

Palliative Care Guideline for Volunteer Nurses

At the Rubingo Medical Aid Station

By

Necia Dorene Kaechele

BSN, University of British Columbia, 2001

A Project Submitted in Partial Fulfillment of the Requirements for The Degree of

MASTER OF NURSING

in the School of Nursing, Faculty of Human and Social Development

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University of Victoria

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Supervisory Committee

Dr. Anne Bruce, (School of Nursing)

Assistant Professor, Supervisor

Dr. Anita Molzahn, (School of Nursing)

Professor, Committee Member

Dr. Joan McNeil, (School of Nursing)

Assistant Professor, External Committee Member and Chairperson

Supervisory Committee:

Dr. Anne Bruce, (School of Nursing)

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Professor, Committee Member

Dr. Joan McNeil, (School of Nursing)

Assistant Professor, External Committee Member and Chairperson

#### Abstract

The devastation of AIDS has brought recognition of the need for end-of-life care in Uganda. Despite the fact that palliative care is included in the national health plan, access to care in the rural village is lacking. The Rubingo Medical Aid Station provides basic health care to a small village staffed by Canadian volunteer nurses. During a two month volunteer period, information was obtained by interview, observation, listening to stories, and working at the Aid Station. A palliative care guideline on accessing care, delivering nursing care, and managing symptoms was developed for this rural village.

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*“If someone is condemned to a premature death  
because of the injustice of global health inequality,  
it is doubly unjust  
for that person to be condemned  
to an agonizing death  
racked by pain.”*

Peter Singer and Kerry Bowman, 2002, p.1291

Palliative care is young in Uganda. The country is poor and up to 10% of its 29.9 million people have AIDS (Jagwe, 2002; World Bank, 2008). Healthcare is limited and access, especially in the village, is difficult. Hospice Africa recognizes the need for palliative care and has three facilities, each providing care to those in their area, however that leaves much of Uganda with very limited support.

My purpose in this project is to develop a palliative care guideline for volunteer nurses at the Rubingo Medical Aid Station in Uganda, East Africa. This Aid Station is a small, two-room mud hut, staffed by an Ugandan Nurse Assistant and, at given times, volunteer nurse/nurses from Canada. This non-profit medical station is in the rural village of Rubingo, approximately a two hour drive (in good weather) from the town of Mbarara, in Southwestern Uganda, and is operated by Africa Community Technical Service (ACTS).

ACTS is a non-government Christian Canadian organization, working in cooperation with the Church of Uganda, with its head office in Comox, British Columbia. The main purpose of ACTS is to provide fresh clean drinking water to local villages. The organization also provides training to local community members on health, sanitation and the environment. At the Rubingo Medical Aid Station, ACTS also offers first aid, a limited number of medications, and basic health care.

Volunteers with ACTS are provided a general orientation to the culture, area and people prior to departure to Uganda. At present there is no guideline, policy, or procedure manual for the Medical Aid Station. A guideline would assist volunteer nurses, once at Rubingo, to orientate to the area, promoting more effective and efficient health care to palliative patients serviced by the Medical Aid Station.

In order to understand the lived experience of palliative patients and their families in Rubingo, I spent two months in Uganda, volunteering at the medical station. During this time, I observed clients and families at the aid station and in the village. I listened to their stories and concerns and held informal discussions. Field notes were taken and I recorded my own thoughts on a tape recorder. I interviewed the nurse assistant and volunteer nurses and I visited Hospice Uganda in Mbarara, spending a day following a palliative nurse in the community. Ethics approval was sought and obtained from the University of Victoria for this project prior to my departure. Once home, data was transcribed and reviewed qualitatively. Themes were identified. Information was then compiled into a guideline for the Rubingo Medical Aid Station.



(University of Texas Libraries, 2007)



## Chapter One: Background and Literature Review

### *Historical and Political Background*

#### *Uganda*

Uganda is a landlocked country slightly smaller than the state of Oregon with a population of almost 30 million; 50% of the people are under the age of 15 (WHO, 2008). Uganda has a long history of wars between ethnic groups, rebels, militias, and government forces, both within its own borders and with its neighbors (WHO, 2008). It gained independence from the United Kingdom in 1962 and came into the news during the dictatorship of Idi Amin (1971-1979) who was responsible for the deaths of some 300,000 Ugandans who opposed him (Columbia Encyclopedia, 2007). Another 100,000 lives were lost to guerrilla war and human rights abuses under Milton Obote's reign, 1980-1985 (United Nations, 2007). Today, under President Museveni, it is generally peaceful; only the northern areas of Uganda remain unsettled due to rebel groups (Clarke, 2004; Columbia Encyclopedia, 2007).

English is the official language of Uganda, and is taught in grade schools; however, there are numerous native dialects used throughout the country. Christianity is the most common religion at 80% of the population, 10% are Muslim, and traditional religions comprise the remainder (Encyclopedia Britannica, 2008).

Agriculture is a major industry employing over 80% of the work force (WHO, 2001). Nevertheless, subsistence farming is common and the United Nations (UN) reports an estimated 35% of the population in 2001 lived below the poverty line. Drought, distribution problems, as well as lack of security in the Northern areas, have led to increased malnutrition (Uganda, 2003).

Economically, Uganda is a poor country. In 2000, Uganda was one of the first countries to qualify for international debt relief under the world's most heavily indebted poor countries (HIPC) initiative (Katsouris, 2000). Over the next few years the economy showed improvement; however, due to continued involvement in a war with the Congo, lack of government determination to press reform, and widespread government corruption (Inspectorate of Government, 2003), there is concern whether the economic growth will continue. The WHO (2001) reports that the average annual income has recently reached \$300, a much higher level than in the 1980s, but it is still half of the average Sub-Saharan African income.

The Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) epidemic, which has devastated much of Sub-Saharan Africa, was first recognized in Uganda in 1982. Eleven years later, the incidence of HIV infection had peaked at 30 percent (Merriman & Heller, 2002, WHO, 2001). In 1988, President Museveni recognized HIV as a problem and brought about an educational and prevention campaign through schools and churches, reaching the village and community level. While some government documents are available for descriptors of epidemiological concerns, there is little independent research or publication that addresses palliative care services in Uganda. For this reason, I have relied on published interviews with Dr. Merriman. Merriman is a distinguished physician in the field of palliative care working and teaching in England and several African countries. She was the first medical director of Nairobi Hospice in Kenya, the founder of Hospice Africa, and received the 2001 Individual Award by the International Association for Hospice and Palliative Care for her achievements and leadership in end of life care worldwide. Merriman (Merriman

& Heller) states that Uganda had the highest HIV incident rate in Africa for about five years and is the first to show a decline in the epidemic. The prevalence of HIV is estimated at 6.7 percent (UNAIDS/WHO, 2007), and the majority are adults between 15 to 40 years of age, with over half being women (Jagwe, 2002; Merriman & Heller). Ninety percent of children infected with HIV contract the disease through mother-to-child transmission but Merriman and Heller state few get to a center where a diagnosis can be made, therefore it is difficult to know exact prevalence rates.

The most common cause of absenteeism from work now is attending funerals (Merriman & Heller, 2002). Merriman, in her role as medical director of Hospice Africa Uganda, states the majority of people dying are between ages 30-39 years, and have left behind two million orphans, the highest recorded number of AIDS orphans in Africa. Families are generally large in Uganda. Grandparents often look after the orphans and the extended community takes on this role when grandparents are absent.

Ugandans face many adversities in their daily living due to a combination of factors, all of which are underscored by poverty. Health care is not exempt. In a country vastly affected by HIV/AIDS, the need for end-of-life care may be assumed, but the ability to provide adequate care remains a challenge.

#### *Palliative Care in Uganda*

The World Health Organization (WHO, 2006) defines palliative care as an approach to improve the quality of life of patients and their families facing a life threatening illness through the prevention and relief of suffering by means of early identification, assessment, and treatment of pain and other physical, spiritual, and psychosocial problems. In Africa, Uganda is the first and only country to make palliative

care for people with AIDS and cancer a priority in its National Health Plan (Stjernsward & Clark, 2003). In a report by Spence, Merriman, and Binagwaho (2004), it is stated that in many African countries, governments give end of life care a low priority compared with preventative and curative diseases. Officials believe resources used on palliative care are often at the expense of those who may be cured. Health professionals may then be faced with the dilemma of choosing between saving lives and easing the suffering of the dying.

In Uganda, life expectancy at birth for males is 48 years and for females 51 years (WHO, 2006). The major causes of mortality are malaria, respiratory infections, and HIV/AIDS. The WHO (2002) estimates the number of deaths in Uganda, in the year 2000, from HIV/AIDS to be 84,000 and the number of deaths from cancer 10,500. However, Merriman and Heller (2002) claim it is difficult to get an accurate picture of HIV or cancer prevalence since the country does not require death certificates and over half the population does not access health care. In a recent study in Nigeria, Adenipekun, Onibokun, Elumelu, and Soyannwo (2005) report that worldwide cancer is on the increase and 60% of new cases are expected to be in the less developed countries. For instance, the incidence of Kaposi sarcoma has drastically increased with the HIV/AIDS epidemic (Adenipekun et al, 2005; Merriman & Heller).

In a report on end-of-life care in Africa, it is estimated that approximately 1 in every 200 people in Uganda need palliative care each year (Sepulveda et al., 2003). This is only considering those in the terminal stage of HIV/AIDS or cancer. Sepulveda et al. claim that when one considers those dying of other diseases, a more realistic total may be

double that number. Nevertheless, no studies were found on the need for palliative care for people dying of diseases other than HIV/AIDS or cancer in Africa.

*Care for the terminally ill.* Given the growing need for palliative care and the lack of resources, it is not surprising that access to care is a challenge. Unlike the Canadian system of publicly funded healthcare, the financial ability to pay affects the ability of Ugandans to receive treatment. Although the annual income is approximately \$300 per capita, 35% of the population earn less than \$1.00 per day (Kikule, 2003; Merriman & Heller, 2002). Putting that into context, Merriman and Heller explain that the Ugandan government and private donors contribute \$3.95 per year for medical treatment to each person in the country. The individual must pay everything beyond that. The cost of treating an episode of malaria, which is prevalent, is \$4. Thus, according to the authors, 57% of Ugandans do not access medical treatment other than traditional medicines.

Kikule (2003), executive director of Hospice Uganda, claims that only 41% of the population have access to basic health care. Foley, Aulino, and Stjernsward (2003) report 88% of the population in Uganda live more than 10 kilometers from any kind of health care facility and many of these facilities lack trained personnel and basic medical supplies and medications. In addition, Stjernsward and Clark (2003) state that with medical facilities scarce in many countries, the Westernized institutionalization of death has been avoided, retaining cultural, ritual, community, and family support systems at the end of life.

Alongside the scarcity of facilities, the number of physicians creates another challenge. Merriman and Heller (2002) state there is one doctor for approximately 19,000

people. However, that number is misleading as half of the doctors work in the capital city of Kampala. These authors claim in rural areas, the ratio is approximately one doctor per 50,000 people. Sepulveda et al. (2003) concur that the number of medical doctors is low in relation to the population size. Harding, Stewart, Marconi, O'Neill, and Higginson (2003), in a study on Sub-Saharan Africa, found that an estimated 80% of patients seek advice only from traditional healers.

In Africa, the primary caregivers of terminally ill patients are family members, with the burden of care not falling on any particular age group. In a study by Sepulveda et al. (2003), it was found in Ethiopia, Botswana, Tanzania, Zimbabwe, and Uganda that between 80-100% of caregivers were either the spouse, parent, or child of the patient. In countries where life expectancy is low, malnutrition is high, and poverty is rampant, carers have little or no education and may also be chronically ill.

For many Ugandans, it is culturally acceptable and preferable for people to die in their own homes and be buried in their household gardens. Kikule (2003), in her study of 173 terminally ill patients near Kampala, the capital of Uganda, states that most Ugandans prefer to die in their own homes with their family caring for them, even when they live within 5 km of healthcare services. Reasons included feeling safer at home, having more privacy, and convenience for friends and family to visit without the cost of transport. The WHO (2002), while assessing the Tororo District in Northeast Uganda, found that it was as acceptable to be cared for at home as in a health facility. This conflicts with what Adenipekun et al. (2005) found in Nigeria where hospice care was preferred to home care.

*Patient needs.* Kikule (2003) identified three main needs in Ugandan palliative care: the control or relief of pain and other symptoms, counseling, and financial

assistance for basic needs such as food, shelter, and school fees for children. In another survey of the needs of 29 terminally ill patients in Uganda, the need for pain relief was reported by 62%, followed by food (52%), relief of other symptoms (48%), family provisions (38%), and counseling (34%) (Sepulveda et al., 2003). Harding, Stewart, Marconi, O'Neill, and Higginson (2003) found that in order to address total psychosocial care for palliative patients, orphan care, income generation, and access to food must be addressed.

Pain was identified as the chief problem by over half the participants in Kikule's (2003) study. This is congruent with studies done in Kenya (Grant, Murray, Grant, & Brown, 2003; Murray, Grant, Grant, & Kendall, 2003) and the Sub-Saharan African region (Harding et al., 2003). In a study of South African HIV patients, pain was the most frequently reported problem (Shawn, Campbell, Mnguni, Defilippi, & Williams, 2005). Uganda, in 2004, made morphine available to districts that have specialized palliative care nurses, but Sepulveda et al. (2003) claim it is still insufficient for the need. The WHO (2006) promotes morphine as an inexpensive yet effective opioid in their pain relief ladder tool. However, in many African countries, it is not available. In a report by The International Observatory on End of Life Care (IOEOLC) (2005) it is reported that between the years 2000-2002, 29 countries show no morphine consumption. During those same years, Uganda recorded four defined daily doses per million inhabitants. This remains low when compared with other African countries: Swaziland 1; Egypt 2; Zimbabwe 13; Botswana 53; Namibia 73; and South Africa 103. Dr. Luande, a Tanzanian oncologist, laments, in his writing on the development of hospice care in

Tanzania, that “African cancer patients live the final end of their lives in more agony than almost anywhere else in the world.” (Hartwig, 2001, p. 122)

While pain control remains a challenge, in a study on quality of life for HIV/AIDS patients in Botswana, Lesotho, South Africa and Swaziland, the most significant predictor of life satisfaction was daily functioning (Phaladze et al., 2005). Those with the least life satisfaction had an impaired ability to carry out activities of daily living. A strong relationship between the intensity of disease symptoms and functional status was found. These authors found financial worries were the second largest predictor of life satisfaction.

Other issues in caring for palliative patients noted repeatedly in studies focusing on Uganda, Kenya and Sub-Sahara Africa include poverty and the lack of emotional support, nutrition, orphan care, clean water, shelter and sanitation (Grant et al., 2003; Harding et al., 2003; Kikule, 2003; Murray et al., 2003). Grant et al. (2003) report that patients feel guilty about sacrifices the family make, quoting one patient, “Money is being spent on me instead of school fees” (p. 165). Merriman and Heller (2002) and Kikule (2003) report school fees for children are a major concern for many dying parents. Although primary education is free in government schools, the community is expected to contribute to buildings and furnishings, therefore parents are required to pay fees. Uniforms are also mandatory, even in the villages.

In the WHO (2002) country report on Uganda, it appears that families generally bear the burden of caring for the terminally ill is supported. While patients report pain and symptom relief as the number one need, followed by food, provisions for the family, and counseling, the families report other needs. The lack of money for basic home



supplies such as soap, salt and antiseptic solutions is a major concern. Nursing a bed-ridden patient, lack of access to health centers, pain relief for the ill, and stigmatization from neighbors were other issues listed. In Kenya, Grant et al. (2003) also found that families struggle with guilt and anxiety due to lack of resources, knowledge, and their inability to ease the pain of the patient. Sepulveda et al. (2003) found a drastic decrease in income of farmers infected with HIV/AIDS. The authors report that as farmers became ill and family members spend more time looking after them, less time is available to work on the family crops. The family loses income and has to buy food they would normally grow themselves. Some people sell land or household goods to survive.

Grant et al. (2003) report that almost half of patients' relatives attempted to keep the news of terminal illness from the patient as long as possible. It was believed that by knowing the prognosis, the patient would quickly deteriorate and die. However, in discussing spiritual issues, all 32 patients in the study believed it unacceptable to expedite or even desire an early death, trusting God as the one who owns life and the one to decide when to take it away.

*Services provided in Uganda.* Despite the fact that palliative care is recognized in Uganda's national health policy, there are few in-patient services. The IOEOLC (2005) in their report on current services in Uganda, states that the Lira Regional Referral Hospital provides a one-bed facility as well as hospital support service, and home care service. The Joy Hospice at Mbale, in Eastern Uganda, provides a five-bed in-patient unit and home care service, and the Mildmay Centre in Kampala has an in-patient pediatric unit. Sepulveda et al. (2003) states homebased care is mainly provided by private organizations. For people with HIV, three organizations provide the majority of palliative

care services. They are The AIDS Support Organization (TASO), the Mildmay Centre, and Hospice Uganda (Kayita, 2002).

In their 2004 annual report, TASO claims to have 10 centres throughout Uganda (Coutinho et al., 2004). Their services include counseling, medical services - such as testing for sexually transmitted diseases and tuberculosis, anti-retroviral therapy (ARV), social support - such as food supplements, and HIV/AIDS education. Although the centers are each located in a city or town, TASO has started outreach clinics to take services closer to the people who need them in rural areas.

The Mildmay Centre is a partnership venture between Britain and the Ugandan Ministry of Health. It provides a clinical outpatient service for adults and children, an inpatient pediatric unit, as well as training programs for care providers (Kayita, 2002; Mildmay Centre, No Date). The Mildmay Centre is located in the city of Kampala.

Hospice Uganda was founded in 1993 and now operates three city based hospices, in Kampala, Hoima, and Mbarara, providing homebased care, a mobile clinic, training, and education in all areas of palliative care (IOEOLC, 2005). Care is provided to patients with cancer or HIV/AIDS. It is estimated that 75% of their cancer patients also have AIDS (Hospice Africa, 2005).

Hospice Uganda in Mbarara (the closest palliative care service to Rubingo, approximately 70 km away) provides home visits to patients within a 20 km radius of their facility (Hospice Africa, 2005). Those who live outside this range, after being assessed at the facility, may report back through their main caregiver. Patients are asked to pay 5,000 Ugandan Shilling (equivalent to approximately \$3 US) per week for service

and medications. However, those who cannot afford this are assisted through the organizations' comfort fund.

### *Nursing in Uganda*

Considering the lack of healthcare in Uganda and the difficulties with accessibility in many places, a nurse is often the only healthcare provider patients come into contact with. Sepulveda et al. (2003) state that in end-of-life care in Africa, nurses provide the majority of the healthcare workforce. Walusimbi and Okonsky (2004) researched the knowledge and attitudes of nurses working with HIV/AIDS patients in Uganda and claim that nurses working in regional hospitals represent the largest group of health care workers in the country. Despite that, professional nurses are often in short supply and frequently not available at the community clinic level; thus, care may be provided by workers with minimal training. Similarly, Stjernsward and Clark (2003) state that developing countries have only five percent of the world's resources (doctors, nurses, drugs, equipment, and funds), but two thirds of the world's disease burden.

Although there is a shortage of nurses, Uganda has a long history of educating nurses. In 1918, nursing education began with a midwifery program in the country. Walusimbi and Okonsky (2004) state that over the years it has developed to include a registered nursing program (2 years), psychiatric nursing, and a registered midwifery program (3 years). Public health nursing, teaching, and nursing administration are post-basic courses. Two new, four year curricula are now offered: the comprehensive nursing curriculum, focusing on community health including psychiatry and midwifery (Matsiki & Kiwanuka, 2003), and the bachelor of science in nursing, focusing on hospital nursing including primary care, midwifery and research (Makerere University, 2005). Hospice

Uganda (Merriman & Heller, 2002) provides palliative care training to health care professions at the Makerere University and the University Hospital in Mbarara. It also offers a distance learning diploma in palliative care for health professionals in distant parts of Uganda and other African countries.

In 2004, the Ugandan Ministry of Health changed a statute in law to allow palliative care nurses with specialized training to prescribe morphine (IOEOLC, 2005). This positive step moves Uganda to the forefront on a continent where many countries have no recorded morphine consumption.

While nurses and midwives are the frontline providers of care for HIV/AIDS patients, Walusimbi and Okonsky (2004) found they were often lacking in knowledge about the disease. The most commonly cited source for information about HIV/AIDS was the radio – reflecting the typical activity of listening to death and funeral announcements interrupted by commercial information about HIV/AIDS. The second source for information was workshops and seminars. The authors found that high levels of knowledge about HIV/AIDS was correlated with positive attitudes and less fear of contracting the disease.

There is little research on the experience of nurses in Uganda. However, the study conducted by Hewlett and Hewlett (2005) on Ebola outbreaks in Central Africa gives insight into the commitment of members of the nursing profession. The authors report that epidemics of Ebola hemorrhagic fever (EHF) affected the Democratic Republic of the Congo (DRC) in 1995, Uganda in 2000-2001, and the Republic of Congo (ROC) in 2003. Nurses, as frontline health care workers, were some of the earliest victims. Twenty percent of those that died in the DRC were nurses. Conditions were difficult and basic

infection control items such as bleach, soap, and gloves were frequently lacking. The authors state nurses and other health care workers were feared for having cared for those infected and many were shunned by their community, colleagues, and family, yet they continued to provide care. Some had their homes or property burned as people attempted to reduce the rate of transmission of the disease. Even though nurses were trained within a biomedical model, they often lacked proper training in precaution and barrier techniques. Hewlett and Hewlett report health care workers frequently worked without pay, or their salaries were delayed for months, sometimes years, and state that this is not an uncommon practice in Africa.

Hewlett and Hewlett (2005) found “local nurses in Africa tend to be embarrassed by their so-called traditional beliefs” (p. 291). Nurses often emphasized modern medicine but participated in local rituals. These authors found that many of the approaches of the traditional healers fit well with the biomedical model. For instance, when the firstline indigenous cures (herbs and traditional healers) failed to stop the EHF outbreak, the people of Uganda classified the illness as no longer a ‘regular illness’ - one due to lack of respect shown to a spirit - but a spirit that comes rapidly, like the wind, and affects many. The protocol then is isolating the patient, identifying the homes and villages affected, restricting gatherings of people, having survivors of the illness care for the sick, and burying the dead far from the village. This is not that different from a biomedical broad-spectrum approach. Hewlett and Hewlett state the nurses and people in the area affected by EHF integrated the cultural model with the biomedical model, purchasing antibiotics and other medicines. In this study, the authors identified the critical role local nurses can play in the control of disease outbreaks. Their understanding of the local culture and indigenous values, beliefs,

and behaviors combined with training in the biomedical model made them an indispensable resource for negotiating between the two philosophies during epidemic outbreaks.

No studies were found on the experience of volunteer nurses in Uganda. Most reports are anecdotal narratives from experience in various African countries. There is value, however, in understanding others' lived experience.

Christine Hancock (2006), as president of the International Council of Nurses (ICN), visited nurses in 20 African countries. She found conditions shocking – overcrowding in hospitals necessitated that two patients occupied each bed, and mattresses were on the floor. She understood why, for example, in Swaziland in 2005, 43 of the 100 graduating nurses immigrated to Britain, where hospitals were clean and supplies readily available. Hancock reports that AIDS is also affecting the nursing population. She states Botswana has lost 17% of its healthcare staff due to the disease.

Skeen (2005), a volunteer midwife from the United Kingdom who spent two years in Cameroon, found it difficult to adjust to the climate change, the isolation, and the slow pace of life. She was presented with disease, illness, and deformities she had only read about in textbooks, and found patients “expected to be given at least five drugs and hopefully an injection or drip.” (p. 6) Skeen reports the focus to be on treating symptoms, not finding the underlying disease. Despite finding lack of knowledge and resources, she also reports positives in the experience. Caesarean rates are low, breech presentations are seen as ‘normal’, and no one has to be convinced to breastfeed. Skeen states the sense of community is high and hands-on skills are excellent.

Gold (2004), a Wisconsin nurse, volunteered for 2 months in 2003 at a Catholic medical mission near Nairobi, Kenya. She found the doctors and nurses to be

“overworked and despairing in ways you can’t imagine” (p. 44). She saw patients with malaria, end-stage AIDS, and grossly infected machete wounds, and reported that the pharmacy stocked only four antibiotics. Gold reported that the goal was primarily to provide comfort but believes the people felt cared for. She claims daily life is hard in Kenya but finds the simplicity and gratefulness of the people rewarding. In her role as one of the volunteers she states, “[We are] always cognizant of being on a team, with the Kenyans our leaders, although they often defer to our judgment and skills. As their guests, not their saviors, we try to teach as much as possible and to never be judgmental.” (p. 44)

In summary, literature supports the fact that there is a need for palliative care in Uganda. The prevalence of AIDS, lack of medical personnel, difficulty in accessing medical care, and lack of available medications illustrate the need. Pain, finances and counseling top the list of patient needs. Although the government includes palliative care in its national plan and Hospice Uganda has made significant strides, health care at the village level remains minimal.

#### *Africa Community Technical Service*

Africa Community Technical Service (ACTS) is a Christian technical mission presently working in Southeastern Uganda. It began in 1972, with headquarters in North Vancouver; at that time, it was called the “Red Sea Desert Development Society”. It concentrated on providing drinking water to people far from towns in Yemen. In 1983, the name was changed to ACTS, and in 1994, the head office was moved to Comox, British Columbia. ACTS is a registered non-government organization (NGO) and continues to focus on providing clean and safe drinking water to rural villages, but

includes training in health, sanitation, and environmental issues. In the near future, ACTS hopes to participate in water projects in Tanzania, Kenya, and possibly Sudan (David Moore, personal communication, July 16, 2006).

ACTS (2004) volunteers work in cooperation with the Church of Uganda and are active in several projects. In 1992, at Lake Bunyoni, they partnered with the Church of Uganda to develop and introduce agro-forestry education to the local people. In the process, an income-generating campground was developed as an eco-tourism facility on Bushara Island, which now employs 40 local people. Today, in addition to the campground, community based programs aimed at reforestation, improved land use, and soil conservation, as well as a community orphan care program have been developed.

In the greater Rubingo area, the Clearwater Communities Project has provided safe drinking water to over 12,000 people, via a gravity-flow water pipeline, and the implementation of bio-sand household filters to other communities where the pipeline is not an option (ACTS, 2004). An agro-forestry education program has been developed as well as the Rubingo Medical Aid Station, which provides first aid, medications for malaria and a few other common illnesses, and basic health care and teaching, to the those in the surrounding area.

#### *The Rubingo Medical Aid Station*

The Rubingo Medical Aid Station averages 140 patients per month, unless a *muzungu*, or white person, is working at the Station (Evas Ankunda, personal communication, February 20, 2006). During my two months in Rubingo, the Station averaged 284 patients per month. Home visits are also made to check on the ill who cannot make it to the Aid Station. The most common ailments treated include malaria,



wound infections, eye infections, fever, cough, arthritis, and intestinal worms.

Malnutrition is apparent and over 100 adults are registered as HIV positive. HIV testing and counseling of approximately 75 adults is done each month at special clinics organized by the Rubingo staff but performed by the AIDS Information Center Organization. HIV testing of children in the area began in April, 2006, the month after my return to Canada.

### *How I Became Involved*

My first introduction to ACTS began at my place of work. A fellow nurse and I were on a coffee break and she mentioned that her husband was in Africa for six weeks. I questioned her more and found he was the director of ACTS. Over the next few months, the topic came up different times until one day in May of 2005, she asked if I might be interested in going to Uganda, as the nurse who had planned to go was now unable to. I immediately said, "Yes!" and went home to discuss the idea with my husband. My husband and I met with David Moore, the director, attended the ACTS Annual General Meeting, and spoke to people who were either presently involved with the organization or had been in the past, including Dale Affleck, a Canadian nurse who started the Medical Aid Station. Once David learned that my husband had skills useful to the ACTS projects and the people in the Rubingo area (aquaculture and construction), David proposed we both go.

I was ready to pack!

Determined to use my nursing skills in Africa, and into my sixth course in the University of Victoria, Masters of Nursing program, I wondered if there was a way to incorporate my project requirement, focusing on palliative care, into the experience. I discussed the idea with my Graduate Advisor and began formulating plans. Between

discussions with my advisor, instructors at the University, David Moore, Dale Affleck, and doing research on Uganda, my husband and I attended orientation sessions for the new volunteers for the 2005-2006 season. We received information on the country, the culture, participated in team building sessions, and learned much about the area in general. However, I still felt at a loss as to how the medical station and the health care system in the rural village worked. Although I asked questions, I had no real context to fit the answers into, so things still seemed foggy at best. It was at that time the idea of a guideline, something tangible, to assist in orientating volunteer nurses began to form. David and Dale were each very encouraging and supportive of the idea. Dale Affleck explained that the Aid Station was very basic, but anything that would facilitate more efficient care was welcome. He encouraged me to spend at least two months in Uganda, explaining that it would take one month to begin to understand how things work, the system, and the people. He gave me information on the resources available at the Aid Station (i.e., a few reference books, thermometer, stethoscope, blood pressure cuff, gloves, medications, and some dressing supplies), and a list of items I might find useful to take with me.

My husband and I left for Uganda January 9, 2006, and returned to Canada March 11, 2006. It was a very rewarding experience.

### *The Guideline*

Developing a nursing guideline for palliative care for volunteer nurses at the Rubingo Medical Aid Station will assist nurses from Canada to orientate to the area more quickly. They will be provided with basic information on how the rural medical system functions and how to access care for patients that have HIV/AIDS and/or cancer. It is not

designed to cover all aspects of palliative care, cancer or HIV/AIDS – there are excellent textbooks for that. Rather, it is designed to give insight into the unique needs of palliative patients in the village and how they can be met with the limited resources available, as well as how to access medications for pain and symptom control when needed.

Ideally, this guideline will only be a beginning. Future nurses may add to it with information in their specialty, such as guidance on caring for a diabetic patient in the village whose diet mainly consists of the starchy matoke and posho, or wound care most suitable in the hot humid climate for patients that can only get to the Aid Station once a week.

The patients in the village find more than help at the Medical Aid Station; they find hope too. As nurses, it is our responsibility to ease pain at the end of life - be it physical, emotional, or spiritual pain - to the best of our ability. This guideline will help empower nurses at Rubingo to identify that ability.

## Chapter Two: Method and Discussion

The palliative care guideline for the Rubingo Medical Aid Station was developed using many of the same processes as a qualitative research study, such as ethics approval, data collection, and analysis. However, because this is a project rather than a thesis, the methods are not described in the same depth as a research study.

Decisions regarding the design of this research project evolved during my two months in Uganda. A descriptive qualitative approach was used and involved several data collection strategies, including interviews, observing local people, listening to their stories, spending time at Mbarara Hospice (a branch of Hospice Uganda), and from my experience working in the Medical Aid Station. Field notes were taken and a personal journal was recorded on a tape recorder. Once back in Canada, notes were transcribed and themes identified. Follow-up e-mails with the Canadian volunteer nurse were used to clarify and confirm information. As mentioned earlier, ethics approval was sought and obtained from the University of Victoria for this project, prior to my departure.

The setting for the interviews was generally on the ACTS grounds, often sitting on lawn chairs in front of my safari tent or at the Medical Aid Station. Home visits were made and discussions were commonly held with clients in their mud hut. One and a half days were spent with Mbarara Hospice, joining them on home visits, discussing protocols and the services their Hospice offers.

Although English is taught in Ugandan schools, the ability to speak and understand the language varies greatly among people in the village. Therefore, the use of an interpreter was required in many cases. To simplify these communications, I often chose not to ask questions but requested that they tell their story about the loved one who

had died, or their own story of illness and life, using an interpreter to translate. Questions were asked only for clarification or to expand on a topic. Limitations regarding the use of an interpreter are recognized, as some words are not directly translatable. There is also the potential for the translator to summarize, placing his/her own perspective on the story. However, for this project, the exact words are not as important as the issues or themes that emerged.

Limitations of the methods used include possible behavioral distortion of those observed and interviewed due to the known presence of the researcher and the cultural differences. The fact that I am Caucasian and from Canada affects the way people respond to me. For example, a 12 year old girl presented at the Medical Aid Station with a rigid and painful abdomen. In asking about the history, she told me she fell on a large rock while playing. Unable to determine the severity of her injury I took her to the government clinic where, after being seen, the doctor told me her brother had beaten her. I asked why she would tell me something different and was told she did not want me to think poorly of her. Despite trying to appear open and non-judgmental, how I am perceived by others, and the preconceptions they have, is sometimes beyond my control.

The 'power-over' perception was also identified as influencing interactions. ACTS and the Medical Aid Station are known in the area to assist with many needs. I was seen as one to potentially provide help and, due to that, I was given certain status. For example, one day I joined a group of women holding a meeting in a garden. When I arrived, a woman put her cloth wrap on the ground for me to sit on; no one else was given such treatment. Attempts were made to minimize any potential risk of coercion during interviews by emphasizing the voluntary nature of the discussion and that care or aid

provided to them through ACTS, and/or the Medical Aid Station, would not be affected. Cultural sensitivities and customs were frequently discussed with the local nurse assistant.

### *Findings*

A thematic analysis was conducted of the information obtained. According to Braun and Clarke (2006), a thematic analysis is a method for organizing and describing data in detail by identifying, analyzing and reporting patterns within the data. In reviewing the data, certain topics and issues repeated themselves. These themes were first sorted into categories of physical or psycho-social needs. Topics were then sorted into sub-themes. Themes identified under physical needs include food, illness symptoms, access to care and money. The psycho-social themes comprise family, emotional concerns, social function and spiritual needs. There was obvious overlap between categories. For example, illness symptoms limited the ability to work in the garden for food which gave rise to emotional concerns regarding providing for the family. It is recognized that one is not able to separate lives into distinctly physical or psycho-social compartments; rather, life is a web of themes.

### *Physical Needs*

Physical needs are a challenge in the Rubingo area. Lack of food is a common problem; many people eat only one meal per day. People work in gardens – on their own land, for others in exchange for food, or in community gardens, but soil conditions are poor, the land is undulating, the climate can be harsh, and monkeys sometimes raid the gardens. Animals are desired for eggs, meat and milk, but land is required and several women told me they sold their animals to buy medicine or to pay school fees. Lack of protein in the diet is a common problem that has led to widespread anemia. A downward

cycle emerges when one is ill and unable to work in the gardens or tend animals, producing less food, while already undernourished and with no ability to purchase food.

Pain control was identified as the greatest need during two of the interviews. This is consistent with literature findings regarding symptom management (Grant et al., 2003; Harding et al., 2003; Kikule, 2003; Murray et al., 2003; Shawn et al., 2005). Open wounds on various parts of the body are also a problem, many of which become infected. The nurse assistant believes there is little cancer in the Rubingo area. Whether or not that is true, or due to lack of diagnosis, is questionable. Tuberculosis and shingles, both opportunistic infections, were noted among patients requiring treatment as well as family members when discussing loved ones who had died from HIV/AIDS.

Access to care is also a great challenge. In all the situations I came across, the terminally ill person was cared for at home by family members. This is consistent with the WHO (2002) report which states family members and relatives are the main caregivers and the home is the preferred site of care. In a survey done by Kikule (2003) it was affirmed that nearly all palliative patients in Uganda die in their own homes under the care of their families.

In the Rubingo area, there are three places for medical assistance. The Medical Aid Station is run by a nurse assistant who is licensed to administer a limited number of medications. Volunteer nurses from Canada, registered with the Government of Uganda, are also allowed to administer antibiotics. Medications are provided at cost, or free to children, widows and those unable to pay. Two other clinics are in the area. Approximately a ten minute drive from Rubingo, is a private clinic with a nurse and lab technician in daily attendance. A doctor is available only on weekends and the clinic

charges for service and medications. The clinic does not carry narcotics. The other clinic, run by the government, is approximately 45 minutes away by vehicle, and is open Monday to Friday. It is staffed by nurses, a lab technician and a doctor; but, of the five times I visited, I found a doctor available only twice. The government clinic is free of charge but seldom has medications of any type. The clinic claims to have access to an ambulance (pick-up truck), although I was told by staff that there is seldom money for gas and the vehicle is frequently out of the area. Two months prior to my arrival in Uganda, a volunteer nurse with ACTS called the clinic requesting the ambulance to assist an elderly woman who was found on the floor in her home, in pain and unable to get up. The ambulance arrived seven days later.

Mbarara University Hospital is located approximately two hours away by vehicle. Public transportation is costly for the average person in the village and not conducive for one ill or in pain. When one is admitted to the hospital they must purchase their own medicine and provide an assistant – usually a family member or friend – who sleeps on a mat on the floor next to the bed. The assistant provides personal care, purchases food and cooks for the patient.

According to literature, Uganda is one of the leading African countries in Hospice care (Kayita, 2002; Wright, Wood, Lynch & Clark, 2006). However, I found an immense void in what is available in the rural villages. During my time there, I found a branch of Hospice Uganda in Mbarara which provides palliative care to cancer and HIV/AIDS patients. Home visits are made to patients who live within a 20 kilometer radius. Those living in the Rubingo area are required to visit the Hospice for an assessment, and then could be followed and supported with medications if a relative reports back at regular



intervals, should the patient be unfit to travel. Medications, which include morphine, are provided at minimal cost, or free of charge if the patient is unable to pay. This does not provide a 'quick response' to palliative needs, but until now the people in Rubingo had no knowledge of access to any palliative care.

Money is scarce in the village and a constant concern. Education is provided by the government and is recognized by many as important and the only hope for improving life for their children and family. However, in order to maintain facilities and teaching tools, school fees are charged for every student. The burden of school fees and the cost of required uniforms are a major concern for those who are ill. Sometimes the choice is between food or school fees. Several times I was asked if I would help a family with school fees, as there wasn't enough money for each child to attend. This is consistent with the findings of Merriman and Heller (2002) and Kikule (2003) who noted income as a major problem in meeting basic needs such as food, rent and school fees as well as medical care.

### *Psycho-Social Needs*

When observing people holistically, it is difficult to draw a line where physical needs end and psycho-social needs begin. This is no more apparent than with the people I met in Rubingo. Concerns over lack of food and money weigh heavily on the minds of almost everyone, but for parents who are ill, the worry over who will look after their children, and how, is an additional burden. Children take on responsibilities early, often caring for their ill parents, tending goats or cattle, and working in gardens. Grandparents often end up raising their grandchildren, sometimes as many as a dozen. Many can only provide one meal per day and can seldom pay school fees for more than two or three

children. It is common to meet people who have integrated orphaned children into their family. One couple I met, with two of their five children still at home, are also raising two of their grandchildren plus an orphaned three-year-old. Another woman told me she has opened her home to a teenager whose family cannot afford to keep her; in addition, they have taken in an orphaned ten-year-old girl.

Very little technical communication is available in the village, but 'word of mouth' is viewed to work well and I was surprised by how effective it was. It is socially acceptable to pass information from one to another in order for word to get to a desired location. Word spreads in the same manner when someone dies. Funerals are important events and many people attend, yet, I was told there is little time to mourn in this subsistence lifestyle.

Several noteworthy comments expressed when discussing the death of a loved one included the fact that one family did not tell the ill person he had cancer for fear he would no longer 'fight'. This is consistent with the findings of an end of life study by Grant et al., (2003) in Kenya, where in nearly half the cases relatives tried to keep the prognosis from the patient, believing the patient would quickly deteriorate if they knew they were dying. One family found it helpful to know when death was approaching in order to prepare themselves and say their goodbyes. Several people showed little emotion in their facial expression or voice when discussing the death of a loved one, looking straight ahead and speaking factually.

Spirituality was important to many people I spoke with. Christianity is dominant in the area and one family told me that because they are Christians they never question 'why' their loved one became ill and died. Another bedridden man, who was HIV

positive with tuberculosis and diabetes, explained he believed in God and Jesus, but felt he had done such terrible things when he was a soldier years before, that could never be forgiven. This concern dominated our conversation.

Cultural tradition also plays a role in the health of Ugandans. Although belief, or hope, in Western medicine is apparent, traditional medicine and beliefs are interspersed. Traditional practices vary from trained healers and the use of herbs to what was described to me as 'witchcraft'. This was not often openly revealed to me, but on occasion I came in contact with it. For example, a four-week old baby was brought to me with deformities of her feet and a burn on her forehead. When I asked about the burn, the nurse assistant shook her head as if I should not ask more and said quietly that it was 'witchcraft' to fix her feet. More time and research is needed in this area in order to learn more about this.

### Chapter Three: Barbara's Story

To put into context the various issues faced by those in Rubingo, I'd like to tell the story of a woman I met. Barbara\* is an HIV positive widow. One day, her eleven year old son arrived at the Medical Aid Station stating they were totally out of food and that his mother was ill. Funds were given in order to provide emergency food and the next day the nurse assistant and I visited their home, a one room mud hut with minimal furnishings – a bed, blankets, bench, jerry can for water, bucket, a few personal items, and a faded poster of Jesus on the wall. Behind her hut, sat a kitchen - another tiny mud hut with a brick fire-pit for cooking.

Barbara told me, through the interpretation of the nurse assistant, that her husband died two years earlier; he was HIV positive. They had three children together; however, he also had another wife and four children. Although he was HIV positive, he did not tell his family or wives. One day when he came back from Mbarara with an antibiotic, Barbara questioned him about it and that was how she learned of his HIV status. He did not appear sick for a year, but then his legs became swollen and he had difficulty walking. He coughed a lot and had sores on his body; some never healed. He had no idea about HIV medication or what to expect from the disease. He tried traditional medicines but at the end he had a lot of pain and was in bed for six months. He spent most of that time at his other wife's house; Barbara and her children didn't see him very often. He died two years after Barbara learned of his HIV status.

\* Not her real name.

ACTS provides transportation for Barbara to go to monthly meetings in Mbarara, at TASO, which monitors her health. Apparently during one of these meetings two weeks earlier, Barbara was diagnosed with shingles, but she had no money with which to purchase medicine. On my visit, her left leg was covered with an herbal poultice in an attempt to ease the pain. She explained how her eleven year old son stays home from school and provides all her personal care, fetches water and does the cooking for the family. They have no land to grow food, she is too ill to work in the community garden, and money is scarce.

It took a week for an ACTS worker to get to the city, track down and purchase the medication Barbara required, transport it to the village, and get it to Barbara. In another week, Barbara was feeling better and able to care for herself. She was hoping to be back to work in the community garden soon.

Barbara's story is just one of many in the Rubingo area. Her plight exemplifies the impact of HIV/AIDS, the poverty, the use of traditional medicines, the role of children as caregivers and the need for access to medication and hospice. One can only imagine the emotional toll on both Barbara and her children.

### Conclusion

When I asked an ill person or family member the question, "What would be helpful?" or "What would have helped the situation?", the answer was always, "I don't know." I stopped asking. I was unsure whether they truly didn't know, or if the thought of possibilities, which seemed unattainable to them, were too painful. Or, perhaps they were so focused on surviving the day that they were unable to use their imagination.

Maybe the question was just too broad. There are so many problems, so many challenges, in everyday living, how could they narrow it down to one simple answer? Where does one start?

That is the challenge. One can easily become overwhelmed by the magnitude of the mountain before them, that it is forgotten that the trail, whether up or down, is made one step at a time. Small steps can be made in palliative care in the rural village. Mobilizing volunteers, organizing emergency food supplies, providing caregiver kits, linking with the local pastor, liaising with Mbarara Hospice, and providing counseling and support to those left behind are all possibilities which could ease the suffering of the dying and their family.

The concerns of palliative patients in the Rubingo area are generally consistent with findings reported in literature of other rural Africa areas. There are many sad stories within the village, but there is also resilience in the people, courage and faith. My hope is that this guideline helps to ease their struggle.

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Appendix

## **Palliative Care Guideline**

By

Necia Dorene Kaechele

BSN, University of British Columbia, 2001

A Project Submitted in Partial Fulfillment of the Requirements for The Degree of

**MASTER OF NURSING**

in the School of Nursing, Faculty of Human and Social Development

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University of Victoria

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Death is a fact of life, and dying is a process.

Being allowed to share in this part of another's personal journey

is an honor and a privilege, although sometimes difficult.

There may be times you feel helpless in what you have to offer a patient,

and in those times I encourage you to just 'be there'.

Knowing someone cares is sometimes the best gift that can be given.

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## Introduction

### *Welcome To the Rubingo Medical Aid Station!*

While working at this station you will meet many interesting people with a variety of health issues, some of whom may have a life-threatening illness. This palliative guideline is not intended to replace any medical or palliative care textbook. The goal is to provide information, suggestion and direction, specific to this rural Ugandan area on accessing care, delivering nursing care and managing symptoms of palliative patients.

### *Who Is The Guideline For?*

This guideline is for nurses from Canada, working with palliative patients at the Rubingo Medical Aid Station. It is recognized that not every nurse is comfortable or experienced in working with palliative patients. Therefore, it is wise to know your limits and work within them.

### *How To Use The Guideline*

This guideline is just that, *a guideline*. It is intended to assist you in the care of your patients; it may provide ideas and suggest possibilities. However, nothing can take the place of your assessment skills, knowledge and intuition.

Some of the suggestions within this guideline may be unfamiliar to you. I have attempted to clarify whether the practice is evidence-based, or a suggestion from what I deemed credible sources but could find no research to support the practice. I have included references for those who would like to investigate further.

It is my hope that as new avenues of care are made available or discovered, they will be added to this guideline in order to ensure information is accessible to future



nurses working in Rubingo. It is also my hope that nurses with other specialties will be inspired to write sections to include additional aspects of care for how best to manage those health issues within the circumstances found in rural Uganda.

### Palliative Care Definition

The World Health Organization (WHO, 2008) defines palliative care as an approach to improve the quality of life of patients and their families facing a life-threatening illness. Emphasis is placed on the prevention and relief of suffering by means of early identification, assessment and treatment of pain and other physical, psychosocial and spiritual problems. The terms, hospice and palliative care, are often used interchangeably, and for the purpose of this guideline, they will be considered one and the same.

The principles of palliative care are applicable to anyone with a chronic or incurable disease, especially in the terminal phase. In Uganda, the majority of palliative care is provided to AIDS and/or cancer patients. It is difficult to quote an exact number, but in 1993, it was estimated that 30% of the population was infected with HIV (Merriman & Heller, 2002). This rate has declined and more recent estimations place the number of people living with HIV at between 5 – 10% of the population, depending on the source (Brugha, et al. 2004; Jagwe, 2002; Stjernsward, 2002). Prior to the HIV epidemic, the incidence of cancer was estimated at 0.1%; however, Merriman (2002) – the founder of Hospice Uganda – states this number is too low under present conditions as cancers related to HIV have increased. Merriman states that approximately 50% of those known to Hospice Uganda with cancer have HIV related cancers (i.e., Kaposi's sarcoma).

### Accessing Further Care

The majority of palliative care is provided in the patient's home in Uganda as in-patient hospice care is extremely limited. People in the village have a subsistence lifestyle and visit a doctor rarely, therefore it would not be unusual for a request to arrive at the Medical Aid Station for the nurse to visit the home of a person in dire distress. It may be difficult to get an accurate picture of what the situation is, however most people who have sought medical aid previously have a booklet (school tablet) containing notes on medical findings, diagnosis and medications ordered. Nurses are encouraged to add findings to the booklet and, should the patient be referred for further medical care, to ensure the booklet accompanies the patient. If the patient has no booklet and is being referred for further medical care, a booklet may be purchased at the local store, as booklets are often required.

#### *Transportation*

People in the village are accustomed to walking long distances to get to their destination, yet, if a ride is available, they are more than happy to be accommodated. A car/taxi service is sometimes available early in the morning to take people from Rubingo into Mbarara returning again late in the day, but it is generally very crowded and too expensive for most to afford. A bus system is available at the main highway junction, if a person is able to get to that point. However, neither mode of travel is conducive for a very ill person. If a patient needs to travel, please discuss possibilities with the local nurse assistant at the Rubingo Medical Aid Station. ACTS may transport patients on an emergency basis, or coordinate plans to provide room on a regularly scheduled trip to Mbarara by an ACTS member. While this is more economical, good communication between ACTS team members is important as there are often many requests for rides

and/or transport of goods. The judgment regarding an ‘imminent need’ and what constitutes an ‘emergency’ is often left to the nurse’s discretion. Discussion with the nurse assistant may assist in determining your action.

### *Clinics*

The Rubingo Medical Aid Station is well known among the locals for providing assistance with health care needs. However, what can be offered is limited. The Byanamira Clinic is a private clinic across the road from *DK and Friends Pub*. The clinic is staffed daily by a nurse and lab technician and has a doctor available on weekends. Since it is a private clinic, there is a charge for service but they carry a variety of medications. The Bugumba Government Clinic is approximately a 45 minute drive from Rubingo, toward Mbarara, and is open Monday to Friday, staffed with nurse, lab technician and physician. Medications are seldom in stock, but may be available for purchase at the Byanamira Clinic.

The Bugumba Government Clinic is said to have an ambulance service, however this is not dependable. The ambulance is a pick-up truck with no special equipment and is seldom available, seldom has fuel, and history demonstrates it can take up to a week to respond to an emergency request.

### *Mobile Hospice Mbarara*

Mobile Hospice Mbarara is located by passing through Mbarara town, (coming from Kampala/Masaka), on the road to Kabale. One half kilometer past the University is a junction to Bushenjyi-Ishaka; turn right at the gas station and right again at the gas station side entrance. Mobile Hospice Mbarara is situated on the hill just behind the gas station. It

is open Monday to Friday, 9:00 a.m. to 5:00 p.m., and on Saturdays and public holidays from 9:00 a.m. to noon.

Mobile Hospice Mbarara provides care and home visits for patients with cancer and/or AIDS within a 20 kilometer radius of their facility. Patients from the village may be referred to the Hospice by a health worker. A definitive diagnosis of cancer and/or AIDS is not required, only indicators/symptoms leading one to believe the patient has one or both of these illnesses (although HIV/AIDS testing is increasing in the village, lack of any diagnosis is not uncommon). Initially, the patient needs to be seen at Mobile Hospice Mbarara for a preliminary assessment. Follow-up is done by reporting back periodically (usually monthly), often via the patient's main caregiver. The Hospice does not have an in-patient unit. A copy of the Patient Referral Form may be found in Appendix A, and copies should be kept at the Rubingo Medical Aid Station. An electronic version is also available:



Mobile Hospice Uganda referral form.pdf

*Contact For Mobile Hospice Mbarara:*

Telephone: **256-485-21010**

Fax: **256-485-21001**

Website: **[www.hospiceafrica.org/mbarara/index\\_mbra.htm](http://www.hospiceafrica.org/mbarara/index_mbra.htm)**

E-mail: **[mrabwoni@hospiceafrica.org.ug](mailto:mrabwoni@hospiceafrica.org.ug)**

Mobile Hospice Mbarara suggests patients with AIDS should be referred to them when pain is uncontrolled by treatment available in their area or when end-of-life care or critical care at home are required. Cancer patients may be referred at any stage. In the village, there may be need for an immediate unplanned trip for a patient in distress to the Hospice. Morphine is now available for palliative pain control in Uganda, and the Hospice

is able to dispense it. However, since the patient needs to be known to the Hospice, for those in the village it is not a 'quick-fix', but it does offer hope. A list of medications in stock at Mobile Hospice Mbarara is provided in Appendix B.

#### *Accessing Mobile Hospice Mbarara*

Ideally the patient should arrive at 9 a.m. at Mobile Hospice Mbarara with a completed referral form. The patient will be asked to pay 5,000 Uganda Shillings (UgS) (approximately \$3 U.S.) per week of care, which includes medications. For those unable to pay, smaller contributions or gifts from their garden are appreciated. A comfort fund is also available and provides for those who cannot pay at all.

Mobile Hospice Mbarara is very accommodating to health professionals and would welcome a visit in order for you to become familiar with their services. Once the patient is seen at the Hospice, they will provide consultations to you as you manage the patient and will treat and send home a month's supply of treatment/medications with the patient. When in doubt, contact them! This is their specialty.

#### *Mbarara University Teaching Hospital*

Critical patients may be taken to Mbarara University Teaching Hospital in Mbarara. The hospital often refers palliative patients to Mobile Hospice Mbarara, where Hospice may take over care or share the care of the patient. When a person is admitted to the hospital, an attendant is also required to stay in order to provide personal care, provide food and cook for the patient, and assist with medications. The attendant – usually a family member - generally sleeps on a mat (provided by the attendant) on the floor next to the patient.

The hospital provides emergency medications but is limited in what it supplies in other circumstances. Therefore, medications may need to be purchased at a local pharmacy if Mobile Hospice Mbarara is not involved.

### *Pharmacies*

There are several pharmacies in Mbarara; the nurse assistant will be able to advise which provides the best price, as it may vary due to circumstances. Prescriptions from doctors are not generally required, although narcotics and children's strength aspirin (not allowed in Uganda) are not available. Other medications may not be available at local pharmacies and need to be purchased in Kampala. As discussed previously, if the patient is known to Mobile Hospice Mbarara, medications may be accessed there.

### Delivery of Care

The primary caregivers of terminally ill patients in Uganda are family members. When a person becomes ill and unable to work to support their family, it is not unusual to move back to their parent's home to be cared for. This often creates a financial burden and difficulty in providing food for everyone. Grandparents are often left to care for their grandchildren. In other homes, children become the main caregiver for their parents and siblings. Empowering family members to care for their loved ones is the most realistic approach to providing palliative care to the ill in the village. The tasks required of the caregivers may be new to them and therefore support and education may be needed, especially in areas such as medication schedules, cleaning and dressing wounds, prevention of bedsores, providing incontinence care, and how to properly safeguard themselves against infection. Ensuring supplies are available to care for the patient is

important. If necessary, basic items such as soap, salt, and dressing supplies may be provided by the Medical Aid Station or through the ACTS humanitarian fund.

Traditional healers are often sought by the ill and their family members. This can be a culturally sensitive subject; some people are hesitant to inform nurses they have sought help from the healers, while others may be fairly open. Sometimes the term 'healer' is translated rather loosely. My suggestion is to take guidance from the nurse assistant in your response, but if the patient finds a source of comfort and to your knowledge it is not causing harm, it is best to support them. It has been recognized that traditional healers may play a key role in end-of-life care. In fact, in some areas, the government has sponsored education sessions for traditional healers on palliative care – although I am unaware whether such education has been accessed by anyone in the Rubingo area.

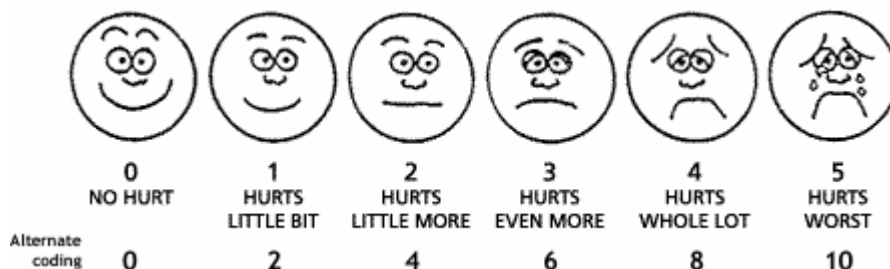
## Symptom Management

### *Pain*

Pain is the most common symptom experienced by the dying. It is important to remember that because pain is not reported it does not mean that pain is not present, and many patients have more than one pain. Using a pain scale, such as a 0 – 5 number system (or fingers on a hand) in which 0 equals no pain and 5 equals the worst pain imaginable, asking the patient to give their pain a number can be useful in determining the intensity of the pain. For some, especially children, the Faces Pain Scale is a better tool to use.

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## Faces Pain Scale



**Brief word instructions:** Point to each face using the words to describe the pain intensity. Ask the child to choose face that best describes own pain and record the appropriate number.

**Original instructions:** Explain to the person that each face is for a person who feels happy because he has no pain (hurt) or sad because he has some or a lot of pain. **Face 0** is very happy because he doesn't hurt at all. **Face 1** hurts just a little bit. **Face 2** hurts a little more. **Face 3** hurts even more. **Face 4** hurts a whole lot. **Face 5** hurts as much as you can imagine, although you don't have to be crying to feel this bad. Ask the person to choose the face that best describes how he is feeling.

Rating scale is recommended for persons age 3 years and older.

From Hockenberry MJ, Wilson D, Winkelstein ML: [Wong's Essentials of Pediatric Nursing](#), ed. 7, St. Louis, 2005, p. 1259. Copyright, Mosby.

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Understanding the cause of the pain is helpful. Cancer pain is often constant and progresses with the disease. In AIDS patients, the most common pains reported are: lower limb pain due to peripheral neuropathy, skin conditions, mouth pain, headache, throat pain, and chest pain (Galen, 2004; Merriman, 2006). Often these pains occur due to opportunistic infections and therefore analgesics might be required only for a short period of time.

Pain is often classified into two categories: nociceptive pain and neuropathic pain (McCaffery & Pasero, 1999). Nociceptive pain generally arises from tissue damage, and



may be either somatic, arising from bone, joint, muscle, skin, or connective tissue, is well localized, and described as aching or throbbing, or visceral arising from visceral organs such as GI tract or pancreas. Visceral pain may be due to tumor involvement or obstruction of a hollow organ, and is often described as deep, dull, and cramping. Nociceptive pain usually responds well to analgesics.

Neuropathic pain is pain caused by damage to the peripheral or central nervous system. Neuropathic pain is often disproportionate to physical findings, for example a light touch of a blanket may be felt as extremely painful. This 'nerve pain' is often described as burning, tingling, shock-like, or shooting. Neuropathic pain may not respond as well to analgesics and often require adjuvant medications (Doyle, Hanks, & MacDonald, 2001; McCaffery & Pasero, 1999).

Many people in the Rubingo area have little history with pain medication and have never used opioids. Therefore, the adage, "start low, go slow" is fitting. The WHO analgesic ladder suggests, when treating mild pain, to begin with a non-opioid, such as aspirin, paracetamol, or ibuprofen (WHO, 2008). If pain persists, or is mild to moderate, a weak opioid is recommended, such as codeine, with or without a non-opioid. However, codeine is quite expensive in Uganda, therefore Hospice Uganda may recommend a low dose morphine for cancer patients. If pain continues to persist or is severe, a strong opioid, generally morphine, is advised. A non-opioid may or may not be useful as well. Since neuropathic pain is often only partially relieved with analgesics, an adjuvant may be added at any point. Adjuvant drugs complement the analgesic and the choice of drug depends on the cause of pain. Adjuvant drugs may include nonsteroidal anti-inflammatory drugs (NSAIDs), anticonvulsants, sedatives, steroids, muscle relaxants or antidepressants.

Morphine is the most common opioid in Uganda, and most frequently provided in the liquid form. It is inexpensive and nurses trained in palliative care – such as at Mbarara Hospice – are now able to provide it to patients. It should be titrated to the pain and taken regularly so the next dose is given before the previous one wears off. Most liquid morphine is prescribed on a 4-hourly basis, yet if a patient takes a double dose at bedtime, they generally do not need a dose in the middle of the night. This promotes an undisturbed sleep for both patient and caregiver.

Constipation is a side effect of opioids, therefore any patient on an opioid should also take a laxative. Conversely, AIDS patients who are susceptible to diarrhea should use laxatives cautiously. The least expensive laxative available is bisacodyl tablets, but these sometimes cause cramps. Some patients may have a favorite herbal laxative that works for them. For example, some chew bitter papaya seeds (papaya may also be known as paw-paw), 5-10 seeds initially, increasing to 15-50, at night, as needed (Merriman, 2006; WHO, 2004).

Other side effects of opioids may occur, but many only last the first few days. Nausea and vomiting is seldom reported by Hospice Uganda, but if it is a problem, metoclopramide or haloperidol may be useful (Doyle, Hanks, & MacDonald, 2001). Sedation may be noticed for 1-2 days. On the other hand, pain can also cause exhaustion and the patient may just be catching up on much needed rest now that the pain is gone. If sedation lasts longer than 2 days, the dose should be titrated back until the patient is alert but pain is still controlled (Merriman, 2006). Respiratory depression is generally not a problem if the initial dose is low, then titrated to the pain. Myoclonic jerks and

hallucinations may indicate opioid toxicity and may improve with hydration and dose reduction (Doyle, Hanks, & MacDonald, 2001; Merriman, 2006).

Addiction is not a concern for those with pain; however, physical dependence can develop if the patient is on opioids regularly anywhere from a few days to a few weeks, it is highly individualized ( B. Fehlau, personal communication, February 5, 2008). Should discontinuation be indicated (e.g., if other forms of treatment, such as radiation, have relieved pain), opioids should be discontinued carefully. Generally, the usual daily dose to prevent withdrawal symptoms is equal to 75 per cent of the previous daily dose (Doyle, Hanks, & MacDonald, 2001). For those on opioids for temporary severe pain (e.g., infection), withdrawal is generally without problem. The patient becomes drowsy as the pain becomes less, indicating the drug can be reduced or discontinued (B.Fehlau, personal communication, Feb 5, 2008).

The oral route is the ideal route of choice for opioids. However, occasionally that is not possible. Morphine solution is absorbed sub-lingually or by the buccal route, but absorption is variable. Morphine suppositories may also be available.

Non-medicinal treatments for pain should also be instituted. Deep breathing and relaxation techniques may be helpful, as well as massage, distraction and imaging. Ensuring questions are answered and explaining what is happening helps to relieve fear and anxiety. Providing company for conversation, sitting quietly with the patient, reading aloud, or singing to them may help a person relax. Organizing a support system, such as ensuring the patient is checked upon at certain intervals, may relieve fear of being alone or abandoned, for both the patient and caregiver.

The concept of *total pain* recognizes suffering is related to a person's physical, psychological, social, spiritual and practical state. For example, pain may originate from a physical response to injury, but the emotional state of a person plays a large part in the tolerance of pain. The total pain concept acknowledges that other things 'hurt' as much as physical pain – such as the anxiety over how to get money for your child's school fees when you are ill, or who will look after your children when you die. Attending to emotional, social, and spiritual needs can be just as important as easing physical distress.

#### *Nausea And Vomiting*

Nausea may be present with or without vomiting and can be caused by a variety of things. Use of an appropriate available antiemetic for the cause (if known) is often helpful. For example, for gastrointestinal tract problems, metoclopramide may be the drug of choice as compared to nausea produced by the chemoreceptor trigger zone (activated by some drugs, toxins, infections) in the brain where haloperidol may be more effective (Doyle, Hanks, & MacDonald, 2001). There is great variation among palliative care programs as to which drug to try first since the cause is often unknown. Therefore, you may need to try whatever is available first and switch if necessary.

Other actions which may be helpful for nausea include having the patient sit up when eating and refrain from lying down for one to two hours after eating. Try soft foods in small amounts frequently and encourage fluids. In a document produced by the Food and Agriculture Organization of the United Nations on HIV/AIDS (2002), it is suggested that the feeling of nausea may be relieved by smelling fresh orange or lemon peel. Drinking lemon juice in hot water or in an herbal or ginger tea is a suggestion in a WHO (2004) guideline.

### *Constipation*

Constipation due to opioids has been discussed under *Pain*. Whatever the reason for constipation, it can cause abdominal discomfort. Prevention is the best defense and increasing fluids and high fiber foods, if the patient tolerates, may help. If consent is given, a rectal exam should be done in order to rule out rectal impaction. Bisacodyl tablets are the least expensive laxative and may be used, however patients may have a herbal remedy which has worked for them in the past. Other suggestions, in publications by Merriman (2006) and the WHO (2004), include chewed or crushed papaya seeds, starting with 5-15 seeds and increasing to 25-50 as needed, a tablespoon of Blue Band margarine or vegetable oil taken in the morning to 'lubricate' the stool, or if suppositories are unavailable, a lump of petroleum jelly placed in the rectum and held for approximately 20 minutes (or as tolerated) may help pass stool.

Constipation can also cause nausea. It is important to note that constipation with severe abdominal pain and/or vomiting may indicate a bowel obstruction. This is a grave situation in the village, and fecal impaction should be ruled out. Laxatives may exacerbate the problem. If tumor mass is causing the obstruction, it may be reduced with the use of steroids, such as dexamethasone (Doyle, Hanks, & MacDonald, 2001; Merriman, 2006). However, in the village a diagnosis may be difficult to obtain. Transport to further medical care would be advised if possible. Nevertheless, managing symptoms is often the most appropriate option for the terminally ill.

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**Sugar and Salt Rehydration Drink:**

In one liter of clean water, mix ½ teaspoon salt and 8 teaspoons sugar. \*

**Cereal and Salt Rehydration Drink:**

In one litre of clean water, mix ½ teaspoon salt and 8 heaping teaspoons of powdered rice cereal or finely ground maize, wheat flour, or cooked and mashed potatoes. Boil for 5-7 minutes to form a watery porridge. Cool.\*

(Cereal drinks spoil in hot weather within a few hours.)

\* Fruit juice or a mashed banana may be added to either drink to add potassium.

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*Diarrhea*

Diarrhea is very common, especially in AIDS patients. The possibility of parasites or infection causing the diarrhea should be considered and the underlying cause treated if possible. Many things can be the cause of diarrhea, such as allergies, spoiled food and contaminated water. Diarrhea can also be ‘overflow’ from a constipated bowel. A proper assessment of the patient’s bowel regime is important to understanding the problem.

The potential for dehydration is great for those with diarrhea, therefore encouraging fluids is important. An easily prepared rehydration drink may help prevent or treat dehydration.

Several suggestions are made in a document by the WHO (2004), regarding food for patients with diarrhea. Rice and potatoes are usually beneficial. Carrot soup contains pectin and helps replace lost vitamins and minerals. Bananas, mangoes, papaya, and

tomatoes also help replace electrolytes. Foods to avoid include coffee, strong tea, alcohol, raw foods, spicy foods, high fiber foods, and high fat foods.

### *Respiratory Symptoms*

Coughing or breathing difficulties may be a sign of infection in the chest and antibiotics might be needed. Tuberculosis is also seen frequently in Uganda, therefore ask the patient if they have been treated for it in the past. If the patient has a new or productive cough more than 2 weeks, it should be investigated for tuberculosis at the government clinic. Any sputum should be handled with care. Encourage the use of a tin with ash for spitting; then cover it. Empty the container in a pit latrine and wash the tin with soap and water, or clean with boiling water (Merriman, 2006).

To help clear mucus associated with coughs and congestion, breathing in hot vapors may help. Instruct patient to take a bowl or pot filled with very hot water and, leaning over the water, cover head with a towel or cloth. Breathe in the vapors for 10 minutes, twice a day. It is suggested that leaves from a eucalyptus tree may be added (found in certain areas outside the village); similarly mint or thyme leaves can be used, if available (FAO, 2002; WHO, 2004). Drinking plenty of fluids is encouraged to loosen mucus. Werner (1993), in his book, *Where There Is No Doctor*, suggests a simple cough syrup can be made by mixing one part honey and one part lemon juice.

Dyspnea can be very distressing for the patient. Positioning the bedridden patient in a semi-sitting position is beneficial. Low dose morphine, given regularly, helps to relieve the sensation of breathlessness, and benzodiazepines can calm a patient (Doyle, Hanks, & MacDonald, 2001). Non-drug measures such as a calming presence, fanning, relaxation therapy, and breathing exercises can also be effective.

### *Anorexia*

Loss of appetite is not unusual in the terminally ill. Often decreased appetite is more of a concern for the caregiver than the patient and it may help caregivers to understand that intake will decrease as end-of-life approaches, and that forcing food will not prolong survival but produce discomfort. Caregivers may be encouraged to offer foods the patient generally enjoys, in small portions.

Anorexia may be due to the consequence of the disease process, or other reasons such as constipation, pain, mouth discomfort, depression, etc. Underlying causes should be treated appropriately.

### *Sore Mouth*

Mouth problems seem to be an issue with many AIDS and cancer patients, which can make eating, drinking, and swallowing difficult. Mouth care should be done regularly by cleaning the mouth, teeth, and gums with a soft toothbrush or a cloth soaked in salt water. Rinsing the mouth with normal saline three or four times per day may help the mouth to feel better. Encourage soft foods and provide food and drink at room temperature. Chewing small pieces of green papaya may help to relieve pain and discomfort (FAO, 2002). Infections of the mouth may require antibiotics and there is belief that, in cases of oral thrush, sweet foods should be discouraged as sugar may worsen the condition.



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### Normal Saline Recipe

Boil water for 5 minutes.

To one cup of boiled water add ¼ teaspoon salt

Store in clean covered container for up to 24 hours.

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### *Skin And Wounds*

Skin problems are very common, especially with AIDS patients. Antibiotics or antifungals may be required. Open wounds should be cleansed with normal saline and covered appropriately. Scabies can be severe and should be suspected in atypical skin infections in AIDS patients. Topical treatment with benzyl benzoate should be used daily for three days after a bath (Anderson, Haugen, Rasch, Haugen, & Tageson, 2000). Others in the household should also be treated. Suggestions for other itching problems include sodium bicarbonate (baking soda) washes, using one tablespoon of sodium bicarbonate in the smallest amount of water to dissolve it, or rinsing the skin after bathing with a 0.05% chlorhexidene solution (Merriman, 2006). For dry itchy skin, bathing the patient with a ratio of one teaspoon vegetable oil to 1 ½ litres of water, is suggested (WHO, 2004).

Fungating tumors often produce a foul odor, causing embarrassment for the patient. This may lead to isolation from friends and family. Regular cleaning of the wound with normal saline is important. Metronidazole tablets (if available) crushed and placed on the area help remove the smell and reduce the anaerobic infection (Wilson, 2005). Cover with a non-adherent dressing. An alternative is to use honey on the tumor as it has antibacterial properties (Hampton, 2007; Nazarko, 2006). The amount of honey and the frequency of

changes depend on the amount of exudate. The more dilute the honey becomes, the less effective it is. Honey may be available in the village as ACTS provided a local farmer with a honey extractor in 2006. The ACTS agriculture intern or Ugandan agriculture leader may provide contact information.

Herpes Zoster (shingles) appears as a rash or blisters on one side of the body and is very painful. Sometimes the pain lasts long after the blisters disappear. Acyclovir may be helpful but may be difficult to find. Analgesics are usually required. A local remedy involves the liquid from the frangipani (plumeria) tree (Merriman, 2006). It is said to temporarily paralyze the nerve endings when applied to the rash; thus it relieves pain for up to 8 hours. However, it is very painful on open blisters, so ensure the rash is dry. Break off a small branch and collect the white fluid in a clean container then paint it onto the affected area. The fluid remains stable for 24 hours; then, new liquid must be obtained.

Pressure sores are a real threat to bedridden patients. It is said, “You can put anything on a pressure sore, except the patient.” In other words, it won’t heal unless you relieve the pressure. Prevention is the best treatment. Ensure caregivers reposition the patient every two to four hours, keep the patient clean, and bedding dry.

Large open wounds should be cleansed daily with normal saline. Honey may be applied, if available, or green papaya can be used (Hewitt, 2002; Pieper & Caliri, 2003). Green papaya has two enzymes which aid in debridement and healing, but these enzymes disappear as the fruit ripens. To use green papaya, it should be washed, peeled, seeded and mashed or grated, using non-metal instruments. It may then be applied directly to the wound or on gauze to be placed on the wound, and covered with a dressing. Fresh papaya

should be prepared every 24 hours. Please note, those with latex allergies may also be sensitive to papaya.

### *Depression And Anxiety*

Depression is a common symptom of those living with AIDS and advanced cancer. Although the patient may be depressed, s/he may not be in a clinical *depressive state*. It is beyond the limits of this guideline to address clinical depression, but a certain amount of sadness and anxiety is to be expected. Time spent listening to the patient and answering questions may help alleviate fears and concerns. Inadequate pain or other symptom control may be identified which contributes to the depression. Other emotional, social, or spiritual issues may arise and knowing someone is empathetic can make a difference. ACTS has an Ugandan AIDS trained counselor, in Rubingo, who may be accessed.

### *Confusion*

Confusion may be caused by uncontrolled pain, metabolic disturbance, meningitis, brain metastases, HIV invasion of brain cells, or drugs. Identifying and treating the underlying cause may be challenging in the village. Encourage caregivers to keep things familiar and in the same place for the patient, as far as possible. Remove dangerous objects. Use simple sentences, but speak confidently to the patient.

### Spiritual Issues

On the whole, Ugandans are a very spiritual people. That being said, one should not assume to know what they believe. The nurse should be prepared to discuss spiritual matters if the patient would like to, but some may prefer to discuss what has meaning in

their life, or ease their mind by sharing a burden of guilt from their past. It is important to listen, be respectful and non-judgmental. You may be asked to pray with them; if you are comfortable and share the same belief, feel free to do so. Connecting the patient with their spiritual leader or the ACTS counselor, may be helpful.

At end-of-life, some people find comfort from spiritual leaders even though they have not been involved with a church or religious group in the past. Others may not want to speak with a spiritual leader, but would like to discuss things with someone they respect. It is important to find out what the patient desires.

### Social Issues

Some of the issues most distressing to the dying patient can be practical issues, such as ‘What will happen to my children when I’m gone?’ Many parents are dying, leaving children in the care of already over-burdened and under-resourced grandparents or other family members. Some have no family left to take their children. These are very difficult issues, but avoiding such discussion does not make the problem go away. Assisting the patient and family to discuss possibilities may aid in bringing peace to the dying patient. Again, it may be helpful to incorporate the ACTS counselor into the discussion.

Generating money for school fees is a constant concern for parents in the village. Many believe school is the means to a better life for their children yet most have little, if any, money set aside for this. Again, discussion regarding possibilities may relieve some distress. The nurse may discuss with the ACTS counselor the possibility of ACTS providing school sponsorship for the child.

The majority of people in the village have a subsistence lifestyle, therefore when a person can no longer work, either because they are ill or they are looking after someone who is ill, they are often faced with difficult choices. Decisions may be made whether to spend money on school fees, food, or medicine, to send children to school or work in a garden, and whether to sell their animals for needed cash, depleting their future food supply. Sometimes discussing these options is helpful, respecting whatever decisions they make. ACTS has a humanitarian fund which may provide emergency relief food, medicine, transport, or housing. Contact the ACTS counselor for more information on how to access funds.

Caregivers, some of whom are ill themselves, are prone to burn-out. Friends of the patient and caregiver can help by providing respite relief, assisting with daily tasks such as cooking, laundry, fetching water, and caring for children. If the patient is part of the Widows Mutual Benefit Society, support may be enlisted on a rotating basis from the group. The organization of this may be key for it to be effective and the counselor may be helpful in setting this up.

### Loss And Grief

Parents who are ill sometimes find it difficult to talk to their children about dying. This may leave the child quite unprepared when death arrives. One method being employed through ACTS is the creation of memory books. Memory books are more than just a scrapbook. They are a way of preserving family memories, traditions and history. When families work on them together, it can promote communication regarding illness and death, as well as the hopes and desires for the future of those left. It can also support

parents to make a plan or will for their possessions and children. Memory books can help all family members in the grieving process. ACTS has held workshops for families to create memory books, providing the necessary resources and examples of what one might like to include in the book.

If the patient and family agree, the ACTS counselor may be enlisted to visit for counseling and support. He may also assist with plans for a will and dealing with bereavement. The patient or family's spiritual leader may also be helpful in this regard.

Another suggestion to aid family members, especially children, in grieving after their loved one has died, is to ensure they keep a personal item which belonged to the deceased. Material belongings are scarce, but this could be as simple as an article of clothing which would be a tangible object for a child to hold, snuggle and smell.

#### As Death Approaches

As the time of death approaches, families need to be reassured of what to expect and what to do. If a patient becomes unable to swallow, liquid morphine can be dropped into the buccal area of the mouth and be absorbed through the mucosa. At this point, only essential medications need to be given. However, analgesics should be given regularly. Keep the mouth and lips moistened. Prepare for possible incontinence of bowel and bladder. Turn the patient every two hours.

It is often customary for family and friends to gather around the patient at this time, which frequently brings comfort to the patient and family. After death comes, it is important to respect rituals and customs related to preparing and displaying the body.

Customs vary, but may include wailing, washing the body, wrapping the body in cloth, burying the body on the third day after death, and burying the body next to the home.

Ugandans are very familiar with death. Funerals are a significant ritual and it is very important culturally for people to attend. However, out of necessity they quickly return to work, gardens, and daily tasks for survival. Grief counseling is scarce. Many have learned to cope in their own way. A visit to the family several days or a week following the funeral may give a sense as to how they are coping. If the ACTS counselor has been involved, it may be appropriate to visit together.

### Self Care

Palliative nursing can be physically and emotionally taxing. It is important to recognize your own limitations, both professionally and personally, and know your boundaries. Take time for yourself to rejuvenate, both in short sessions – such as by taking a walk – and in longer sessions – ensuring your days off *are* days off. Be self-nurturing.

Uganda is a beautiful country with beautiful people, yet it has many problems. Sometimes the magnitude of them can become overwhelming. Occasionally you may find you need to refocus and remember you are only one person, and you can only do so much. But remember that what you are doing is very important, and you **are** making a difference.

## Appendix A: Mobile Hospice Mbarara Patient Referral Form

Mobile Hospice Mbarara  
 P.O. Box 1038, Mbarara (U)  
 Tel: 256-0485-21010/ 077-384938  
 Fax: 21001  
 E-mail: mhbarara@utlonline.co.ug  
 Ag. Project Manager: Martha Rabwoni



Executive Director  
 Dr. Ekiria Kikule, M.B.Ch.B.  
 Dip. Health Admin,  
 DPH, M.Med (PH)  
 Tel: 256-41-266867  
 256-41-766867  
 E-mail: ekikule@hospiceafrica.or.ug

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PATIENT REFERRAL FORM

**SECTION 1 PATIENT INFORMATION:**

Date of referral \_\_\_\_\_

Name: (underline family name) \_\_\_\_\_ M.S.D.W.

Address: \_\_\_\_\_ Tel: \_\_\_\_\_

Village \_\_\_\_\_ Sub County \_\_\_\_\_

District \_\_\_\_\_ RCI Zone \_\_\_\_\_

Age \_\_\_\_\_ DOB \_\_\_\_\_ Religion \_\_\_\_\_ Occupation \_\_\_\_\_

Tribe \_\_\_\_\_ Presently patient is at home: [ ] in hospital [ ]

Name of hospital: \_\_\_\_\_ Ward: \_\_\_\_\_

Next of kin: \_\_\_\_\_ Lives with: \_\_\_\_\_

**Please note that Hospice asks for 5000/= per week towards Patient care, for those who can manage it.**

**SECTION 2 : DOCTORS INFORMATION:**

Name of referring doctor: \_\_\_\_\_

Address: \_\_\_\_\_

Name of principal doctor: \_\_\_\_\_

Other doctors involved with care: \_\_\_\_\_

Other agencies involved: \_\_\_\_\_

Do you want?: Consultation only: \_\_\_\_\_

Hospice to take over patient: \_\_\_\_\_

Joint care: \_\_\_\_\_

Note: Our home care covers 20km around Mbarara. We can advise in other cases and liaise with families.

**PTO**



**SECTION 3 CONFIDENTIAL INFORMATION**

Reason for referral: Pain ( ) Symptom: ( ) Other: ( )

Please give details: \_\_\_\_\_

\_\_\_\_\_

Brief history: \_\_\_\_\_

\_\_\_\_\_

Positive physical findings \_\_\_\_\_

\_\_\_\_\_

Relevant positive investigation supporting diagnosis: \_\_\_\_\_

\_\_\_\_\_

Diagnosis: Cancer: Primary \_\_\_\_\_ histology: \_\_\_\_\_

Metastases and site(s) \_\_\_\_\_

Immunosuppression? ( )

HIV status: Pos: ( ) Neg: ( ) Not known ( )

Current treatment: (including laxatives, analgesics, sedative, antibiotics etc)

Generic name	Dose	Date started
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Further information:

Signed (referring doctor) \_\_\_\_\_ Date \_\_\_\_\_

Thank you for your co-operation in filling this form. It will greatly assist our work.

## Appendix B: Mobile Hospice Mbarara Medication List

Drug Name, Strength, and Form

1. Acyclovir 200mg tablets
2. Amitriptyline 25mg tablets
3. Amoxicillin 250mg capsules
4. Aqueous Cream
5. Bisacodyl 5 mg tablets
6. Chloroquine 150mg tablets
7. Chloroquine (base) 200mg/5ml injection
8. Chlorpheniramine 4mg tablets
9. Chlorpromazine 25mg tablets
10. Ciprofloxacin 500cg tablets
11. Clotrimazole 1% cream
12. Clotrimazole 500mg pessaries (suppositories)
13. Cloxacillin 250mg capsules
14. Co-Trimoxazole 480mg tablets
15. Dexamethasone 0.5mg tablets
16. Dexamthasone 8mg/2ml injection
17. Diazepam 5mg tablets
18. Diclofenac 50mg tablets
19. Fansidar tablets
20. Fluconazole 200mg tablets

21. Frusemide 20mg/2ml injection
22. Frusemide 40mg tablets
23. Haloperidol 5mg tablets
24. Hibicet concentration (pre-packed)
25. Hyoscine 10mg tablets
26. Ibuprofen 200mg tablets
27. Ketoconazole 200mg tablets
28. Magnesium Trisilicate liquid (pre-packed)
29. Magnesium Trisilicate tablets
30. Mebendazole 100mg tablets
31. Metoclopramide 10mg tablets
32. Metoclopramide 10mg/2ml injection
33. Metoclopramide 200mg tablets
34. Nystatin 100,000IU liquid
35. Nystatin 100,000IU pessaries
36. Paracetamol 500mg tablets
37. Phenytoin 100mg tablets
38. Prednisolone 5mg tablets
39. Spironolactone 25mg tablets
40. Tamoxifen 20mg tablets
41. Thioridazine 25mg tablets
42. Water for injections 10ml vials

Also In Stock:

Carbamazepine

Quinine

Arbemether

Domperidone

Cimetidine

K-Y Jelly

Metronidazole mouthwash

Morphine:

- 5mg in 5ml solution
- 50mg in 5ml solution
- MST 10mg tablets
- MST 30mg tablets

List provided by Mobile Hospice Mbarara, March, 2006.

## Appendix C: Electronic Resources Available

AIDS Palliative Care. UNAIDS Technical update, (2000).

[www.hospicecare.com/resources/pdf-docs/unaidspallcare-aids.pdf](http://www.hospicecare.com/resources/pdf-docs/unaidspallcare-aids.pdf)

British Medical Journal Articles on Palliative Care:

[www.familypractice.ubc.ca/undergraduate/from\\_RNP/plinks.htm](http://www.familypractice.ubc.ca/undergraduate/from_RNP/plinks.htm)

Living Well with HIV/AIDS. Food and Agriculture Organization of the United Nations.

[www.fao.org/DOCREP/005/Y4168E/Y4168E00.htm](http://www.fao.org/DOCREP/005/Y4168E/Y4168E00.htm)

HIV Health and Your Community: A Guide for Action, by R. Granich & J. Mermin,

(2001). [www.hesperian.org/publications\\_download\\_hiv.php](http://www.hesperian.org/publications_download_hiv.php)

IAHPC Palliative Care Manual, (2004).

[www.hospicecare.com/manual/IAHPCmanual.htm](http://www.hospicecare.com/manual/IAHPCmanual.htm)

Palliative Care for Women With Cervical Cancer: A Field Manual, (2003).

[www.path.org/files/RH\\_palliative\\_care\\_guide.pdf](http://www.path.org/files/RH_palliative_care_guide.pdf)

Palliative Care: Symptom Management and End-of-Life Care, (2004).

[www.who.int/3by5/publications/documents/en/genericpalliativecare082004.pdf](http://www.who.int/3by5/publications/documents/en/genericpalliativecare082004.pdf)

Palliative Medicine: Pain and Symptom Control in the Cancer and AIDS patient in

Uganda and other African countries, (2006).

[www.hospicecare.com/resources/pdf-docs/painsym\\_uganda.pdf](http://www.hospicecare.com/resources/pdf-docs/painsym_uganda.pdf)

Where There Is No Doctor, by David Werner (2007).

[www.hesperian.org/publications\\_download\\_wtnd.php](http://www.hesperian.org/publications_download_wtnd.php)

World Health Organization (2004). *Palliative care: Symptom management and end-of-*

*life care.* [www.who.int/3by5/publications/documents/imai/en/](http://www.who.int/3by5/publications/documents/imai/en/)

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World Health Organization (2008). Retrieved January 4, 2008, from:

[www.who.int/cancer/palliative/en](http://www.who.int/cancer/palliative/en)