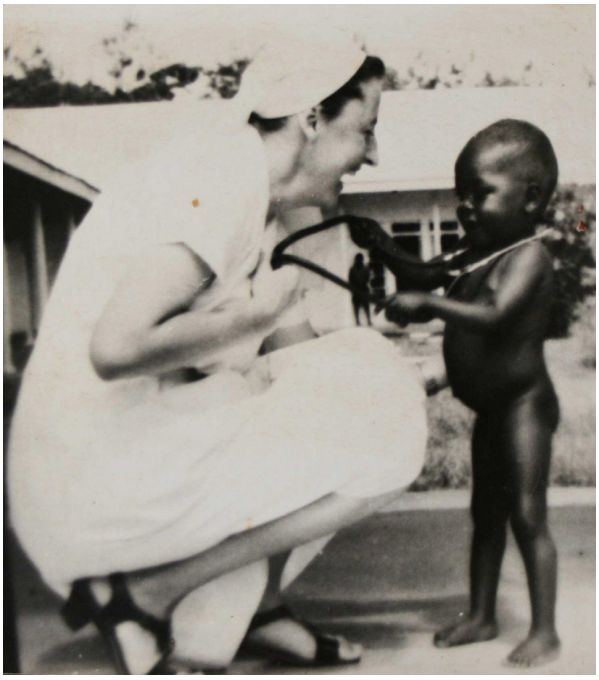
From Nun to Nobel Nominee

BY SHELLEY ENARSON



Dr. Anne Merriman in 1970 with a malnurshied child in Nigeria.

Outside the Hospice Africa Uganda (HAU) complex in Makindye, Kampala, the street is occupied with small wooden *chappati* stands, a country club, and a quaint coffee shop that also sells hamburgers and French fries. Twenty years ago, bullet-ridden homes along the same street told the story of Uganda's two-decade-long civil war. A pervasive military presence and barracks occupied Makindye then, and there were no country clubs or French fries in the vicinity.

When Professor Dr. Anne Merriman first looked for a facility in 1993 to care for Kampala's destitute and those dying from HIV/AIDS and cancer, a house left vacant with 20 tons of bat feces in the roof seemed like the perfect fixer-upper. In a neighborhood that appeared to be a post-conflict hazard, she saw a potential haven from which pain relief could flourish.

Indeed it has. Today, Kampalites from across the city, rich and poor alike, know where "Hospice" is, a word usually spoken with a quiet, reverent undertone. They may not be able to articulate the ethos behind its services, but they know it as a place that provides peace and comfort for those nearing the end of life. Over the last 20 years, their loved ones have likely been among the 21,000 patients HAU has serviced—a relatively small number by public health standards. But for Merriman, who has been practicing medicine for five decades, it's not about numbers—it's about the quality of care each of these patients receives.

In Africa and throughout the world, Dr. Anne Merriman has advocated for effective palliative care and greater access to a simple solution of oral morphine as an affordable form of pain control.

Now she is a Nobel Prize nominee.

Merriman's life work in establishing HAU as a center of excellence in palliative care has earned her consideration for this year's Nobel Peace Prize. The prestigious nomination is in recognition for her bringing a simple solution of oral morphine to Africa as an affordable form of pain control, coupling it with holistic palliative care services. However, for affordable oral morphine to get off pharmaceutical shelves into patients' hands, Merriman knows that a major policy shift must take place in how it is prescribed and who has access to it.

The origins of palliative care advocacy in Africa

During the apex of the AIDS epidemic, tens of thousands of Ugandans lay bedridden in their villages—not only in pain but also wrapped in shame from societal accusations of bewitchment, as the cause of AIDS was not clearly understood. Hospitals turned patients away as new cases overloaded their ability to serve their communities. For many Ugandans, this was not only a death sentence; it was also a sentence of excruciating pain with no relief in sight.

"Like most countries around the world today, morphine prescriptions could only be administered by a registered practitioner, such as a doctor or surgeon," recalls Dr. Jack Jagwe, the founding chair of the National Drug Authority (the drug regulatory body of Uganda). To leave morphine prescriptions in the exclusive hands of the few doctors in the country meant that pain relief would only reach a privileged sliver of the population.

Together, Merriman and Jagwe decided to persuade Uganda's highest legislative bodies to allow clinical officers and nurses to prescribe morphine so that the supply addressed as much of the demand as possible.

The two worked hand-in-hand: Jagwe tapping his influence as chair of the Ministry of Health committee, which formulated the National Drug Policy; Merriman relentlessly advocating for oral morphine to be produced locally and cheaply, while simultaneously treating patients and modeling a novel ethos of patient care in Africa.

"As Uganda was already a signatory to the

Hospice Africa Uganda tends to the needs of the poorest individuals and families.

international convention on the use of morphine of 1961 and the amendment on psychotropic drugs of 1972," says Jagwe, "it was required to abide by these conventions. Therefore, morphine was already available in the country in the form of injections and tablets. What Merriman's introduction of liquid oral morphine did was make pain relief affordable for the Ugandan Ministry of Health to provide it free of charge to patients in need."

Training a continent's workforce

Merriman envisioned HAU as a place where the patient's comfort is a priority in care and where Africa's future health workforce could receive accredited palliative care training. With the doctor-to-patient ratio standing at 1 to 24,000 when Merriman arrived on the scene in Uganda, this was no small challenge.

It quickly became apparent that international attention to mortality rates of non-communicable diseases was growing; estimates now run as high as 29 million annually in low and middle-income countries. What's more, the World Health Organization projects the largest increases in such deaths will occur in Africa by 2020. To Merriman, professional training in palliative care was an obvious priority.

In 2009, Merriman took a visionary step in anticipation of what it would take should palliative care be integrated into global health work plans. With this in mind, the Institute of Hospice and Palliative Care in Africa (IHPCA) set out to train Africa's workforce to meet the demands of patients that curative measures could no longer treat.

Today, the IHPCA is the largest and most established academic palliative care institution on the continent, offering short courses in English and French and internationally accredited degree programs. Students receive training from specialist instructors in oncology, radiotherapy, and surgery, and the curative part of the curriculum is coupled with culturally appropriate training in symptom control and approaches to psychological, social, and spiritual care.

Photo courtesy of Dr. Katherine Pettus

As palliative care grows as an evidence-based discipline, Merriman remains resolute to ensure that students graduating from the IHPCA program retain a deep understanding of the spirituality and ethos behind hospice services.

At HAU, doctors and nurses are encouraged to avoid becoming complacent or calloused to patient suffering. The white coat remains in an office as the palliative care provider sits on the patient's mattress, listening to earnest worries and deepest wishes. With sensitivity to the patient's physical cues and demeanor, the provider offers spiritual support and salves the patient's pain through dialogue and prayer when this is solicited. Caregivers are comforted as well, as such psychosocial support is intentionally inclusive of family members. In the last days and hours, the patient feels safe, the family shielded from false hope and distressing memories. The end can be peaceful.

Dr. Merriman attended the palliative care resolution deliberations in May at the 67th World Health Assembly in Geneva (left). HAU staff and volunteers gather outside the clinic (above). With a caring spirit, they salve the patient's pain through dialogue and prayer when this is solicited (right).

"I see palliative care as the key to bring caring back into medicine, not measuring our success in the numbers cured but in the numbers we care for, bringing them to peace in their life and in their death," says Merriman.

A relentless work ethic

In Kampala, a city with one of Africa's highest youth populations and a myriad of idealistic expatriate professionals in their 20s, Merriman is one the few *muzungu jajjas*, Luganda for "white grandmother." At age 79, she fits in seamlessly.

Her self-imposed 85-hour workweek comprises many hours on email, in meetings, and international travel. This May and June alone, Merriman crisscrossed eight countries. In Nigeria, she was keynote speaker at a conference. In Ireland, she was a commencement speaker to new graduate doctors. In France, she met with francophone faculty to plan a course. Retirement is not on her horizon, ever.

Merriman's driven pursuit started at an early age. "I want to go and help the suffering of Africa when I grow up," she told her mother at age four. By age 13, coming from a devout Catholic family, she knew exactly which Catholic order she wanted to join: the Irish Medical Missionaries of Mary, a small Catholic order that allowed nuns to study medicine and hem their garments above the ankle. They also would allow her to show some of her thick black curls beneath her headdress while moving around comfortably on a bicycle—a dream come true for a teenager contemplating becoming a nun.

Merriman's mother was deeply spiritual, and her father was a teacher with a degree, a rare combination in the era immediately after World War II. Merriman carried forward these undertones of spirituality and education to ensure palliative care's sustainability in Africa.

> **“The center of care is the love for patient and family and our concern to relieve suffering, support with love, and to be there with them as long as we are needed. The care arises from our own acknowledgement that we too are in need of care. That caring is an essential part of God’s plan for the world and that caring and being cared for are two sides of the human condition that can make us fully human.”**
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> Ethos of care, Hospice Africa Uganda

Maintaining the ethos

This has been a good year for palliative care advocates globally. In May, member states of the World Health Assembly adopted a landmark resolution on palliative care, incorporating it into the continuum of care within global health systems. Merriman’s nomination, an award she does not wear on her African-print sleeve, has also given global prominence to pain relief as a high priority. While these developments are celebrated, what keeps Merriman up at night is the legacy of the hospice ethos of care. This is far more difficult to measure than pain control, but it is highly pertinent.

“We have to treat patients as our guest. That means they have choices for their treatments as well as the place where they would like to be looked after before the end of life, usually at home. They’ve lived with their bodies all their lives and know better than us what suits them,” says Merriman.

“When you have a guest in the house, you don’t say, ‘Sit there, drink this.’ You say, ‘Let’s try something else, change the dose.’ We do it in such a way that lets them know they’re in control. An approach of hospitality needs to be extended to the whole of medicine.”

To sustain this ethos, Merriman along with an inner circle of colleagues, are revitalizing the Hospice Africa Foundation. “Now I’m in the last phase of life, and I need to ensure there are things in place to ensure Hospice’s sustainability in the future,” she says.

As she aims to ensure that the mission and ethos of hospice care remains central, Merriman spends a good deal of effort raising funds for the foundation in order to support other organizations in Africa interested in getting hospices off the ground. She is also seeking support for medical education at the IHPCA, which Merriman views as paramount to the expansion of palliative care services on the continent.

“What the nomination means to me is that the work done so far has helped patients in Africa,” she says. “But what I would want the nomination to do is to bring the attention of the world to the suffering of patients in Africa, most of whom have not yet been reached, and to enthuse people to support the work.”

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