

Minireview

The Creation of Community and Home Care in Palliative Care: The Key to Equitable Access to Healthcare Services

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Abstract

To date, access to healthcare services is still limited for large portions of the population in most African Countries. Most cancer patients seek treatment only at advanced stages of the illness, when the cancerous lesions are already inoperable; thus, the only remaining treatment option is palliative care. Unfortunately, there are still many obstacles to obtaining early diagnosis and treatment, primarily due to cultural and traditional mannerisms, along with low-health literacy. Furthermore, this poor access to health care restricts too many patients, especially those who live below the poverty line, from receiving basic treatment protocols. Uganda is a pioneer in breaking the “glass ceiling” by advancing community palliative care services, in great part due to the support of the Ugandan Government and the remarkable initiative of British-born physicians who have devoted their lives to assisting, supporting and accompanying cancer patients residing outside of the big cities. This movement came to fruition by virtue of the high sense of volunteerism among Ugandan’s professional personnel as well as non-professional workers in the community.

Introduction

As a clinical discipline, palliative care relies on the collaboration of professionals, such as nurses, physicians and social workers, who have a fundamental role in running the team. Furthermore, primary care personnel - which includes family physicians, medical specialists, paediatricians, geriatricians, general practitioners, nurses from a variety of settings (home care, community care), social workers, pharmacists, physiotherapists, occupational therapists and volunteers - have a central function in this arena [1].

For communities, this requires a cooperative approach between the primary care and palliative care practitioners, both within the community and among experts in the hospital. It is these primary care professionals, who have core competencies in palliative care and access to specialist palliative care teams, who should manage the care of patients and families.

To date, most physicians in the community feel ill-prepared to deal with patients with palliative care requirements, due to their lack of training in pain and symptom management as well as the

psychological issues that befall patients and their family caregivers. Thus, the most urgent need is to train physicians, nurses and social workers in the community to be able to practice basic palliation care principles [2].

One critical element that must be made available in order to support caregivers is the access to skilled homecare nursing, 24/7 [1]. Utilizing other providers, such as paramedics trained in palliative care, could fill some of the voids where round-the-clock home visits are not feasible.

Palliative care nurses have a pivotal role in community palliative care services. Not only do they treat, advise and help with ongoing treatment, they also assist in coordinating appropriate and timely care in the various institutions that are able to provide the appropriate treatment. In straight-forward situations, the palliative care nurses may simply advise the primary care physicians after consulting with a palliative care specialist. Unfortunately, the recommendations for the staffing of a palliative care team in the community are not yet applicable for the developing world.

It is the profession's obligation to ensure equitable availability of palliative care for rural and other vulnerable populations [3]. Let us not forget that the goal of palliative care is not just to save lives, but even more so to alleviate suffering. Thus, alleviating the suffering, be it physical or emotional, should guide us throughout.

The initial step in alleviating patients' suffering is pain control. All those working in the field have experienced how unrelenting, agonizing pain impacts individuals and families and the magnitude of the hardship it engenders.

By and large, there is still very limited access to medication for moderate and severe pain in most low- and middle-income countries, worldwide. Under-treatment of severe pain is reported in more than 150 countries, accounting for about 75 percent of the world's population, thereby creating profound global health inequity [4].

As already mentioned, in the greater part of the world there is an urgent need for basic palliation care services in the community; one important reason for this is the insufficient awareness of palliative care among primary healthcare providers as well as the extreme shortage of palliative care specialists in each region.

More recently, an innovative intervention – Project Extension for Community Healthcare Outcome – Palliative Care in Africa (ECHO-PACA) – was conducted in several sub-Saharan countries. One of the important things learned was the necessity to reach out to the primary care providers in the community and to develop a curriculum and guidelines for best practices, based on local palliative care requirements [5].

Our story describes the gradual development of community-home care services in Uganda. It tells, first-hand, of the arduous, yet successful and praiseworthy palliative care experiences owing to the endless devotion, endurance, goodwill and compassion of a dedicated physician and her nurse.

Our Personal Story

Having worked in Palliative Care for over 28 years, Dr. Anne Merriman introduced Palliative Care (PC) to Uganda through Hospice Africa Uganda (HAU), its goal being to reach “all in need of palliative care in Africa”. Hospice Africa Uganda (HAU) is now a model for Palliative Care services in all of Africa. During her 40 years in Africa, Dr. Merriman has travelled through many African countries, primarily LMIC's, and realizes that each has its unique traditions.

Although Uganda was one of the poorest countries in Africa and was just out of a long war, the people were so caring. The country had one of the lowest rates of corruption. Now, 28 years later, many things have changed. The divide between the rich and poor has increased, the population has doubled and, unfortunately, the caring spirit for each other (called ‘ubuntu’, meaning ‘humanity’) has declined. Those who have been blessed with greater financial wealth often have the attitude of caring only for oneself and lesser values when it comes to caring for the less fortunate. This is the situation in many African countries today.

With billions of people in the world falling under the poverty line, access to good quality health care services is becoming impossible despite the great advances in medicine. Quality, yet

genuine, healthcare services are only available to the few lucky ones who can afford it. Most patients have to travel miles and miles to reach these services. The poor have been left to suffer in the hands of ‘quacks’. The little savings they are able to accrue goes to out-of-pocket payment for medical bills, yet the services received are often substandard and predisposes them to more ill health. It is for such reasons that the poor are now shunning hospital-based care and are seeking cheaper, friendlier and more accessible interventions. Community health systems must therefore prioritize the needs of the poor.

As a Sister in charge of a gynaecology ward, Rose (the first HAU nurse, in 1994) had witnessed the unbearable suffering of patients with advanced cancer disease. Patients were in pain and some had a foul smell stemming from the fungating tumour. In such agony, doctors on ward rounds discharged these patients to go home, telling them, “nothing more can be done”. Rose wondered, what then happens to these patients when they go home in such agony? The needs of these suffering patients were as paramount then as they are today.

Rose left a promising Hospital Nursing career and, with much opposition, in 1993 joined the new Hospice Africa Uganda, travelling daily to local communities and providing professional palliative care within the homes. She was always mindful to adapt her care to the specific culture, economy and the tribe to which they belonged, while also respecting the spiritual and traditional beliefs of each family. Although Dr. Anne had already worked in Nigeria for 10 years, the Ugandan culture was so different and there was so much to learn from Rose. So while Rose was learning from Anne, Anne was learning from Rose!

In Uganda, where 95% of those who are stricken with cancer cannot access treatment, there is an especially heavy burden on poorer families. These families are left abandoned as they watch a loved one writhing in pain, many times suffering in isolation due to the unpleasant smells that result from disease and decay. Simply attempting to attain a cancer diagnosis may throw the family into further poverty, no longer able to afford food; children stop attending school, as every penny is put toward reaching a cancer cure. The few who are able to pay for a biopsy then find that they cannot afford the cost of treatment, and are often sent home.

Community health funding is based on statistics - but are the cancer statistics realistic when they are often based on the number of biopsies and diagnoses which are unaffordable for most? When birth and death certificates are not mandatory in many parts of Africa?

By 1993, a new disease known locally as ‘Slim’ due to a resistant fungal infection in the oesophagus which prevented eating due to pain on swallowing, was obvious wherever Dr. Anne and Rose went. This was HIV, and the pain associated with many opportunistic infections was often severe and uncontrolled. Over 30% of Uganda's population was infected by HIV and the incidence of cancer had doubled.

What could be done to alleviate the suffering of these patients, as well as those in the community? Dr. Anne introduced the affordable formula for oral morphine for home use. With support from the then presiding Minister of Health, Dr. James Makumbi,

the importation of morphine into Uganda for reconstitution in the pharmacy was endorsed. Dr. James said, “My people are suffering... you are welcome. Please come immediately”. Patients with moderate to severe pain have since been given the green liquid oral morphine, many of whom now call it the ‘magic’ medicine as it has greatly relieved unnecessary suffering. Patients are now free of pain and ‘living until they die’, counting it as a true miracle. This drug has since modified pain control throughout Africa, albeit only in those countries that have overcome the myths and fears perceived by governmental officials and senior doctors who have never heard of palliative care and who equate using oral morphine with euthanasia. Beginning with only three countries in 1993, 37 African countries currently offer palliative care and 27 of them are now using this formula.

Looking at these advances, how can our medical students understand their own country’s needs, so distant from Western standards where health services reach nearly all, when they are trained in hospitals that use Western recommendations? How can international organisations, sometimes staffed by those who have never lived or worked in African countries, understand the local culture and make vital decisions affecting those communities on a daily basis? These are questions that must be considered.

In 1994, Dr. Anne, Rose and a medical student from UK studied pain in HIV and applied the treatment methods tried and proven for cancer to HIV pain management. They were careful to withdraw the pain treatment when the infection was under control. Realizing their success, they began teaching ‘pain management’ to health professionals, undergraduates and postgraduates of University Medical and Hospital Nursing schools.

Rose has now retired after 27 years in palliative care. She and her daughter, Dianah (currently a Nurse Trainer at Hospice Africa Uganda) are exemplifying the use of a community-based care approach to reach out to patients in their community by riding on the ‘ubuntu’, a spirit that has been in existence in Uganda for many years. The two have started a Community-Based Organization called Lweza Community Health Program (LCHP) with a vision towards a healthy, informed and productive community. The LCHP was established in April 2020, at a time when the country was under a total lock-down as a result of COVID-19 restrictions, and has registered a number of successes in its short existence. The organization has adopted some ideas from the community-based approach of HAU and tailored them to the needs of its community by strengthening Primary Healthcare to ensure that even the poorest patients can access quality medical healthcare services. This approach is destined to be a model for other areas within Uganda and, possibly, throughout Africa and beyond, but it is still in its early days.

Rose and other LCHP members have mobilized community volunteers and health workers living in the village to attend to the needs of patients. The healthcare providers work with community volunteers and go door-to-door, identifying patients in the community and offering them appropriate support.

During the home visits, the LCHP team has learnt that some patients attribute their illness to witchcraft or traditional or spiritual beliefs and, thus, do not see the benefit of modern medicine.

As a result of these beliefs and the costs attached to diagnosis, some patients have not had the opportunity to get a proper diagnosis. The interface with the LCHP health worker is sometimes the first opportunity for them to consult a qualified health worker.

It was also evident that it is not only diseases that affect the health of members in Lweza community. There are a number of elements that determine the well-being of individuals, ranging from poverty, overcrowding, especially where large families are cramped into tiny dwellings without adequate facilities for privacy or protection for teenagers and women, mental illness as a result of substance abuse, gender-based violence, which is not surprising in a traditionally male-dominated society, as well as other social problems. With all these issues and many more, where does one start? The solution was to get the backing of the community and work with the local leaders.

A few days ago, Dr. Anne attended a medical health camp organized by Lweza Community Health Program. The camp was funded primarily by the local community and was hosted in a resident’s compound. It was a three-day camp and thirteen governmental and private health institutions provided free services to everybody who sought them. Services included screening for; heart disease, diabetes, HIV, cancers, including breast, cervix and prostate, eye problems, hepatitis B and vaccination. Other services provided were: family planning, blood donation, orthopaedic assessment, nutritional education, general counselling, legal health services, spiritual counselling and palliative care sensitization.

The camp attracted over six hundred people from not only Lweza, but also from neighbouring villages. A number of people were identified with health issues, especially hypertension, which they were not aware of previously. Those who were identified with health issues were advised on where to get health services; the LCHP team continues to guide, encourage and liaise with the health care workers in various health facilities to ensure that they get the necessary services.

Dr. Anne was privileged to be the only m’sungu (white person) there. She attended the camp with a child survivor of Hospice Africa Uganda, Cathy, who had suffered a terrible tumour that, in spite of being classified histologically as non-malignant, had invaded her spine and, on several occasions, almost cost her life. Furthermore, the steep health care expenses that began to accrue six years prior, when Cathy was diagnosed at 14 years of age, had also cost the family all of their properties and personal income and caused the interruption of education for her two siblings. Despite being extremely disabled, Cathy shared a heart-rending speech in the local language to the attendees, inspiring others with her hope for her own future as well as theirs. She encouraged the attendees to embrace early screening for diseases and she touched many hearts present.

While treating diseases, LCHP members find it paramount to also address the issues that promote ill health in the community as these are major determinants to the success of any intervention. The LCHP performed a needs assessment and the main issues affecting the community identified were found to be: poor sanitation; domestic violence, child abuse/neglect, substance

abuse and youth unemployment.

The LCHP, working with the local council leaders of the village, has continued to address these issues. The first undertaking was to keep the surroundings clean in order to prevent diseases that arise from poor sanitation. The community members are mobilized, sensitized and motivated through communal participation and empowered to keep their surroundings clean. Bi-weekly community cleaning is known locally as Bulungi Bwansi, when every person takes part in cleaning public areas and shares responsibility for maintaining a healthy and clean environment.

Some of the victims of substance abuse were identified and are now undergoing rehabilitation. A few cases of child abuse were identified and referred to legal aid services and other supportive organizations, in addition to ensuring that they are reunited with their parents.

Although there is still so much to be done to realize LCHP's vision, the results so far are very promising. The good traditional values of the local community such as 'ubuntu' are regaining ground and need to be preserved if the community health care approach is to be successful.

Local community health workers must be recognized as the experts for designing culturally appropriate community-based health care programs and should be empowered to own them.

Discussion

Palliative care is gaining ground globally and is endorsed in high-level policy commitments, however service provision, supporting policies, education and funding are incommensurate with rapidly growing needs. Uganda, along with only three other African countries (Côte d'Ivoire, South Africa and Zimbabwe), have reached level 4a, indicating that hospice-palliative care services reached the stage of preliminary integration into mainstream service provision [6]. Hence, Uganda has succeeded in developing a critical mass of palliative care activism in a number of locations; awareness of palliative care on the part of health professionals and local communities; the availability of morphine; the provision of a substantial number of training and education initiatives by a wide range of organizations; and the existence of a national palliative association.

In Uganda, like many developing countries, cultures have expressly prohibited informing patients of their diagnosis and prognosis at all stages of the disease (cancer, HIV) [7]. With time and training, views have been changing to the point where there is now some acceptance of idea that patients should be informed of their real condition and, accordingly, be given the opportunity to take a more active role in decisions related to their treatment planning.

We are currently in the midst of the global COVID-19 pandemic. The number of lives lost throughout the world to the coronavirus is a harsh reminder of the necessity to ensure that care, especially at the end of life, is a priority for healthcare providers, regardless of their geographical location and health system [8].

Unfortunately, inequities still remain in the provision of palliative care, both among and within countries, especially in the

community. The majority of those needing palliative care, worldwide, continue to be those with non-malignant conditions. While traditionally associated with the care of people with cancer, palliative care should be available to all who need it, regardless of their diagnosis, particularly children and the elderly [9,10].

Let us reiterate that compassionate communities play an important role in access to palliative care, wherever they may be, by providing the required care, e.g. volunteer community caregivers and family members. It is especially important to understand and address the particularly gendered nature of caregiving, which falls upon women and girls in communities and families, without recompense, support or equipment, all contributing to ongoing gender inequalities [11].

In our efforts to treat individuals with cancer and to understand how to provide the best possible care to underserved populations, we must first acknowledge cultural diversity. Each culture is comprised of language, religion, social norms, history, tradition and spirituality. By recognizing each patient's particular spiritual and cultural beliefs, and by utilizing all available approaches, we can help to improve care outcomes and, in turn, patients' access and adherence to treatment [12].

Conclusion

This manuscript has described the recent advances in communal and home-care palliative care for cancer patients in Uganda, highlighting the role of volunteers and the progress made owing to the immense contributions of dedicated nurses and the support of physicians. Uganda, from any international perspective, performs well in Africa and is one of the few countries in the world that permits nurses to provide opioids to cancer patients. Nevertheless, further improvement is required to enable appropriate palliative care services to rural populations.

References

1. Henderson JD, Boyle A, Herx L, et al. Staffing a Specialist Palliative Care Service, a Team-Based Approach: Expert Consensus White Paper. *J Palliat Med.* 2019.
2. Silbermann, M. Preface: In *Palliative Care for Chronic Cancer Patients in the Community: Global Approaches and Future Applications* (Silbermann, M. ed.) Springer-Nature, Switzerland. 2021; pp ix-xl.
3. Khan CP, Parver S, Lesch JK, et al. Comparative Clinical Effectiveness Research Focused on Community-Based Delivery of Palliative Care: Overview of the Patient-Centered Outcomes Research Institute's Funding Initiative. *J Palliat Med.* 2019;
4. Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and pain relief-an imperative of universal health coverage: the Lancet Commission report. *The Lancet.* 2018; 391:1391-1454.
5. Yennurajalingam S, Amos CE, Weru J, et al. Extension for Community Healthcare Outcomes-Palliative Care in Africa Program: Improving Access to Quality Palliative Care. *J Global Oncol.* 2019;
6. Clark D, Centeno C, Clelland D, et al. How are palliative care services developing worldwide to address the unmet need for care? In: *Global Atlas of Palliative Care* (Connor S. ed.) 2nd Edition, London, UK. 2020;45-57.
7. Brant J, Silbermann M. Global perspectives in palliative care for

- cancer patients. Not all countries are the same. *Current Oncol Report*. 2021;23.
8. Silbermann M, Berger A. The need for a universal language during the COVID-19 pandemic: Lessons learned from the Middle East Cancer Consortium (MECC). *Palliative & Supportive Care*. 2021; 18: 757-758.
 9. Kebudi R, Cakir FB, Büyükkapu SB, et al. Palliative Care in high and low resource countries. *Current Pediatric Reviews* (in press).
 10. Ling J. Forward in: *Global Atlas of Palliative Care* (Connor S., ed.) 2nd Edition, London, UK, 2020; p: 11.
 11. Morris C, Davies H. What is the way forward? In: *Global Atlas of Palliative Care* (Connor S., ed.) 2nd Edition, London, UK. 2020; 92-95.
 12. Silbermann M, Berger A. Preface in: *Global Perspectives in Cancer Care: Religion, Spirituality and Cultural Diversity in Health and Healing* (Silbermann M and Berger A eds.). Oxford University Press, UK (in press).

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