

VOICES

The Start of a New Movement: Access to Justice for Palliative Care Patients

September 14, 2012 | by Tamar Ezer | Public Health Program | 2 comments

It all started in late 2006 when palliative care providers and legal advocates came together in Cape Town, South Africa, to discuss how best to address the needs of patients with life-threatening illness, such as AIDS, TB, or cancer. The palliative care providers spoke of patients desperate to make arrangements for their children's care, anxious about the disposition of their property and their family's future, unable to access needed pain medication, falling into debt and struggling to secure social benefits, grappling with discrimination and violence, and laboring to navigate complex application procedures for identity documents and death certificates. The palliative care providers turned to their legal companions and urged, "Help us become better advocates for our patients." Many of these issues are the bread and butter making up the daily work of legal service providers, and a partnership was born.

0

1

1

0

Email

Republish

In the eloquent words of one of its founders, palliative care focuses on "adding life to the days rather than days to the life." Palliative care aims to improve the quality of life for patients and families facing life-threatening diseases by relieving pain and suffering through physical, psychosocial, and spiritual care. Addressing legal and human rights issues that arise is thus a natural part of palliative care's holistic approach. In South Africa, a country where over 5.54 million people live HIV—more than 10 percent of the population, many of whom are coinfectd with TB—it is critical to look at both acute physical needs and the social dimensions of the epidemic.

The Hospice and Palliative Care Association of South Africa (HPCA) decided to squarely address the legal and human rights problems facing people with life-threatening illness through [partnerships with law schools](#), legal NGOs, and pro bono attorneys. Together, they organized a series of workshops for hospice caregivers and nurses. Given the lack of materials on palliative care and law, they produced a manual, *Legal Aspects of Palliative Care*, to help hospice and palliative care staff identify legal

issues and provide referrals where necessary and to enhance legal practitioners' understanding of palliative care patient needs.

Six years later, much has been achieved, and hundreds of patients have benefited from the new alliance between palliative care providers and legal professionals. HPCA has just released the second edition of [*Legal Aspects of Palliative Care*](#). The manual now not only includes case studies, legal recommendations, and resources, but has been restructured as a training manual with step-by-step lessons for hospice and palliative care staff and legal practitioners.

Integrated palliative care and legal services have also caught on in the [country of Georgia](#) and in Eastern Africa. In Uganda, the African Palliative Care Association has partnered with the Uganda Network on Law, Ethics and HIV/AIDS to provide access to justice to palliative care patients and families. In Kenya, the Kenya Hospice and Palliative Care Association has trained health workers as paralegals to provide legal advice to patients during home visits and established partnerships with pro bono lawyers. They have also developed a [range of leaflets](#) addressing the legal rights of palliative care patients, including a template for writing a will and guidance on appointing a power of attorney.

As we have learned over the years, legal services can play a critical role in improving the quality of life for patients and families dealing with life-threatening illnesses. They address human rights violations that negatively affect their health and contribute to patients' and families' peace of mind and well-being by providing answers to urgent and often difficult questions. Integrated health and legal services allow for both holistic care and increase access to justice, taking the law out of the courtroom and private offices and into the community.

Learn More:

Africa, Europe, Health, Rights & Justice, Law and Health, Palliative Care

2 Comments HIDE

ADD YOUR VOICE

Nicola GunnClark

posted on Sep 20, 2012

The updated edition of the hospice law manual was launched yesterday (19 Sept 2012) at the HPCA 25th anniversary conference in Cape Town South Africa. Was a resounding