OVERVIEW OF UGANDA



Source: CIA, 2005

Kabarole District



Source: Safari, 2005

Appendix 2: Information Letter for Study Participants (PLWAs)

University of Alberta
Department of Public Health Sciences

Information Letter
Primary Respondents

Project Title: The role of traditional medicine in the treatment of HIV/AIDS patients in western Uganda.

Principal Investigator: Deanne Langlois, Public Health Sciences, University of Alberta, Edmonton, Canada

Supervisors: Dr. Walter Kipp, Public Health Sciences, University of Alberta, Edmonton, Canada
Prof. Stella Neema, Makerere University, Kampala, Uganda
Tom Rubaale, Team Leader, Health Department, Kabarole District Administration, Fort Portal, Uganda

Date: September to December 2004

Dear Sir or Madam:

You are being asked to participate in a research project about the role that traditional herbal medicine has in the treatment of HIV and AIDS ('slim disease'). The study is being done by the University of Alberta, Canada with the support of the Kabarole District Health Department and the Makerere University, Uganda.

Purpose of the study:

In Uganda, about 4 out of every 5 people use traditional medicine. There are plans being made to provide AIDS medicine to increasing numbers of people who have HIV. However, as AIDS medicines are fairly new in Uganda, no research has been done about the benefits and risks of using AIDS medicine and Ugandan herbal treatments together. To know what kind of research must be done, we first need to know if people who are taking AIDS medicines ("ARVs") use herbal medicine differently than people who are not on AIDS medicines. The purpose of this study to gain a better understanding of the use of herbal medicine by people with HIV/AIDS in western Uganda to help ensure that medicines are used together in a safe and helpful way.

Appendix 3: Consent Form for Study Participants (PLWAs)

Appendix 4: Clinical Personnel Tracking Sheet for Subject Recruitment

Name of Treatment Facility and Program:_____

Name of Staff Member:_____

Instructions:

1. HIV positive patients between the ages of 18 and 55.
2. Ask every second male and every second female if they would be interested in participating in a research study about the treatment of HIV/AIDS.
3. If the person is interested in participating in the study, please have them talk to Ann or Allan for more information.

	Date Asked	Gender		Participation		District of Residence	On ARV?	
1		Male	Female	Agreed	Refused		Yes	No
2								
3								
4								
5								
6								
7								
8								
9								
10								
11								
12								
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28								
29								

Appendix 5: Interview Questionnaire for HIV-Infected Persons

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

Demographic Information					
1. Gender	☐ Female			☐ Male	
2. Date of Birth	Year:				
3. Marital Status	☐ Single	☐ Married	☐ Divorced	☐ Separated	☐ Widow/Widower
4. Tribal Ethnicity					
5. Education Level	What is the highest grade of school that you completed?				
6. District of Residence					

General Use of Medicine (i.e. Modern Medicine)

7. Do you use medicine for any kind of illness or poor health?	☐ Yes Why do you use medicine? ☐ Cost ☐ Accessibility: What is meant by accessibility: ☐ Distance to get the medicine ☐ Availability of the medicine ☐ Other (describe): ☐ Familiarity/Knowledge ☐ Other (specify): Do other people in your family use modern medicine? ☐ Yes ☐ No If yes, what is the family member's relation to you How do you get the medicine? ☐ Drug shop ☐ Prescriptions ☐ Other (specify):	☐ No Why?

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:

8. Did you use modern medicine before being diagnosed with HIV?	Yes	No
9. Did you use modern medicine after being diagnosed with HIV?	Yes	No

10. What symptoms or illnesses do you use modern medicine for? *List in the order provided*	11. What is the name of the modern medicine that you use?	12. How long do you have this illness (symptom) before you start using modern medicine? *Weeks*	13. Does the modern medicine help with these symptoms? **A** - Cured symptoms (completely gone) **B** - Helped quite a bit **C** - Somewhat helped symptoms **D** - Helped a little bit **E** - No help at all
1.			
2.			
3.			
4.			
5.			
6.			
7.			
8.			
9.			
10.			
11.			
12.			
13.			
14.			
Additional information:			

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

General Use of Traditional Medicine		
14. Do you use herbal medicine for any kind of illness or poor health?	☐ Yes Why do you use herbal medicine? ☐ Cost ☐ Accessibility: What is meant by accessibility: ☐ Distance to get the medicine ☐ Availability of the medicine ☐ Other (describe): ☐ Familiarity/Knowledge ☐ Other (specify): What other types of traditional medicine do you use? ☐ Divining ☐ Bone Setter ☐ Traditional Birth Attendant ☐ Other (specify):	☐ No Why?
	Do other people in your family use herbal medicine? ☐ Yes ☐ No If yes, what is the family member's relation to you?	
15. Did you use herbal medicine:	Before being diagnosed with HIV? Yes No	After being diagnosed with HIV? Yes No

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

16. What symptoms or illnesses do you use herbal medicine for?	List the symptoms in the order provided:		17. Does/did herbal medicine help your symptoms? For each of the symptoms in question 16, ask if traditional medicine helped the specific symptom. Classify the answers according to the following: A - Cured symptoms (completely gone) B - Helped quite a bit C - Somewhat helped symptoms D - Helped a little bit E - No help at all
	1.		
	2.		
	3.		
	4.		
	5.		
	6.		
	7.		
	8.		
	9.		
	10.		
	11.		
	12.		
	13.		
	14.		
	Additional information:		

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:

Use of Traditional Herbal Medicine for AIDS Symptoms			
18. How long have you known that you have had HIV/AIDS?	Number of weeks or months since advised of HIV positive blood test:		
19. What kinds of illness (symptoms) have you experienced that are caused by AIDS? *List in the order provided*	**20. Which of the illnesses related to AIDS do you use herbal medicine for?** *Check Mark*	**21. How long do you have this illness (symptom) before you start using herbal medicine?** *Weeks*	**22. Does the herbal medicine help with these symptoms?** **A** - Cured symptoms (completely gone) **B** - Helped quite a bit **C** - Somewhat helped symptoms **D** - Helped a little bit **E** - No help at all
1.			
2.			
3.			
4.			
5.			
6.			
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11.			
12.			
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15.			
16.			
17.			
Additional note:			

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

23. What are the names of the herbs or herbal medicine that you use to treat your AIDS illnesses/symptoms? *List the names of the herbs and/or herbal medicines used, in the order provided.*	**24. How often do you use this herbal medicine?** *e.g. weekly, daily, number of times per day, etc*	**25. What symptoms do you use this herb/medicine for?** *Use the symptom reference number from question 19 and list any new symptoms not identified in question 19*	**26. How do you take the herbal medicine?** *E.g. liquid by mouth; chewing; inhalation; etc*	**27. When was the last time that you used this herbal medicine?** *Days or weeks*	**28. Would you use this herbal medicine for this/these symptoms again?** *Yes/No and why*
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					
11.					
12.					
13.					
14.					
Additional notes:					

29. Where do you get the herbal medicine?	☐ Traditional Healer Which herbal medicines? (refer to question 23 for number reference) How often do you see a healer? ☐ Self Which herbal medicines? (refer to question 23) How do you know what to use? Do you gather the herb yourself? Prepare it yourself? Buy it (if yes, from where)? ☐ Other:(specify)

Antiretroviral (AIDS MEDICINE) Use			
30. Do you currently use antiretroviral medicine?	☐ Yes Why are you using AIDS medicine?		☐ No Why are you not using AIDS medicine?
	How long have you been taking ARV? (weeks)		
	What symptoms did you start using ARV for?	**Does the medicine help with these symptoms?** **A** - Cured symptoms (completely gone) **B** - Helping quite a bit **C** - Somewhat helping symptoms **D** - Helping a little bit **E** - No help at all	
	1.		
	2.		
	3.		
	4.		
	5.		
	6.		
	7.		
	8.		
	9.		
	10.		

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

Concurrent Medicine Use		
31. Do you ever use herbal medicine and modern medicine together in the same day?	☐ Yes What are the names of the herbal medicine that and modern medicine that you take in the same day? Do you take them together (i.e. at the same time or within the same day)? Explain. Why? Do you feel that there are any benefits to taking them together? Do you feel that there are any risks in taking them together?	☐ No Why? Do you feel that there are any benefits to taking them together? Do you feel that there are any risks in taking them together?

For ARV subjects ONLY:

Did you ever use herbal medicine to treat your AIDS symptoms?
☐ No ☐ Yes.
Why?

If yes and the person is no longer using herbal medicine, why did they stop?

Did you ever ask your doctor about using herbal medicine together with ARV?
☐ Yes ☐ No
Why?

Did your doctor ever provide any advice or information about using herbal medicine and ARV together?
☐ No ☐ Yes. If yes, what advice or information was given?

If use ARV and herbal medicine currently:
Do you take any herbal medicines in the same day as ARV?
☐ No
☐ Yes. If yes, what are the names of the herbal medicines that are taken on the same day as the ARV?

Do you take these together (at the same time) in the day?
☐ No
☐ Yes. Specify which herbal medicines are taken together with the ARV.

Why (or why not)?

Do you feel that there are any benefits in taking herbal medicine and ARV together?

Do you feel that there are any risks in taking herbal medicine and ARV together?

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

Treatment Preference	
32. Do you prefer to use herbal medicine or modern medicine when you are sick?	☐ Herbal Medicine ☐ Modern Medicine Why? What do you use first?
33. What do you do first when you are sick: treat yourself; see a healer; or see a doctor?	☐ Traditional Healer ☐ Doctor ☐ Self Why? If you do not get better, what treatment would you use next? ☐ Traditional Healer ☐ Doctor ☐ Self Why?
34. Do you feel that herbal medicine is more accepted by people in your community than modern medicine?	☐ More accepted ☐ Equally accepted ☐ Less accepted Why? Does this impact your decision(s) on what type of medicine you use?
35. How effective do you feel that herbal medicine is compared to modern medicine?	☐ More effective ☐ Equally effective ☐ Less effective Why? Does this impact your decision(s) on what type of medicine you use?

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

Communication		
36. Do you tell your doctor that you use herbal medicine?	☐ Yes Does your doctor ask you if you use herbal medicine? ☐ Yes ☐ No	☐ No Has your doctor ever asked you about using herbal medicine? ☐ Yes ☐ No If yes, did you tell your doctor the truth about using herbal medicine? ☐ Yes ☐ No Why? Would you tell your doctor about using herbal medicine if asked? ☐ Yes ☐ No Why? Have you ever told a doctor that you use herbal medicine? ☐ Yes ☐ No Explain:

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:

	Does your doctor usually ask you about using herbal medicine? ☐ Yes ☐ No Explain: Did you provide accurate information when asked? ☐ Yes ☐ No Why?	Did you volunteer the information to your doctor without being asked for it? ☐ Yes ☐ No Why? If no, how did you doctor know you were using herbal medicine?
	What was the doctor's reaction when you told them about using herbal medicine? Would the doctor's reaction: ☐ Encourage you to tell doctors about using herbal medicine in the future? ☐ Discourage you from telling doctors about using herbal medicine in the future? What would you tell your family and friends about telling their doctors about using herbal medicine?	

37. Do you tell your healer that you use modern medicine?

☐ Yes

Did your healer ask you if you used modern medicine?
☐ Yes ☐ No

Does your healer usually ask you about using modern medicine?
☐ Yes ☐ No
Explain:

Did you provide accurate information when asked?
☐ Yes ☐ No
Why?

Did you volunteer the information to your healer without being asked for it?
☐ Yes
☐ No
Why?

If no, how did you healer know you were using modern medicine?

What was the healer's reaction when you told them about using modern medicine?

Would their reaction:
☐ Encourage you to tell a healer about using modern medicine in the future?

☐ Discourage you from telling a healer about using modern medicine in the future?

What would you tell your family and friends about telling their healers about using modern medicine?

☐ No

Has your healer ever asked you about using modern medicine?
☐ Yes
☐ No

If yes, did you tell your healer the truth about using modern medicine?
☐ Yes

☐ No
Why?

Would you tell your healer about using modern medicine use if asked?
☐ Yes
☐ No
Why?

Have you ever told your healer that you use modern medicine?
☐ Yes
☐ No
Explain:

38. If your doctor told you to stop using herbal medicine, would you?	☐ Yes Explain:	☐ No Explain:
39. If your healer told you to stop using modern medicine, would you?	☐ Yes Explain:	☐ No Explain:
40. If you were/are on AIDS drugs and your doctor told you that using herbal medicine and AIDS drugs together was beneficial, would you use the medicines together?	☐ Yes Explain:	☐ No Explain:
41. If you were/are on AIDS drugs and your doctor told you that using herbal medicine and AIDS drugs together was harmful to you, would you stop using the medicines together?	☐ Yes Explain: Which medicine would you stop using: ☐ AIDS medicine ☐ Herbal medicine Why:	☐ No Explain:

University of Alberta Department of Public Health Sciences	Interview Questionnaire Primary Respondents Subject Number:_____

Interview completed by: _____

Location of interview: _____

Interviewer's Impressions/Thoughts:

Appendix 6: Group Discussions with PLWAs - Ground Rules

DISCUSSION GROUP 'GROUND RULES'

To be read aloud by the focus group facilitator at the start of each focus group session:

This group meeting is part of a research study being conducted by Deanne Langlois of the University of Alberta, in Canada. Previously, you were all provided with an information letter about the study and all of you have provided consent to participate in this study.

We would like your help in creating a discussion and surrounding that is safe and comfortable to all of you. To do that, we must show respect and trust for each other by listening as we take turns speaking. Everyone's opinion and viewpoints will be equally valued and respected during the discussion and everyone will be treated equally and fairly. There are no wrong answers. As well, we don't believe in pressuring other people to answer questions and we will not make assumptions about people.

We also ask that you respect the confidentiality of the group and the privacy of the individual. It is very important that the names of people who participate in the group discussion and what they said remain private. Unfortunately, we cannot promise you that information does not get shared outside of the group. So, if there is something you would not like to discuss or have known, please do not feel any pressure to share it with the group. However you must understand that complete confidentiality cannot be guaranteed in group discussions.

You can chose not to answer any questions you are uncomfortable with, just say "pass" to indicate that you do not wish to answer or have nothing to contribute. Also, remember that you are free to leave at any time without an explanation. There will be no repercussions to you.

Does anybody have any questions or concerns before we begin?

Appendix 7: Questions for Traditional Healer Interviews

Interview Questions for Traditional Healers

Do you provide treatment to people with HIV?

Have they had HIV blood tests completed?

What are the most common symptoms that you treat HIV patients for? (free-list)

Do you treat the HIV directly or just the symptoms caused by HIV?

Can you treat HIV directly?

Can you cure HIV?

Do you sell people the medicine?

Do you teach people how to gather and prepare the medicines on their own?

Where do people see you for treatment (i.e. home, herb clinic, their home, etc)?

Do you gather and prepare the medicines yourself? If not, where are the medicines from?

How do people know about you/your treatments? (i.e. word of mouth, radio, etc)

Do you give patients information about using herbal medicine and modern medicine together? What do you tell them?
Is it good to use herbs and modern medicine together (i.e. benefits)?

Are there any risks/dangers in using the medicine together?

Do you know if any of your patients are on ARVs?

Are herbal medicines more effective than modern medicine for HIV symptoms?

Is herbal medicine accepted in the community?

Do medical doctors refer patients to you?

Do you refer people to modern doctors?

How did you learn about herbal medicine?

What do you call yourself? (i.e. herbalist, healer, etc) Do you ever use spirits in your treatments?

Appendix 8: Frequency Distributions of Symptoms Treated with Pharmaceutical Drugs and Those Treated with Herbal Medicine

Frequency Distributions of Symptoms Treated with Pharmaceutical Drugs (n=137) and Those Treated with Herbal Medicine (THM n=130)

Pharmaceutical Drugs		Traditional Herbal Medicine	
Symptom	**Frequency**	**Symptom**	**Frequency**
Fever (general)	119	Cough	67
Headache	99	Fever (general)	62
Cough	95	Stomach/Abdominal Pain	34
Stomach/Abdominal Pain	63	Diarrhea	32
Flu	42	Yellow Fever (Enkaka)	27
Diarrhea	41	Rash	22
Rash	30	Herpes Zoster	21
Other Pain (Muscle, Body, Flesh, etc)	29	Headache	16
Back Pain	21	Parasites	14
Chest Pain	21	Other Pain (Muscle, Body, Flesh, etc)	10
Parasites	20	Flu	8
Genital Itching	14	Genital Itching	8
Herpes Zoster	14	Ulcer	7
Tuberculosis	12	Loss of Appetite/Weight Loss	7
Ulcer	12	Chest Pain	7
Syphilis	12	Boils	7
Sight & Eye Problems	11	Skin Sores	5
Malaria	10	Itchiness (non-genital)	5
Boils	9	Vomiting	5
Joint & Bone Pain	8	Syphilis	5
Limbs 'Fall Asleep' (Kusarara)	7	Back Pain	4
Dizziness	7	Breathing Problems/Pneumonia	4
Sores in Mouth	6	Malaria	4
Vomiting	6	Menstrual Pains	4
Itchiness (non-genital)	6	Dizziness	3
Fungal infection (e.g. Ringworm)	6	Sight & Eye Problems	3
Breathing Problems/Pneumonia	5	Lethargy	3
Loss of Appetite/Weight Loss	5	Tonsillitis	3
Gonorrhoea	4	Anaemia	3
Swelling	4	Infertility	2
Menstrual Pains	4	Pregnancy/Labour/Delivery	2

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Pharmaceutical Drugs		Traditional Herbal Medicine	
Symptom	**Frequency**	**Symptom**	**Frequency**
Lethargy	3	Fungal infection (e.g. Ringworm)	2
Skin Sores	3	Swelling	1
Tonsillitis	3	Joint & Bone Pain	1
Weakness	3	Limbs 'Fall Asleep' (Kusarara)	1
Anaemia	2	Gonorrhoea	1
Genital Sores/Swelling	2	Heart Problems	1
Typhoid Fever	2	Amenorrhoea	1
Ear Problems	2	Fracture	1
Heart Problems	1	Molluscum Contagious	1
Yellow Fever (Enkaka)	1		
Pregnancy/Labour/Delivery	1		
Filaria	1		
Shivering	1		
Amenorrhoea	1		
Herpes (not specified)	1		
Insomnia/Sleep Disturbance	1		
Goitre	1		
Constipation	1		

Appendix 9: Frequency Distribution of Culturally-Defined HIV Symptoms

Frequency Distribution of Culturally-Defined HIV Symptoms (n=137 cases)

HIV-Related Symptom	Frequency	HIV-Related Symptom	Frequency
Fever (general)	89	Joint & Bone Pain	6
Cough	72	Swelling	5
Rash	63	Ulcer	5
Headache	62	Anaemia	5
Diarrhea	46	Fungal infection (e.g. Ringworm	4
Stomach/Abdominal Pain	36	Breathing Problems/Pneumonia	3
Herpes Zoster	33	Parasites	3
Loss of Appetite/Weight Loss	25	Yellow Fever (Enkaka)	3
Sores in Mouth	23	Tonsillitis	3
Flu	19	Amenorrhoea	3
Genital Itching	18	Sight & Eye Problems	2
Itchiness (non-genital)	18	Typhoid Fever	2
Back Pain	16	Stress	2
Tuberculosis	16	Molluscum Contagiosum	2
Other Pain (Muscle, Body, Flesh, etc)	15	Depression	1
Lethargy	14	Malaria	1
Vomiting	14	Poor Immunity	1
Dizziness	13	Sweating	1
Boils	13	Urinary Problems	1
Weakness	12	Herpes (not specified)	1
Syphilis	11	Dry Mouth	1
Limbs 'Fall Asleep' (Kusarara)	10	Constipation	1
Chest Pain	10	Lymph Nodes	1
Genital Sores/Swelling	8	Hair Changes (e.g. colour, texture)	1
Skin Sores	6	Runny Nose	1

Appendix 10: HIV-Related Symptoms Treated with Herbal Medicine

Frequency Distribution of HIV-Related Symptoms Treated with Herbal Medicine (n=79 cases)

HIV-Related Symptom	Frequency	HIV-Related Symptom	Frequency
Fever (general)	40	Tonsillitis	3
Cough	37	Dizziness	2
Diarrhea	23	Ulcer	2
Rash	20	Anaemia	2
Herpes Zoster	18	Breathing Problems/Pneumonia	1
Stomach/Abdominal Pain	17	Swelling	1
Headache	9	Joint & Bone Pain	1
Genital Itching	7	Limbs 'Fall Asleep' (Kusarara)	1
Itchiness (non-genital)	7	Lethargy	1
Boils	7	Parasites	1
Flu	6	Sores in Mouth	1
Loss of Appetite/Weight Loss	6	Tuberculosis	1
Other Pain (Muscle, Body, Flesh, etc)	4	Amenorrhoea	1
Syphilis	4	Fungal infection (e.g. Ringworm)	1
Back Pain	3	Herpes (not specified)	1
Vomiting	3	Chest Pain	1
Yellow Fever (Enkaka)	3		

Appendix 11: Frequency Distribution of Herbal Medicines Used for the Treatment of HIV-Related Symptoms (Rutooro and Botanical Names)

Frequency Distribution of Herbal Medicines Used for the Treatment of HIV-Related Symptoms: Rutooro and Botanical Names (n=79 cases)

Rutooro Name	Botanical Name	Frequency
Ekibirizi * / Omubirizi ** / Ekyesembya	Vernonia amygdalina	42
Enkoko Rutanga	Barbadensis (i.e. Aloe vera)	24
Omwihura	Vernonia turbinata or Momordica foetida	14
Omuyembe / Amababi G'emiyembe	Mangifera indica (i.e. Mango bark & Mango leaves)	11
Ekijaja * / Omujaja **	Ocimum Suave	10
Omusikamooli	Eurphorbia spp.	10
Kalitunsi	Eucalyptus spp.	9
Ekinyamunsunga	Plectranthus langinosus or Solenostemon latifolius	9
Amapera (Guava)	Psidium guajava	9
Omweya	Cythula spp.	8
Omwani / Amababi G'omwani	Coffea spp. (i.e. Coffee/coffee leaves)	7
Moringa	Moringa oliefera	7
Ekitokotoko ** / Ebitokotoko *	Vernonia auriculifera or Erlangea tomentosa	6
Vacado	Persea Americana (i.e. Avocado Leaves)	6
Embiribiri	Crassocephalum spp.	6
Omufooka	Conyza hypoleuca	6
Wankura	Thunbergia alata	5
Obunyanyambuzi ** / Akanyanyambuzi *	Oxalis spp. (Note: Oxallis corniculata and Oxallis latifolia commonly used in Kabarole District)	5
Orutotoima	Ocimum basilicum linni or Hoslundia opposita	4
Omuturuka	Crassula alba or Phyllanthus capillaris	4
Endimo	Citrus spp. (Note: Citrus eureka commonly used in Kabarole District)	4
Kalifuha	Cimbogona citrus	4
Omuko	Erythrina abyssinica	4
Enyabarasaana / Ensaka / Obukurra	Bidens pilosa (i.e. Blackjack)	4
Omusekera	Lantana trifolia	4
Ekibombo	Cyphostemma adenocaule	4

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Rutooro Name	Botanical Name	Frequency
Bingirebityo	Ipomoea hildebrandtii	4
Enakarukaru	Aspilia pluriseta	3
Omugusa	Sorghum bicolor	3
Isangura	Maytenus senegalensis	3
Ehuukya	Lantana spp.	3
Kacuucu	Plectranthus zatarhendi (or Crassocephalum vitellium)	3
Omutoma	Ficus natalensis (i.e. "Bark-cloth tree")	3
Kwiniini (Quinine tree or plant)	Citrus tahiti (i.e. Quinine tree or plant)	3
Omuhangabagenzi	Maesa lanceolata	3
Akanyankamba	Lobelia baumaniii	3
Rukunyamunzigu	*Botanical name not identified*	3
Emisambya * / Omusambya **	Markhamia platycalyx	3
Ejubwa	*Botanical name not identified*	2
Ekiragi	Crotolaria deflersii or Pseudarthria hookeri	2
Akahendarugo	*Botanical name not identified*	2
Enyikaranyenka	*Botanical name not identified*	2
Eseeba	*Botanical name not identified*	2
Akajegejege	Crotolaria recta	2
Entendigwa	Cajanus cajan	2
Neem Tree	Azandaracatindic (or Neem sp.)	2
Ekisunsa	Coccinia grandis (i.e. Pumpkin variety)	2
Omubuza	Lantana camara	2
Akatunda	Passiflora incarnata (i.e. Passion fruit)	2
Enyondo	Scaevola plumieri	2
Amababi Gengere/Ebisika	Musa spp.	1
Orumbugu	Digitaria scalum	1
Orutuutu	Physalis peruviana	1
Enjoka Etaruma	Hewittia sublobata	1
Ensoimya	Spilanthes manritians	1
Akakwatandiga	Pupalia lappacea	1
Amarunga	Abrus precatorius	1
Enyakasunsa	Veronia lasiopus	1
Amata G'oruyenje	Euphorbia tirucalli	1
Enyabuliko	Grewia bicolor	1
Eherre	Veronia brachycalyx or vernonia cistafolia	1

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Rutooro Name	Botanical Name	Frequency
Amatojo	Acanthus pubescens	1
Kalya Buzimba (herbalist indicates kalyabuzimba)	*Botanical name not identified*	1
Omugorogoro / Ebisusu Byomugorogoro (Tree/bark)	Dracaena steudneri	1
Omwitanjoka	Cassia laevigata & Cassia occidentalis	1
Enjagi	Solanum melongena (i.e. Egg plant)	1
Ehohwa	*Botanical name not identified*	1
Ebikyora	Cassia didymobotrya	1
Ebikoora Byebitakuli	Ipomoea batatas (i.e. Sweet potato leaves)	1
Amababi Gamuhogo	Manihot sp. (i.e. Cassava leaves)	1
Akadoodo	Amaranthas hybridus	1
Kicumucumu	Leonotis nepetifolia or Leonotis martiniensis	1
Byarabitanu	*Botanical name not identified*	1
Omurubata	*Botanical name not identified*	1
Ekikaka	Saccharum officinarum (i.e. Sugar cane)	1
Ekiterankuba	Aspilia (Sunflower Family) or Helichrysum rhodolepis or Guizotia scabra	1
Mukuruataitabya	Dissotis irvingiana hook	1
Ekitugutu	Pennisetum purpyreum (i.e. young elephant grass used)	1
Fene/ Amababi ga fene	Citrus spp. (i.e. Jackfruit / Jackfruit leaves)	1
Amalere	Ferns	1
Ekiziira	*Botanical name not identified*	1
Akabaani	Pinus patula	1
Enfunjo */Omufunjo **	Cyperus papyrus	1
Omutatembwa	Fagara macrophylla	1
Omuhoko	Phytolacca dodecandra	1
Akaramata	Rubia cordifolia	1
Ekinanange	*Botanical name not identified*	1
Muhiira	*Botanical name not identified*	1
Omucunguwa	Citrus sinensis (i.e. orange)	1
Enderema	Basella alba	1
Omwitango	Hypoestes aristata	1
Olive Tree	*Botanical name not identified*	1
Omwataibaale	*Botanical name not identified*	1

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Rutooro Names	Botanical Name	Frequency
Omusirra	Ficus sp. (Note: Commonly Ficus brachypoda or Ficus ovata in Kabarole District)	1
Katungurucumu	Allium sativum (i.e. Garlic)	1
Omujuma	Veronia issiopus	1
Ekiteeza	Comelina benghalensis	1
Enanansi	Ananas comosus (i.e. Pineapple)	1