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Development of legal and human rights guidelines for palliative care in Uganda

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Feature | Policy



Dr Isaac Ezati, Director of Policy and Planning at the Ugandan Ministry of Health, with Dr Emmanuel Luyirika and a poster explaining the palliative care patients' rights

Continuing our legal aspects series, Dr Emmanuel Luyirika and Fatia Kiyange write about the development of legal and human rights guidelines for palliative care patients and their families in Uganda.

Palliative care patients and their families in Uganda, like elsewhere in the world, are very vulnerable; not only physically but also socially, culturally, psychologically and spiritually. Many health workers are ill-informed about legal issues and palliative care workers often do not have adequate legal training, or a network of support to draw on for legal advice for their patients. Many palliative care programmes lack multidisciplinary teams with legal capacity.

In 2009, the African Palliative Care Association (APCA), in collaboration with the Open Society

Legal and human rights issues in palliative care materials developed for Uganda

[Human rights, ethical and legal issues in palliative care – A guide for patients and their families](#)

[Human rights, ethical and legal issues in palliative care – A guide for health care providers](#)

[Palliative care is a basic human right – Poster](#)

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Foundations' Law & Health Initiative, International Palliative Care Initiative (IPCI) and Open Society Institute for East Africa (OSIEA), reviewed laws and practice guidelines in Kenya, Uganda and Tanzania related to the legal needs of palliative care patients and their families.

[The palliative care patients' rights – Poster](#)

[Will-making and succession – Poster](#)

Materials for patients and their families have also been translated into one of the largest spoken local languages, Luganda, and there are plans for these to be translated into another four languages which cover the various regions of the country.

The group undertook a rapid appraisal among legal practitioners, policy makers, palliative care providers and patients in Kenya and Uganda to identify their understanding of the legal and human rights issues that hinder palliative care provision.

The review and appraisal identified some of the legal and human rights barriers that affect the advancement of palliative care, particularly the availability of medications.

There are several legal and human rights-related problems which face palliative care patients and their families. These include:

- gender-based violence
- property ownership
- land evictions
- unfair cultural practices
- will making and issues that arise after death
- divorce and related issues
- children's rights
- ethical issues
- lack of access to medications.

Patients are often ignorant of their own rights and entitlements and do not have access to legal services.

For such problems to be addressed, palliative care programmes need to have clear guidelines and access to legal support within the health system.

A series of activities were undertaken as part of the process of developing such guidelines:

Palliative care sensitisation for legal practitioners

A round table meeting targeting legal experts and palliative care service providers was held in May 2011 in Kampala, Uganda, to sensitise the legal experts on palliative care and discuss legal and human rights issues that affect its scale-up in Uganda. Legal companies and societies were identified such as The Uganda Law Society. This society provides free legal services e.g.: support in the writing and execution of Wills, defence in courts of law, and ensuring that patients have access to legal services.

Introductory palliative care training for legal practitioners

A curriculum was developed for the training of legal practitioners based on a five-day palliative care introductory course for lawyers. Using the curriculum, eight legal practitioners from within human rights and legal organisations received in-depth training on palliative care, including site visits to see first-hand the work of the palliative care organisations in Uganda and the needs of the patients with life threatening illnesses. This resulted in linkages between legal and palliative care organisations which may assist patients and their families in accessing legal services.

Developing national guidelines to meet human rights, ethical and legal issues in palliative care

Following these activities, APCA entered into an arrangement with the Uganda Network on Law, Ethics and HIV/AIDS (UGANET), a non-governmental organisation working with health rights and legal issues with a main focus on HIV. UGANET would be the leading legal and human rights partner with which APCA, the Ugandan Ministry of Health and the Palliative Care Association of Uganda (PCAU) would work to develop the legal and human rights guides and Information Education and Communication (IEC) materials in palliative care.

The partners reviewed and identified sections relevant to palliative care from the Constitution of Uganda and other relevant laws and regulations, which provided context-specific framework for the materials. This comprehensive process ensured that all aspects of palliative care with legal and ethical implications were covered. The resulting [documents and guidelines](#) defined the required skills and tools for the benefit of patients and their families, health providers and the country at large.

The documents were launched on 5 April 2013 as official Ministry of Health documents by Dr Isaac Ezati, the Director of Policy and Planning of the Ministry of Health in Uganda, on behalf of the then Minister of Health, Hon. Dr Christine Ondo.

The legal and human rights guidelines and IEC materials on palliative care are being used in various ways:

- by palliative care sites to strengthen legal support to patients and their families
- by PCAU to integrate legal and human rights issues in palliative care as part of introductory palliative care training for health professionals
- by health facilities to provide guidance for service provision
- by patients and their families as a resource to help them seek legal support when required and for them to understand and claim their rights
- by communities to learn about the legal and human rights issues in palliative care, especially the rights of palliative care patients and where they may access legal services
- by legal practitioners to gain an understanding of palliative care.

Important outcomes and lessons from the legal and human rights interventions in palliative care in Uganda

The orientation of legal practitioners to palliative care has resulted in active advocacy for its integration in the legislation of Uganda and Eastern Africa. For example: UGANET has advocated for the inclusion of palliative care in the East Africa HIV Bill. Similar advocacy is going on to ensure that palliative care is included in Uganda's HIV Bill.

Legal practitioners bring a wealth of legal and human rights expertise that is critical to palliative care advocacy and service provision. It is, therefore, important to involve them as valuable stakeholders in the advancement of palliative care.

Palliative care has taken a lead in ensuring that legal aspects and human rights are actively embedded in health services in Eastern Africa.

It is important to know the local needs and challenges of patients, their families and palliative care providers.

It is important to involve all relevant arms of national or regional government stakeholders and for legal NGO structures to take ownership of the process. Also to set up a system that fits the identified needs and gaps not covered by existing structures and services.

The role of legal support in improving the quality of life of patients and their families in palliative care is currently well recognised in Uganda by the MoH, PCAU and its member organisations.

Collaborative relationships have been established between palliative care service providers and advocates, and human rights and legal services in the country. These relationships form a platform for further work in ensuring that human rights and legal needs of patients and their families are addressed.

The Uganda experience could inform similar interventions in Africa, to ensure that legal and human rights concerns of palliative care patients are addressed.

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