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UGANDA, REPUBLIC OF

President	Museveni, Yoweri Kaguta
Vice President	Kazibwe, Wandira Specioza, <i>M.D.</i>
Prime Minister	Musoke, Kintu
First Dep. Prime Min.	Kategaya, Eriya
Second Dep. Prime Min.	Ali, Moses
Third Dep. Prime Min., Min. of Disaster Preparedness & Refugees	Etiang, Paul Orono
Min. of Agriculture, Animal Industry, & Fisheries	Kazibwe, Wandira Specioza, <i>M.D.</i>
Min. of Defense	Museveni, Yoweri Kaguta
Min. of Education & Sports	Nsimbabi, Apolo, <i>Prof.</i>
Min. of Energy & Minerals	Kajjuka, Richard
Min. of Finance, Planning & Economic Development	Sendawula, Gerald
Min. of Foreign Affairs	Kategaya, Eriya
Min. of Gender, Labor & Social Development	Mukwaya, Janati B.
Min. of Health	Kiyonga, Crispus W.C. B., <i>Dr.</i>
Min. of Internal Affairs	Butime, Tom. Maj.
Min. of Justice & Constitutional Affairs	Mayanja-Nkangi, Joshua S.
Min. of Local Govt.	Bidandi-Ssali, Jaberu
Min. of Public Service	Mushega, Amanywa
Min. of Tourism, Trade, & Industry	Ali, Moses
Min. of Water, Lands, & Environment	Muganwa, Kajura Henry
Min. of Works, Housing, & Communications	Nasasira, John
Min. Without Portfolio	
Min. of State for Agriculture	Sebunya, Kibilige
Min. of State for Animal Industry	Miyingo, Kezimbila
Min. of State for Communication	Kadaga, Rebecca
Min. of State for Economic Monitoring	Bbumba, Syda
Min. of State for Ethics & Integrity	
Min. of State for Fisheries	
Min. of State, General	Mugerwa, Kisamba
Min. of State for Higher Education	Rwendeire, Abel, <i>Dr.</i>
Min. of State for Information	Nsadhu, Basoga
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Governor, Bank of Uganda	Kikonyogo, Charles Nyonyintono
Ambassador to the US	Ssempala, Edith Grace
Permanent Representative to the UN, New York	Kiwanuka, Matia Semakula Mulumba

UGANDA BACKGROUND NOTES

U.S. - UGANDA RELATIONS

Our bilateral relationship with Uganda is sound. Our primary goal in Uganda is to support broad-based economic growth, which in turn supports our efforts to encourage the development of democratic institutions. An important secondary goal is to secure the involvement of women in the political process. Uganda has been a regional partner, for example by serving as a staging area for U.S. humanitarian operations after the Rwandan genocide. It is also one of the so-called Front Line States that are attempting to counter Sudanese efforts to destabilize its neighbors. The Ugandan government was instrumental in helping to thwart a plot to bomb the U.S. Embassy in Kampala in September.

The presence of large numbers of Ugandan troops in the Democratic Republic of the Congo has caused concern and we continue to urge the Ugandan Government to work toward a cease fire as rapidly as possible. Also, President Museveni has flown to Libya twice in six months to discuss the Congo war with Muammar Qadaffi in contravention of UN resolutions barring direct flights to and from Libya. These actions do not eclipse our view of Uganda as a generally responsible actor in regional affairs.

POLITICAL BACKGROUND

The National Resistance Movement, under the leadership of President Yoweri Museveni, has dominated the political scene since taking power in 1986 (see 1997 Human Rights Report). Political party activity is restricted as a result of the Movement's view that political parties in Uganda are based on ethnic divisions and contribute to the type of instability that devastated Uganda in the 1970s and 1980s. Uganda will hold a referendum in 2000 on whether to end restrictions on multiparty activity or continue the so-called no-party system. Several opposition leaders have called for a boycott of the referendum, which they believe will be manipulated by the Ugandan Government to consolidate restrictions on multiparty activity. This issue will dominate the political scene throughout 1999 as a preview of the general elections scheduled for 2001.

Since early 1998, tensions have increased throughout Uganda. Attacks by the Sudan-backed Lords Resistance Army (LRA) in the northern part of the country have continued unabated, and the Ugandan government faces a strengthened Allied Democratic Front (ADF) insurgency in the southwest. The ADF is believed responsible for the deaths of 80 university students and the kidnapping of 80 others in a single incident in June. Three public buses were bombed in August. No group claimed responsibility for the bus bombings.

ECONOMIC BACKGROUND

Uganda's macroeconomic performance continues to be good. In 1998, Uganda became the first country to qualify for and receive relief under the Heavily Indebted Poor Countries Initiative. However, deficiencies remain in the privatization campaign, and export earnings are still keyed to a few agricultural commodities. Kampala hosted a donors' Consultative Group (CG) meeting in early December, at which the donors noted Ugandan economic reforms but underscored the need to address corruption and governance issues.



U.S. Department of State

Background Notes: Republic of Uganda, February 1998

Released by the Office of East African Affairs, Bureau of African Affairs.

Official Name: Republic of Uganda

PROFILE

Geography

Area: 241,040 sq. km. (93,070 sq. mi.); about the size of Oregon. Cities: *Capital*--Kampala (1991 pop. 774,214). *Other cities*--Jinja, Mbale, Mbarara.

Terrain: 18% inland water and swamp; 12% national parks, forest, and game reserves; 70% forest, woodland, grassland.

Climate: In the northeast, semi-arid--rainfall less than 50 cm. (20 in.); in southwest, rainfall 130 cm. (50 in.) or more. Two dry seasons: Dec.-Feb. and June-July.

People

Nationality: *Noun and adjective*--Ugandan(s).

Population (1995): 19 million.

Annual growth rate (1994): 2.9%.

Ethnic groups: African 99%, European, Asian, Arab 1%.

Religions: Christian 66%, Muslim 16%, traditional and other 18%.

Languages: English (official); Luganda and Swahili widely used; other Bantu and Nilotic languages.

Education: *Attendance* (1995, primary school enrollment, public and private)--56%.

Literacy (1993)--62%.

Health: *Infant mortality rate*--81/1,000. *Life expectancy*--37 yrs.

Government

Type: No-party "Movement" system.

Constitution: The new Constitution was ratified on July 12, 1995, and promulgated on October 8, 1995. Uganda held its first presidential election under the 1995 Constitution on May 9, 1996, followed by parliamentary elections on June 27, 1996. The Constitution provides for an executive president, to be elected every five years, but with significant requirements for parliamentary approval of presidential actions.

Independence: October 9, 1962.

Branches: *Executive*--president, vice president, prime minister, cabinet. *Legislative*--parliament. There are 214 directly elected representatives and special indirectly elected seats for representatives of women 39, youth 5, workers 3, disabled 5, and the army 10. *Judiciary*--magistrates courts, High Court, Court of Appeals, Supreme Court.

Administrative subdivisions: 45 districts (6 recently authorized).

Political parties (political party activity is largely suspended): Uganda People's Congress (UPC), Democratic Party (DP), Conservative Party (CP).

Suffrage: Universal adult.

Commonwealth membership.

In succeeding years, supporters of a centralized state vied with those in favor of a loose federation and a strong role for tribally based local kingdoms. Political maneuvering climaxed in February 1966, when Prime Minister Milton Obote suspended the constitution, assumed all government powers, and removed the president and vice president. In September 1967, a new constitution proclaimed Uganda a republic, gave the president even greater powers, and abolished the traditional kingdoms. On January 25, 1971, Obote's government was ousted in a military coup led by armed forces commander Idi Amin Dada. Amin declared himself president, dissolved the parliament, and amended the constitution to give himself absolute power.

Idi Amin's 8-year rule produced economic decline, social disintegration, and massive human rights violations. The Acholi and Langi tribes were particular objects of Amin's political persecution because Obote and many of his supporters belonged to those tribes and constituted the largest group in the army. In 1978, the International Commission of Jurists estimated that more than 100,000 Ugandans had been murdered during Amin's reign of terror; some authorities place the figure much higher.

In October 1978, Tanzanian armed forces repulsed an incursion of Amin's troops into Tanzanian territory. The Tanzanian force, backed by Ugandan exiles, waged a war of liberation against Amin's troops and Libyan soldiers sent to help him. On April 11, 1979, Kampala was captured, and Amin fled with his remaining forces.

After Amin's removal, the Uganda National Liberation Front formed an interim government with Yusuf Lule as president. This government adopted a ministerial system of administration and created a quasi-parliamentary organ known as the National Consultative Commission (NCC). The NCC and the Lule cabinet reflected widely differing political views. In June 1979, following a dispute over the extent of presidential powers, the NCC replaced President Lule with Godfrey Binaisa. In a continuing dispute over the powers of the interim presidency, Binaisa was removed in May 1980. Thereafter, Uganda was ruled by a military commission chaired by Paulo Muwanga. The December 1980 elections returned the UPC to power under the leadership of President Obote, with Muwanga serving as vice president. Under Obote, the security forces had one of the world's worst human rights records. In their efforts to stamp out an insurgency led by Yoweri Museveni's National Resistance Army (NRA), they lay waste to a substantial section of the country, especially in the Luwero area north of Kampala.

Obote ruled until July 27, 1985, when an army brigade, composed mostly of Acholi troops and commanded by Lt. Gen. Basilio Olara-Okello, took Kampala and proclaimed a military government. Obote fled to exile in Zambia. The new regime, headed by former defense force commander Gen. Tito Okello (no relation to Lt. Gen. Olara-Okello), opened negotiations with the insurgent forces of Yoweri Museveni and pledged to improve respect for human rights, end tribal rivalry, and conduct free and fair elections. In the meantime, massive human rights violations continued as the Okello government murdered civilians and ravaged the countryside in order to destroy the NRA's support.

Negotiations between the Okello government and the NRA were conducted in Nairobi in the fall of 1985, with Kenyan President Daniel Moi seeking a cease-fire and a coalition government in Uganda. Although agreeing in late 1985 to a cease-fire, the NRA continued fighting, seized Kampala in late January 1986, and assumed control of the country, forcing Okello to flee north into Sudan. Museveni's forces organized a government with Museveni as president.

Since assuming power, the government dominated by the political grouping created by Museveni and his followers, the National Resistance Movement (NRM), and his followers, the National Resistance Movement (NRM), has largely put an end to the human rights abuses of earlier governments, overseen the successful efforts of a human rights commission established to investigate previous abuses, initiated substantial political liberalization and general press freedom, and instituted broad economic reforms after consultation with the International Monetary Fund (IMF), World Bank, and donor governments. A constitutional commission was named to draft a new constitution, which was debated and ratified by a popularly elected constituent assembly on July 12, 199

National Savings as a percentage of GDP was estimated at 20.9% in 1995/96. The Ugandan Government also has worked with donor countries to reschedule or cancel substantial portions of the country's external debts.

Agricultural products supply nearly all of Uganda's foreign exchange earnings, with coffee alone (of which Uganda is Africa's leading producer) accounting for about 65% of the country's exports in 1995/96. Exports of hides, skins, vegetables, fruits, cut flowers, and fish are growing, and cotton, tea, and tobacco continue to be mainstays.

Most industry is related to agriculture. The industrial sector is being rehabilitated to resume production of building and construction materials, such as cement, reinforcing rods, corrugated roofing sheets, and paint. Domestically produced consumer goods include plastics, soap, cork, beer, and soft drinks.

Uganda has about 30,000 kilometers (18,750 mi.), of roads; some 2,800 kilometers (1,750 mi.) are paved. Most radiate from Kampala. The country has about 1,350 kilometers (800 mi.) of rail lines. A railroad originating at Mombasa on the Indian Ocean connects with Tororo, where it branches westward to Jinja, Kampala, and Kasese and northward to Mbale, Soroti, Lira, Gulu, and Kapwach. Uganda's important road and rail links to Mombasa serve its transport needs and also those of its neighbors--Rwanda, Burundi, and parts of Zaire and Sudan. An international airport is at Entebbe on the shore of Lake Victoria, some 32 kilometers (20 mi.) south of Kampala.

FOREIGN RELATIONS

The Ugandan Government seeks good relations with all nations and welcomes contacts without reference to ideological orientation. Relations with Kenya have been periodically strained because of security concerns and occasional disagreements on trade.

In the past, neighbors were concerned about Uganda's relationship with Libya, which had supplied military equipment and bartered fuel to Uganda. In addition to its friendly ties to Western nations, Uganda has maintained ties with North Korea. Uganda's strained relations with Sudan have been due to Sudan's support of the Lord's Resistance Army (LRA) and other rebel groups. The LRA seeks to overthrow the Uganda Government and has inflicted brutal violence on the population in northern Uganda, including rape, kidnapping, torture, and murder.

A group operating in western Uganda near the Rwenzori Mountains, the Allied Democratic Forces, emerged as a localized threat in 1996 and has inflicted substantial suffering on the population in the area.

DEFENSE

The Uganda Peoples Defense Force (UPDF)--previously the National Resistance Army--constitutes the armed forces of Uganda. Due to the Sudanese-backed insurgencies, the Ministry of Defense increased defense spending in 1995, 1996, and 1997. In 1996, the United States announced that it would provide \$4.5 million in non-lethal military assistance to Uganda to assist in maintaining internal security. U.S. military forces also have participated with the UPDF in training activities for the African Crisis Response Initiative.

U.S.-UGANDAN RELATIONS

U.S.-Ugandan relations were strained and ultimately all but broken during Idi Amin's rule. In 1973, persistent security problems and increasingly difficult operating circumstances forced withdrawal of U.S. Peace Corps volunteers and the termination of bilateral U.S. economic assistance. In November 1973, after repeated public threats against U.S. embassy officials and after the expulsion of Marine security guards responsible for protecting U.S. Government property and personnel, the embassy was closed. In 1978, Congress legislated an embargo of all U.S. trade with Uganda.

Relations improved after Amin's fall. In mid-1979, the United States reopened its embassy in Kampala. Relations with successor governments were cordial, although Obote and his administration rejected strong U.S.

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Situation of Orphans in Uganda

From "Integrated District Planning for Vulnerable Children in Uganda:
Is It Enough? By Susan Hunter, March 11, 1998

1. Current and Future Estimates of Orphans in Uganda

The Uganda AIDS Commission estimates that by 1997, 1.5 million children under age 18 had lost one or both parents in Uganda, at least 1 million of whom had been orphaned by AIDS. This is commonly understood to represent 1 in 9 Ugandan children, or 11% of children under 18. As can be seen from the box at right, official government estimates of the number of orphaned children in Uganda are substantially lower than those prepared for *Children on the Brink*, a 1997 USAID-sponsored study with estimates of orphans for 23 countries made by the U.S. Census Bureau. There are several reasons for this:

Orphan Estimates for Uganda		
	Children on the Brink (0-15)	Uganda Census and NACP (0-18)
1990	1.667 million	1 to 1.2 million
1995	2.246 million	1.5 million
2000	2.763 million	--
2005	3.199 million	--
2010	3.506 million	--

1. The Ugandan estimates were prepared by the National AIDS Control Programme several years ago, using older data;

2. They rely on AIDS case data, which is acknowledged to be under reported by as much as a factor of 5, representing as little as 20% of the actual number of cases. Uganda's NACP recorded a cumulative total of 51,344 AIDS cases in 1996 officially reported by health care facilities, what they estimate to be a small fraction of the actual number in the country.

The overall seroprevalence rate for the country was estimated to be 12.8% in 1996. The 1997 National Strategic Framework for AIDS estimates that the number of HIV positive Ugandans would peak at 1.84 million in 1998,

While Uganda Is A Leader, It Still Has Many Problems that Constrain HIV/AIDS Services, According to the Uganda AIDS Commission:

- ✓ Current interventions won't stop the spread of HIV/AIDS in Uganda
- ✓ Children and adolescents are especially vulnerable to HIV infection
- ✓ Rural residents and the poor have much less access to HIV/AIDS services
- ✓ PHAs and their families still suffer from stigmatization and isolation
- ✓ Many leaders at all levels still have low awareness and negative attitudes
- ✓ Most HIV/AIDS programmes operate under serious technical and material constraints

Source: Observations from the Ugandan AIDS Commission 1997 National Strategic Framework

provided by official Uganda sources, although a study conducted by Makerere University scholars in 1992 and repeated in 1995/96 shows that HIV/AIDS is a major reported cause of death in Ugandan children.

5. Overall growth of the under 15 population will be substantially curbed by the epidemic as a result of fertility declines and the deaths of infants and children who are HIV positive. The U.S. Census Bureau estimates a higher population loss from AIDS morality than Uganda's official estimates, so the surviving numbers of children are lower. Hence, by 2010, the under 15 population of Uganda is anticipated to be 12.2 million, only 4 million more children than Uganda had in 1990.

6. The impact of HIV on the growth of tuberculosis infections is not included in the National Strategic Plan, but in neighboring countries, it is estimated that HIV has caused a three to four fold increase in TB cases. As a consequence of this interaction, HIV deaths in adults may be even higher than that projected for AIDS alone, with obvious implications for orphan rates in Uganda.

The mushrooming of the Ugandan orphan population which has occurred in the last 10 years due to the epidemic is a typical result of the exponential growth of AIDS infections and death in Uganda and its neighbors in East and Southern Africa. Uganda is fortunate, however, because it is believed that seroprevalence has leveled in the past several years. This means that the proportion of children under 15 who are orphans will peak around 2010, earlier than in any other neighboring country. However, **Uganda will still be experiencing unusual numbers of orphaned children through 2020.**

Beyond 2010...

If we assume that HIV seroprevalence peaked in the Ugandan population in 1998, orphan populations will not peak until 2010. **This means that Uganda will have a high orphan population through 2020.**

2. Estimates of Other Vulnerable Children

It is widely accepted that children orphaned by AIDS and other causes do not constitute the only group of vulnerable children in Uganda, and that through their life cycle, children may move in and out of the various categories of vulnerability as their life circumstances change. In Uganda, it appears that there may be considerable overlap between orphaned and war affected children, and that many street children are missing one or both parents. Estimates for various types of vulnerable children are as follows:

War Affected Children. The 1998 Uganda Vulnerability Assessment of the USAID-sponsored FEWS Project, identifies three districts with high levels of insecurity (Gulu, Kasese and Kitgum) and four with medium levels of insecurity (Arua, Kotido, Moroto, and Moyo). As noted above, the 1991 Census data show that the proportion of children orphaned in war affected districts is higher than other areas of the country. However, overlap between the two populations of

ANNEX C

Draft Policy Statement on Orphaned Children

It is the position of the Government of Uganda, in keeping with the standards set forth in the United Nations Convention on the Rights of the Child, that every effort must be made by public and private bodies to ensure the immediate and future well being and development of orphaned children. Uganda's strong traditions for the care and protection of orphaned children within their own extended families and communities is hereby affirmed as the cornerstone Uganda's national policy with regard to such children.

Our position in favor of care within the extended family calls for affirmative steps to be taken by all relevant Governmental and non-governmental bodies to support actively the capacity of families to provide for the immediate and ongoing needs and to promote their physical, mental, spiritual, moral and social development. Government will discourage initiatives such as orphanages and boarding schools for orphans as they undermine the efforts of families and communities to develop local solutions.

The Government of Uganda will provide policy leadership and resources to address orphans needs. However, our resource capacity is extremely limited. We recognize the concern of other Governments and non-governmental organizations to assist in the endeavor.

The Ministry of Labour and Social Welfare is hereby designated as having leadership responsibility within the Government for developing a strategy to guide the use of public and private resources, both national and international, toward the goal of strengthening the capacities of Ugandan families to care for orphaned children. This role shall include:

AN 4 5

The material that follows has been provided by Child Newsline

Five children to support, and a long walk to school

As the AIDS toll increases, so does the number of children left with the task of looking after younger brothers and sisters, nephews and nieces. Child Newsline looks at a project in Uganda that is helping child-headed households.

By Elaine Eliah, a freelance journalist based in Uganda

Kampala: Fatuma Nalunkuuma was in the sixth grade when her father died of AIDS. That was in 1995 and meant the end of her formal education. The following year, her stepmother died, leaving her four young children to look after.

She maintains what the Ugandan organisation, AIDS Widows and Orphans Family Support (AWOFS), refers to as a "child-headed household."

"My own mother died when I was very young," she recalls. "My father's second wife was always jealous of me. She thought my father loved me too much, more than he loved the children they had together."

Though Fatuma's stepmother was an AWOFS client, it was a beloved aunt who enrolled her on the organisation's training programme for orphans.

"She picked up a form and she told me I should register with her as my mother. She was afraid my mother would not approve," says Fatuma, who is now 22.

In just over a year, training at the church-run Centenary Vocational School in Kampala, Fatuma became proficient in screenprinting.

During the year, however, her aunt died. Fatuma became surrogate parent to one of the aunt's children, in addition to the four young children already in her care.

AWOFS clients are generally mothers whose husbands have died from AIDS. Most are themselves infected with HIV, the virus that leads to AIDS. Many have been abandoned by their own families or by their husbands' families.

Traditional family law in Uganda held that a man's brothers inherited his property, but it also dictated that the deceased's widow and orphans would become wards of those brothers and be cared for by them. Today, many of those claiming inheritance fail to accept the accompanying family responsibility.

The sheer weight of numbers has hastened the breakdown of this old community system.

AWOFS has over 800 families under its wing, with an average of six children per family - 5,000 new orphans. With the help of legal volunteers, AWOFS encourages infected parents to write wills to protect their children from losing property when they die.

Inheritance rights protection is particularly important in AWOFS client families who have begun income-generating projects.

The organisation has helped 14 families to become tailors, 20 have gone into farming, 41 into piggeries, 130 into poultry and 392 into retail sales. Children are encouraged to learn their parents' trade so that they are competent to take over the business.

AWOFS workers speak with pride about one young woman who has supported a family for five years since inheriting her mother's poultry farm.

In Fatuma's case, there was no family business to inherit. As with the rest of Centenary's 49 female students, her training began with general vocational studies in cooking, sewing, and machine embroidery. (Lack of facilities means AWOFS' 23 boys are sent to other established schools.)

When the class began screenprinting, Fatuma found her niche. She demonstrated an aptitude for the craft and now specialises in it at a higher level institution.

After completing the one-year course, most graduates want to run their own businesses. To this end, girls are trained in book-keeping, business management and marketing. On successfully completing the course, girls are given equipment and \$60 start-up capital. Graduates who pool talents and resources are also eligible to apply for collective loans.

Starting up a new business is never easy, and many of the girls labour under difficult conditions with heavy responsibilities at home.

A workshop is under construction which students will be able to use as they start up their fledgling businesses. Teachers will be available to supplement training and guide inexperienced hands. This will save many students the overhead of renting shop space, while at the same time teaching the girls the importance of keeping regular work schedules.

"One thing that keeps me going in this project," explains a Centenary teacher, "is watching the transformation take place from girls to women - their sense of achievement, of seeing what they can accomplish."

Fatuma earns about \$20 profit on every 50 T-shirts she prints. She pays \$15 rent for the one small room she shares with three of her young wards. A sum of just \$100-150, she believes, would provide her family with a comfortable living.

Fatuma is not about to become rich, yet she is proud to be working so hard and grateful not to be making her living in the streets. Despite cramped quarters, and the several kilometres she must walk to get to her training classes, Fatuma believes her schoolwork will prepare her not only for a job, but for an independent, self-supporting career./ CHILD NEWSLINE

The plight of Uganda's AIDS orphans

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MASAKA, Uganda (December 25, 1997 11:18 p.m. EST <http://www.nando.net>) — Gray-haired Joanita Nakanwagi is one of the many heroes in Uganda's continuing battle against AIDS. At the age of 61, Nakanwagi, a widow, is raising seven young children orphaned by AIDS. Four of them are her own grandchildren. Three others — two one-year-olds and one two-year-old — were found suffering from malnutrition.

"I am proud to be able to look after these orphans," says Nakanwagi, speaking in the Luganda language. "I can feed them properly, and I am pleased that most of them are going to school and doing well. As their parent, I tell them they must study hard or their future will be very difficult."

The scourge of AIDS has created a nationwide health problem in Uganda — one in five of the population is HIV positive — and not just because of the number of deaths, but because of the orphans left behind. Uganda has 1.5 million such orphans out of a total population of 18 million.

Thousands of Ugandan women like Nakanwagi are coping with this daunting national crisis at grass-roots level, by raising the AIDS orphans in their rural homes. They are being supported by the Uganda Women's Effort to Save Orphans (UWESO).

"When I heard about UWESO, I knew they could help," says Mrs. Nakanwagi. "UWESO assists me with school fees and it has helped me start a business to earn money for my family."

UWESO was founded in 1986 by Janet Museveni, wife of President Yoweri Museveni, to deal with the plight of the orphans created by the country's lengthy civil war. At first, the organization simply provided food, clothing and blankets to orphans. Then, as the country became engulfed by the AIDS epidemic, UWESO shifted its emphasis from the children of war to those stranded by the disease.

The numerous health problems plaguing Uganda today — including AIDS, malaria and chronic malnutrition — are compounded by a shortage of health clinics, health workers and medicines. According to the Uganda National Council for Children, the infant mortality rate is 97 per 1,000 births — in other words, one in every 11 babies born will not survive to one year. All these problems confront the women adopting orphans.

"UWESO now concentrates on community-based fostering of orphans," says Nancy Yuill, UWESO's program development advisor. "Often it is the grandmother or aunt or older sister who will provide a home for the orphaned child. We are drawing on the strength of the African extended family. Our work is to support these women. UWESO promotes the concept that the whole community must come forward to help care for the children."

UWESO has 35 branches throughout the country which together have 7,500 members. On average, each woman takes care of seven orphans. UWESO sponsors orphans in primary school and also funds formal vocational and artisan training.

"We are trying to get away from simply providing charity and instead offer women assistance to improve their incomes themselves," says Yuill. "If their incomes increase, then they can feed the children better, clothe them better and pay school fees."

The UWESO branches are now encouraging women to become small traders and participate in the local markets. A micro-financing scheme lends women up to \$100 to set up "duikas" (kiosks) to sell essential items like soap, sugar, flour, cooking oil, matches and vegetables.

"The mothers take a step up the ladder from subsistence farmer to trader, and the entire family benefits from the improved income," says Yuill. "In addition the mother often benefits from increased knowledge and self-confidence."

Certainly Joanita Nakanwagi appears to relish her new status as a trader. "I sell kerosene, salt, cooking oil and ground nuts that I grow myself," she says. "I have learned how to use the banking system, I have repaid my loan and got a second one. I now have one cattle and I hope to soon get another."

Nakanwagi appears undaunted by the tasks ahead. "AIDS is still killing people, so we know there will be more orphans. We will just have to take care of more children."

By ANDREW MELDRUM, Scripps Howard News Service

□

Uganda

■ **Epidemiological Fact Sheet**
on HIV/AIDS
and sexually
transmitted
diseases



UNAIDS
UNICEF • UNDP • UNFPA
UNESCO • WHO • WORLD BANK



**World Health
Organization**

Estimated number of people living with HIV/AIDS

In 1997 and during the first quarter of 1998, UNAIDS and WHO worked closely with national governments and research institutions to recalculate current estimates on people living with HIV/AIDS. These calculations are based on the previously published estimates for 1994 (WER 1995; 70:353-360) and recent trends in HIV/AIDS surveillance in various populations. Epimodel 2, a microcomputer programme originally developed by the WHO Global Programme on AIDS, was used to calculate the new estimates on prevalence and incidence of AIDS and AIDS deaths, as well as the number of children infected through mother-to-child transmission of HIV, taking into account age-specific fertility rates. An additional spreadsheet model was used to calculate the number of children whose mothers had died of AIDS.

The current estimates do not claim to be an exact count of infections. Rather, they use a methodology that has thus far proved accurate in producing estimates which give a good indication of the magnitude of the epidemic in individual countries. However, these estimates are constantly being revised as countries improve their surveillance systems and collect more information. This includes information about infection levels in different populations, and behaviours which facilitate or impede infection.

Adults in this report are defined as women and men aged 15 to 49. This age range covers people in their most sexually active years. While the risk of HIV infection obviously continues beyond the age of 50, the vast majority of those who engage in substantial risk behaviours are likely to be infected by this age. Since population structures differ greatly from one country to another, especially for children and the upper adult ages, the restriction of the term adult to 15-to-49-year-olds has the advantage of making different populations more comparable. This age range was used as the denominator in calculating adult HIV prevalence.

Estimated number of adults and children living with HIV/AIDS, end of 1997

These estimates include all people with HIV infection, whether or not they have developed symptoms of AIDS, alive at the end of 1997

Adults and children	930000		
Adults (15-49)	870000	Adult rate (%)	9.51
Women (15-49)	430000		
Children (0-15)	67000		

Estimated number of AIDS cases

Estimated number of AIDS cases in adults and children that have occurred since the beginning of the epidemic:

Cumulative no. of AIDS cases	1900000
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Estimated number of deaths due to AIDS

Estimated number of adults and children who died of AIDS since the beginning of the epidemic:

Cumulative deaths	1800000
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Estimated number of adults and children who died of AIDS during 1997:

Deaths in 1997	160000
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Estimated number of orphans

Estimated number of children who have lost their mother or both parents to AIDS (while they were under age 15) since the beginning of the epidemic:

Cumulative orphans	1700000
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Estimated number of children who have lost their mother or both parents to AIDS and who were alive and under age 15 at the end of 1997:

Current living orphans	1100000
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Assessment of epidemiological situation

Assessment of country epidemiological situation

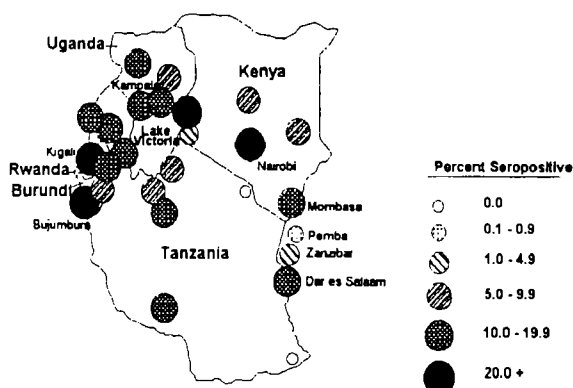
Information on HIV prevalence among antenatal clinic attendees has been available from Uganda since the mid-1980s. In Kampala, the major urban area, HIV prevalence among antenatal clinic attendees tested increased from 11 percent in 1985 to 31 percent in 1990. Beginning in 1993, however, HIV prevalence among antenatal clinic attendees began to decline in Kampala reaching 15 percent in 1996. HIV prevalence by age was available since 1991. In 1991, 38 percent of antenatal clinic women tested who were less than 20 years of age were HIV positive. This rate has since declined. In 1996, seven percent of antenatal clinic women less than 20 years of age were HIV positive. Sentinel surveillance of antenatal clinic attendees outside of Kampala began in 1989. Median HIV prevalence of antenatal clinic attendees outside of Kampala has remained around ten percent. However, some individual sentinel surveillance sites are seeing declines similar to those seen in Kampala. HIV prevalence information by age is available from one or two sites over the years since 1990. In 1990, 21 percent of antenatal clinic women less than 20 years of age tested outside of Kampala were HIV positive. This rate declined to seven percent of antenatal clinic attendees less than 20 years of age tested in 1996.

There is no information available on HIV prevalence among sex workers in Uganda.

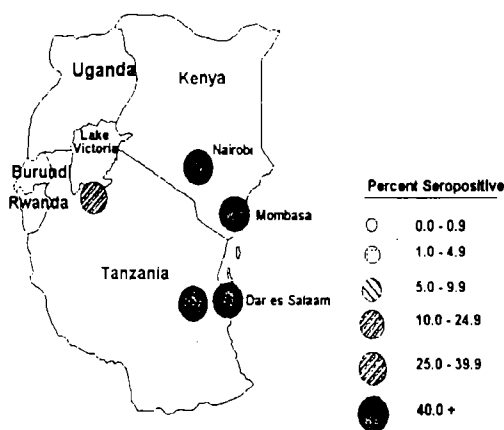
In 1989, 42 percent of male STD clinic patients tested in Kampala were HIV positive. By 1992, HIV prevalence had increased to 46 percent. In 1995, 34 percent of male STD clinic patients tested were HIV positive.

Regional maps

Seroprevalence of HIV-1 for Pregnant Women East Africa



Seroprevalence of HIV-1 for Sex Workers East Africa



Curable STDs

Control and prevention of sexually transmitted diseases (STD) have been recognized as a major strategy in the prevention of HIV infection and ultimately AIDS. Consequently, monitoring different components of STD control can also provide information on HIV prevention within a country. One of the cornerstones of STD control is adequate management of patients with symptomatic STDs. This includes diagnosis, treatment, and individual health education and counselling on disease prevention and partner notification.

Estimated incidence and prevalence of curable STDs

STDs	Incidence				Prevalence			
	Year	Male	Female	All	Year	Male	Female	All
Chlamydia trach.					1996	2	3	
Gonorrhoea					1996	1.5	2	
Syphilis					1996	11	12	
Trichomonas					1996	4	24	
Comments	Rate in percent (%).							
Source	Rakai Project Preliminary Data							

STD Incidence, men

Prevention Indicator 9: Proportion of men aged 15-49 years who reported episodes of urethritis in the last 12 months.

Year	Area	Age	Rate	N=
1995	Rural	15-49	11.7	
1995	Urban	15-49	18.7	

Comments: Figures are high in Uganda but we shall need to see repeat surveys due next year to be able to establish trends.

Sources: Population based KABP surveys in 4 districts in Uganda by STD/ACP

STD Prevalence, women

Prevention Indicator 8: Proportion of pregnant women aged 15-24 years attending antenatal clinics whose blood has been screened with positive serology for syphilis.

Year	Area	Age	Rate	N=
1997	Rural	15-24	2	
1997	Urban	15-24	15	

Comments: Data available for syphilis is from sentinel surveillance of HIV infection but with widened scope of syphilis serology in the WB STI project. More data will be available. The sample size ranges from 150-200 per site in each of 20 sentinel sites.

Sources: STD/ACP - Sentinel Surveillance

STD Case management (counselled)

Prevention Indicator 7: Proportion of people presenting with STD or for STD care in health facilities who received basic advice on condoms and on partner notification.

Year	Area	Age	Rate	N=
1996	All	All	18.5	

Comments: Condoms are classified by Programme e.g. Family Planning and complicated accountability dictates that these be dispensed specifically for family planning and not necessarily for STD prevention.

Sources: STD Control Unit, STD/ACP MOH - Baseline Survey

STD Case management (treatments)

Prevention Indicator 6: Proportion of people presenting with STD in health facilities assessed and treated in an appropriate way (according to national standards).

Year	Area	Age	Rate	N=
1996	All	All	14.3	

Comments: Actual cases were not stratified by sex during analysis of quality of care.

Sources: STD Control Unit, STD/ACP MOH - Baseline Survey

Knowledge and behaviour

Information on knowledge and behaviour related to HIV/AIDS is essential in identifying populations at risk for HIV infection. It is also critical in assessing changes over time as a result of prevention efforts. Guidelines and recommendations have been published in the publication: "Evaluation of a National AIDS Programme: A methods package. 1. Prevention of HIV infection. WHO/GPA/TCO/SEF/94.1 Geneva, 1994".

Knowledge of HIV-related preventive practices

Prevention Indicator 1: Proportion of people citing at least two acceptable ways of protection from HIV infection.

Year	Area	Age group	Male	Female	All
1995	Rural	15-19	70	65.3	67
1995	Rural	20-24	79	73.4	76
1995	Rural	25-49	83	62.8	73
1995	Rural	15-49	80	65.5	72
1995	Urban	15-19	79	80.1	80
1995	Urban	20-24	89	88.8	89
1995	Urban	25-49	89	83	86
1995	Urban	15-49	87	83.4	85

Comments: Sample for all agegroups: rural: 1358 and Urban: 1438.

Sources: Population based KABP surveys

Reported non-regular sexual partnerships

Prevention Indicator 4: Proportion of sexually active people having at least one sex partner other than a regular partner in the last 12 months.

Year	Area	Age group	Male	Female	All
1989	All	15-19	83	36.7	
1989	All	20-24	57.3	18.3	
1989	All	25-39	33.6	14.2	
1989	All	40-49	22.3	13.2	
1989	All	15+	39.2	18.4	
1995	Rural	15-19	17.9	1.1	5
1995	Rural	20-24	18.5	3.5	9
1995	Rural	25-49	12.8	4.2	9
1995	Rural	15-49	14	3.6	8
1995	Urban	15-19	40	26.9	30
1995	Urban	20-24	37.5	16.4	24
1995	Urban	25-49	21.1	8.2	14
1995	Urban	15-49	25.2	12.6	18

Comments: Over-representative of Kampala in 1989.

Sources: KABP/Behavioural Studies - GPA/MOH-Population based KABP surveys, 1995

Reported condom use in risk sex (gen pop)

Prevention Indicator 5: Proportion of people reporting the use of a condom during the most recent intercourse of risk.

Year	Area	Age group	Male	Female	All
1995	Rural	15-19	20	0	17
1995	Rural	20-24	0	20	5
1995	Rural	25-49	20	19	19
1995	Rural	15-49	16	18	16
1995	Urban	15-19	70	22	39
1995	Urban	20-24	64	63	64
1995	Urban	25-49	63	55	60
1995	Urban	15-49	64	49	58

Comments: Sample for all agegroups: rural: 1358 and Urban: 1438.

Sources: Population based KABP surveys, 1995

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Uganda's Response to the AIDS Epidemic and Current Trends

Presentation by:
Elizabeth Marum, Ph.D.

Technical Advisor in HIV/AIDS

Centers for Disease Control & Prevention/USAID Uganda

Government of Uganda Response

- President Museveni spoke openly and widely about AIDS as early as 1986
- AIDS Control Programme established in 1986; educational programs, mass media and blood safety efforts began
- Intense public information efforts have continued to the present
- International AIDS researchers encouraged to work in Uganda; President Museveni requests vaccine trials
- 1991: multisectoral Uganda AIDS Commission established

Response of Non-Governmental Organizations

- Mission hospitals began AIDS care programs
- The AIDS Support Organization (TASO) established in 1987 by 16 Ugandans affected by the epidemic
- The AIDS Information Centre (AIC) began providing HIV counseling and testing in 1990
- Numerous smaller NGOs established to provide care to persons with AIDS and support for orphans
- Associations of PWAs (People with AIDS) organized for education, mutual support

Response of Religious Communities

- with USAID funding, Church of Uganda (Protestant) and the Islamic Medical Association of Uganda initiated active programs of AIDS education for religious leaders and lay workers at the community and parish level
- Catholic church active in AIDS care and orphans programs

Response of the USG

- NIH funding for numerous research projects
- CDC technical assistance; research in variant strains, health information systems, and evaluation of interventions
- since 1988, USAID has provided very generous and sustained funding for multi-faceted, intense and extensive AIDS prevention activities
- USAID funding for AIDS activities has now exceeded \$40 million

USAID funded Activities

- AIDS education in the workplace, military, local communities, religious groups
- professionally designed information and education campaigns through mass media and local level IEC activities
- condom promotion and distribution
- HIV counseling and testing
- AIDS care and support
- detection and treatment of other STDs
- capacity building and technical training

Response of U.S. Universities

- US Universities active in Uganda include Case Western Reserve University, Columbia University, Johns Hopkins Univ
- with NIH funding, long term biomedical research projects began in 1988 in the areas of:
 - pediatric AIDS
 - mother to child transmission
 - HIV and TB
 - community epidemiology
 - STDs, Kaposi's sarcoma & HIV
 - Vitamin A for HIV+ children
 - preparation for AIDS vaccine trials
 - social and anthropological aspects of the epidemic

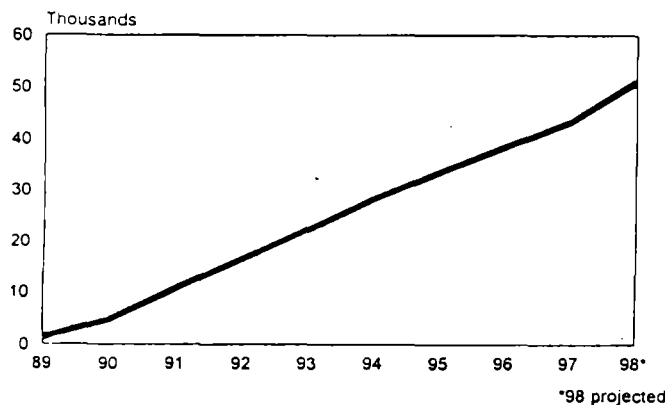
Results of USG supported efforts

- greater understanding of the epidemic in Africa, esp in the area of HIV/TB and mother to child transmission
- application of therapeutic interventions in Africa-- trials of short course AZT during delivery, HIVIG, preventive TB therapy, vaccine trials, mass STD treatment
- behavioral impact of interventions documented, esp for HIV CT and community education
- Hundreds of Ugandan scientists, physicians, social workers, health educators, and program managers have been trained and developed skills
- feasibility of projects demonstrated
 - community education, esp with religious groups
 - increased acceptance, use, and sales of condoms
 - AIDS care and support
 - voluntary counseling and testing

Results: Community Education through Religious Groups

- over 2,000 religious leaders trained
- over 14,000 community workers and volunteers trained
- over 1.6 million documented contacts with individuals and families
- decrease in multiple and/or casual partners reported by those reached by the projects
- increase in condom acceptance and use

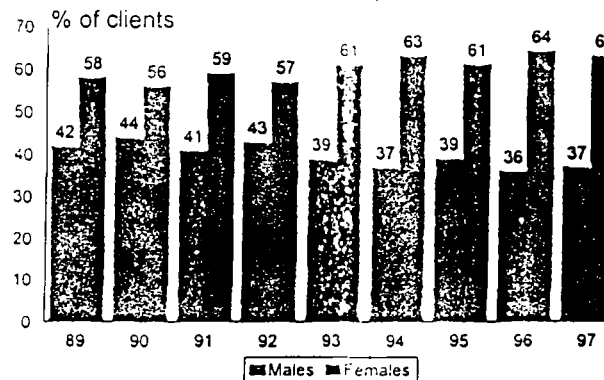
Cumulative Demand for TASO Services: Numbers of New Clients Registered



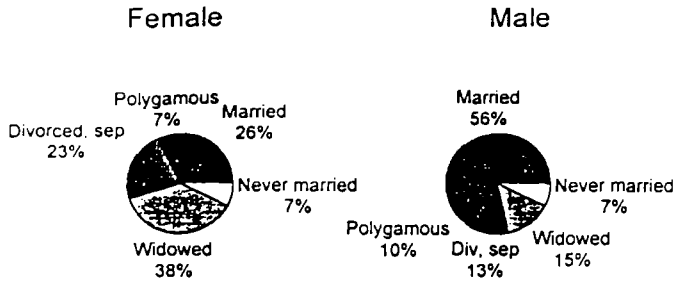
Results: AIDS Care and Support

- through TASO, The AIDS Support Organization, over 50,000 persons living with AIDS given care and support
- TASO has also trained over 600 AIDS counselors and thousands of local volunteers
- a model of AIDS care and counseling developed which is being replicated throughout Uganda and throughout Africa

TASO Clients by Gender

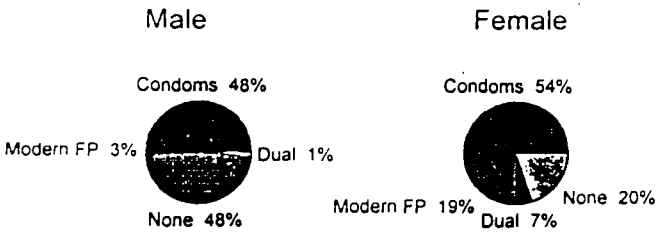


Marital Status of New Clients - 1997



66% of men are in a union, but only 33% of women

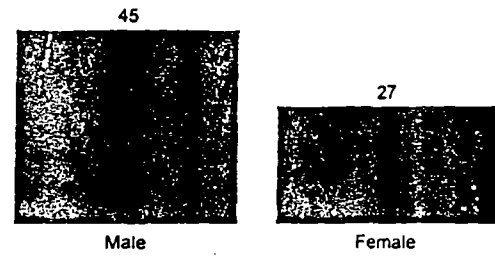
Contraceptive Use among TASO Clients - 1997



n=3000

Percent of Adult TASO Clients reporting Sexual Activity

Most Clients are not sexually active

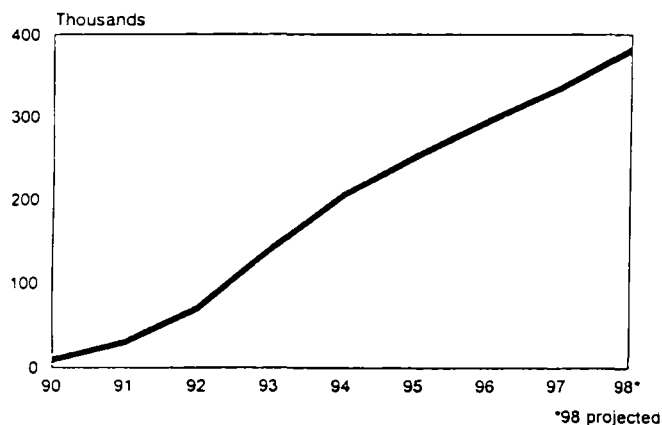


total n with data: 9129

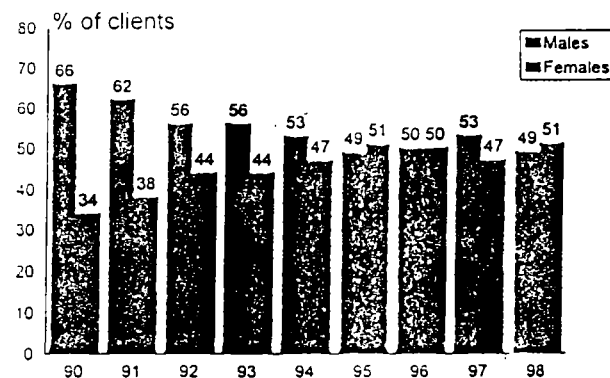
Results: Voluntary Counseling and Testing (VCT)

- USAID/Uganda supported the first site to offer voluntary counseling and testing (VCT) in Africa
- project has successfully served almost 400,000 since 1990
- other donors are now funding VCT (DFID, UNFPA, UNAIDS)
- the AIDS Information Centre (AIC) has served as site for research on effectiveness of VCT, TB preventive therapy, discordant couples, and will assist with prevention of mother to child HIV transmission projects in Uganda
- AIC has piloted the use of rapid tests for same day results
- AIC is now providing integrated reproductive health services, including family planning and STD detection and treatment
- VCT demonstrated to be feasible and well accepted by local population; model is now being replicated in other sites in Africa

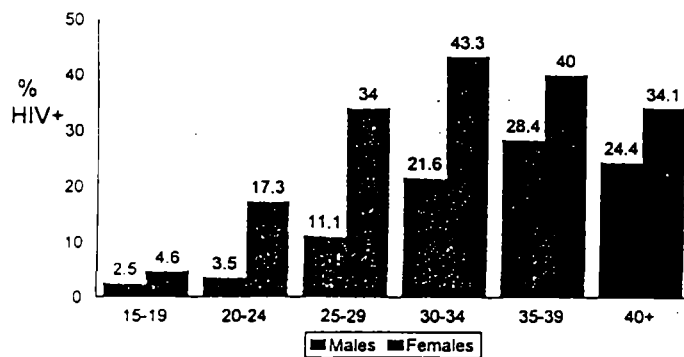
Cumulative Demand for VCT at AIC



VCT Demand by Gender at AIC

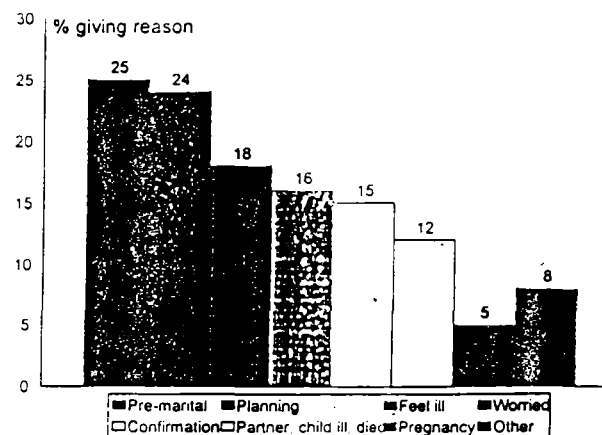


Women who request VCT in Uganda are more likely to be HIV+ than men in all ages

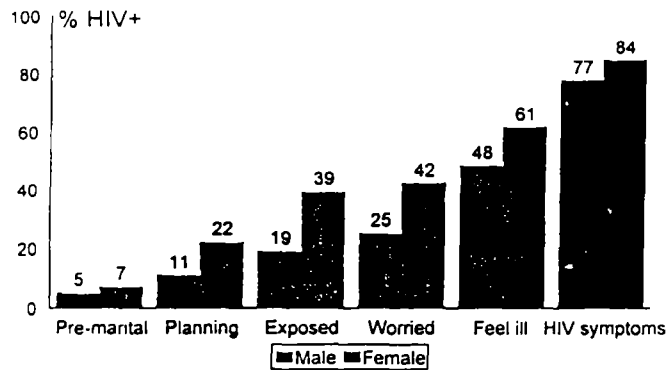


source: 1997 data, the AIDS Information Centre, n=37,694

Reasons for seeking VCT, 1997



HIV rates by Reasons for Requesting VCT -- 1997

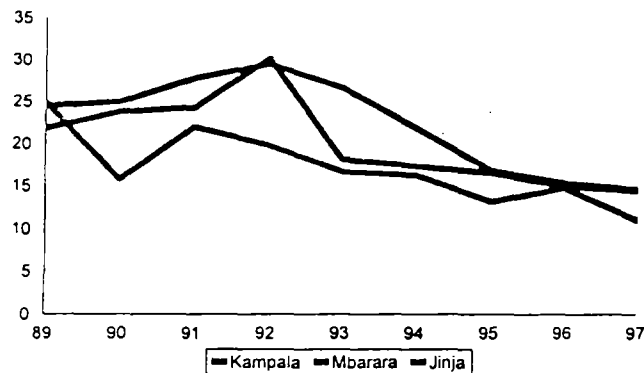


Overall Results of Uganda's Response to AIDS

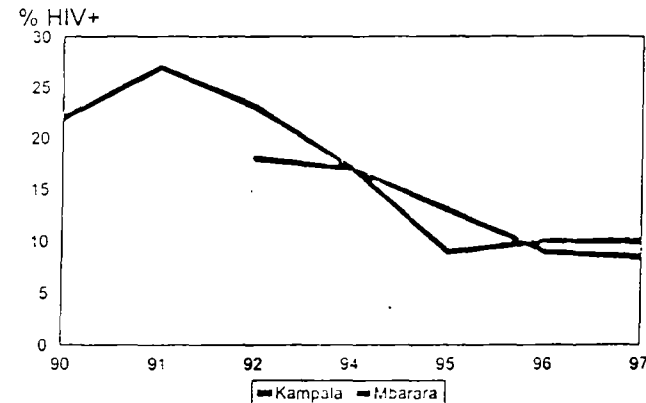
- almost 100% level of awareness of AIDS
- evidence for behavioral changes
- evidence of changing social norms, esp regarding multiple partners, condom use, pre-marital testing
- restoration of hope for the future of Uganda
- citizens have observed the power of candid and collaborative approach to national problems
- evidence of declining trends, esp in rate of new infections in young people

HIV Infection Rates in antenatal clinics in Uganda

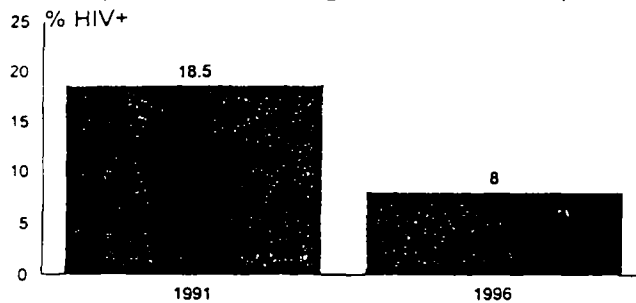
Ministry of Health Data



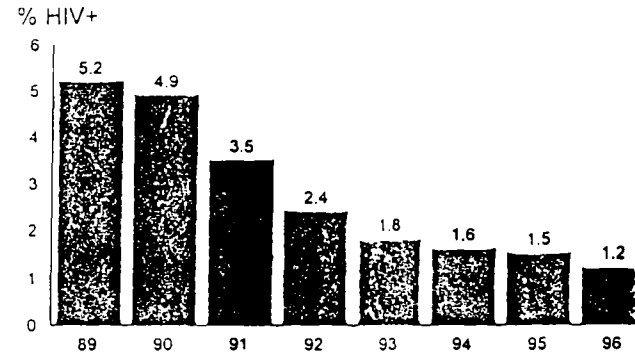
HIV Rates in 15-19 year old ANC attenders



HIV Prevalence in young men aged 19-22 entering the army (Gov't of Uganda data)



HIV Prevalence in Secondary School Blood Donors



Essential Components in Uganda's Response to AIDS

- consistent political support for AIDS interventions from the highest level
- consistent and generous donor support, esp USAID, since 1988
- PWAs have been involved in the design and implementation of projects
- PWAs, TASO, and other groups have successfully reduced stigma, discrimination, and fear of testing
- Religious groups have had active community programs and for the most part now support condom education and promotion
- well run pilot projects (AIDS care, VCT) have been sustained long after pilot phase
- interventions and local organizations have gained credibility and trust from both public and donors

Conclusion

- intense response to the AIDS epidemic can achieve measureable results
- intense & sustained collaboration between host government, non-governmental organizations, American scientists, & USG agencies (USAID, NIH, CDC) can significantly enhance a nation's response to the AIDS epidemic



U.S. Agency for
International Development
The AIDS Story in Uganda



Though AIDS was only recognized as a new disease in the United States in 1981, by 1982 Ugandan physicians began observing unexplained deaths in young adults. This mysterious wasting condition was soon called "slim," and that nickname for AIDS still sticks in Uganda today. Soon after taking over leadership of the country in 1986, President Museveni confronted the growing epidemic with candor and activism, and by the end of 1986, the Ministry of Health had established an AIDS Control Program, which began collecting data and conducting public information campaigns.

By 1988, USAID began providing assistance to Uganda and the fledgling non-governmental organizations struggling to respond to the dual needs of preventing further infections and caring for those already infected with the virus. The National Institutes of Health began providing research grants to American scientists investigating various aspects of the epidemic, including mother-to-child HIV transmission, the link between HIV and tuberculosis, and the epidemiology of AIDS in rural communities.

- ▶ This 10-year collaboration between Uganda and the United States has produced remarkable results. The AIDS Support Organization, TASO, now recognized as the premier agency in sub-Saharan Africa providing care to persons living with AIDS, was first given USAID assistance in 1988, and TASO continues to receive USAID support.
- ▶ By the end of 1997, TASO had cared for over 40,000 clients and their families and had trained hundreds of AIDS counselors in Uganda and elsewhere in Africa. TASO has also provided national leadership in reducing the stigma and discrimination typically associated with AIDS.

By 1989, it became apparent that many Ugandans were knowledgeable about AIDS and were eager to learn whether they had already been infected. In the absence of HIV counseling and testing sites, people were donating blood to learn their HIV test results, creating a serious problem for the national blood transfusion service, which was not equipped to provide intensive counseling.

- ▶ Once again, USAID responded quickly, and in February 1990, the AIDS Information Center opened, the first program in Africa offering voluntary and anonymous HIV counseling and testing.

What are the factors contributing to Uganda's remarkable success in responding to the AIDS epidemic? Perhaps most important has been the leadership provided by President Museveni, creating a national environment that encouraged the development of innovative and pioneering programs such as the AIDS Support Organization and the AIDS Information Center.

The courage shown by many people living with AIDS, who publicly talk about how they became infected, the importance of getting tested, and how they "live positively" with AIDS, has made a dramatic and emotionally compelling key to the success of HIV prevention programs. The commitment and professional competence of Ugandan public health workers, AIDS educators and activists, and health care workers has helped these programs achieve successful results. Finally, the early, intense and sustained level of USAID assistance given to these Ugandan partners has enabled them to achieve a first in Africa: a decline in new HIV infections in young people.

U.S Government Economic Assistance to Uganda

The U.S. Government, through the U.S. Agency for International Development, has provided over \$81 million in economic development and humanitarian/emergency food assistance to Uganda during FY 1998. Uganda is an excellent partner for U.S. development programs and is recognized for its commitment to macroeconomic reform.

The nature of U.S. assistance is determined by a process of close consultation with the Government of Uganda, Ugandan private sector leaders, other donors and U.S. Private Voluntary Organizations. The process takes fully into account the priorities of Ugandans. Currently, the U.S. development program has five strategic objectives (SOs) for the country and one newly approved special objective (SPO) for northern Uganda:

1. **Increase Rural Household Income** by increasing non-traditional agricultural exports, improving the productivity of key food crops and providing financial services to engage in productive off-farm enterprises.
2. **Conserve Critical Ecosystems to Sustain Biological Diversity and to Enhance Benefits to Society** by strengthening institutional and community capacity and practices to better manage specific ecosystems, and strengthening Uganda's environmental policy.
3. **Increase the Percentage of Ugandan Children who Receive Quality Basic Education** to enable Ugandan children to become productive members of society.
4. **Increase Service Utilization and Change Behaviors Related to Reproductive, Maternal and Child Health** by improving the quality of reproductive and child health services, expanding the number of service providers, and fostering HIV testing and counseling.
5. **Constitutional Checks and Balances Utilized** by strengthening legislative and judicial capacity to perform constitutionally mandated functions and by helping citizens to participate in decision making at the local level.
6. **Special Objective: Reintegration of Northern Uganda** by improving household food security and income generation activities, increasing access to emergency basic needs (including basic health care), and generating awareness and capacity to resolve and prevent disputes.

**US BILATERAL ASSISTANCE
UGANDA**

Millions of US Dollars						
		FY 95	FY 96	FY 97	FY 98	FY 99
		Actual	Actual	Actual	Actual	Request
— Economic						
DFA		44.250	37.025	42.518	44.714	48.300
ESF		1.500				
PL 480						
Title I (Loan)						
Title II (Grant)		10.439	6.365	25.072	29.012	5.284
Title III (Grant)						
Section 416						
Special Self Help		0.125	0.080	0.090	0.073	
Refugee Programs						
O.F.D.A.				0.905	1.505	
Peace Corps		1.109	1.207	1.453	1.764	1.821
Af. Dev. Foundation				0.389	1.089	0.625
Subtotal		57.423	44.677	70.038	77.068	55.405
— Military						
FMF						
CIT						
IMET		0.138	0.200	0.342	0.400	0.400
NEPDC						
PKO		0.300				
Subtotal		0.438	0.200	0.342	0.400	0.400
— Democracy/Human Rights						
116(e) Fund (DHRF)		0.190	0.090	0.090	0.050	
AREAF		0.042	0.329			
Subtotal		0.232	0.419	0.090	0.050	0.000
Total		58.093	45.296	70.470	77.518	55.805

Indicates estimated figures.

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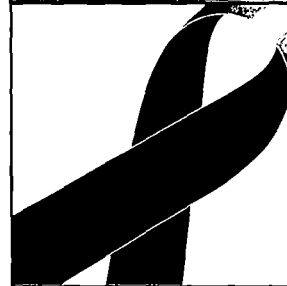
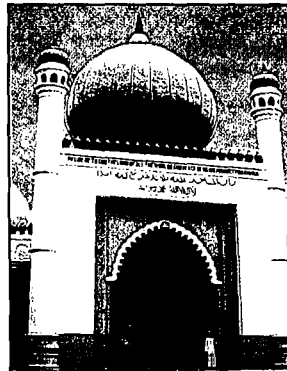
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Islamic Medical Association of Uganda

AIDS education through Imams:

*A spiritually motivated
community effort
in Uganda*



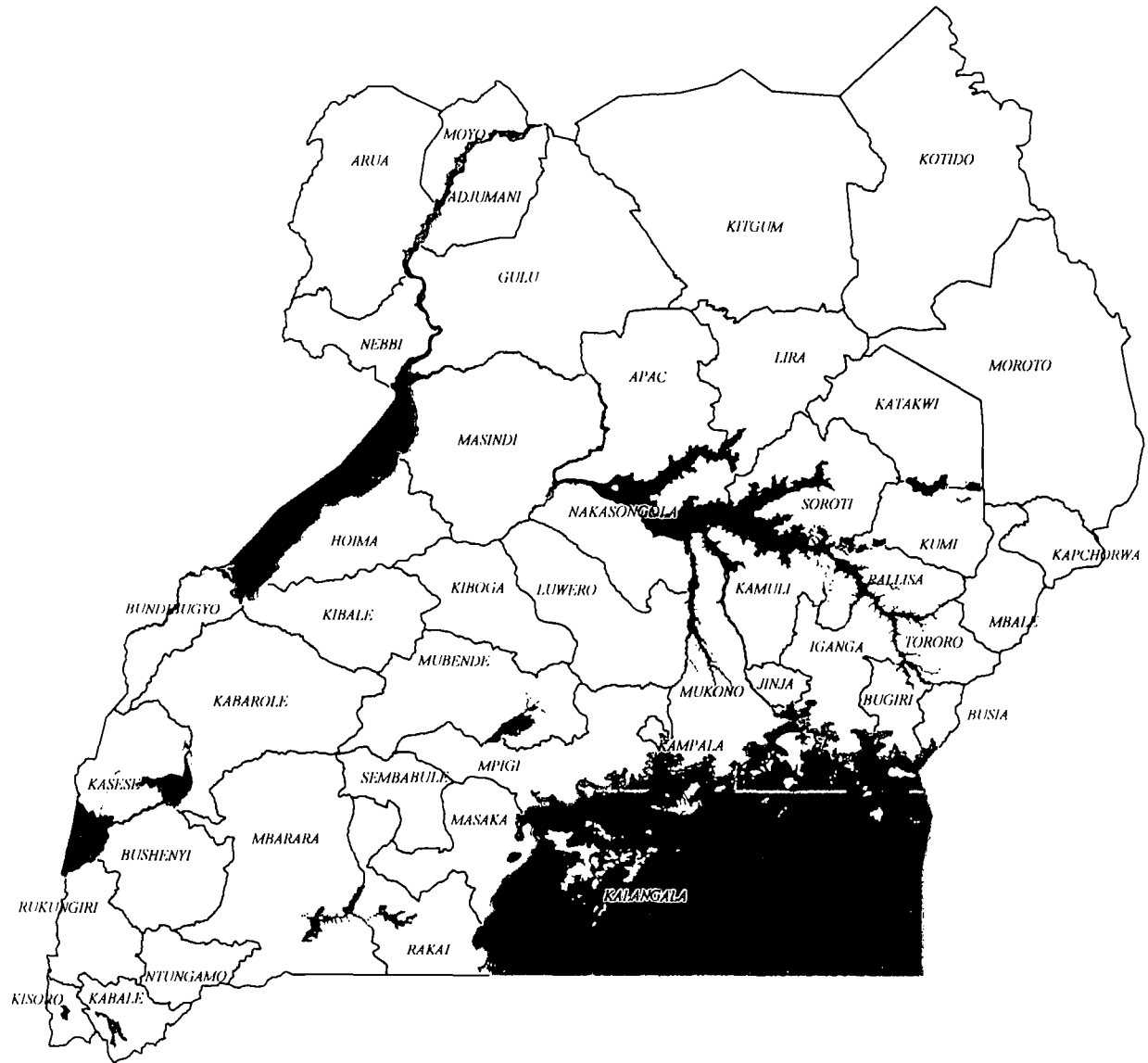
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Case study**

October 1998

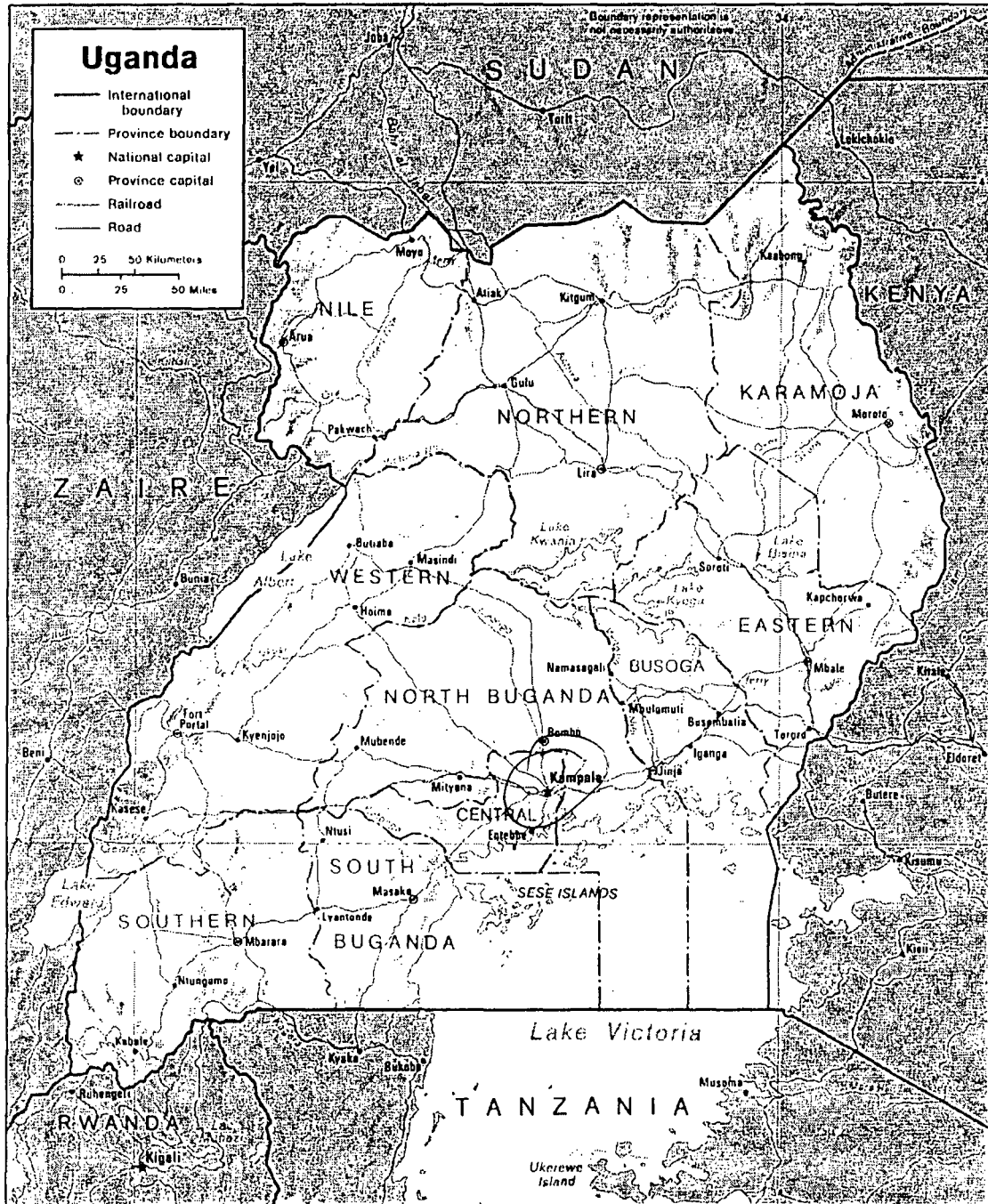
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Uganda



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UNITED STATES AGENCY FOR INTERNATIONAL
DEVELOPMENT

UGANDA PROGRAM



FACT SHEET

THE AIDS INFORMATION CENTRE

In 1987, the Government of Uganda began responding to the emerging AIDS epidemic, and with USAID, WHO, and other donor support, instituted an aggressive information and education campaign. Before long this resulted in high rates of knowledge of AIDS, its symptoms, and how HIV is transmitted. Soon there was a notable public demand for HIV testing, and by 1989 a group of Ugandan and international AIDS activists organized an effort to provide HIV testing, accompanied by counseling.

The AIDS Information Centre (AIC) initiated services in Kampala in early 1990, and demand elsewhere led to the opening of branches in three other cities by 1993. Studies in Uganda, Kenya, Tanzania, Rwanda and Zambia have documented the important role of HIV counseling and testing in helping people adopt and maintain risk-reduction behaviors to prevent further spread of HIV infection.

AIC clients now receive not only HIV testing and counseling, but also syphilis testing and treatment, diagnosis and treatment for other sexually transmitted diseases, family planning services, and education and referral for tuberculosis testing and treatment. Long term support for behavior change and coping with HIV infection is offered through "Post Test Clubs" at all sites where clients, both those infected and those not, receive on-going counseling, provide mutual support, and conduct AIDS-education activities in various community settings.

In 1997, AIC became the first large program in the world to use new rapid tests to provide on-site, same day results. This elimination of a one or two week waiting period has been popular with both clients and staff, and is now being emulated in other African countries.

By the end of 1998, almost 400,000 clients had been served by AIC. In 1998, over 55,000 persons were served. When AIC first opened, many more men than women came for VCT, but since 1995, about half of AIC's clients have been women. Since 1990, however, female clients have been consistently more likely to be HIV infected than men, though rates in both have steadily declined. In 1990, 35 percent of female clients and 23 percent of male clients were HIV infected; by 1997, this had declined to

26 percent in female clients and 14 percent in males. Over the years, about half of AIC's clients have been people in their twenties, and these young clients have rates of infection lower than clients over 30. The differential in rates of HIV infection between males and females is particularly acute in younger people, with only 3.5 percent of males 20 to 24 infected but 17 percent of women in this age group already HIV positive.

Since 1997, AIC has engaged in an active program of training lab technicians and counselors in rural health facilities in DISH districts to expand the availability of testing and counseling. With USAID assistance, voluntary counseling and testing is now available in 12 districts; DFID supports expansion activities in 5 districts, and UNFPA supports this service in two districts

USAID currently funds about 70 percent of AIC's annual budget of \$1.5 million with the remainder coming from DFID, UNICEF, the German agency DED and from the approximately \$2.50 user fee paid by AIC clients. In addition, USAID has funded substantial amounts of technical assistance from the U.S. Centers for Disease Control and Prevention (CDC).

During your visit to AIC, you will be briefed by the Acting Director Jane Harriet Namwebya. You will tour the facilities, hear testimonials from clients who have benefited from the program, and see a brief presentation of educational songs presented by the post-test club members.

41 test sites nationally

Responding to the AIDS Epidemic in Uganda:

The Uganda and USAID Partnership

Around the same time as AIDS was recognized as a new disease in the U.S. in 1981, Ugandan physicians, by 1982, began observing an unexplained wasting disease in young adults that ultimately led to death. This wasting condition was soon called "slim" disease. Soon after assuming leadership of the country in 1986, President Yoweri Museveni confronted the growing epidemic with candor and activism. By the end of 1986, the Ministry of Health had established an AIDS Control Programme that began funding data collection and public information campaigns. In 1988, the United States Agency for International Development began providing funds and technical assistance to the government of Uganda and the fledgling non-governmental organizations struggling to respond to the dual needs of preventing further infections and caring for those already infected by the virus. Also in 1988, the U.S. National Institutes of Health began providing research grants to American scientists investigating various aspects of the epidemic, including mother-to-child HIV transmission, the link between HIV and tuberculosis, and the epidemiology of AIDS in rural communities.

As of June, 1998, UNAIDS estimated that out of a population of over 20 million, there are 870,000 Ugandan adults living with HIV infection, or 9.5% of the adult population, and an additional 67,000 children under the age of 15 who may be infected with HIV. UNAIDS also estimates that 1.8 million Ugandans have already died of AIDS.

In addition to dealing with the AIDS epidemic, by mid to late 1980's, there was increasing recognition that the combination of civil war and the AIDS epidemic was resulting in increasing numbers of children who had lost one or both parents. The situation of AIDS orphans was particularly acute, as these children were more likely to lose both parents because of HIV transmission between couples. The current and projected numbers of orphans remain difficult to determine, however, and estimates on the part of the government and international agencies have ranged widely, partly because of different definitions of "orphan" including children who have lost only one parent.

Based on the 1991 Uganda census, and the observations of local workers, there may be as many as 1.2 million children who have lost one parent, of whom 250,000 to 300,000 may be "double orphans" who have lost both parents. It is estimated that about half of orphans have lost parents due to AIDS; government policies, however, discourage identifying children as "AIDS orphans".

From 1989 to 1998, USAID provided funds to Save the Children UK (SCF) to work with the Department of Child Care and Protection (CCP) in the Ministry of Gender, Labour, and Social Development. SCF's activities included developing a national response to the problems of orphans and children separated from their parents due to war. In 1991, USAID funded an assessment of the orphan situation in Uganda, and also funded a conference in 1992 to bring together all players in the child welfare arena. This process resulted in the GOU articulating policies and legislation regarding orphans, and in particular, policies supporting efforts to keep orphans in the community rather than in institutions or children's homes. As a result, the number of registered children's homes or orphanages in Uganda has declined from 75 to 46, and most of the remaining homes are providing an acceptable standard of care, with support from external donors.

Government policies and the Children's Statute of 1996 continue to emphasize the importance of keeping orphaned and vulnerable children in their home communities with relatives. There are now an increasing number of programs to assist "orphan households," families who have taken in orphans and/or families headed by widows. These programs often provide small loans or grants to help the household begin an "income-generating project" to supplement family income; some programs also provide funding for school fees for orphans.

The Uganda Women's Effort to Support Orphans, UWESO, was founded by First Lady Janet Museveni in 1986, and has provided national leadership in responding to the plight of orphaned children. Currently, UWESO emphasizes "micro-enterprise" projects to provide loans, grants, and technical assistance to help households with orphans. USAID has also provided funds for a number of projects assisting orphans; most of these funds since 1995 have been for micro-enterprise projects assisted by FINCA, The International Foundation for Community Assistance. **Overall, since 1989, the total amount of USAID funding for projects relating to orphans has totaled \$4,185,000.**

This ten-year collaboration between Uganda and the United States in the fields of HIV prevention, AIDS care, and orphan support has produced remarkable results. In terms of care and support for people living with AIDS, USAID has continuously supported The AIDS Support Organization (TASO), now recognized as the premier AIDS support agency in sub-Saharan Africa, since 1988. By the end of 1998, TASO had cared for almost 50,000 clients and their families, and had trained hundreds of AIDS counselors in Uganda and elsewhere in Africa. TASO has also provided national leadership in reducing the stigma and discrimination typically associated with AIDS.

In the field of HIV prevention, by 1989 it became apparent that many Ugandans were knowledgeable about AIDS, and were eager to learn whether they had already been infected. In the absence of HIV counseling and testing sites,

people were donating blood in order to learn their HIV test results, creating a serious problem for the national blood transfusion service, which was not equipped to provide intensive counseling. USAID responded quickly, and in February 1990, the AIDS Information Centre (AIC) opened its doors, the first program in Africa offering voluntary and anonymous HIV counseling and testing. By the end of 1998, almost 400,000 clients had been served, an astonishing accomplishment not yet matched elsewhere in sub-Saharan Africa. The important role of HIV counseling and testing in helping people adopt and maintain risk reduction behaviors has now been documented not only in the US but also in Uganda, Kenya, Tanzania, Rwanda, and Zambia.

USAID provided leadership, funding, and technical assistance for other AIDS prevention efforts in Uganda as well, including the first "AIDS in the Workplace" project in Africa and one of the first "AIDS in the Military" projects. By 1992, USAID was also funding community AIDS education activities implemented at the local level by churches and mosques, and by 1995, these projects had recorded contacts with over one million individuals, most of them living in rural areas. Condom education and distribution have also been funded by USAID since 1987, and in 1998, about 8 million USAID subsidized condoms were sold.

Overall, between 1988 and 1998, approximately \$40 million in USAID funds have been provided for AIDS prevention and care in Uganda.

The cumulative impact of these intense and widespread HIV prevention efforts became apparent in 1994 and 1995, when behavioral surveys began documenting that Ugandans were reporting fewer casual sexual partners, increased condom use, and young people were reporting a delay in becoming sexually active. Social norms were also changing, with peer reinforcement of abstinence, faithfulness, and condom use. Religious leaders and parents began demanding that young couples get tested before marriage, and now one-third of the clients at the AIDS Information Centre come as couples for pre-marital counseling and testing.

Most encouraging has been the documented decline in HIV infection rates in young pregnant women. Based on routine testing of pregnant women attending antenatal clinics in a number of locations in Uganda, beginning in 1989 and continuing to the present, there is increasing evidence that HIV prevalence in Uganda is declining, especially among young women. The declines are particularly pronounced among pregnant women aged 15 to 19, but are also observed in women 20 to 24. For example, in one site in Kampala, 15 to 19 year old women had an HIV prevalence rate of 26% in 1992, by 1997 this rate declined to 8%. Demographers believe this reduction in prevalence is directly related to 50% drop in the rate of new infections in these young women.

What are the factors contributing to Uganda's remarkable success in responding to the AIDS epidemic? Perhaps most important has been the leadership

provided by President Museveni, creating a national environment which encouraged the development of innovative and pioneering programs such as The AIDS Support Organization and the AIDS Information Centre. The courage shown by many people living with AIDS, who publicly talk about how they became infected, the importance of getting tested, and how they “live positively” with AIDS, has made a dramatic and emotionally compelling contribution to the success of HIV prevention programs. Condom education, promotion, and distribution to many areas of the country has also played an important role in enabling Ugandans to take specific HIV prevention measures. The commitment and professional competence of Ugandan public health workers, AIDS educators and activists, and health care workers has helped these programs achieve successful results. Finally, the early, intense, and sustained level of USAID funding and technical assistance given to these Ugandan partners has enabled them to achieve a first in Africa: a decline in new HIV infections in young people.

The Ugandan response to orphans has also resulted in successful models. The Children’s Statute of 1996 has codified all legislation relating to children, and has emphasized the responsibility of families and the community for the care and protection of children. This Statute is widely regarded as very progressive and a model for Africa. In spite of the large numbers of orphans, many resulting from AIDS, less than 1% are institutionalized, and communities and families have for the most part been able to support these children; the extra income provided by the various micro-enterprise projects has been of great assistance to many families.

Overall, though Uganda has high rates of HIV infection, large numbers of orphans, and inadequate government funds to deal with these problems, the last decade has seen the implementation of successful projects to respond to the AIDS epidemic and the associated increase in orphans. USAID has played a key role in providing funds and technical assistance to these efforts, and this collaboration between the US government and Uganda has resulted in successful and replicable models to control the spread of AIDS, and to mitigate the social and health impacts of the epidemic.



Participatory evaluation of counselling, medical and social services of The AIDS Support Organization (TASO) in Uganda

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Abstract *The AIDS Support Organization (TASO) is an indigenous non-governmental organization (NGO) of HIV-infected and affected people in Uganda. TASO provides counselling, social support, medical and nursing care for opportunistic infections at 7 centres affiliated to district hospitals in Uganda. Between 1993 and 1994, the services provided by TASO were evaluated through a participatory approach between staff and clients. TASO counselling services helped clients and their families to cope with HIV and AIDS, with 90.4% of clients revealing their serostatus, and 57.2% reporting consistent use of condoms in the past 3 months. TASO was also the main source of medical care for clients with opportunistic infections in the last 6 months (63.8%). As a result of counselling, over half of the clients (56.9%) made plans for the future and 51.3% wished to make wills. There was a high level of acceptance of people living with HIV/AIDS (PWAs) by families (79%) and the community (76%). Care was provided to PWAs at home mainly by women (86.2%). TASO has demonstrated that individuals and their families are able to live positively with HIV/AIDS. Through counselling, medical care and material support to clients and their families, TASO has effected change in people's attitudes, knowledge and lifestyles. In particular, TASO has demonstrated a strong capacity to overcome four problems that haunt AIDS care in most places: (1) revealing one's HIV-serostatus to relevant others; (2) accepting PWAs in family and community; (3) seeking early treatment; and (4) combining prevention and care. In general, TASO has shown that specialized services to meet AIDS care needs can be added to existing health services at district levels. As a result of the participatory evaluation, a well-accepted monitoring system was established.*

Introduction

Following the first reported AIDS cases in Uganda in 1982, the National AIDS Control Programme (NACP) was set up with assistance from WHO in 1986. By mid-1991, an estimated 9% of the general population and 20% of the sexually-active population had been infected with HIV. By early 1994 43,000 AIDS cases were reported to the NACP, a figure which was estimated to be only one-sixth to one-fifth of the actual number of cases. Both the government of Uganda, NGOs and communities were conducting AIDS prevention and care

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activities. TASO has been one of the NGOs in the country providing services to people with HIV/AIDS and their families.

TASO has its origins in a support group of persons infected and affected by HIV/AIDS in Uganda which began meeting in 1987. It has since evolved into a fully-fledged voluntary organization that provides psychosocial support to those affected by AIDS and helps them cope. By the end of 1993, TASO had expanded into seven districts in Uganda and was providing counselling, medical care and social support to a cumulative number of over 22,000 people with HIV/AIDS and their families.

Along with the National AIDS Control Programme (NACP) and other organizations, TASO is carrying out a variety of AIDS prevention and care activities in Uganda. These include counselling training courses for other organizations and providing support to community efforts in responding to the AIDS epidemic.

In spite of the positive comments from beneficiaries and the conviction of TASO staff that their services were in response to needs not being met and that they were beneficial, no systematic assessment to verify these opinions had been conducted. Therefore, TASO decided to carry out an evaluation of their services to PWAs and their families. This evaluation did not attempt to compare TASO with other AIDS service organizations but was aimed at gauging the level of accomplishment of TASO's objectives and satisfaction among the clients. Technical assistance was obtained from the World Health Organization Global Programme on AIDS to help with a participatory evaluation of TASO services from August 1993 over a 1-year period. An evaluation steering committee provided guidance to the study and a TASO core evaluation team was formed to implement the evaluation.

This article summarizes the method and results of this participatory evaluation process, where both care providers and beneficiaries assessed services. The approach ensured the involvement of those offering services (TASO staff), those receiving services (PWAs and their families), as well as those relating to TASO on a formal or informal basis (TASO Centre board members, donors, community members). These groups, to differing extents, took part in the design, data collection and analysis, and also the interpretation of the findings. It is the belief of TASO that even though the objectivity may appear to have been partially compromised by the participatory process, the gains in acceptance of the findings for programme strengthening more than compensated for the risk of bias due to staff involvement.

Overview of AIDS care services

Counselling in developing countries

Counselling is provided for PWAs because it has been observed that HIV/AIDS is associated with severe emotional stress, and counselling is seen as an appropriate means of providing the necessary support to allay this stress. Emotional support and disease acceptance has been reported to be worse for PWAs than for patients with other diagnoses (Baker & Seager, 1991). Such responses to HIV/AIDS could justify a personalized confidential counselling model.

Since TASO was founded by individuals who were directly or indirectly affected by AIDS, the TASO model reflects what those affected desired to have done for themselves and/or their loved ones: 'Some of those working with TASO are antibody positive. The warm relationship they have formed with one another and their clients, their capacity to listen is born of shared experience of pain, of loss, of stigma, of isolation' (Seidel, 1988).

TASO uses a one-to-one counselling approach. Although this model of counselling has largely been accepted by most health and social care providers in Africa (Lie *et al.*, 1994), it

is still a much-debated subject. There is increasing support in some rural socio-cultural settings (Seeley *et al.*, 1991) for a family-focused rather than a one-to-one approach. In an African setting serious problems are usually discussed in the extended family with a caring and supportive person who is respected and expected to understand the circumstances better. The TASO model promotes the idea of involving the family, but only as an extension from and after the consent of the person infected. This can include the inner family members and eventually the neighbours or community members (Kalibala & Kaleeba, 1989).

Although the TASO evaluation did not analyse the nature of emotional problems of PWAs in Uganda, other reports (Mukisa, 1990) indicate that such problems manifest as anxiety, loneliness, depression or a wish to die. HIV/AIDS is a condition which is emotionally loaded and as such it has been associated with high levels of psychosocial distress including denial, blame of others for the infection and hopelessness about the future (Peltzer *et al.*, 1989). Reports suggest that provision of psychological support and restoration of hope is associated with improved quality of life (Camara *et al.*, 1990; Mukisa, 1990; Schopper *et al.*, 1996).

Counselling has been reported to play a positive role in sharing of serostatus (Mukisa & Rubagiza, 1991). Muhongayire & Raynaut (1994) observed that in their study cohort, the women who denied their HIV-positive results altogether were those whose material, psychological or family situation were clearly the least capable of supporting such an announcement. Thus, divulging HIV results may depend on the assurance of social support, as much as on the effectiveness of counselling received in relation to learning one's test result. Other studies indicate that the high level of fear to reveal serostatus is related to fear of spousal abuse, rejection and eventual divorce (Maggwa *et al.*, 1990; Meursing & Sibindi, 1995). In recognition of the necessity of the social support network, TASO services, and those of a number of care organizations provide counselling to not only the individual client but to their family as well.

Counselling also deals with the reality of an uncertain future. The need to plan for survivors is reportedly a frequent cause of stress for PWAs. For example, education, food and shelter are among the most commonly-expressed concerns of PWAs for their children. In TASO, social support, such as material goods and financial help, has also been added to counselling services to facilitate the coping abilities of counselled clients. The TASO evaluation thus examined the social support needs of the clients and families, and whether those needs were being met.

AIDS services in hospitals and homes

The TASO model of an NGO-supported clinical service for PWAs, provided along with counselling and social support, has been promoted and put into practice in many African countries.

There are some historical reasons for specialized AIDS clinics. The AIDS epidemic started at the time when most of the African states were undergoing harsh economic situations, with declining abilities to maintain the necessary infrastructures and to provide salaries and supplies for the health sector. Existing services were poor, hence TASO offered special services on hospital premises, in addition to normal hospital services. It is now realised that much care can be provided in complementary settings (WHO/GPA/HCS/95.14). The family unit plays a major role in care of PWAs (Ankrah, 1993), hence the importance of providing them with adequate information and knowledge on care of PWAs in the home. The burden of AIDS care, as with other chronic illnesses, will increasingly fall on families, especially as hospitals become less able to cope with numbers and as long as families are

willing to care. Home care programmes have mushroomed and are convenient for both the care providers, the patients and their families. However, the quality of these programmes can only be sustained with external input. Most are already overwhelmed by the growing number of patients. The coverage of these programmes is also limited, with research studies showing that only patients within a certain catchment area of home care programmes are within reach of services (Chela *et al.*, 1994; Ndyabangi *et al.*, 1995; Woelk, ongoing study).

Health care workers have reported that caring for AIDS patients is more time-consuming and stressful than caring for patients with other diagnoses (Kalibala, 1995). Thus, even without the unfavourable socio-economic setting of Africa, AIDS-associated stress and stigma are bound to affect the relationship of PWAs with health care providers. PWAs may avoid or reduce stigma by concealing the diagnosis of HIV or of associated illnesses. With declining health, PWAs and their families avoid outside contact. At more peripheral clinics, dispensaries and health centres, it has been observed that HIV status is rarely mentioned between PWAs and health care staff (Friesen, 1993, unpublished). If conditions are perceived to be HIV-related, patients bypass these facilities and go to district hospitals.

Due to the difficulties experienced by health workers in handling HIV/AIDS and the shortages of ordinary medicines, access to clinical care by PWAs could not be assured. This has probably been the major driving force behind the formation of specialized HIV/AIDS clinics in some countries in sub-Saharan Africa and certainly was the driving force for TASO to provide AIDS-specific medical services.

Social support services

In Uganda the problem of needy children affected by HIV/AIDS is enormous and will continue to grow in the foreseeable future. In a World Vision-commissioned baseline survey it was observed that in Rakai District, Uganda, 43% of households were caring for 3–5 orphans, 18% were caring for 6–10 and 35% were caring for more than 10 (WHO/GPA/TCO/HCS/94.7). Children's problems begin long before a parent dies of AIDS. With the parent's illness, family income falls and even meagre resources are diverted to modern and traditional treatments. As a consequence, resources are lacking for children to start or to continue going to school.

AIDS appeared on the scene when the African economies were already battered by political and social strife and when families were barely able to fend for themselves. A direct impact of AIDS is to decrease economic resources. Therefore, some families need help in order to care for AIDS patients. Based on these observations it has become routine for AIDS care programmes to incorporate some kind of social support package for PWAs and their families. This package varies but usually consists of one or the other of the following: bedding, clothing, school fees, food, income-generating activities (IGAs), day centres, cash, etc.

Although economic needs of PWAs were a factor in coping with their condition, income-generating projects for PWAs need to be carefully undertaken, if at all, through feasibility studies and in collaboration with other organizations experienced in small-scale projects in developing countries.

Methodology

Sampling

A TASO client is defined by TASO as one who has been confirmed as being HIV-positive

or having an AIDS-related illness and who has registered with the organization after self-referral, or referral from a health institution. TASO services, however, are provided to the client's family and to other people who walk in to seek counselling and information about HIV/AIDS. The sample was drawn from those who were registered with TASO as clients between the period of January 1991 and March 1993 ($n = 4,000$). The TASO core evaluation team compiled a list of these clients and their family care-givers. Among these 4,000, convenience sampling was used to select every fourth client who happened to come to the clinic within a period of 3 months, to be enrolled into the study and be interviewed as they arrived at the TASO centre. Those clients among the 4,000 (and their family care-givers) who were unable to attend TASO clinics were interviewed during home visits.

The final study population consisted of 324 clients who were currently attending TASO clinics, 322 clients who were visited at home and 74 client drop-outs who no longer used TASO services. A total of 232 family care-givers of clients were also interviewed.

In addition, clients used a checklist to gather information from other clients regarding use of TASO services and safer sex practices. Two case studies were conducted with a male and female PWA, selected as typical clients, one from a rural area and the other from an urban area. Focus group discussions were held at each TASO Centre for male and female clients, counsellors, counsellor supervisors and community representatives. A total of 24 key informant interviews were conducted and 49 counselling sessions were observed by counsellors to determine what topics were covered.

Data collection

Participatory study and potential for bias. A primary objective of the participatory study was to evaluate services offered. While a participatory evaluation has the advantage of including providers and users in assessing services and jointly planning for improvements, a disadvantage is the potential for biased information.

The participatory nature of the TASO evaluation meant that staff and clients took part in data collection and analysis, leading to possible biased responses in favour of the programme. The evaluation did not include a comparison of non-users of TASO services, or comparison among the 7 TASO centres, or other AIDS-related organizations providing services similar to those of TASO.

An attempt was made to address the issues of validity and reliability by emphasizing the need for interviewers to conduct the interview during a normal counselling session in which the questions were discussed and the recorded responses were the result of this discussion. In addition, combined sessions were held in TASO centres with key evaluation participants to validate findings from the different data sources. An attempt was made to standardize the structured questionnaire and to reduce error through a process of translation and back-translation into the relevant local languages.

As part of the participatory process, evaluation results were discussed with all TASO centres for clarification and interpretation of the meaning of the results. Such a process enabled each centre to identify with and accept the study results, and to actively participate in formulating and implementing recommendations.

Data collection methods. TASO counsellors and supervisors collected data in all 7 TASO centres over 3 months beginning August 1993. Information was collected during normal delivery of services throughout the study, thus minimizing disruption of services. Informed

consent was obtained before each interview. Interviewers were trained in conducting interviews and carrying out focus group discussions in the local languages.

The evaluation used a combination of data-gathering methods consisting of semi-structured interviews, open-ended interviews, focus group discussions, checklist, guidelines and case studies. This combination was intended to provide data of different types for a reliable and accurate understanding of the services under investigation.

(a) Semi-structured interviews

The interviews designed to last about 60 minutes were administered to clients and caregivers. Client interviews centred around medical, counselling and social support services, and safer sex practices. Family caregivers were interviewed about their source of information on care and the type of home care they provided to clients.

(b) Open-ended interviews

Key informant guidelines were developed for obtaining information on TASO and other AIDS-related organizations and health facilities, constraints in service provision and possible solutions.

(c) Focus group discussions

Discussion guides were developed on medical, counselling and social support services, and safer sex practices. Data were collected from clients, counsellors and community representatives. Discussions with community members also included their responses to PWAs.

(d) Client checklist

As part of the participatory evaluation process, clients developed a checklist of key items they wished to ask other clients. The list included condom use, number of sexual partners and use of TASO services.

(e) Guidelines for observing counselling sessions

These concerned the content of counselling sessions and whether these sessions covered safer sex practices, coping with infection and diseases and planning for the present and future by clients.

(f) Case studies

Two case studies were carried out to provide in-depth, detailed information on living with HIV/AIDS. The subjects, one male and one female, were not chosen by a formal sampling process: rather, they were selected because they exemplified and presented issues of revealing serostatus, living with HIV/AIDS and using services such as those offered by TASO.

Data analysis

Quantitative data were entered for computer analysis using the statistical package Dbase III and imported into EPI Info for analysis. Quantitative data were primarily analysed by means of simple frequencies. Qualitative data from notes and audiotapes were compared for accuracy and completeness. Data were then compiled using WordPerfect 5.1 word processing programme and imported into Text Base ALPHA for further analysis which included categorizing data, identifying variables and summarizing findings. The quantitative and qualitative data were then compared for consistency.

Results and discussion

Sample characteristics

The majority of the client respondents were females (68%), which reflects the gender ratio of TASO clients. The average age of respondents was 32.3 years. Forty-one per cent were widowed, 29% married or cohabiting, 19% separated or divorced and 11% were single. Fifty-one per cent had obtained 7 years of formal education, 29% had 11 years of education, 13% had no formal education and 7% had more than 11 years of education but without reaching university level. Only two clients had university education.

Occupational groups were peasant farmers (26%), business or skilled workers (26%), unemployed (23%), unskilled workers (12%) and other kinds of workers (13%). The majority of clients lived within a 10-mile radius from a TASO centre.

The family caregiver respondents had similar demographic characteristics. The majority were females (86.2%), of whom half had 7 years of education (50.5%) and were either farmers (37%), unemployed (21%) or were unskilled workers (16%).

Counselling services

For the purposes of the evaluation counselling was defined as a dialogue between a counsellor and a client during which issues are discussed, options are examined and possible plans for coping are made. The relationship between a client (and family) and a counsellor is continuous and on the average a client receives one counselling session per month.

Coping of clients and families. Coping was defined by the staff and clients to be an acceptance of being HIV-positive and having a positive attitude toward making the most of each day. In 23 (46.9%) of the 49 observed counselling sessions, the following coping mechanisms were addressed: acceptance of being HIV-positive; revealing serostatus to spouse and family; continuing to work and self-care. In the focus group discussions, clients indicated that TASO counselling and drama groups for social contacts provided them with emotional support. The drama performances depict different scenarios of living with HIV/AIDS, with the aim of creating awareness among the communities, increasing acceptance of PWAs and boosting their coping capacity. Case studies contained in the full report illustrate clients who are 'living positively with HIV' and who have been helped to cope by TASO. One client said:

TASO has helped to reduce thoughts and helped to realise that I am not alone ... and I am still useful.

In concurrence with findings elsewhere (Chaava, 1990; Sittitrai & Williams, 1994), the evaluation of TASO has indicated that counselling PWAs can be provided along with health services, and that it enables a discussion of emotional problems which makes them feel better and helps them to gain the strength to cope with HIV/AIDS. The evaluation suggested that counselling, as is currently provided by TASO, is an appropriate response to the emotional needs of PWAs and their families. However, during the focus group discussions with TASO counsellors they mentioned their own emotional stress and the difficulties of lack of knowledge of medicine and basic nursing care, even though clients expected this kind of service from them, as well as difficulties in counselling discordant couples on condom use and pregnancy.

Revealing of serostatus. Most (90.4%) of the sampled TASO clients reported to have revealed their serostatus. There was no statistical difference in those revealing their serostatus by either gender or marital status. Such a high proportion of those revealing their serostatus is rarely reported. Perhaps this is due to repeated counselling sessions over time.

Among TASO clients a high level of acceptance in families (79%) and in communities (76%) was reported, although fear of stigma was the main reason given by 58% of those who had not revealed their serostatus. These findings seem to suggest that the TASO counselling model enables individuals to cope with their HIV status, and that this enables them to inform those of their social circle who are likely to provide individual support.

In the TASO sample most clients (85.3%) reported revealing their serostatus to relatives other than household member or spouse/partner. While over 67% of clients revealed their serostatus to household members, fewer (36%) revealed their status to spouses or regular partners. This suggests the sharing of emotions over a broader family and community network. But it could also be due to the fact that 41% of the respondents had been widowed.

The TASO study suggests that, with consistent counselling and opportunity for social contact and emotional support, clients are more willing to share their serostatus, particularly with their relatives. The high level of family (79%) and community acceptance (76%) of PWAs may be due to the high level of awareness of HIV/AIDS in the community (Moodie, 1991) and, in turn, the high level of acceptance of PWAs in the community may also encourage revealing of serostatus to relatives.

Thus, unlike reports from elsewhere, the TASO counselling model appeared to enable the majority of PWAs to reveal their HIV serostatus to someone. However, as consistent with other studies (Lie & Biswalo, 1996), the TASO evaluation clearly indicated that the spouse or regular sexual partner is not the confidant of choice for sharing serostatus of many PWAs.

Knowledge and practice of safer sex. One of the aims of the TASO counselling model is to enable clients to evaluate personal risk of HIV transmission and facilitate preventive behaviour. Indeed, counselling sessions are used to discuss issues related to safer sex practices and to reinforce clients' behaviour. In the TASO evaluation, of the 49 counselling sessions observed, 39 (79.6%) addressed safer sex practices. Of the 730 client respondents, 68.2% knew all four major modes of transmission: unprotected sexual intercourse with an HIV-infected person; infected mother to infant; transfusion with infected blood; and sharing infected skin-piercing instruments. Most clients (98%) knew about HIV transmission through unprotected sexual intercourse. The most frequently-reported knowledge of safer sex practices was condom use (85%) and abstinence (39.4%).

The most commonly-reported current safer sex practices by males and females included abstinence (45%) and condom use (33%). Use of condom was mentioned more by males (48%) than females (26%), while abstinence was more frequently mentioned by females (56%) than males (28%). However, it should be noted that abstinence may be a temporary, rather than a permanent measure.

Although 19.7% of the respondents cited faithful monogamy as their method of choice to prevent transmission, the perception of most clients was that monogamy without using condoms was not safe enough. One client stated: 'I got married to my husband in 1962 and I have never had sex with any other man, but here I am infected with HIV from him'. Community members called on TASO to strengthen its preventive role, as well as care: 'TASO should come out with programmes of educating the public instead of waiting for people to get infected and counsel'.

Data on abstinence may be more difficult to interpret. In a 1992 survey in a Ugandan

community at Kasangati (Konde-Lule & Sebina, 1993), 35% of the respondents reported not to have had any sexual relations in the previous 6 months. It is not clear whether the reported abstinence in the Kasangati community was a conscious choice of safer sex practice or a reflection of general sexual behaviour; however, among TASO clients it was reported as a conscious choice.

Of those reporting use of condoms, most (81.3%) started using condoms after joining TASO. Over half (57.2%) reported consistent condom use in the previous 3 months and 74% in the last sexual encounter. Reasons for consistent use of condoms were to prevent HIV re-infection, infecting others, pregnancy and STD infections. Discussions with clients revealed that those with irregular sexual partners had higher bargaining power for condom use than those who were married or had regular partners. Of the 42 respondents who did not use condoms in the last sexual encounter, 14 were female. Only two of the female respondents reported asking their partners to use a condom.

The rate of condom use by TASO clients (49.6% ever use and 33% current use) is higher than in a general community in Uganda (10% ever use—Konde-Lule & Sebina, 1993). Some reports from Zambia (Ndawa *et al.*, 1990) tend to agree with TASO that previously-counselled clients are using condoms more frequently.

Planning for the future. As part of coping, TASO clients are encouraged to make plans for themselves and their families. In over half of the counselling sessions (55.1%) clients discussed plans for starting income-generating activities, making a will, building/repairing a house and continuing to work and educate children. Of the clients interviewed, 56.9% had made specific plans for the future, a remarkable percentage in view of the disadvantaged socio-economic environment.

In Uganda making a will is usually viewed as a man's responsibility. In addition the general poverty and the concern that a will is potentially disruptive to the family are some of the factors which may hinder most clients from writing wills. Wills were discussed in the observed counselling sessions by 39% of TASO clients, with 51.3% of clients expressing willingness to make wills. However, only 16.8% had made wills. Some clients indicated that there was no need to make a will as they had nothing to pass on (22.3%). Other findings indicate that writing wills remains a difficult task. In Zambia, in a review of 55 PWAs, only 7 (12.7%) had written legal documents relating to their property (Ndawa *et al.*, 1990).

Medical and home care services

HIV-related symptoms and treatment. TASO provides care for its clients by operating weekly clinics where diagnosis and treatment of opportunistic infections and symptomatic relief are provided. TASO is used by clients almost to the exclusion of other health services, which places a burden on the organization. The average monthly clinic attendance in the first quarter of 1994 varied from 260 in TASO Mbale to 1377 in TASO Mulago, having more than doubled since 1991. Over 80% of clients sought early treatment, that is, within 2 weeks of onset of symptoms. The most frequently mentioned symptoms were fever (60%), cough (45%), continuous diarrhoea (32%), sores on the inside of the mouth (18%), weight loss (14%), swellings on the neck (10%) and herpes zoster (6%). None of the clients mentioning symptoms reported being hospitalized.

TASO was cited as the major source of health care in the previous month by 63.8% of the clients. Other sources of medical care used by clients to a lesser extent were private practitioners (18.3%), public health services (16.2%), family (10.5%), pharmacist (9.0%)

and traditional healer (4.1%). TASO was also cited by 75.2% of clients as the most helpful source of medical care. Twelve out of 14 focus groups indicated satisfaction with TASO medical services. The appreciation by clients of the subsidized medicines indicated the importance of availability of medicines for PWAs in treating HIV-related symptoms.

Of the 74 clients who dropped out, 65% gave the reason that they were not sick, with 16% mentioning that they lacked transport and 16% went elsewhere. Other comments indicated some were fearful of being recognized, and others had alternative access to nearby treatment centres.

Family caregivers. TASO was the main source of information on AIDS care and prevention for family caregivers (31.8%) and clients (68%). There was no significant difference in knowledge on HIV between clients and family caregivers.

Of those clients sampled at home, 49.4% were on medications. During questioning, 57% appeared to be taking the medicines correctly. Family caregivers knew how to make sugar-salt solutions from home ingredients (50.7%), while 78.6% knew how to use ready-made sachets for treating diarrhoea.

Women still bear the greater burden of home care. Of the 232 family caregivers interviewed, the majority were females (86.2%), most of whom were either mothers of clients (26.3%), sisters (18.5%) or daughters (15.1%). Spouses or partners of clients comprised 12.1% of family caregivers. These figures confirm the sad reality that in an African family the woman bears the burden of caring for the sick and that when she is sick herself, another woman (daughter, sister or mother) is recruited to bear this burden. Health workers should educate and encourage both men and women to be involved in giving care.

While this study indicates that the majority of families were providing care for their loved ones it should be noted that, in Uganda, most families do not have adequate resources to care for their own sick. Given the slow response to treatment and sometimes long period of care needed by persons with AIDS, family expenditure on medicines—both traditional and modern—as well as food, supersedes the family income (Ankrah, 1993).

Home care services. Families are providing physical care (changing bedding, giving medicines at the right times and providing food). In addition to the prompt seeking of care by clients for HIV-related symptoms, the TASO medical team provide care to bedridden clients in their homes which may minimize the need for hospital care.

Ways of linking hospital care to home care through appropriate referral and greater involvement of communities in care of PWAs need to be identified. For example in TASO, home care services are restricted to a 20 km radius from a TASO centre, which limits the coverage. TASO through its community initiatives is pilot-testing the idea of more involvement of community members in the provision of medical care and social support to PWAs.

Apart from TASO, the community has an important role of providing emotional support to PWAs and their families. Views from family caregivers and the community were that a PWA should be cared for at home by a close relative in order to 'avoid negligence in hospitals ... provide basic care to the patient and ... avoid expenses'. Clients (57.1%) also viewed family members and relatives as the major family caregivers at home. Beyond the family unit, TASO was the major source of extra help according to 71.3% of the family caregivers interviewed.

Social support services

Material support to PWAs and their families. The importance placed on material assistance and support for children's school fees by clients reflected the poor economic conditions of the population currently served by TASO. Material assistance provided by TASO consisted of basic foodstuffs (rice, oil). These supplies were irregular and dependent on donations.

A third of clients and family caregivers considered financial assistance as a main need. On joining TASO, 34% of the sampled clients expected material assistance. Of these clients, 56.2% reported that this need had been met by TASO. Slightly less than half of clients interviewed (48.1%) mentioned that provision of material assistance would improve their care at home. Of the family caregivers interviewed, 23.7% mentioned material assistance as important in the care of their patients.

Day Centre activities for PWAs. Of the sampled respondents, only a small proportion (8.6%) were members of the TASO Day Centre. The majority of these (81%) were female. The main benefits of attending the Day Centre were sharing experiences with one another (95.2%) and learning skills to earn a living (84.1%).

While clients acquired skills in crafts and benefited from sale of handicrafts, a major benefit from the Day Centre was the emotional support of sharing experiences among PWAs. There was also potential for support groups to be formed in the communities for a larger number of PWAs.

The majority of clients sampled (60%) mentioned the need for capital to start income-generating projects. Eighty-one per cent ($n = 25$) of the clients with projects completed them. Of the 75% of clients capable of paying back to the revolving fund, 12% actually repaid their loans.

In spite of the intentions of TASO to assist clients financially and to promote self-reliance, the low repayment rate of loans by clients indicated the general difficulty of making small projects viable. The majority of clients were not self-sufficient at the completion of their projects. Factors contributing to the low performance of the income-generating projects included low start-up capital, inadequate technical support, lack of a clear policy towards funding of projects and the uncertain health condition of clients.

In Lusaka a group of care providers from east and southern Africa met in January 1994 and wrote a declaration proposing that relief aid, though at times necessary, should be short-term and limited to critical circumstances in order to avoid family dependence on such grants (WHO/GPA/TCO/HCS/94.7). In the Lusaka declaration it was observed that failures in income-generating activities (IGAs) are due to lack of feasibility studies (e.g. outlet analysis) and lack of training on project proposals and planning. It was noted that families affected by HIV/AIDS experience great difficulty in implementing IGAs and that communities should be involved in implementing and monitoring IGAs, with the support of NGOs.

Needy children of PWAs. In the beginning TASO identified school fees payment for needy children of PWAs as a priority. Nonetheless, due to limited funding, out of 1,957 children assessed as needing assistance with school fees, TASO was only able to provide fees to 370 (35%) to cover 7 years of primary education. It is therefore apparent that paying school fees for a few of the needy children may only be a short-term option. Probably, in situations where whole communities are impoverished by AIDS and other calamities, supporting whole primary schools may be the long-term answer. In Kyotera, Uganda, World Vision has

undertaken to rebuild a once-collapsed school. Of the 250 pupils in this school 210 are orphans (WHO/GPA/TCO/HCS/94.7).

Conclusion

This study evaluated services offered by TASO, a non-governmental organization, in providing counselling, medical and social support to PWAs and their families. Findings indicated that the clients, their families, TASO staff and communities acknowledged that TASO services were being received by those in need. The services were ranked high in addressing the needs. The provision of TASO services was also perceived as instrumental in bringing about family and community support, as well as positive behaviour change in sexual practices and in seeking early treatment for opportunistic infections.

In general, ongoing counselling appeared to assist PWAs in coping with their situation and families in accepting and providing care to people with HIV/AIDS. However, it was noted that more effort could be placed on involving the spouses and partners of the clients in counselling sessions, especially discordant couples.

The evaluation helped TASO to look at itself critically and to question some of their programme assumptions, for example:

- Should TASO continue to provide services in all areas because of need, even if TASO is not best qualified to do so?
- Should TASO keep expanding to attempt to fill the needs, or should TASO define its limits and link with other health and social service providers?

This study helped TASO move ahead to concentrate on their areas of success, such as counselling and clinic services, and phase down less successful areas such as IGAs and school fees. In addition, the study yielded joint recommendations to strengthen the services:

- TASO should broaden its programme, using counsellors, community workers and PWAs, to sensitize religious leaders about care and support and positive living.
- Counselling should emphasize revealing of serostatus to spouse/partner in order to enhance coping, make support possible and enable behaviour change.
- Counselling for infected people should reinforce consistent use of condoms, even in faithful monogamous relationships.
- Counsellor training should address how to deal with emotional fears about making wills and how to help women and children handle legal and social problems related to property.
- Early diagnosis of opportunistic infections, including tuberculosis, and compliance with treatment should be strengthened.
- All TASO health care staff should be trained to teach clients and families about home care, correct use of medicines and when to seek help.
- TASO should facilitate the capability of communities to contribute towards the care of PWAs, such as community contributions for medicines and enabling community member to provide emotional support to PWAs and their families.
- TASO should establish linkages with social welfare services and NGOs in order to refer clients for material support.
- The drama group should be assisted by professionals to develop skills to deliver information on HIV/AIDS and to enable them to earn an income at the same time.
- A major evaluation of TASO services should be carried out every 3 years, using the present evaluation study as a baseline.

And lastly, the study helped TASO establish a consistent rational monitoring system, based on uniform simple forms. This system is already yielding information that helps each centre analyse their progress measured by key indicators, and helps supervisors, organizers and donors identify the strengths and weaknesses and make decisions about use of funds, setting priorities and finding the way forward.

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Notes

A copy of the report *TASO Uganda—the inside story* is available from TASO (for within Uganda): The Director, TASO, P.O. Box 10433, Kampala, Uganda. Tel. 256 41 231138; Fax 256 41 251982; or from UNAIDS (please quote ref. WHO/GPA/TCO/HCS/95.1): UNAIDS, Documentation Centre, World Health Organization, CH-1211 Geneva 27, Switzerland. Fax 41 22 791 4187; E-mail: UNAIDSDOC@WHO.CH (Internet).

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Participatory evaluation of counselling, medical and social services of The AIDS Support Organization (TASO) in Uganda

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Abstract *The AIDS Support Organization (TASO) is an indigenous non-governmental organization (NGO) of HIV-infected and affected people in Uganda. TASO provides counselling, social support, medical and nursing care for opportunistic infections at 7 centres affiliated to district hospitals in Uganda. Between 1993 and 1994, the services provided by TASO were evaluated through a participatory approach between staff and clients. TASO counselling services helped clients and their families to cope with HIV and AIDS, with 90.4% of clients revealing their serostatus, and 57.2% reporting consistent use of condoms in the past 3 months. TASO was also the main source of medical care for clients with opportunistic infections in the last 6 months (63.8%). As a result of counselling, over half of the clients (56.9%) made plans for the future and 51.3% wished to make wills. There was a high level of acceptance of people living with HIV/AIDS (PWAs) by families (79%) and the community (76%). Care was provided to PWAs at home mainly by women (86.2%). TASO has demonstrated that individuals and their families are able to live positively with HIV/AIDS. Through counselling, medical care and material support to clients and their families, TASO has effected change in people's attitudes, knowledge and lifestyles. In particular, TASO has demonstrated a strong capacity to overcome four problems that haunt AIDS care in most places: (1) revealing one's HIV-serostatus to relevant others; (2) accepting PWAs in family and community; (3) seeking early treatment; and (4) combining prevention and care. In general, TASO has shown that specialized services to meet AIDS care needs can be added to existing health services at district levels. As a result of the participatory evaluation, a well-accepted monitoring system was established.*

Introduction

Following the first reported AIDS cases in Uganda in 1982, the National AIDS Control Programme (NACP) was set up with assistance from WHO in 1986. By mid-1991, an estimated 9% of the general population and 20% of the sexually-active population had been infected with HIV. By early 1994 43,000 AIDS cases were reported to the NACP, a figure which was estimated to be only one-sixth to one-fifth of the actual number of cases. Both the government of Uganda, NGOs and communities were conducting AIDS prevention and care

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activities. TASO has been one of the NGOs in the country providing services to people with HIV/AIDS and their families.

TASO has its origins in a support group of persons infected and affected by HIV/AIDS in Uganda which began meeting in 1987. It has since evolved into a fully-fledged voluntary organization that provides psychosocial support to those affected by AIDS and helps them cope. By the end of 1993, TASO had expanded into seven districts in Uganda and was providing counselling, medical care and social support to a cumulative number of over 22,000 people with HIV/AIDS and their families.

Along with the National AIDS Control Programme (NACP) and other organizations, TASO is carrying out a variety of AIDS prevention and care activities in Uganda. These include counselling training courses for other organizations and providing support to community efforts in responding to the AIDS epidemic.

In spite of the positive comments from beneficiaries and the conviction of TASO staff that their services were in response to needs not being met and that they were beneficial, no systematic assessment to verify these opinions had been conducted. Therefore, TASO decided to carry out an evaluation of their services to PWAs and their families. This evaluation did not attempt to compare TASO with other AIDS service organizations but was aimed at gauging the level of accomplishment of TASO's objectives and satisfaction among the clients. Technical assistance was obtained from the World Health Organization Global Programme on AIDS to help with a participatory evaluation of TASO services from August 1993 over a 1-year period. An evaluation steering committee provided guidance to the study and a TASO core evaluation team was formed to implement the evaluation.

This article summarizes the method and results of this participatory evaluation process, where both care providers and beneficiaries assessed services. The approach ensured the involvement of those offering services (TASO staff), those receiving services (PWAs and their families), as well as those relating to TASO on a formal or informal basis (TASO Centre board members, donors, community members). These groups, to differing extents, took part in the design, data collection and analysis, and also the interpretation of the findings. It is the belief of TASO that even though the objectivity may appear to have been partially compromised by the participatory process, the gains in acceptance of the findings for programme strengthening more than compensated for the risk of bias due to staff involvement.

Overview of AIDS care services

Counselling in developing countries

Counselling is provided for PWAs because it has been observed that HIV/AIDS is associated with severe emotional stress, and counselling is seen as an appropriate means of providing the necessary support to allay this stress. Emotional support and disease acceptance has been reported to be worse for PWAs than for patients with other diagnoses (Baker & Seager, 1991). Such responses to HIV/AIDS could justify a personalized confidential counselling model.

Since TASO was founded by individuals who were directly or indirectly affected by AIDS, the TASO model reflects what those affected desired to have done for themselves and/or their loved ones: 'Some of those working with TASO are antibody positive. The warm relationship they have formed with one another and their clients, their capacity to listen is born of shared experience of pain, of loss, of stigma, of isolation' (Seidel, 1988).

TASO uses a one-to-one counselling approach. Although this model of counselling has largely been accepted by most health and social care providers in Africa (Lie *et al.*, 1994), it

is still a much-debated subject. There is increasing support in some rural socio-cultural settings (Seeley *et al.*, 1991) for a family-focused rather than a one-to-one approach. In an African setting serious problems are usually discussed in the extended family with a caring and supportive person who is respected and expected to understand the circumstances better. The TASO model promotes the idea of involving the family, but only as an extension from and after the consent of the person infected. This can include the inner family members and eventually the neighbours or community members (Kalibala & Kaleeba, 1989).

Although the TASO evaluation did not analyse the nature of emotional problems of PWAs in Uganda, other reports (Mukisa, 1990) indicate that such problems manifest as anxiety, loneliness, depression or a wish to die. HIV/AIDS is a condition which is emotionally loaded and as such it has been associated with high levels of psychosocial distress including denial, blame of others for the infection and hopelessness about the future (Peltzer *et al.*, 1989). Reports suggest that provision of psychological support and restoration of hope is associated with improved quality of life (Camara *et al.*, 1990; Mukisa, 1990; Schopper *et al.*, 1996).

Counselling has been reported to play a positive role in sharing of serostatus (Mukisa & Rubagiza, 1991). Muhongayire & Raynaut (1994) observed that in their study cohort, the women who denied their HIV-positive results altogether were those whose material, psychological or family situation were clearly the least capable of supporting such an announcement. Thus, divulging HIV results may depend on the assurance of social support, as much as on the effectiveness of counselling received in relation to learning one's test result. Other studies indicate that the high level of fear to reveal serostatus is related to fear of spousal abuse, rejection and eventual divorce (Maggwa *et al.*, 1990; Meursing & Sibindi, 1995). In recognition of the necessity of the social support network, TASO services, and those of a number of care organizations provide counselling to not only the individual client but to their family as well.

Counselling also deals with the reality of an uncertain future. The need to plan for survivors is reportedly a frequent cause of stress for PWAs. For example, education, food and shelter are among the most commonly-expressed concerns of PWAs for their children. In TASO, social support, such as material goods and financial help, has also been added to counselling services to facilitate the coping abilities of counselled clients. The TASO evaluation thus examined the social support needs of the clients and families, and whether those needs were being met.

AIDS services in hospitals and homes

The TASO model of an NGO-supported clinical service for PWAs, provided along with counselling and social support, has been promoted and put into practice in many African countries.

There are some historical reasons for specialized AIDS clinics. The AIDS epidemic started at the time when most of the African states were undergoing harsh economic situations, with declining abilities to maintain the necessary infrastructures and to provide salaries and supplies for the health sector. Existing services were poor, hence TASO offered special services on hospital premises, in addition to normal hospital services. It is now realised that much care can be provided in complementary settings (WHO/GPA/HCS/95.14). The family unit plays a major role in care of PWAs (Ankrah, 1993), hence the importance of providing them with adequate information and knowledge on care of PWAs in the home. The burden of AIDS care, as with other chronic illnesses, will increasingly fall on families, especially as hospitals become less able to cope with numbers and as long as families are

willing to care. Home care programmes have mushroomed and are convenient for both the care providers, the patients and their families. However, the quality of these programmes can only be sustained with external input. Most are already overwhelmed by the growing number of patients. The coverage of these programmes is also limited, with research studies showing that only patients within a certain catchment area of home care programmes are within reach of services (Chela *et al.*, 1994; Ndyabangi *et al.*, 1995; Woelk, ongoing study).

Health care workers have reported that caring for AIDS patients is more time-consuming and stressful than caring for patients with other diagnoses (Kalibala, 1995). Thus, even without the unfavourable socio-economic setting of Africa, AIDS-associated stress and stigma are bound to affect the relationship of PWAs with health care providers. PWAs may avoid or reduce stigma by concealing the diagnosis of HIV or of associated illnesses. With declining health, PWAs and their families avoid outside contact. At more peripheral clinics, dispensaries and health centres, it has been observed that HIV status is rarely mentioned between PWAs and health care staff (Friesen, 1993, unpublished). If conditions are perceived to be HIV-related, patients bypass these facilities and go to district hospitals.

Due to the difficulties experienced by health workers in handling HIV/AIDS and the shortages of ordinary medicines, access to clinical care by PWAs could not be assured. This has probably been the major driving force behind the formation of specialized HIV/AIDS clinics in some countries in sub-Saharan Africa and certainly was the driving force for TASO to provide AIDS-specific medical services.

Social support services

In Uganda the problem of needy children affected by HIV/AIDS is enormous and will continue to grow in the foreseeable future. In a World Vision-commissioned baseline survey it was observed that in Rakai District, Uganda, 43% of households were caring for 3–5 orphans, 18% were caring for 6–10 and 35% were caring for more than 10 (WHO/GPA/TCO/HCS/94.7). Children's problems begin long before a parent dies of AIDS. With the parent's illness, family income falls and even meagre resources are diverted to modern and traditional treatments. As a consequence, resources are lacking for children to start or to continue going to school.

AIDS appeared on the scene when the African economies were already battered by political and social strife and when families were barely able to fend for themselves. A direct impact of AIDS is to decrease economic resources. Therefore, some families need help in order to care for AIDS patients. Based on these observations it has become routine for AIDS care programmes to incorporate some kind of social support package for PWAs and their families. This package varies but usually consists of one or the other of the following: bedding, clothing, school fees, food, income-generating activities (IGAs), day centres, cash, etc.

Although economic needs of PWAs were a factor in coping with their condition, income-generating projects for PWAs need to be carefully undertaken, if at all, through feasibility studies and in collaboration with other organizations experienced in small-scale projects in developing countries.

Methodology

Sampling

A TASO client is defined by TASO as one who has been confirmed as being HIV-positive

or having an AIDS-related illness and who has registered with the organization after self-referral, or referral from a health institution. TASO services, however, are provided to the client's family and to other people who walk in to seek counselling and information about HIV/AIDS. The sample was drawn from those who were registered with TASO as clients between the period of January 1991 and March 1993 ($n = 4,000$). The TASO core evaluation team compiled a list of these clients and their family care-givers. Among these 4,000, convenience sampling was used to select every fourth client who happened to come to the clinic within a period of 3 months, to be enrolled into the study and be interviewed as they arrived at the TASO centre. Those clients among the 4,000 (and their family care-givers) who were unable to attend TASO clinics were interviewed during home visits.

The final study population consisted of 324 clients who were currently attending TASO clinics, 322 clients who were visited at home and 74 client drop-outs who no longer used TASO services. A total of 232 family care-givers of clients were also interviewed.

In addition, clients used a checklist to gather information from other clients regarding use of TASO services and safer sex practices. Two case studies were conducted with a male and female PWA, selected as typical clients, one from a rural area and the other from an urban area. Focus group discussions were held at each TASO Centre for male and female clients, counsellors, counsellor supervisors and community representatives. A total of 24 key informant interviews were conducted and 49 counselling sessions were observed by counsellors to determine what topics were covered.

Data collection

Participatory study and potential for bias. A primary objective of the participatory study was to evaluate services offered. While a participatory evaluation has the advantage of including providers and users in assessing services and jointly planning for improvements, a disadvantage is the potential for biased information.

The participatory nature of the TASO evaluation meant that staff and clients took part in data collection and analysis, leading to possible biased responses in favour of the programme. The evaluation did not include a comparison of non-users of TASO services, or comparison among the 7 TASO centres, or other AIDS-related organizations providing services similar to those of TASO.

An attempt was made to address the issues of validity and reliability by emphasizing the need for interviewers to conduct the interview during a normal counselling session in which the questions were discussed and the recorded responses were the result of this discussion. In addition, combined sessions were held in TASO centres with key evaluation participants to validate findings from the different data sources. An attempt was made to standardize the structured questionnaire and to reduce error through a process of translation and back-translation into the relevant local languages.

As part of the participatory process, evaluation results were discussed with all TASO centres for clarification and interpretation of the meaning of the results. Such a process enabled each centre to identify with and accept the study results, and to actively participate in formulating and implementing recommendations.

Data collection methods. TASO counsellors and supervisors collected data in all 7 TASO centres over 3 months beginning August 1993. Information was collected during normal delivery of services throughout the study, thus minimizing disruption of services. Informed

consent was obtained before each interview. Interviewers were trained in conducting interviews and carrying out focus group discussions in the local languages.

The evaluation used a combination of data-gathering methods consisting of semi-structured interviews, open-ended interviews, focus group discussions, checklist, guidelines and case studies. This combination was intended to provide data of different types for a reliable and accurate understanding of the services under investigation.

(a) Semi-structured interviews

The interviews designed to last about 60 minutes were administered to clients and caregivers. Client interviews centred around medical, counselling and social support services, and safer sex practices. Family caregivers were interviewed about their source of information on care and the type of home care they provided to clients.

(b) Open-ended interviews

Key informant guidelines were developed for obtaining information on TASO and other AIDS-related organizations and health facilities, constraints in service provision and possible solutions.

(c) Focus group discussions

Discussion guides were developed on medical, counselling and social support services, and safer sex practices. Data were collected from clients, counsellors and community representatives. Discussions with community members also included their responses to PWAs.

(d) Client checklist

As part of the participatory evaluation process, clients developed a checklist of key items they wished to ask other clients. The list included condom use, number of sexual partners and use of TASO services.

(e) Guidelines for observing counselling sessions

These concerned the content of counselling sessions and whether these sessions covered safer sex practices, coping with infection and diseases and planning for the present and future by clients.

(f) Case studies

Two case studies were carried out to provide in-depth, detailed information on living with HIV/AIDS. The subjects, one male and one female, were not chosen by a formal sampling process: rather, they were selected because they exemplified and presented issues of revealing serostatus, living with HIV/AIDS and using services such as those offered by TASO.

Data analysis

Quantitative data were entered for computer analysis using the statistical package Dbase III and imported into EPI Info for analysis. Quantitative data were primarily analysed by means of simple frequencies. Qualitative data from notes and audiotapes were compared for accuracy and completeness. Data were then compiled using WordPerfect 5.1 word processing programme and imported into Text Base ALPHA for further analysis which included categorizing data, identifying variables and summarizing findings. The quantitative and qualitative data were then compared for consistency.

Results and discussion

Sample characteristics

The majority of the client respondents were females (68%), which reflects the gender ratio of TASO clients. The average age of respondents was 32.3 years. Forty-one per cent were widowed, 29% married or cohabiting, 19% separated or divorced and 11% were single. Fifty-one per cent had obtained 7 years of formal education, 29% had 11 years of education, 13% had no formal education and 7% had more than 11 years of education but without reaching university level. Only two clients had university education.

Occupational groups were peasant farmers (26%), business or skilled workers (26%), unemployed (23%), unskilled workers (12%) and other kinds of workers (13%). The majority of clients lived within a 10-mile radius from a TASO centre.

The family caregiver respondents had similar demographic characteristics. The majority were females (86.2%), of whom half had 7 years of education (50.5%) and were either farmers (37%), unemployed (21%) or were unskilled workers (16%).

Counselling services

For the purposes of the evaluation counselling was defined as a dialogue between a counsellor and a client during which issues are discussed, options are examined and possible plans for coping are made. The relationship between a client (and family) and a counsellor is continuous and on the average a client receives one counselling session per month.

Coping of clients and families. Coping was defined by the staff and clients to be an acceptance of being HIV-positive and having a positive attitude toward making the most of each day. In 23 (46.9%) of the 49 observed counselling sessions, the following coping mechanisms were addressed: acceptance of being HIV-positive; revealing serostatus to spouse and family; continuing to work and self-care. In the focus group discussions, clients indicated that TASO counselling and drama groups for social contacts provided them with emotional support. The drama performances depict different scenarios of living with HIV/AIDS, with the aim of creating awareness among the communities, increasing acceptance of PWAs and boosting their coping capacity. Case studies contained in the full report illustrate clients who are 'living positively with HIV' and who have been helped to cope by TASO. One client said:

TASO has helped to reduce thoughts and helped to realise that I am not alone ... and I am still useful.

In concurrence with findings elsewhere (Chaava, 1990; Sittitrai & Williams, 1994), the evaluation of TASO has indicated that counselling PWAs can be provided along with health services, and that it enables a discussion of emotional problems which makes them feel better and helps them to gain the strength to cope with HIV/AIDS. The evaluation suggested that counselling, as is currently provided by TASO, is an appropriate response to the emotional needs of PWAs and their families. However, during the focus group discussions with TASO counsellors they mentioned their own emotional stress and the difficulties of lack of knowledge of medicine and basic nursing care, even though clients expected this kind of service from them, as well as difficulties in counselling discordant couples on condom use and pregnancy.

Revealing of serostatus. Most (90.4%) of the sampled TASO clients reported to have revealed their serostatus. There was no statistical difference in those revealing their serostatus by either gender or marital status. Such a high proportion of those revealing their serostatus is rarely reported. Perhaps this is due to repeated counselling sessions over time.

Among TASO clients a high level of acceptance in families (79%) and in communities (76%) was reported, although fear of stigma was the main reason given by 58% of those who had not revealed their serostatus. These findings seem to suggest that the TASO counselling model enables individuals to cope with their HIV status, and that this enables them to inform those of their social circle who are likely to provide individual support.

In the TASO sample most clients (85.3%) reported revealing their serostatus to relatives other than household member or spouse/partner. While over 67% of clients revealed their serostatus to household members, fewer (36%) revealed their status to spouses or regular partners. This suggests the sharing of emotions over a broader family and community network. But it could also be due to the fact that 41% of the respondents had been widowed.

The TASO study suggests that, with consistent counselling and opportunity for social contact and emotional support, clients are more willing to share their serostatus, particularly with their relatives. The high level of family (79%) and community acceptance (76%) of PWAs may be due to the high level of awareness of HIV/AIDS in the community (Moodie, 1991) and, in turn, the high level of acceptance of PWAs in the community may also encourage revealing of serostatus to relatives.

Thus, unlike reports from elsewhere, the TASO counselling model appeared to enable the majority of PWAs to reveal their HIV serostatus to someone. However, as consistent with other studies (Lie & Biswalo, 1996), the TASO evaluation clearly indicated that the spouse or regular sexual partner is not the confidant of choice for sharing serostatus of many PWAs.

Knowledge and practice of safer sex. One of the aims of the TASO counselling model is to enable clients to evaluate personal risk of HIV transmission and facilitate preventive behaviour. Indeed, counselling sessions are used to discuss issues related to safer sex practices and to reinforce clients' behaviour. In the TASO evaluation, of the 49 counselling sessions observed, 39 (79.6%) addressed safer sex practices. Of the 730 client respondents, 68.2% knew all four major modes of transmission: unprotected sexual intercourse with an HIV-infected person; infected mother to infant; transfusion with infected blood; and sharing infected skin-piercing instruments. Most clients (98%) knew about HIV transmission through unprotected sexual intercourse. The most frequently-reported knowledge of safer sex practices was condom use (85%) and abstinence (39.4%).

The most commonly-reported current safer sex practices by males and females included abstinence (45%) and condom use (33%). Use of condom was mentioned more by males (48%) than females (26%), while abstinence was more frequently mentioned by females (56%) than males (28%). However, it should be noted that abstinence may be a temporary, rather than a permanent measure.

Although 19.7% of the respondents cited faithful monogamy as their method of choice to prevent transmission, the perception of most clients was that monogamy without using condoms was not safe enough. One client stated: 'I got married to my husband in 1962 and I have never had sex with any other man, but here I am infected with HIV from him'. Community members called on TASO to strengthen its preventive role, as well as care: 'TASO should come out with programmes of educating the public instead of waiting for people to get infected and counsel'.

Data on abstinence may be more difficult to interpret. In a 1992 survey in a Ugandan

community at Kasangati (Konde-Lule & Sebina, 1993), 35% of the respondents reported not to have had any sexual relations in the previous 6 months. It is not clear whether the reported abstinence in the Kasangati community was a conscious choice of safer sex practice or a reflection of general sexual behaviour; however, among TASO clients it was reported as a conscious choice.

Of those reporting use of condoms, most (81.3%) started using condoms after joining TASO. Over half (57.2%) reported consistent condom use in the previous 3 months and 74% in the last sexual encounter. Reasons for consistent use of condoms were to prevent HIV re-infection, infecting others, pregnancy and STD infections. Discussions with clients revealed that those with irregular sexual partners had higher bargaining power for condom use than those who were married or had regular partners. Of the 42 respondents who did not use condoms in the last sexual encounter, 14 were female. Only two of the female respondents reported asking their partners to use a condom.

The rate of condom use by TASO clients (49.6% ever use and 33% current use) is higher than in a general community in Uganda (10% ever use—Konde-Lule & Sebina, 1993). Some reports from Zambia (Ndawa *et al.*, 1990) tend to agree with TASO that previously-counselled clients are using condoms more frequently.

Planning for the future. As part of coping, TASO clients are encouraged to make plans for themselves and their families. In over half of the counselling sessions (55.1%) clients discussed plans for starting income-generating activities, making a will, building/repairing a house and continuing to work and educate children. Of the clients interviewed, 56.9% had made specific plans for the future, a remarkable percentage in view of the disadvantaged socio-economic environment.

In Uganda making a will is usually viewed as a man's responsibility. In addition the general poverty and the concern that a will is potentially disruptive to the family are some of the factors which may hinder most clients from writing wills. Wills were discussed in the observed counselling sessions by 39% of TASO clients, with 51.3% of clients expressing willingness to make wills. However, only 16.8% had made wills. Some clients indicated that there was no need to make a will as they had nothing to pass on (22.3%). Other findings indicate that writing wills remains a difficult task. In Zambia, in a review of 55 PWAs, only 7 (12.7%) had written legal documents relating to their property (Ndawa *et al.*, 1990).

Medical and home care services

HIV-related symptoms and treatment. TASO provides care for its clients by operating weekly clinics where diagnosis and treatment of opportunistic infections and symptomatic relief are provided. TASO is used by clients almost to the exclusion of other health services, which places a burden on the organization. The average monthly clinic attendance in the first quarter of 1994 varied from 260 in TASO Mbale to 1377 in TASO Mulago, having more than doubled since 1991. Over 80% of clients sought early treatment, that is, within 2 weeks of onset of symptoms. The most frequently mentioned symptoms were fever (60%), cough (45%), continuous diarrhoea (32%), sores on the inside of the mouth (18%), weight loss (14%), swellings on the neck (10%) and herpes zoster (6%). None of the clients mentioning symptoms reported being hospitalized.

TASO was cited as the major source of health care in the previous month by 63.8% of the clients. Other sources of medical care used by clients to a lesser extent were private practitioners (18.3%), public health services (16.2%), family (10.5%), pharmacist (9.0%)

and traditional healer (4.1%). TASO was also cited by 75.2% of clients as the most helpful source of medical care. Twelve out of 14 focus groups indicated satisfaction with TASO medical services. The appreciation by clients of the subsidized medicines indicated the importance of availability of medicines for PWAs in treating HIV-related symptoms.

Of the 74 clients who dropped out, 65% gave the reason that they were not sick, with 16% mentioning that they lacked transport and 16% went elsewhere. Other comments indicated some were fearful of being recognized, and others had alternative access to nearby treatment centres.

Family caregivers. TASO was the main source of information on AIDS care and prevention for family caregivers (31.8%) and clients (68%). There was no significant difference in knowledge on HIV between clients and family caregivers.

Of those clients sampled at home, 49.4% were on medications. During questioning, 57% appeared to be taking the medicines correctly. Family caregivers knew how to make sugar-salt solutions from home ingredients (50.7%), while 78.6% knew how to use ready-made sachets for treating diarrhoea.

Women still bear the greater burden of home care. Of the 232 family caregivers interviewed, the majority were females (86.2%), most of whom were either mothers of clients (26.3%), sisters (18.5%) or daughters (15.1%). Spouses or partners of clients comprised 12.1% of family caregivers. These figures confirm the sad reality that in an African family the woman bears the burden of caring for the sick and that when she is sick herself, another woman (daughter, sister or mother) is recruited to bear this burden. Health workers should educate and encourage both men and women to be involved in giving care.

While this study indicates that the majority of families were providing care for their loved ones it should be noted that, in Uganda, most families do not have adequate resources to care for their own sick. Given the slow response to treatment and sometimes long period of care needed by persons with AIDS, family expenditure on medicines—both traditional and modern—as well as food, supersedes the family income (Ankrah, 1993).

Home care services. Families are providing physical care (changing bedding, giving medicines at the right times and providing food). In addition to the prompt seeking of care by clients for HIV-related symptoms, the TASO medical team provide care to bedridden clients in their homes which may minimize the need for hospital care.

Ways of linking hospital care to home care through appropriate referral and greater involvement of communities in care of PWAs need to be identified. For example in TASO, home care services are restricted to a 20 km radius from a TASO centre, which limits the coverage. TASO through its community initiatives is pilot-testing the idea of more involvement of community members in the provision of medical care and social support to PWAs.

Apart from TASO, the community has an important role of providing emotional support to PWAs and their families. Views from family caregivers and the community were that a PWA should be cared for at home by a close relative in order to 'avoid negligence in hospitals ... provide basic care to the patient and ... avoid expenses'. Clients (57.1%) also viewed family members and relatives as the major family caregivers at home. Beyond the family unit, TASO was the major source of extra help according to 71.3% of the family caregivers interviewed.

Social support services

Material support to PWAs and their families. The importance placed on material assistance and support for children's school fees by clients reflected the poor economic conditions of the population currently served by TASO. Material assistance provided by TASO consisted of basic foodstuffs (rice, oil). These supplies were irregular and dependent on donations.

A third of clients and family caregivers considered financial assistance as a main need. On joining TASO, 34% of the sampled clients expected material assistance. Of these clients, 56.2% reported that this need had been met by TASO. Slightly less than half of clients interviewed (48.1%) mentioned that provision of material assistance would improve their care at home. Of the family caregivers interviewed, 23.7% mentioned material assistance as important in the care of their patients.

Day Centre activities for PWAs. Of the sampled respondents, only a small proportion (8.6%) were members of the TASO Day Centre. The majority of these (81%) were female. The main benefits of attending the Day Centre were sharing experiences with one another (95.2%) and learning skills to earn a living (84.1%).

While clients acquired skills in crafts and benefited from sale of handicrafts, a major benefit from the Day Centre was the emotional support of sharing experiences among PWAs. There was also potential for support groups to be formed in the communities for a larger number of PWAs.

The majority of clients sampled (60%) mentioned the need for capital to start income-generating projects. Eighty-one per cent ($n = 25$) of the clients with projects completed them. Of the 75% of clients capable of paying back to the revolving fund, 12% actually repaid their loans.

In spite of the intentions of TASO to assist clients financially and to promote self-reliance, the low repayment rate of loans by clients indicated the general difficulty of making small projects viable. The majority of clients were not self-sufficient at the completion of their projects. Factors contributing to the low performance of the income-generating projects included low start-up capital, inadequate technical support, lack of a clear policy towards funding of projects and the uncertain health condition of clients.

In Lusaka a group of care providers from east and southern Africa met in January 1994 and wrote a declaration proposing that relief aid, though at times necessary, should be short-term and limited to critical circumstances in order to avoid family dependence on such grants (WHO/GPA/TCO/HCS/94.7). In the Lusaka declaration it was observed that failures in income-generating activities (IGAs) are due to lack of feasibility studies (e.g. outlet analysis) and lack of training on project proposals and planning. It was noted that families affected by HIV/AIDS experience great difficulty in implementing IGAs and that communities should be involved in implementing and monitoring IGAs, with the support of NGOs.

Needy children of PWAs. In the beginning TASO identified school fees payment for needy children of PWAs as a priority. Nonetheless, due to limited funding, out of 1,957 children assessed as needing assistance with school fees, TASO was only able to provide fees to 370 (35%) to cover 7 years of primary education. It is therefore apparent that paying school fees for a few of the needy children may only be a short-term option. Probably, in situations where whole communities are impoverished by AIDS and other calamities, supporting whole primary schools may be the long-term answer. In Kyotera, Uganda, World Vision has

undertaken to rebuild a once-collapsed school. Of the 250 pupils in this school 210 are orphans (WHO/GPA/TCO/HCS/94.7).

Conclusion

This study evaluated services offered by TASO, a non-governmental organization, in providing counselling, medical and social support to PWAs and their families. Findings indicated that the clients, their families, TASO staff and communities acknowledged that TASO services were being received by those in need. The services were ranked high in addressing the needs. The provision of TASO services was also perceived as instrumental in bringing about family and community support, as well as positive behaviour change in sexual practices and in seeking early treatment for opportunistic infections.

In general, ongoing counselling appeared to assist PWAs in coping with their situation and families in accepting and providing care to people with HIV/AIDS. However, it was noted that more effort could be placed on involving the spouses and partners of the clients in counselling sessions, especially discordant couples.

The evaluation helped TASO to look at itself critically and to question some of their programme assumptions, for example:

- Should TASO continue to provide services in all areas because of need, even if TASO is not best qualified to do so?
- Should TASO keep expanding to attempt to fill the needs, or should TASO define its limits and link with other health and social service providers?

This study helped TASO move ahead to concentrate on their areas of success, such as counselling and clinic services, and phase down less successful areas such as IGAs and school fees. In addition, the study yielded joint recommendations to strengthen the services:

- TASO should broaden its programme, using counsellors, community workers and PWAs, to sensitize religious leaders about care and support and positive living.
- Counselling should emphasize revealing of serostatus to spouse/partner in order to enhance coping, make support possible and enable behaviour change.
- Counselling for infected people should reinforce consistent use of condoms, even in faithful monogamous relationships.
- Counsellor training should address how to deal with emotional fears about making wills and how to help women and children handle legal and social problems related to property.
- Early diagnosis of opportunistic infections, including tuberculosis, and compliance with treatment should be strengthened.
- All TASO health care staff should be trained to teach clients and families about home care, correct use of medicines and when to seek help.
- TASO should facilitate the capability of communities to contribute towards the care of PWAs, such as community contributions for medicines and enabling community member to provide emotional support to PWAs and their families.
- TASO should establish linkages with social welfare services and NGOs in order to refer clients for material support.
- The drama group should be assisted by professionals to develop skills to deliver information on HIV/AIDS and to enable them to earn an income at the same time.
- A major evaluation of TASO services should be carried out every 3 years, using the present evaluation study as a baseline.

And lastly, the study helped TASO establish a consistent rational monitoring system, based on uniform simple forms. This system is already yielding information that helps each centre analyse their progress measured by key indicators, and helps supervisors, organizers and donors identify the strengths and weaknesses and make decisions about use of funds, setting priorities and finding the way forward.

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Notes

A copy of the report *TASO Uganda—the inside story* is available from TASO (for within Uganda): The Director, TASO, P.O. Box 10433, Kampala, Uganda. Tel. 256 41 231138; Fax 256 41 251982; or from UNAIDS (please quote ref. WHO/GPA/TCO/HCS/95.1): UNAIDS, Documentation Centre, World Health Organization, CH-1211 Geneva 27, Switzerland. Fax 41 22 791 4187; E-mail: UNAIDSDOC@WHO.CH (Internet).

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