

# Providing Palliative Care to Patients with Cancer: Addressing the Needs in Kenya

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## ABSTRACT

Cancer is the third highest cause of death in Kenya, preceded by infectious and cardiovascular diseases, and in most cases, diagnosed in later stages. Nurses are the primary caregivers, assessing and managing these patients in the clinic, in inpatient settings, and in rural and remote communities. While cancer rates remain high, the burden to the patient, the caregiver, and society as a whole continues to rise. Kenya's poverty complicates cancer even further. Many Kenyans are unaware of cancer's signs and symptoms, and limited diagnostic and treatment centers are available. Despite these barriers, there is still hope and help for those in Kenya, who suffer from cancer. The World Health

Organization has stated that palliative care is a basic human right and nurses providing this care in Kenya are making efforts to support cancer patients' ongoing needs, in order to promote compassionate palliative care and prevent suffering. The purpose of this paper is to address the palliative care needs of patients with cancer in Kenya by providing education to nurses and influencing health-care policy and education at micro and macro levels. A case study weaved throughout will highlight these issues.

**Key words:** Cancer care, oncology nurses, palliative care

## Introduction

Cancer remains a major cause of death in Kenya and with it comes many challenges. While accurate data from rural areas are difficult to obtain, estimates are that annually, 40,000 Kenyans are diagnosed with cancer and more than 27,000 will die from the disease within 1–2 years of being diagnosed.<sup>[1]</sup> At the time of diagnosis, over 80% of patients present with advanced disease, with little hope of cure.<sup>[2]</sup> In 2013, the leading cause of cancer deaths for

men in Kenya was esophageal and for women, it was cervical, with 1423/2007 deaths reported, respectively.<sup>[3]</sup> Kenyatta National Hospital (KNH), the country's largest and only public cancer treatment facility, currently has only two radiotherapy machines, with more than 1800 patients scheduled for radiotherapy per year.<sup>[4]</sup> Some private hospitals in Nairobi provide both radiotherapy and

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chemotherapy, but the cost ranges from \$1600–\$5000, which is prohibitive given that many Kenyans live on only \$1.00/day or less.<sup>[1]</sup> In addition, many Kenyans live in rural and remote areas and making the long journey to take advantage of these services are challenging. Nurses provide much of the care for rural patients as well as for those in the urban communities. Physicians are few in Kenya, and nurses are educated to assess and manage patients and understand and advocate for pain and symptom control to prevent suffering.

## Case Study

Thomas is 16-year-old and lives in a rural village in Kenya with his mother and four siblings. He loves to go to school and play soccer. Two months ago, he began experiencing pain and swelling just below his left knee. As the swelling and pain increased, his mother, Naomi, was alarmed and decided to take him 50 km to a hospital in Eldoret, Kenya, the nearest urban hospital to their rural village. Naomi stayed at the hospital with Thomas for 4 days as the diagnosis of osteosarcoma with lung metastasis was determined. Unfortunately, Naomi had to return home, so she could work and care for her other children. Naomi was heartbroken leaving her son at the hospital, knowing doctors were going to amputate his leg the next week, and fearing that he might die before she could return.

## Assessing the Needs

Fifty percent of Kenyans live below the poverty line.<sup>[5]</sup> The cost of diagnosing, administering chemotherapy and/or radiation therapy, and performing surgery are financially prohibitive for most Kenyans. Inadequate care and immense suffering are compounded due to the failure to diagnose and treat diseases in a timely manner. Many who live in remote villages travel hundreds of kilometers to medical facilities and most, including children, remain in these facilities to die alone, without family and friends surrounding them. In addition, health-care professionals fail to disclose the extent of the illnesses, so few patients and families get to say “good-bye,” “I love you,” or “I will miss you” to their loved ones. The human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have ravaged Kenya and affected families significantly. Approximately 1.6 million Kenyans live with HIV/AIDS, and over 1 million children are orphaned, their families dispersed.<sup>[5]</sup> In 2013, approximately 58,000 people died from AIDS-related illnesses, including lymphoma, sarcomas, and cervical cancer.<sup>[6]</sup> Lack of education about disease prevention, signs and symptoms of cancer, palliative care, and available interventions play a tremendous role in hindering good cancer care. Many die in rural villages or in urban areas not knowing they even have cancer. More palliative care

education is needed for health-care professionals and communities, along with better access to care in rural and remote areas. Pediatric palliative care in Kenya is not well-developed, which unfortunately, is common throughout the world.<sup>[7]</sup> Many sick children have witnessed the deaths of their parents and siblings and they carry fears and anxieties related to the dying process as they face their own mortality. Some of the key barriers to providing excellent pediatric palliative care in Kenya include poor access to community and health-care services, restricted access to pediatric formularies, lack of education about the pediatric population, limited access to affordable chemotherapy, radiation, and antiretroviral services.<sup>[7]</sup> In addition, research specific to Kenya’s needs is necessary.<sup>[8]</sup> Until palliative care is included in the national or county health budgets, barriers and challenges to quality cancer care will persist.<sup>[2]</sup>

Inadequate supplies of pain medications are another major barrier to good palliative care in Kenya. In 2010, Human Rights Watch released *Needless Pain: Government Failure to Provide Palliative Care for Children in Kenya*,<sup>[9]</sup> which highlighted that most children and adults in Kenya, with cancer or HIV/AIDS, were unable to obtain necessary pain medications. Although oral morphine can cost just a few cents a day, the Kenyan government is working diligently to procure enough morphine for all in desperate need of it. KNH is the central place in which morphine will be accessed and produced and it is estimated that this procurement will meet the needs of approximately 70% of patients with terminal cancer throughout Kenya.<sup>[10]</sup>

## Palliative Care and its Impact on Cancer Care

The World Health Organization (WHO) has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”<sup>[11]</sup> In 2014, the WHO, in partnership with the Worldwide Palliative Care Alliance, published a report entitled *Global Atlas of Palliative Care at the End of Life*.<sup>[12]</sup> This document mapped the need for and the availability of palliative care globally and stressed that palliative care must be implemented in every health-care system worldwide. The report also highlighted the primary barriers of providing this care (e.g., the lack of policies to promote palliative care, resources to implement necessary services, education for both health-care professionals and the public).<sup>[13]</sup>

Palliative care can provide medicines to relieve many of the common side effects of cancer such as pain,

nausea/vomiting, and diarrhea. Throughout Kenya, there are palliative care teams, composed mostly of nurses, in acute care facilities, in urban and rural clinics, and in community settings. Today, palliative care is provided in 43 public hospitals across Kenya.<sup>[14]</sup> In addition, the Kenya Hospices and Palliative Care Association (KEHPCA) has supported Kenya Medical Training College to introduce a higher diploma in palliative care course to educate palliative care nurse specialists.

Nurses play a significant role in the development and implementation of palliative care in Kenya. They provide leadership as they develop teams, communicate, counsel, mentor, treat and prescribe as appropriate, educate, advocate, and support patients as well as their caregivers. There are approximately 4500 physicians throughout Kenya (1/10,000) and 37,000 nurses and midwives.<sup>[14]</sup> While the needs are great and while they witness much suffering, nurses are committed to working closely with their interprofessional colleagues to improve care across the lifespan.

## Addressing the Needs Throughout Kenya: Macrolevel

As in most countries across the globe, the vision for improving care for the most vulnerable in each society comes from a group of like-minded people dedicated to changing the system and becoming involved in the government, to address the needs and barriers that are preventing excellent care. The KEHPCA was organized to create a voice for the many unmet needs of cancer patients and others with serious, life-threatening illnesses across Kenya. KEHPCA is dedicated to promoting and providing palliative care, supporting hospice and palliative care professionals, and working diligently to provide services to cancer patients and their families [Table 1]. Their mission is to provide palliative care so those with serious illnesses can receive accessible, affordable, safe, and quality care. To sustain their mission, KEHPCA works closely with Kenyan ministries, legislators, regulators, nongovernment organizations, and interest groups so that Kenyans are aware of available oncology and palliative care services throughout their country. With the Ministry of Health's support, palliative care has been integrated into various services in 11 provincial government hospitals throughout Kenya, permitting the establishment of public hospital palliative care units linked with local hospices,<sup>[8]</sup> increasing access to palliative care services in numerous parts of Kenya. Knowing that nurses and other health-care professionals cannot practice what they do not know, KEHPCA's primary focus is on education, research, provision of technical support, building new service

**Table 1: Kenya Hospices and Palliative Care Association - Activities to promote excellent palliative care throughout Kenya**

Provides program to empower patients and families to recognize their right to have palliative care (this includes access to the care, access to the right pain medications, and other medicines targeted to relieve symptoms associated with cancer, right to choose a power of attorney/to make a will, and the opportunity to make succession plans for one's children)

Developed national palliative care guidelines

Integrating palliative care into the public healthcare system, undergraduate medical, and nursing curriculum, in the national cancer control strategy and the national guidelines for cancer management as well as in the Kenya national strategy for the prevention and control of noncommunicable diseases documents

Working with government officials to place palliative care services in the national health budget

Increasing palliative care education to healthcare professionals

Setting up palliative care units and ensuring that all essential medications are available

Increasing availability of palliative care services to not only hospitals and hospices but also out in the community health centers

Reference: KEHPCA, 2014: [http://kehPCA.org/wp-content/uploads/Annual-Report-2014\\_draft.pdf](http://kehPCA.org/wp-content/uploads/Annual-Report-2014_draft.pdf)

centers, advocating for improved care, developing new programs, and fundraising to sustain the work.<sup>[2]</sup>

This commitment was evident in 2009, when the KEHPCA Executive Director, Zipporah Ali, MD, invited five palliative care experts from the United States (four advanced practice nurses and one physician) representing the National End-of-Life Nursing Education Consortium (ELNEC) to provide 1 week of palliative care training in Nairobi, Kenya. The course was strategically planned as 49 health-care professionals and educators from every province in Kenya were accepted to attend the ELNEC course and review its eight modules [Table 2]. Each participant received a copy of the ELNEC curriculum, a CD-Rom, and the PowerPoint slides needed to present this education. Twenty-seven (55%) of the attendees were nurses who taught in colleges of nursing. Other nurses were from the administration, acute and community care, and hospice attended, along with a social worker and two physicians.<sup>[15]</sup> This was significant, as palliative care content must be included in nursing curriculum, so nurses graduate with this education. On completing this course, the participants returned to their schools of nursing with a multitude of resources, able to embed the palliative care content into existing nursing curriculum. Having student nurses graduate with palliative care knowledge, and experience is vital to meeting the diverse needs of the seriously ill. Since providing the ELNEC course in Kenya, the nursing schools who offer a Bachelor of Science degree in nursing have agreed to include 45 h of palliative care content into their existing curriculum.<sup>[15]</sup> Today, KEHPCA continues to monitor these efforts and encourages medical schools to integrate palliative care within their curriculum.



**Table 2: End-of-Life Nursing Education Consortium modules**

Module 1: Introduction to palliative nursing care
Module 2: Pain management
Module 3: Symptom management
Module 4: Ethical and legal issues in palliative nursing
Module 5: Cultural and spiritual considerations
Module 6: Communication
Module 7: Loss/grief/bereavement
Module 8: Final hours

Other noteworthy efforts are occurring throughout Kenya to improve palliative care education and practice. For example, The Aga Khan Network, which has several hospitals across East Africa, has recently started a palliative care program. In March 2016, The Aga Khan University Hospital in Nairobi used the ELNEC curriculum and other palliative care resources to educate 64 nurses. Nurses came from every Aga Khan Hospital and satellite clinic throughout Kenya and Tanzania. The overall goal of the education was to teach nurses to identify palliative care needs throughout their community and to assess and manage those needs. While ELNEC has been presented in various parts of Kenya, it is worthy to note that it is just an example of current educational resources used throughout Kenya, to educate nurses and other health-care professionals in providing excellent palliative care.

## Addressing the Needs Throughout Kenya: Microlevel

Throughout Kenya, there are many institutions that provide hospice and palliative care services, including 15 free-standing hospices, eight hospice and palliative care services in rural communities, nine mission hospitals, 24 government hospitals, four private institutions, and two teaching and referral hospitals.<sup>[16]</sup> Nurses are the primary health-care professionals who provide and oversee this care, meeting the needs of patients and caregivers. In addition, nurses educate the community about cancer and palliative care.

One of the newest hospices/palliative care centers in Kenya is Kimbilio, a 24-bed inpatient facility, built in 2010 in the small rural village of Chebaiywa in Western Kenya. A part of Living Room International (LRI), Kimbilio cares for seriously ill children and adults. In Kenya alone, over 1 million children are orphaned,<sup>[5]</sup> malnourished, and have HIV/AIDS. Kimbilio was started by an American family nurse practitioner Juli McGowan Boit, who came to Kenya in 2004 to work in an HIV/AIDS clinic. As access to antiretroviral therapies was becoming more prevalent in the late 2000s, Mrs. Boit witnessed the ravages that HIV/AIDS had left behind, especially to children in the rural areas. She had lived in the village for 5 years and had developed

a relationship with the leaders, who shared her vision for improving the quality of life for those in their village who were seriously ill. Since its 2010 opening, Kimbilio has provided compassionate palliative care to over 1200 children and adults with life-threatening illness and their families.<sup>[17]</sup>

Because Kimbilio has met the needs of so many in Kenya, LRI is building the second hospice, this one in Eldoret, Kenya. In preparation for this expansion, ELNEC held a course at Kimbilio in May 2015. Over twenty nurses and physicians attended from Kimbilio, and other African countries such as Ethiopia, Swaziland, and Uganda. In May 2016, four members of the USA ELNEC-International team (three nurses and one physician) provided a 3-day leadership course, to promote and sustain the work throughout Kenya. Twelve nurses, physicians, and social workers attended from regions and organizations throughout Kenya, including the Aga Khan University Hospital, KEHPCA, Kimbilio, Moi Teaching and Referral Hospital, Nairobi and Nyeri Hospices. While most of the course was didactic, case studies and role-plays were provided to enhance the educational experience. The ELNEC course focused on ten modules, centered on leadership development [Table 3].

## Case Study: Preparing for a Good Death Despite Tremendous Grief

Thomas remained at the hospital in Eldoret for 1 month after doctors amputated his left leg. The postoperative days were difficult as Thomas experienced an infection in the stump and became septic. The numerous dressing changes were time-consuming and due to lack of staff, the dressings were not always changed as they needed to be. Thomas' mother, Naomi, was very distraught after learning about her son's infection. She wanted to bring him home, but she worked full-time, provided care for her four other children - all under the age of 8 - and for her ill mother, who lived close to her in the village. She had to continue to work to pay for Thomas' medical expenses. The palliative care team at the hospital in Eldoret spoke with Thomas and his mother about moving him to Kimbilio Hospice, a few kilometers from their home. As Thomas' disease progressed, his care became more complicated. His pain and dyspnea became more acute; his wound care more intricate and time-consuming and he required more frequent assessments. He appeared to be depressed, stating he was "lonely." Thomas' mother and siblings wanted to be closer to him so they could visit frequently, as Thomas was very homesick. After being assessed by both the hospital's palliative care team and a nurse from Kimbilio, the team recommended to Naomi that Thomas be transferred to Kimbilio. Two days later, the transfer occurred, after the hospital social worker's assessment of the family's financial

**Table 3: Leadership modules**

What is a leader? Do I qualify?
Challenges and opportunities for leaders
Teamwork/team building
Changing culture to advance leadership in palliative care
How to make the case presentation skills
Communication: Negotiation and feedback
Delegation: Key to successful leadership
Conflict resolution
How to motivate others
Self-care: Role model this for your team

needs justified the waiving of the remaining hospital costs. Although he was critically ill, Thomas was grateful to be closer to his home so that his family and friends could visit. The nurses provided oral morphine before each dressing change, and when Thomas was experiencing pain. His pain scores decreased dramatically. His dyspnea also was improved by the oral morphine. Thomas' school teacher came to Kimbilio for a visit and brought greetings from his classmates. Thomas was grateful to know that he was being remembered by so many friends. The social workers spent many hours providing counseling to Thomas, Naomi, and Thomas' siblings. The chaplain delivered spiritual support. Three weeks after his transfer to Kimbilio, Thomas died peacefully, with his mother at his bedside. Today, Naomi and her children receive bereavement care from both the Kimbilio social worker and chaplain, who make home visits throughout the villages.

## Conclusion

Throughout history, people have witnessed extreme needs and responded to them. Today, nurses in every part of Kenya work tirelessly to provide excellent care to those with serious illnesses. Many of these nurses work remotely and provide this care alone. Trusting their critical thinking skills, judgment, and confidence, nurses collectively work to provide excellent care to their patients. Through education, leadership, advocacy, and research, nurses in Kenya continue to promote excellent palliative care for the seriously ill.

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### Conflicts of interest

There are no conflicts of interest.

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