Uganda: Initiating a Government Public Health Approach to Pain Relief and Palliative Care

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Introduction

Uganda is the first and only country in Africa that has made palliative care for AIDS and cancer victims a priority in their National Health Plan.[1–3] The World Health Organization (WHO) has highlighted the importance of palliative care in the developing world. Using strong advocacy,[4,5] it has produced manuals for scientifically valid but still simple and affordable methods for pain and symptom control,[6–10] including policy and managerial guidelines.[11–13] WHO has supported effective implementation of palliative care by a rational public health approach that can reach most in need.[14]

Effective and inexpensive methods exist for symptom control but the tragedy is that they are not being offered to the majority of people who need them. Before prevention takes effect and affordable and curative therapies become available, the only realistic and humane thing to do is to offer pain and symptom control. Most African governments and large international AIDS organizations do not consider palliative care a priority. Instead, they prioritize expensive and marginally effective therapy approaches in a situation with mainly incurable patients. Uganda is an exception.

World Epidemiology

More than 55 million people die every year, 80% of them in the developing world. In 2000, an estimated three million died from AIDS. Some 36 million people have HIV/AIDS, 95% of them in the developing world (25 million in Subsaharan Africa). Currently 10 million people develop cancer every year and this figure is expected to rise to 15 million in 2020 and to 24 million by 2050 (15). Ten million cancer sufferers will be from developing countries in 2020, this will rise to 17 million in 2050.

Most will be incurable and will not have access to adequate medical services. To these figures can be added the fact that the number of persons older than age of 65 will increase dramatically over the next 50 years. By 2050, there will be an increase from the 0.2 billion elders today to 1.2 billion in the developing countries, while the increase in the developed countries will be from 0.2 billion to 0.3 billion.

Although the number of hospices has grown tremendously, their reach is still quite limited. Out of about 7000 hospices in existence, only 20% are in the developing countries, and the number of patients they reach are relatively limited, usually a few hundred patients per hospice. Uganda, since 1993, has had one of the few hospices in Africa, the first being in South Africa, Zimbabwe and Kenya.

Uganda

In Uganda, with more than 200,000 AIDS victims and 22,000 cancer sufferers each year, fewer than 250 patients yearly receive palliative care during 1993–1998. The Hospice Uganda

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has served as a lifebuoy in an ocean of suffering, showing what could be possible. They also had a strong, culturally-sensitive training program ongoing since 1993. The 800 health professionals trained could have practiced palliative care, but morphine was not available to most. Palliative care has not been considered a major problem in the health care system and the awareness of simple affordable solutions was nonexistent.

Uganda has a population of 22 million; 51% are 0–14-years-old and 1.14 % are 65 years and older. The death rate is 18-deaths/1000 population and the life expectancy is 43.4 years. The prevalence of adult HIV/AIDS is 8.3%; the number living with HIV/AIDS is estimated to 820,000, and annual HIV/AIDS deaths number 110,000 (1999 est.). There are numerous religions: Roman Catholic 33%, Protestant 33%, Muslim 16%, and indigenous beliefs 18%. The literacy rate for the population over 15 is 62% (male 61.8%, female 50.2%). The gross domestic product per capita has purchasing power parity of $ 1,100.[16] Around 57% of the population will never encounter a nurse or a doctor in their lifetime. Uganda has many sophisticated, highly educated leaders, and has had the tradition of having the leading university in Black Africa. The country has recently documented their leadership, for example, in curbing the AIDS epidemic.

What to Do

The WHO recommends four low-cost foundational measures, which are important for establishing sustainable palliative care[8–10] (Fig. 1):

1. Establish a national policy of palliative care, with solutions specific for the country/culture and outline how palliative care will be developed within the health services.
2. Make a commitment to train all health workers in managing pain and other symptoms while also informing and educating the public.
3. Ensure that the necessary drugs for pain control are easily available, particularly affordable opioids like morphine, and can be prescribed by appropriately trained professionals.
4. Ensure that pain and palliative care programs are incorporated into a country's health care systems, as separate systems will not achieve necessary coverage. Ensure a multidisciplinary and multidisease approach, covering not only cancer but also AIDS, and ultimately the elderly terminally ill.

Initiating a Governmental Policy

It is not enough to provide the latest scientific state-of-the art information and technical manuals. Guidelines on how to set priorities and approaches have usually been found helpful when addressing the establishment of a national program using a public health approach to reach those in need.[11–13] The principles, outlined in "National Cancer Control Programmes: Policies and Managerial Guidelines," WHO 1990 and 1995, were applied in Uganda, addressing

- Assessment of the magnitude of the problem
- Setting measurable objectives
- Evaluating possible strategies
- Choosing priorities for initial activities

It is important that each country establish their national program according to their own culture and socio-economic circumstances.

Holding a workshop offers an effective opportunity to create awareness, establish the size of the problem, identify key problems, work out solutions, set priorities, and identify champions (see Annexes 2 and 3 from Reference 12). It is important to select the right participants, many the future stakeholders, so ownership also is achieved. The participants should be multidisciplinary (nurses, doctors, pharmacists, social workers, religious leaders), and also include public health officials, representatives from key Ministries and leading nongovernmental organizations (NGOs). Two and a half days is usually enough for a workshop. Having objectives and goals upfront is helpful, and it is important thereafter to modify them or repeat them with the aim of achieving concrete proposals, solutions and commitments that can be presented the last day of the workshop. Intermittently breaking up in selected working groups is usually helpful.

Recruiting leaders, finding champions and thereafter supporting them is important for success in the follow-up of most workshops. A champion is defined as a person who has charisma, credibility, neutrality, independence,

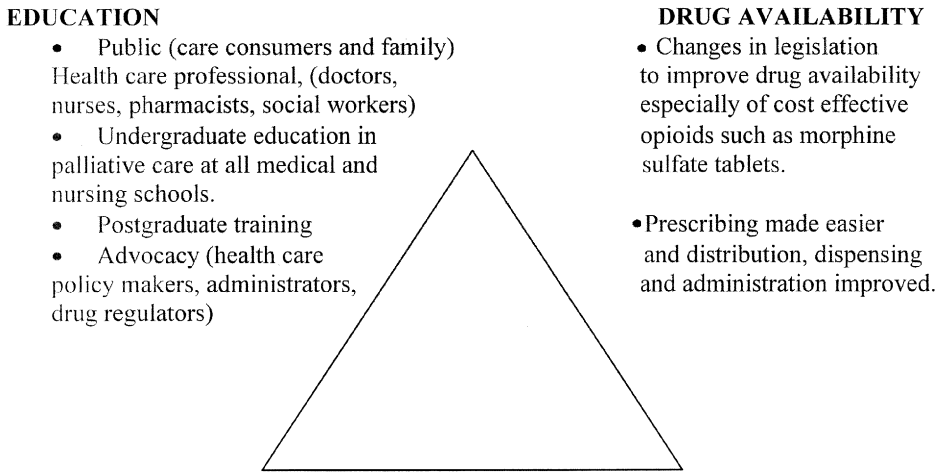

Fig. 1. Foundation measures: Little cost, big effect.

commitment, political awareness, managerial effectiveness, and ability to mobilize resources, communication skills and understanding of the health care system.[12,13] The workshop should end with clear recommendations and include:

- Specific actions to be taken
- Focal persons responsible
- Indicators for monitoring
- Expected deadlines
- Financing necessary

The recommendations from the 1998 Ugandan workshop [17] are given in Table 1. The table may be helpful to consider when others are planning workshops to initiate a government policy or national program.

A workshop, if successful, is not an end but a start, and it is advised to have some minimal funding mobilized for supporting implementation of recommendations, remuneration to identified champion(s), if needed, and for supporting a second follow-up workshop or visit.

In Uganda, the first workshop for officials and key personnel was held in March 1998. This was followed by a second in March 1999, and a "mini "workshop in 2000. Many champions were identified. Uganda had one already in Dr. Anne Merriman, originally in tropical medicine, in Nigeria, then in geriatric medicine and later palliative care. She initiated hospice care in Singapore and assisted as the first physician in Nairobi Hospice, Kenya. In 1993, she established Hospice Africa Uganda. She knows Africa well and loves it with a pragmatic realism. For the first workshop sponsored by the WHO, the Ministry of Health, Hospice Uganda and GCC, all the right participants had been identified. They were leading clinicians, doctors and nurses from the AIDS and cancer establishment, pharmacists, the Drug Commissioner, the Dean of Makarere University, the directors of the nursing schools, and representatives from the Ministry of Health and WHO.

WHO also had a high achiever, the Country Representative in place, Dr. Njie, who had the confidence of the government and supported the Ministry of Health's finalization of their new five-year health plan. Furthermore, a new

Table 1
Recommendations from the Conference on "Freedom from Cancer and AIDS Pain," Entebbe, March 1998

TARGETS-ACTION	FOCAL PERSON	INDICATORS	DATE TO BE COMPLETED	COMMENTS + FINANCIAL
1. National Policy (NP) on palliative care (PC), cancer pain relief (CPR), AIDS pain relief (APR)	Dr. Njie, Dr. Okullo, and Ministry of Health	PC + CPR + APR identified priorities in National Health Plan National coordinator appointed	1998 1998	Suitable person to be identified 1/2 time salary to be found for 2 years (J.S.)
2. Education				
2.1 Training of all undergraduate doctors	Dr. Lydia Mpanga Dr. Okullo Dr. Anne Merriman	Included in curricula at Makarere and Mbarara	1998	
2.2 Training of all undergraduate nurses	Ms. Nannusua	Included in National Nursing curricula	1998	
2.3 CME for drs includes PC	Dr. Kanyeresi, Dr. Twatwa	First course started		
2.4 Postgraduate (MMed) training includes PC	Postgraduate Dean	Curricula accepted officially	1999/2000	
2.5 Include management of CPR and APR in National Treatment Guidelines	Chairman NDA Dr. Lukgwa Committee on Essential Drugs Chief Nurse, MoH	Inclusion in National Treatment Guidelines	1999	
2.6 Pharmacist training Undergraduate level Postgraduate level	Head, Dept. Pharmacology Pharmaceutical Society Uganda	In curriculum In CME	1998 1998	
2.7 General public, especially family members to be empowered in PC	Hospice Uganda (Med. Dir.) and AIDS control program (Dr. Madraa)	Educational material produced Approaches agreed Training started	1999	
2.8 East African Regional Education Courses established	Dr. Gaya (Eldoret, Kenya) Dr. F. Omaswa	EAPC Diploma established	1999	
2.9 Specific African Distant Learning PC Course established	Dr. Anne Merriman	Agreement with overseas established course achieved. "Africanized" material produced. Course started.	1999/2000	UK Centers having such courses to be contacted: Dundee, Newcastle, Oxford
3. Drug availability				
3.1 Rewrite National Drug laws on morphine	Dr. J. Jagwe	Submitted to Parliament	Before May 1998	
3.2 Estimate morphine needs	Dr. Lydia Mpanga	Submitted to Dr. Jagwe	Before May 1998	Notify NDA
3.3 Update essential drug list	Drs. Merriman, Mpanga	Submitted to Dr. Jagwe Included in EDLU	Before May 1998 1999	

(continued)

Table 1
Continued

TARGETS-ACTION	FOCAL PERSON	INDICATORS	DATE TO BE COMPLETED	COMMENTS + FINANCIAL
3.4 Notify Medical Superintendents on availability of morphine	Dr. Merriman JMS	Available in JMS & NMS Hospital Pharmacies	March 1998	
3.5 Authorization of PC Nurse Practitioners to prescribe morphine to cancer and AIDS patients	Dr. Jagwe Nursing Council Hospice Uganda	Changes of law introduced by Dr. Jagwe Official	Before May 1998 Nationally 2000	Stepwise introduction depending on qualified PC nurses trained/ identified
3.6 Request to INCB for increased national morphine allowance	Dr. Jagwe	Request mailed to INCB Permission granted.	Before June 1998 January 1999	Permission takes 6 months
3.7 Tender for immediate-release morphine tablets	Mr. Kisto, NMS	Tender out Available	January 1999 June 1999	Restricted tender
4. Coordination of PC activities AIDS and cancer	Drs. Madraa, Merriman, Mpanga and Moss	Coordinated policies, teaching and services.	December 1998	
5. Multidisciplinary clinics for cancer patients	Drs. Lynette (CI), Bataganya and Merriman	Occurring weekly	April 1998	
6. Increased awareness of PC, CPR, APR needs and solutions for public and health care professionals	Dept. of Health Education, MoH Dr. Paul Kagwe Director Support Services, Dr. Kyabaggu Journalist: Mr. Kagambirwe, New Vision Drs. and Nurses who are MPs Dr. Jagwe to prepare materials for MPs	Fact sheets. Feature stories. Written and audio visual awareness material.	December 1998	
7. District Demonstration Project, MoH, WHO, GCC	Hoima District Dr. Stella Tibumanywa Biostatistician	Project proposal including indicators for monitoring and budget established. Budget available. KAP test for baseline assessment. Implementation started. KAP test 2 done-evaluated. Coverage evaluated. Audit and evaluation.	April 1998 September 1998 Autumn 1998 January 1999 Every second year 2001	Should be done within the existing health care system. Budget only for research, monitoring and evaluation. Estimated budget: 10,000$ US per year 1998–2001.

champion emerged at the Workshop, Dr. Jack Jagwe, who knew the health care system well. He was Chairman of the National Drug Authority and knew all the legislative "in-and-outs" necessary for making class A drugs available, e.g. morphine. He came up with pragmatic solutions to most queries. He was soon to retire and we mobilized a salary to enable Dr. Jagwe to become part-time in his role as advocate with the Ministry of Health and senior advisor in national policy for Hospice Uganda, with the mandate to follow up the implementation of the recommendations from the workshop. This included the establishment of a committee to advise on a national policy, making pain and palliative care for AIDS and cancer victims a priority in Uganda's new health plan.

Three sides of the WHO triangle of foundational measures have now been established. Education had been in place from 1993, together with drug availability at the hospice. This is now to be extended throughout the country with the assistance of the national policy. Together with the Ministry of Health, sensitization and education of the leaders in the health care system, including Community and District Health Care levels were addressed. Coordination between cancer and AIDS palliative care activities, which was not occurring earlier, was also agreed upon.

A District Demonstration Project in Hoima, where there was already an established branch of Hospice Uganda, was endorsed. This started with a situation analysis and an assessment of patients and families needs. This was completed in 2002 and is now being followed through.

Morphine prescribed by nurses will be unique to Uganda. This was based on a recommendation from a nurse participant and was encouraged by Dr Jagwe. It was pointed out that midwives are allowed to use pethidine (meperidine) by law and this statute could be altered to allow nurses qualified in palliative care to give morphine.

One year later in 1999, a second workshop monitoring the recommendations from the first was held. A third mini-workshop was held in 2000 in connection with an International Pan- African Psycho-Oncology (PAPOS) Conference in Kampala.

Another champion emerged within the Ministry of Health in 1999. A young doctor who, when a medical officer at Arua Referral Hospital in the northwestern corner of Uganda, had realized the futility of referring incurable patients for classic curative therapy efforts in Kampala, Dr. Jacinto Amandua ,was appointed in late 1999 as Commissioner for Curative Health Services in the Ministry of Health, Kampala. This included clinical services for cancer and HIV/AIDS. He had taken pain relief and palliative care to heart. He was thus responsible for working out the details for palliative care in the new National Health Strategy Plan.

In 2000, a volunteer pharmacist with VSO UK, Mrs. Vanessa Adams, was based with the Ministry of Health and Hospice Uganda for a year with a mandate to facilitate the mobilization and use of morphine throughout Uganda. She travelled extensively and produced a detailed plan, with the overall objective to increase access to the drugs required for comprehensive palliative care throughout Uganda. She produced a "generic" model for Uganda and other African countries for the introduction of oral morphine, and for handling and monitoring its safe use. This resulted in the "Guidelines for Handling of Class A Drugs," Ministry of Health, Uganda, March 2001. Again this is a first for Africa and will serve as a model.

Morphine has been on the essential drug list in Uganda since 1996 as a branded extended-release formulation, which was too expensive for most. Liquid morphine is now on the essential drug list. Previously, it was only Zimbabwe—in its excellent "Essential Drugs List for Zimbabwe (EDLIZ)"— that had included morphine hydrochloride oral liquid in its essential drug list, together with a chapter on pain management.[18]

Government Policy

Uganda is the first and only country in Africa that has palliative care for the chronically and terminally ill persons as a priority, under "Essential Clinical Care" in its "National Health Policy" [1] and with detailed specification on implementation in the "Health Sector Strategic Plan."[2] In this policy document, output, indicators, means of verifications and activities at the operational level are given (Figs. 2 & 3). Based on the government policy and the educational achievements of Hospice Uganda, the interna-

Fig. 2. A medical first for Africa: making palliative care and pain relief for AIDS and cancer victims one of the priorities in the Government's National Health plan.

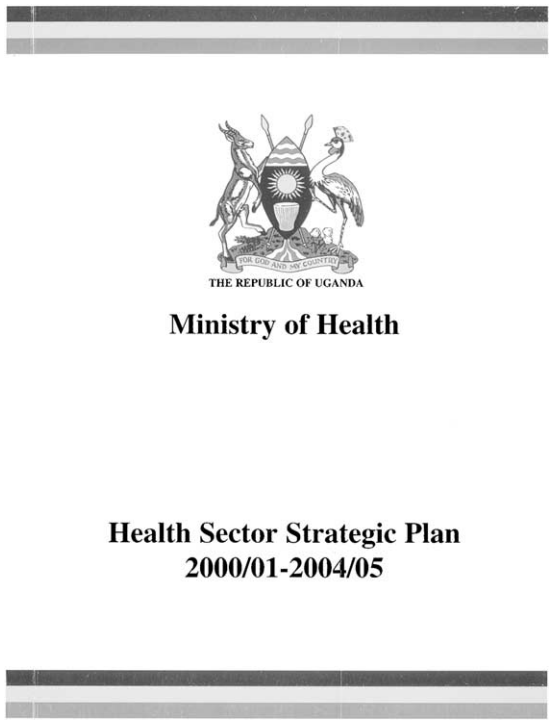

Fig. 3. Establishing pain relief: a part of "minimal essential care" with clear details for output, verifiable mediators, means of verifications and activities at operational levels.

tional donor community has recognized Uganda's leadership in palliative care in Africa. Thus, it has become the main recipient of funding from "Diana's Palliative Care Initiative" of the Diana Princess of Wales Memorial Fund[19] in 2000–2001. Uganda has also become a key demonstration country in WHO's "Community Health Approach to Palliative Care for HIV/AIDS and Cancer patients in Africa" a joint project of WHO, Botswana, Ethiopia, Tanzania, Uganda, Zimbabwe, and South Africa.

What Next? A Key Problem Still Unsolved

Even in a country such as Uganda, more than half of the population never will see a nurse or a doctor. Just as frustrating as it is to see the absolute minimal fraction of all those in need benefiting by the expertise of the classical medical palliative care approach, it is frustrating to realize that this approach, even if successful, will only reach half of the population. However, as the old Vikings said," If you have a hammer, everything looks like a nail" and we have to start somewhere.

What about the other half? Unique cultural specific community systems and rituals exist that for hundred of years have helped people cope with dying and suffering. Certainly, old cultural traditions for curbing total pain could be empowered rationally in such infrastructures, reassuring all that they will not be lost. Symptom care, bedsore prophylaxis, appropriate food and hygiene, and spiritual and existential pains can be addressed by culturally-specific approaches. Finding ways of empowering the families and community in such care is thus an urgently needed priority. The socio-economic cultural solutions will be as important as the medical for achieving a meaningful coverage. They should be integrated in parallel with the medical palliative care approaches, being interdependent as well as complementary, so as to achieve a nationwide meaningful coverage of palliative care. The District research projects, like the one initiated in Hoima, and the community approach done by South Coast Hospice and HASA in South Africa,[20,21] may help indicate the way forward.

Summary

Uganda is the first and only African country that has made pain relief and palliative care for the chronically and terminally ill a priority in their National Health Plan. Uganda serves as a helpful model for what other countries urgently ought to do.

Acknowledgments

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