

Legal Support for Palliative Care Patients



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Abstract

Context. Palliative care patients face legal issues that impact their quality of life. Legal support, embedded in holistic palliative care services, has developed globally over the last decade to address this.

Objectives. This article aims to trace the origins of legal support for palliative care patients, detail models of legal support, and describe achievements and challenges.

Methods. The article draws on years of work in this area and the available literature.

Results. Common legal issues include disposing of property and drafting wills, planning for children, dealing with debt and securing social benefits, and addressing discrimination. Diverse approaches to integrating legal support include developing paralegal skills, accessing skilled legal advice, empowering patients and families, and building awareness of rights among health care workers.

Conclusion. There is robust and growing acceptance of legal support as a key component of holistic palliative care, and many palliative care professionals are identifying and addressing the legal needs they encounter through mediation, guidance on basic rights, or referrals to a lawyer. Addressing legal problems can contribute to peace of mind, well-being, and the health of patients. *J Pain Symptom Manage* 2018;55:S157–S162. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Palliative, law, legal, advocacy

Introduction

Palliative care aims to improve the quality of life for patients and families facing life-limiting illnesses by relieving pain and suffering through physical, psychosocial, and spiritual care. In the eloquent words of one of the founders of palliative care, Dame Cicely Saunders, palliative care focuses on adding life to the days rather than days to the life. Through this approach, palliative care providers have long led the health profession in challenging and pushing the boundaries of holistic care.

In the early years of this century, a number of palliative care specialists observed that their patients faced legal issues that impacted their quality of life. Responding to this need, palliative care providers from

across the globe began to explore ways to address these legal concerns. During the past decade, these providers have established innovative partnerships with legal actors to enable them to provide their patients with care that encompasses legal support and access to justice, and in doing so, have established a new norm and component in holistic palliative care.

In this article, we trace the origins of this work, detail models of legal support, and describe achievements and challenges in implementing and embedding legal support into holistic palliative care services. Because legal services generally connotes the involvement of a lawyer, we use the broader term legal support to encompass the assistance of actors other than lawyers in addressing patients' legal issues as well as advice and/or representation from a lawyer.

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Origins of Legal Support in Palliative Care

Inspiration for the integration of legal support in palliative care came from the medical-legal partnerships in the U.S. in the late 90s. They pioneered the integration of legal services into health care, advancing the idea that lawyers and doctors could be partners in addressing health and its underlying determinants.^{1,2} Particularly influential was the work of Legal Health, a division of the New York Assistance Group, with palliative care patients.³

The integration of legal support in palliative care gained momentum outside the U.S. in 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, tuberculosis, or cancer. With more than 5.54 million people living with HIV in South Africa at the time—more than 10% of the population, and many coinfecting with tuberculosis,⁴ there was particular urgency to look at both acute physical needs and the social dimensions of the epidemic. 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. They urged their legal companions to "help us become better advocates for our patients."⁵ Many of these issues are the bread and butter making up the daily work of legal services providers, and thus a partnership was born.

The Hospice Palliative Care Association of South Africa set out to address the legal and human rights issues faced by people with life-threatening illness through partnership with law schools⁶ as well as legal nongovernmental organizations (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.^{7,8}

South Africa leadership in legal support inspired similar initiatives globally. This article will highlight initiatives in the following seven countries: Georgia, Hungary, Kenya, Malawi, Romania, South Africa, and Uganda.

Global Trends in Patient Legal Needs

Although each individual faces unique challenges, globally, there are some commonalities in the legal

and rights issues patients face. Common legal issues include disposing of property and drafting wills, family law matters and planning for children, dealing with debt and securing social benefits, addressing discrimination—particularly for patients living with HIV—or navigating obstacles in the justice system. The following case studies highlight these common legal issues.

In recognition of the vulnerability of widows, the Palliative Care Association of Malawi (PACAM) has initiated work to destigmatize wills. Since 2014, PACAM and partner hospices have supported patients to understand the utility of wills and consider whether they need to leave a will to ensure their home and assets are preserved and passed on to their immediate family members. Patrick, a patient at Ndi Moyo Hospice, was one of the first to take up a (trained) social worker's offer to guide him through the formal process of drafting a will. Ndi Moyo held an executed copy of his will with their records for safe keeping. Ndi Moyo reports Patrick was greatly relieved to know that his wife and children would be taken care of on his death and that Patrick's widow used the will to successfully defend her ownership of the family land.

In Romania, Hospice Casa Sperantei sought advice from a lawyer regarding the custody and care of two young children left without parents after their mother, a hospice patient, passed away. The lawyer initiated relevant processes at the Family Court of Brasov and secured a court order for the placement of the children with their maternal grandmother, taking into account the best interests of the children.

In Uganda, the Uganda Network on Law Ethics and HIV/AIDS (UGANET), in partnership with the Palliative Care Association of Uganda (PCAU), intervened to uphold the property rights of a female hospice patient in Western Uganda. The patient had been threatened with violence by her estranged husband and told to move off the family property, notwithstanding her extremely weak health. The UGANET lawyer initiated a meeting of the husband's family and guided the elders of the family in mediating and monitoring an agreement to allow the patient to continue living on the family land. UGANET reports the patient finds it easier to look after her health and adhere to treatment when she is not threatened with violence and homelessness.⁹ In Georgia, lawyers and hospice workers cooperated to facilitate an in-person reunion of a hospice patient with her husband, who was serving a prison sentence. The patient passed away just four days after the reunion, comforted to have been able to say goodbye.¹⁰

Legal Support Models

Across the seven country examples documented and analyzed, legal support models tend to include (and innovate around) four core components:

- Developing paralegal skills.
- Accessing skilled legal advice.
- Empowering patients and families.
- Building awareness of rights among health care workers.

Developing Paralegal Skills

Similar to the doctor-nurse model in broader health care, a trained paralegal has the skills and knowledge to supplement some lawyers' services—providing day-to-day assistance with legal information or guiding a patient in resolving less complex legal issues. For complex legal issues and representation, a paralegal calls in a lawyer. This also makes sense in terms of resources—in resource poor settings, because lawyers require more years of formal training, they are likely to be a more limited resource than paralegals. The term paralegal is used in its most broad sense to refer to a person with basic knowledge of the law and skills to address legal or human rights issues (whether through formal training or by gaining experience on the job). Hospice paralegal models showcased later vary from specialized or focused paralegal support (Romania and Malawi) to models where paralegals deal with many issues—a more generalist approach (Kenya and South Africa).

In the relatively new legal support initiatives implemented in Romania and Malawi, hospice staff or social workers identified a frequently occurring legal issue among their patients and then developed a focused strategy and the necessary skills to enable them to address it. Hospice Casa Sperantei in Romania conducted an extensive analysis of the issues taken on by their social worker team during a period of five years (beginning in 2010). Noting the number of legal issues taken on by social workers, this analysis motivated Hospice Casa Sperantei to design a legal support model tailored to address common patient needs. Hospice Casa Sperantei is now implementing a paralegal system comprising one specialized social worker, who also serves as a paralegal, supported by the broader hospice team of social workers who have general awareness of legal and rights issues.

Specifically, this analysis alerted Hospice Casa Sperantei to the fact that social workers struggled to support their young adult patients claim adult benefits for the first time on turning 18. In response, the lead social worker/paralegal researched and identified the pension and social security benefits relevant to young adults, and then developed a step-by-step flowchart to support the broader team of social workers to navigate the process with (up to nine) government agencies.

The PACAM in partnership with six hospices around the country recognized that land rights and

property issues were causing significant concern to their patients. In addition to this, in the case of a male patient dying intestate, widows and children were left extremely vulnerable to being dispossessed—with ongoing ramifications for the health, stability, and well-being of the family. In response, at each of the six partner hospices, staff members (usually a social worker) conduct monthly information sessions on writing a will. Hospice staff are supported to understand the importance of writing a will and trained in how to support their patients to draft a will; the hospices have also put in place practical mechanisms to ensure that the patients' intentions documented in the will are upheld (a copy of the will can be left with the hospice or stored with a local government office, the latter for a fee).

Nyeri Hospice, together with the Kenya Hospice and Palliative Care Association (KEHPCA), has a generalist paralegal model. At Nyeri Hospice, two social workers participated in paralegal training enabling them to identify legal issues raised by patients and develop the skills to respond to legal issues or refer technical issues to a lawyer. The Nyeri Hospice paralegal model is further notable for two reasons: first, for the comprehensive documentation of this work; and second, because the paralegal services are embedded in home-based care. The social workers take on legal issues arising as a result of conversations with patients during the home-based care, bringing services directly to patients and greatly enhancing access to justice.

In 2015, Nyeri Hospice and KEHPCA commenced a pilot project documenting patient legal issues via an electronic data management system. All patients' legal issues are recorded manually using a legal assessment tool (not dissimilar in approach to the health assessment forms used by the hospice).¹¹ Paralegals are sensitive to patient concerns about data and do not record information without the patient's consent. Hard copy files are then entered into an online database using unique identifiers rather than patient names to protect the patient identity. KEHPCA manages the online database and can see data input in real time. KEHPCA can now quickly analyze data to deepen understanding of trends in patient legal issues or analyze the effectiveness of paralegal support. Nyeri Hospice and KEHPCA hope the data can be used as evidence to boost awareness of patients' legal needs as part of holistic palliative care services or advocate for scale up of legal support in palliative care in Kenya.^{12,13}

Accessing Skilled Legal Advice

Of the four core components of legal support programs, there is arguably greatest innovation and diversity in how hospices establish and formalize their

patients' access to lawyers. Hospice partnerships with lawyers come from private, public, university, and nonprofit sectors and may be based on institutional or individual relationships.¹⁴

In Georgia, the Open Society Georgia Foundation (an institution actively involved in both palliative care and human rights) held an introductory session on palliative care for lawyers and human rights actors. This session and a related documentary film resonated with a number of lawyers and inspired partnerships between three private law firms and the hospice. The law firms dedicate pro bono lawyers to work on cases for palliative care patients.^{15,16} The Open Society Georgia acts as a clearing house linking hospice referrals to these pro bono firms.

In Romania, Hospice Casa Sperantei benefited from occasional pro bono support from a local lawyer for a number of years. In 2015, the hospice offered the lawyer a modest monthly retainer to support him to dedicate more time and resources—to assist hospice patients (legal advice and representation on complex matters) and to support the lead social worker/paralegal in developing her paralegal skills.

In 2015 in Malawi, PACAM negotiated a Memorandum of Understanding with the State Legal Aid body (Legal Aid Malawi), successfully placing patients' legal needs on the government agenda. Legal Aid Malawi committed one lawyer and two paralegals to respond to hospice referrals. Paralegals conduct legal information sessions with hospice staff and patients. PACAM contributes transport and lunch costs to facilitate the lawyer and paralegals' involvement.

In 2015, Pécs-Baranya Hospice Program (Pécs) in Hungary initiated a partnership with the faculties of law and medicine at the University of Pécs to develop and pilot an interdisciplinary clinic, providing legal support to palliative care patients. They started by analyzing the legal framework and gathering data on doctor interactions with palliative care patients. This analysis will inform the development of a toolkit with guidelines and templates on advance directives and end-of-life decisions. Going forward, the faculty will train 10–12 students from the faculties of law and the faculty of health on substantive content, as well as practical skills (including interviewing, counseling, and drafting documents). Students will work in medical-legal student pairs to support holistic care for patients.

In Uganda and Kenya, hospices have developed partnerships with NGO legal aid groups. In Kenya, the Kenya Hospices and Palliative Care Association (KEHPCA) has partnered with legal NGO, KELIN (the Kenya Legal and Ethical Issues Network on HIV and AIDS) to expand access to legal services for palliative care patients—patients access KELIN predominantly via hospice referrals. KELIN lawyers or an

affiliated pro bono lawyer (part of KELIN's pro bono legal network) take on the cases of palliative care patients and their families.¹⁷ In Uganda, the PCAU has partnered with advocacy and the UGANET. UGANET provides legal aid in 10 districts across Uganda and has memoranda of understanding with 15 hospitals, hospices, and HIV care centers—in which UGANET legal aid lawyers conduct (free) monthly legal aid clinics for palliative care patients.^{18,19}

Although these models vary, they all integrate legal services into palliative care settings and take the law out of private offices and into communities. They thus increase access to justice and contribute to better quality of life and health outcomes.

Empowering Patients and Families

Patient and family legal empowerment is a critical component and outcome of legal support in palliative care. As a first step, this usually occurs through information transfer and knowledge sharing with a view to creating legal literacy and reducing the opacity of justice.²⁰ More advanced initiatives in legal empowerment recognize the central role of the patient and family.

All the seven country case studies have taken steps to inform patients of their rights through legal information sessions (verbal transfer of knowledge) and/or through information materials and guides. Information about rights catalyzes patients' claims and triggers requests for legal and paralegal support.

In Malawi, PACAM developed legal information materials and translated text into the relevant local language. Patients and families can also join monthly informal legal information discussions (often focused on making a will) at six hospices around the country. Similarly, in Romania, the lawyer and social worker/paralegal schedule monthly meetings where patients and families can drop in to discuss their queries and/or ask questions about the law and rights. In Uganda and Kenya, palliative care actors and lawyers have worked together to develop and disseminate information brochures or guides on patients' rights, drafting a will—these materials are made available in multiple languages and at hospices and health care facilities.^{21,22} A compilation of guides and templates for patients and families from the various projects are also available through an electronic toolkit, hosted by an online global legal empowerment network.²³

At Nyeri Hospice in Kenya, the Victors—a breast cancer survival group—represent the next level of patient and family empowerment. The Victors offer support for their peers at the hospice, speak out about their experiences, and advocate for patients' rights in their community and at broader convenings.²⁴ The Victors convey a powerful and personal message and demonstrate strong rights literacy. As Victor

Elizabeth Njeri explains “*I have learned that I am not a victim. At the legal clinic, I learned how to make a will, and that a will is not just for the terminally ill—it’s everyone’s right. Now that I’ve inherited my parents’ property, I understand that the title deeds need to be put in my name if I want to leave my land to my two boys.*”²⁵

Building Awareness of Rights Among Health Care Workers

Informed and aware health care workers (to be construed in the broadest sense to include doctors, clinical officers, nurses, and social workers)—are the final core component of legal support for palliative care patients and families. Through day-to-day health care delivery and interactions, health care workers are the central referral point for patients’ and families’ needs.

In South Africa, law students from the Universities of Cape Town and Witwatersrand conduct legal workshops for hospice caregivers and nurses.⁶ This model promotes maximum access to learning about legal and human rights issues for hospice staff. In Kenya, hospice workers participate in training to enable them to identify legal and human rights issues and to furnish them with basic legal knowledge—enabling them to respond to patient questions and concerns. KEHPCA and select partner hospices have integrated paralegals and lawyers (pro bono or via legal NGOs) into the range of referral options for health care workers.²⁶ Learning and development in both Kenya and South Africa is supported by a handbook on legal aspects of palliative care.^{7,8}

In Uganda, PCAU and UGANET partnered with the Ministry of Health and the African Palliative Care Association to publish a guide and implement training on legal and human rights for health care workers at scale. PCAU has since used this guide to integrate legal and human rights issues into introductory palliative care training for health professionals. The guidelines are also used to support trained palliative care practitioners to update their knowledge and by health facilities to provide guidance for service provision.^{21,22}

Conclusion

The work of palliative care leaders and legal partners on the development of legal support for palliative care during the past 10 years has transformed thinking around both patients’ rights and access to justice as well as the definition of holistic care. There is a robust and growing acceptance of legal support as a key component of holistic palliative care in theory; and in practice, many palliative care professionals are identifying and addressing the legal and human rights they encounter—be it through mediation, guidance on

basic rights, or referrals to a lawyer. The diverse and innovative range of approaches in integrating legal support into palliative care is not only evidence of the importance of tailored approach but also speaks to the feasibility of this initiative.

Progress is backed by an emerging body of guidance, case studies, and handbooks on legal support in palliative care—from reflection on approaches to legal support to iterations of the rights of palliative care patients. As the aforementioned case studies highlight, justice can be healing. Addressing legal problems can contribute to peace of mind, well-being, and the health of patients. Significantly, feedback from patients, families, and palliative care professionals across the seven country case studies indicates that legal support in palliative care has contributed to improved quality of life for patients and families—a true measure of holistic care.

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